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Death and late-stage dementia in institutions: a cultural analysis

A thesis submitted in total fulfilment of the requirements for
the degree of Doctor of Philosophy

School of Nursing
Faculty of Health and Behavioural Sciences
Deakin University, Geelong, Victoria

by

Jennifer Ann Abbey, RN, Dip Teach, BEd(Nursing)

October, 1995
I certify that the thesis entitled...Death and late-stage dementia in...
...institutions: a cultural analysis

submitted for the degree of...Doctor of Philosophy

is the result of my own research, except where otherwise acknowledged, and that this
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Name .......................................................... JENNIFER ANN ABBEY, RN, Dip Teach, BEd(Nursing)

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Acknowledgments

This work is a culmination of experiences over many years, and therefore the people who have assisted me and whom I would like to acknowledge are far too numerous to detail here; but I do say thankyou to all of them.

Special thanks go to the staff, residents and their relatives in both the nursing homes included in the study. They were unfailingly generous with their time, their feelings and their critique.

Thanks go to all those friends and colleagues who said an encouraging word, often at the most difficult moments, with special thanks to Lyndall for getting me through the biggest hurdle and to Jan for being there at the beginning and the end.

Thankyou to my supervisor, Professor Alan Pearson; his commitment to nursing and to the importance of matching theory with the realities of practice has been an inspiration; his belief in me a comfort. To my family: thankyou Georgina, Jane and Mum for all your practical help and support and to Amy for making sure that work did not take over my life.

Finally, in the same way that I have struggled to tell the difficult story of a certain kind of caring, some of which is on the edge of our conscious understanding, so I struggle to find the words to say thankyou to Brian, my husband and greatest friend. Living a life wrapped in his love constantly reminds me how precious life is and has helped me respond to the sadness I watched and wrote about. Thankyou Brian.
# Table of contents

Terms and abbreviations .......................................................... v

Abstract ................................................................................. viii

Summary ................................................................................ x

Part 1: Prelude and literature review ......................................... 1
   Chapter 1: Background of dementia and nursing home care ........ 2
   Chapter 2: Policy, laws and moral standpoints, emotional work ........ 34
   Chapter 3: Undertaking the study ........................................... 58
   Chapter 4: The exploration .................................................. 80

Part 2: The dying ...................................................................... 90
   Chapter 5: Resident profiles and synopsis of death trajectory .......... 91
   Chapter 6: The context in which these deaths took place .............. 202

Part 3: Conclusion .................................................................... 234
   Chapter 7: Changing the focus of care .................................... 235

Appendices

Appendix 1: Consent form for relatives giving permission on behalf of residents ..................................................... 265
Appendix 2: Plain language statement ......................................... 266
Appendix 3: Letter sent to relatives re draft of thesis for perusal ........ 267
Appendix 4: Information attached to draft thesis left at both nursing homes .......................................................... 268
Appendix 5: In-depth Interview guide ........................................ 269
Appendix 6: Field Interview guide ............................................ 270
Appendix 7: Colleen's story in her words .................................... 271

References .............................................................................. 283
Terms and abbreviations

Abbreviations

AD  Alzheimer's disease
ADLs  Activities of daily living
BNO  Bowels not open
CAM care  Care Aggregated Module, funding model for nursing and personal care in non-government nursing homes.
CBP  Complete blood picture
CCF  Congestive cardiac failure
CVA  Cerebrovascular accident
DAT  Dementia of the Alzheimer's type
GAT  Geriatric Assessment Team, now called ACAT, Aged Care Assessment Team
GP  General Practitioner
MID  Multi-infarct dementia
MSSU  Mid-stream specimen of urine (Collected for laboratory testing to investigate a probable urinary tract infection)
N/H  Nursing home
Pt  Patient
PRN  A medication order that allows nurses to give medications when they consider it is necessary
RCI  Resident Classification Instrument: used to categorise care needs of nursing home resident
Rx  Prescribe
SAM  Standard Aggregated Module, nursing home infrastructure funding
SDAT  Senile Dementia of the Alzheimer's type
SMTs  Standard Monitoring Teams
TIA  Trans Ischaemic attack
UTI  Urinary tract infection

Nursing hierarchy

DON  Director of Nursing
CNC  Clinical Nurse Consultant
CN  Clinical Nurse
RN  Registered Nurse
EN  Enrolled Nurse
Careworker  Employees called Nurse Assistants at Bayside and Personal Care Attendants at Beachdale.
Terms that could be classed as nursing home 'jargon' or are repetitive features of the case histories

'met' and 'not met'  Terms used to indicate that the nursing home has met the criteria for the Outcome Standards to the satisfaction, or otherwise, of the Standard Monitoring Teams.

E coli A causative organism for urinary tract infections

IntraSite A gel to be used in conjunction with other dressings that acts to loosen and absorb slough, absorb excess exudate, rehydrate necrotic tissue and promote wound healing

OpSite Semi-permeable non-adhesive dressing used for necrotic tissue.

Pressure sores, Pressure area or Bed sore Decubitus ulcer. Ulcers which form due to interference of circulation, usually over a bony prominence such as the sacrum, hip, heel or shoulder

Standards Outcome Standards for Australian Nursing Homes: 31 Standards set by Commonwealth against which care is measured

supp Suppository

Medications

Amoxycillin Antibiotic
Anginine (Glycceryl trinitrate) Vasodilator used to relieve angina
Chloromycetin Antibiotic
Clozapine Atypical neuroleptic (may prove to be more beneficial than anti-psychotic agents)
Cogentin (Benztropine) Anti-cholinergic agent for treatment of tremor and rigidity.
Donnatabs (Donnalix) Decrease hypermotility, hypertonicity and spasticity of smooth muscle
Fungilin lozenges Antifungal lozenges to treat infections such as 'thrush'
Haloperidol (Serenace) Anti-psychotic agent. Psychotropic drug, used to depress the central nervous system at the sub-cortical level

Imodium (Loperamide hydrochloride) Antidiarrhoeal agent, inhibits gastric motility and peristaltic reflex

Kelex (Cephalexin) Antibiotic
Lomotil Slows intestinal motility

Marijuana Psychoactive drug, produces sedation and decrease in aggressive behaviour

Melleril (Thioridazine hydrochloride) Anti-psychotic agent with psychosedative action.
Morphia (Morphine sulphate) Narcotic analgesic
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<td>Analgesic and antipyretic. Contains 500mg of paracetamol and 8mg of codeine phosphate</td>
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<td>Prothiaden</td>
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<td>Prozac (Fluoxetine)</td>
<td>Anti-depressant</td>
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<td>Rectinol suppository</td>
<td>Anaesthetic, anti-inflammatory and decongestant action for relief of haemorrhoids, anal fissures or pruritus.</td>
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<tr>
<td>Risperidene</td>
<td>Atypical neuroleptic (may prove to be more beneficial than anti-psychotic agents)</td>
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<td>Serenac (see Haloperidol)</td>
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<tr>
<td>Serepax (Oxazepam)</td>
<td>An anti-anxiety agent</td>
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<tr>
<td>Valium (Diazepam)</td>
<td>An anti-anxiety agent. It is used to obtain muscle relaxation and has a sedative, hypnotic effect.</td>
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Abstract

The first purpose of this study was to describe the deaths of fifteen nursing home residents with late-stage dementia. The devastating effect of dementia on a person has been called a 'living death' (Woods, 1989). The caring which occurs when someone is going through this process in a nursing home was recorded and analysed.

In analysing this act of caring, the second purpose was to look for the origins of the structures and the sources of pressure that shaped the context and therefore helped determine the behaviour of the various groups under observation. These groups were residents and their relatives, the staff of the nursing home and the treating doctors.

Before commencing observations and carrying out this study, an understanding needed to be developed of: the condition of dementia as it is perceived by health professionals and presented in the media; the institutions in which the majority of people with dementia end their days; the background and conditions of the staff who nurse in them; the models of care that guide and determine policies; and the conceptions of life and death which underpin relevant laws and moral standpoints.

Accordingly, in part 1, chapter 1 the history, causes, pathology and effects of dementing conditions are examined. Relevant medical and lay literature including media influences are examined which pertain to the subject of death and dementia and nursing home care. The history of this institutional care is briefly examined together with the growth of the discipline of gerontological nursing. Chapter 2 discusses some of the effects of this history on present day care and the concept of emotional work being carried out within the present day aged care public policy regulations. The moral arguments surrounding illness and dying in Australian society today are briefly discussed.

Chapter 3 describes the conceptual framework for the study, the ethnographic method that has been employed and an outline of critical theory as the basis for analysis. The chapter concludes by recounting the practical steps taken to arrange the field work, secure the consent of participants, record data and gather documents, and outlines the ethical considerations given to the undertaking of the study. Chapter 4 describes the context in which the study took place and the first tentative exploration of the culture from an etic perspective.

Part 2 describes the death trajectories observed and raises some questions about alternative strategies that may have been considered within a different paradigm of caring. In chapter 5 the death trajectories of each of the fifteen residents in the study are described, each written with a particular emphasis to illustrate aspects of the
culture of care that emerged through thematic analysis. Observations, comments and feelings from staff and family are wound in and around these case studies. Chapter 6 looks more closely at the impact of policy and institutional pressure on the milieu in which these deaths took place.

Part 3 draws conclusions from the observations and makes suggestions for emancipatory change as viewed from the author's standpoint of critical ethnographic analysis. In the final chapter an argument is presented for policy change that leads a movement towards palliative care practices for people with late-stage dementia. Approaches to implementation of palliative care will need to take account of any expression by the resident such as an advanced directive, indicating a preferred approach to treatment in the period prior to death; a need for a better understanding of such issues as the significance of body breakdown, the manifestations of pain and electrolyte imbalances; the surrounding ethical complexities and shift in public opinion, and perhaps, most of all, the culture of the institutions in which this dying will take place. A definition of late-stage dementia which might be used in determining patterns of care is set out.

A discussion about changes in practice which relate to communication with treating doctors, the administering of antibiotics, the relief of pain, the mobilisation of residents and the provision of food and water takes place in light of the evidence found. The discussion of these issues is raised in the form of debate. Each aspect needs more rigorous analysis and information so that evidence-based practice, rather than care which is value-laden and emotional, can be used when treatment decisions are made for people with late-stage dementia.
Summary

Events leading up to the moment of death of fifteen residents suffering from the last stages of a dementing illness were studied using critical ethnographic methodology. The study took place over four years in two nursing homes. Most of the death trajectories observed were prolonged and painful. The difficulties for staff and relatives coping with this drawdown process are recorded. A complex set of interactions is revealed; between family perspectives, the sometimes-incongruent paradigms employed by different groups of health professionals and ancillary staff, the pull of personal and group loyalties, and contemporary ethical sensitivities.

The patterns of care and case management that emerged were analysed to assess the various impacts on them of established nursing home practices, the structures of professional training, the levels of intimacy with the residents, the requirements of public policy, and the changing health demands of Australian society.

The study raises questions about the benefit of the life-sustaining procedures which are considered to be an essential part of good routine care within nursing home culture and which appear to flow from assumptions buried in public policy. Instructions to provide 'nursing care only' or 'conservative care' for the residents with late-stage dementia were found to be applied without the benefit of a coherent policy and ethical framework, and seemed to depend heavily on the values and personalities of staff rather than agreed protocols.

This leads the writer to question present methods of body maintenance, including the administering of antibiotics, mobilisation of residents and the giving of food and fluids for such residents. The possibility of introducing palliative care procedures that may involve changes to these three aspects of care (among others) would be limited within the present cultural framework. This thesis opens for debate the need for a paradigm shift in the meaning of some aspects of nursing home care, suggesting the need for withdrawal of life support for some people with late-stage dementia.

Jennifer Ann Abbey

Death and late-stage dementia in institutions: a cultural analysis

A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

Professor Alan Pearson
Part 1

Prelude and literature review
Chapter 1

Background of dementia and nursing home care

The condition of dementia as it is perceived by health professionals

A consideration of history may provide 'an active force in unpacking the culture of our time' (Quantz, 1992, p.493) and to this end an understanding of the condition of dementia, now and in the past, can be a start to the background of this study.

The progress of an organic condition causing irreversible dementia leads to the loss of any ability to care for oneself. Prima facie, it seems humane then for others to take over the care of the ailing person. Pitt outlines what can happen, however. He says:

*Skilled nursing care can maintain life in a frail elderly patient whose general condition is such that a comparable state in an animal might well lead to prosecution of the owner. Sentele dementing processes sometimes lead to a relatively quick and peaceful death. Many, however, particularly under modern conditions of treatment, can be very cruel illnesses indeed.* (Pitt, 1987, p.324)

This comment explains why such caring is worthy of scrutiny.

It is not possible to study what it feels like to be suffering from end-stage dementia. We cannot find out if it is so terrible that a person would rather be dead, or if it is like a certain kind of living in another world where peace is found in a confusion of thoughts we do not understand. By observing the person who is suffering from dementia and the events surrounding their care some opinions can be formed, even though these opinions will be dependent on a complexity of factors on which they are based.

Dementia is described in medical terms as:

*A syndrome due to disease of the brain, usually of chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation,*
comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by, deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

(Jorm & Henderson, 1993, p.1)

Ineichen (1989) maintains that awareness of dementia has a history going back thousands of years, quoting 'an ancient Egyptian papyrus of about 1500 BC' that 'contains the sentence "the heart grows heavy, and remembers not yesterday"' (Ineichen, 1989, p.1) and suggests that this may be the first written reference to the condition of dementia. 'Demens' was the original Latin word from which the condition of dementia was first named - this meant literally 'being out of one's mind' and was used to describe any behaviour or group of behaviours that was irrational, abnormal or outside social norms. People who were demented were incarcerated in mental institutions and labelled 'mad'. One has only to scan the many histories of the treatment accorded to those perceived as insane (Foucault, 1967; Barton, 1976; Bates, 1977; Porter, 1987) to discover a record of what seems in retrospect to be barbaric institutional practices and individual cruelty based on ignorance, superstition and insensitivity.

By the early twentieth century the work of Alois Alzheimer and others began to identify specific changes in brain tissue that led to behaviour characteristic of sufferers from dementia. In 1907 Alzheimer first described the pathological changes found at autopsy in the brain of one of his patients. This patient was 51 years of age. Gubrium (1986) maintains this initial description of Alzheimer's disease (AD), being in a person of 51 years, has led to years of terminological and analytical confusion in discussions about Alzheimer's so-called 'disease'. The unanswered question still is - is Alzheimer's disease a disease entity or is it, eventually, an inevitable result of old age? Forbes and Hirdes (1993) review the literature and arguments in relation to this topic, and suggest that the jury is still out on the question, but that there is no doubt that the chances of developing dementia increase with age.

The characteristic plaques and tangles of AD and arteriosclerotic changes that can lead to the formation of thromboses that cause multi-infarct dementia (MID) may be present in all our brains as we age and it may only be a matter of the quality and quantity of these agents as to whether they will cause impaired functioning or not. Gubrium's (1986) study maintained that the original condition described in 1907 is
no different to senile dementia of the Alzheimer's type and, in essence, this finding has not been challenged.

In 1978 Kral's work on benign senescent forgetfulness investigated the difference between memory loss usually occurring in old age and true organic dementias. Attention began to turn and people began to recognise dementia as symptoms of an organic condition even if it was contributed to by the inevitable consequence of ageing (U'Ren, 1987). Useful distinctions began to be made between being ill and being old.

Studies such as Elsie Harwood's (Swan, 1986) longitudinal study of cognitive functioning in old age has dispelled many myths about losing one's ability to remember as one grows older and confirmed that the elderly, without cognitive impairment, have as much capacity to learn new tasks as the young. Accumulating research knowledge has enabled the building, piece by piece, of a picture of dementia. Although this picture does show that it is a condition which mainly affects the aged population, it may or may not be an inevitable result of wearing out as one ages.

**Causes of dementia**

The main causes of non-reversible dementias are Alzheimer's disease and multi-infarct dementia or a combination of both (Schmitt & Sano, 1994). Dementia can be caused by conditions such as Parkinson's disease, Huntington's disease, Wilson's disease, Pick's disease, Multiple sclerosis, Jakob-Creutzfeld's disease and the human immunodeficiency virus (HIV). Dementia can also be caused by conditions such as infections, alcoholism, subdural haematoma, neoplasms, hydrocephalus. These are only a few examples; Brodaty maintains that there are over 100 causes of dementia (Brodaty, 1983). Some of these conditions may be able to be treated and the dementia reversed (Cumming & Benson, 1992).

The causes of dementia listed here do not constitute a comprehensive list; they are a sample of some of the conditions which are not common and account for a small number of the total number of people with dementia in comparison to the numbers of people affected by AD and MID. Dementia from any of these causes will not be considered in this study. All the residents in the study suffered from senile dementia of the Alzheimer's type (SDAT). AD, MID and SDAT are irreversible conditions and will result in progressive worsening of a person's cognitive and behavioural functioning. A semantic debate surrounds the names to be used to provide a general classification of this group of conditions but SDAT is a generally accepted term for
the range of dementing illnesses from which most residents in nursing homes suffer (Forbes & Hides, 1993). SDAT will be used throughout this thesis whenever the condition that produces dementing behaviour is discussed in general terms.

Pathology of dementia

The pathological changes in the brain of a person with AD are neurofibrillary degeneration and the development of senile plaques. Neurofibrillary tangles are protein filaments that appear in great number in and around the nuclei, axons and dendrites of the neurons in the brain of a person with Alzheimer's disease. These changes indicate that the cell is disintegrating and the ability of the neurons to pass messages over the tiny gaps called synapses is reduced. Senile or neuritic plaques are pieces of amyloid protein that have been broken off from nerve endings and are now decayed (Carroll, 1989).

New understandings of Alzheimer’s disease were presented by Professor Colin Masters at the 1992 National Conference of the Alzheimer’s Association (Australia). He outlined research that had identified an amyloid precursor protein (APP) and bA4 amyloid that are considered to be essential in the aetiology of Alzheimer's disease. The amyloid protein deposited in blood vessels, plaques and neurofibrillary tangles leads to neurological impairment resulting in demented behaviour. Mutation in the gene that leads to these pathological changes has been identified in a Dutch study (Jorm, 1992). These findings lead to the possibility of rational therapeutic strategies. Since the identification of the structure of the bA4 amyloid (Masters, 1992) research has continued looking at genetic links that could lead to identification of those most at risk. Masters also considers that a 'major environmental risk factor exists which as yet has not been identified' (Masters, 1994, p.23). With the progress of this scientific research the chance of a cure for SDAT must be considered as a possibility in the foreseeable future. There have been small trials of the drug Tacrine (THA) that have shown some measurable improvement in function in people with dementia, thereby raising hopes of an effective treatment. But subsequent work has highlighted serious side effects of the drug, such as liver damage, and found that the improvement in behaviour and reduction of disorientation are limited if present at all. The consumer magazine Health Reader summarises the present information that is publicly available for the lay reader:

There isn't much information on whether tacrine helps in the long run and the best that can be said at the moment is that tacrine may slow the disease or produce modest improvement. Those desperate families who are caring for someone with this destructive disease (AD) and want more dramatic benefits will have to wait for new medications
which are under development at present. Even so it is hard to see how
any drug can largely reverse the damage of full blown Alzheimer's,
which is why many researchers are pinning their hopes on drugs
which may halt or slow the disease in the early stages. (Anon. 1994,
p.4)

It may be because of the intense interest in a 'cure' for SDAT that the public seem to
be getting as much up-to-date information as is published in the specialised medical
research literature. In the American publication Geriatric Medicine Jones reports that
'Drugs like tacrine and velpnacrine probably represent the first light at the end of what
is undoubtedly a long tunnel' (Jones, 1993, p.41), indicating that these drugs are
really only at the stage of clinical trials.

However, for the next decade, the outcome of this new research is not likely to have a
significant effect on the number of people entering nursing homes with dementia.
Advice from David Ames, an Australian geriatric psychiatrist, in the newsletter of The
Australian Alzheimer's Association is that:

Even the most optimistic advocates would only claim that the current
range of new drugs might offer only mild, temporary improvement in
some people. Most people with Alzheimer's disease will not have a
mild enough illness to benefit from Tacrine or to take part in current
drug trials. (Ames, 1994)

MID, sometimes referred to as vascular dementia (Cummings & Benson, 1992) is
caused by occlusion of multiple blood vessels in the brain. Many infarcts occur that
leave brain tissue permanently damaged. Infarctions cause symptoms that are abrupt
and immediate, such as flaccidity or paralysis of one side of the body, but as the
inflammation subsides and the clot is absorbed the person's condition may improve.
To be more precise, the immediate symptoms may improve but the person's overall
cognitive functioning may not return to the level of function that was present before
the episode. It may, in fact, deteriorate and then settle. This results in the progress of
the disease being stepwise with periods of plateauing, rather than progressing in the
same way as is found with the characteristic steady decline of SDAT. It is very
common to have mixed conditions where the cause of the dementia is both AD and
multiple infarcts. In any of the conditions the progress of the disease is likely to be
very individual and unpredictable, depending on the part of the brain affected, the
characteristics of the person before becoming demented, the presence or absence of
concomitant illnesses and the social and economic conditions of their life.

Chronological age is the most relevant risk factor for SDAT. The risk of developing
SDAT doubles every year after the age of 60. It is agreed that the intellectual and
cognitive decline of a person with AD will continue until death. However, whether Alzheimer's disease causes a shortened life-span is a matter of debate (Gubrium, 1986), but Mace is confident that it does, and that it may of itself be the cause of death. She says:

*In the final stages of a progressive dementing illness, so much of the nervous system is failing that the rest of the body is profoundly affected. The person will die of the dementing illness.* (Mace & Rabins, 1991, p.110)

**Characteristics of dementia**

The first sign of dementia is usually that forgetfulness increases to the point where it becomes enough of a problem to interfere with normal daily management of life and either the affected person or spouse seeks medical advice. The dementia syndrome is characterised by the triad of memory impairment, intellectual deterioration and personality change.

An accurate diagnosis of SDAT is difficult. Diagnosis is made by exclusion. A Computerised Axial Tomography (CAT) scan of the brain may show widen sulci and shrunken gyri in the cerebellar tissue which are characteristic of AD and may assist in diagnosis. Other radiological techniques may provide marking indicators (Cummings & Benson, 1992, p.49). Mental status tests, although these have some drawbacks, (Connor *et al.*, 1989; Jorm & Jacob, 1989), other test of cognitive function such as clock drawing (Wolf-Klein *et al.*, 1989) and the history of the illness can be used to make an accurate medical diagnosis.

One sad aspect of dementia is that for some there is insight as to what is happening to them, at least at the start of their disease.

Whatever the cause, as AD progresses people are thought to lose perception and awareness and enter a world of their own. Researching the lives of residents in this study, conversations with others who observe and interpret the moods of people with dementia and my own experience as a practitioner caring for such residents seems to confirm the reported stories that some insight exists, often in the early stages of the disease, and may be evident until the point of death (Forsythe, 1990; Brown, 1995). Nay (1994) has researched the literature seeking an understanding of dementia from the sufferer's perspective, rather than from observations such as this study will undertake. She was only able to find two examples, both of which seem to support this claim. Nay also claims that:
personal clinical experience suggests that dementia sufferers experience fear, depersonalisation, anxiety, depression, sadness, anger, indignity and bereavement associated with their losses. (Nay, 1994, p.148)

A phenomenological study being undertaken by Nay and a team of researchers from the University of New England will assist in understanding the perception of sufferers and hopefully throw further light on the needs of those in the end-stage of the disease.

Although studies have outlined the characteristics of various stages of dementia (Reisberg et al., 1982; Hughes et al., 1982; Heyman et al., 1987; Cohen et al., 1984), how uniform these are is questioned (Maslow, 1990). The very late stages of the disease have received little attention and have not been clearly delineated.
Figure 1 shows how the stages are described in medical terms (Cummings & Benson, 1992). Here the progress of the disease is defined by measurable aspects of behaviour and the results of diagnostic tests.

**Principal clinical findings in each stage of DAT.**

(An Electroencephalogram (EEG) records the changes in electric potential in various parts of the brain; a CAT scan and MRI (Magnetic Resonance Imaging) are non-invasive radiological techniques that produce a cross-sectional view of the brain (Miller and Keane, 1978). Positron Emission Tomography (PET) and Single Photon Emission Tomography (SPECT) are nuclear imaging techniques that can be used to detect metabolic alterations in the brain as an indicator of SDAT (Morris, 1994).)

**Stage I (duration of disease 1 to 3 years)**
- **Memory** — new learning defective, remote recall mildly impaired
- **Visuospatial skills** — topographic disorientation, poor complex constructions
- **Language** — poor wordlist generation, anomia
- **Personality** — indifference, occasional irritability
- **Psychiatric features** — sadness or delusions in some
  - **Motor system** — normal
  - **EEG** — normal
  - **CAT/MRI** — normal

**PET/SPECT** — bilateral posterior parietal hypometabolism/hyperfusion

**Stage II (duration of disease 2 to 10 years)**
- **Memory** — recent and remote recall more severely impaired
- **Visuospatial skills** — poor constructions, spatial disorientation
  - **Language** — fluent aphasia
  - **Calculation** — acalculia
  - **Praxis** — ideomotor apraxia
- **Personality** — indifference or irritability
- **Psychiatric features** — delusions in some
  - **Motor system** — restlessness, pacing
  - **EEG** — slowing of background rhythm

**CAT/MRI** — normal or ventricular dilatation and sulcal enlargement
**PET/SPECT** — bilateral parietal and frontal hypometabolism/hypoperfusion

**Stage III (duration of disease 8 to 12 years)**
- **Intellectual functions** — severely deteriorated
- **Motor** — limb rigidity and flexion posture
- **Sphincter control** — urinary and fecal incontinence
  - **EEG** — diffusely slow

**CAT/MRI** — ventricular dilatation and sulcal enlargement
**PET/SPECT** — bilateral parietal and frontal hypometabolism/hypoperfusion

(Adapted from Cummings & Benson, 1992, p.49)
Very few people who have dementia will be subjected to this amount of intensive diagnostic activity. It is far more usual for authors to divide the stages of dementia into mild, moderate and severe, and describe them in behavioural terms. There is an acknowledgment that the individual and uncertain progression of SDAT means that no definite answers can be given to how stages will progress, or, the hidden message may say, the stage the person will have reached when they die. Jacques (1992) for example, makes the point that the following table is an attempt to classify the stages of dementia but can be used only as a guide.

**Mild dementia**  Moderate recent memory loss affecting daily life, some disorientation in time, may be disoriented in place in strange surroundings, difficulty in handling any complex problems, cannot maintain outside interests, abandons complicated tasks at home, needs some prompting in self care.

**Moderate dementia**  Severe memory loss, retains only highly learnt material, disoriented in time and often in place, cannot handle problems or make judgements, unable to function independently away from home. only does the simplest chores at home, needs some assistance in dressing, hygiene etc.

**Severe dementia**  Severe memory loss, fragmentary mental activity, completely disoriented except as to own identity, unable to solve any problems or make judgements, unable to care for self or to function at home or outside, often incontinent. (Jacques, 1992 p.284)

At the final stage in the dementing process a person may lose his or her awareness of the identity of others. This loss of awareness may progress to a loss of any sense of self. The resident with late-stage dementia is very likely to be incontinent and to be able to make only grunting sounds, but otherwise may be physically quite well. There is some common agreement that a person is nearing the later stages of the disease when they are regularly incontinent and/or lose the ability to eat independently, lose the ability to recognise family or friends, stop speaking, or speak only in single words or odd phrases and lose their ability to comprehend what is occurring in their environment. Some may progress to a 'vegetative' state where they are totally uncommunicative and bedridden. This state is not the same as the definition used for a persistent vegetative state as described in acute settings. Outerbridge and Hersh (1991) define this condition as one where a person is in:

... a chronic state of unconsciousness caused by overwhelming damage to the brain. The body continues to awaken and sleep cyclically, but there is no cognitive function or ability to respond in a
Residents in this study were sometimes able to respond in a 'learned manner' but their ability to respond appropriately to external events or stimuli was variable. Whether or not any were in a 'vegetative' state, even in the very last stages of life, is open to debate. A definition of a final stage of dementia has been proposed through observations in this study. The need for this definition was confirmed by a review of the literature that deals with the death of people with dementia.

Death and dementia

The literature surrounding the understanding of dementia is voluminous, complex and very rapidly increasing. It has been estimated that one paper about dementia is published 'every five hours day and night' (Editorial, 1992, The Lancet).

Very little of this literature deals with death and dementia and the research that does exist does not ordinarily deal with the practicalities of bedside nursing, home care or death. Publications relating to dementia are dominated by reports of medical investigations.

For example, in 1993 a Medline search produced 862 articles relating to dementia with 36 of these including some discussion about death, none within a nursing home setting. Of the 36 articles that included death only six could be classed as non-medical. In the next year there was an increased interest in death and dementia especially dementia associated with Acquired Immune Deficiency Syndrome (AIDS). The profile from a Medline search in the nine months from January 1994 to August 1994 reveals a total of 812 articles relating to dementia - an increase of 69%. Thirty-eight of the articles included the word death - an increase of 158%. The breakdown of the profile is disappointing from the point of view of this study which seeks background information about the process of dying in the late-stages of dementia in institutional settings. Ten of the articles relate to AIDS, compared to three in the previous twelve months, and only five of the articles were non-medical.

A comprehensive review of current information sources that deal only with Australian research and comment about dementia can be obtained from the entries in the 'Dementia Research Register'. This register is compiled and produced by the Alzheimer's Association (Australia), the first edition being published in 1993.

In this first edition 73 articles could be considered to be related to medical, biological, epidemiological or pharmacological investigations. Of the 17 abstracts not in these
categories all dealt with service provision or carer needs. None, with the exception of a description of this study, dealt with bedside nursing care. Much the same pattern emerged in the 1994 edition.

Of the articles that consider death and dementia none discuss the difficulties of finding meanings from the culture of care that necessarily surrounds the end-of-life for people who have lost the ability to survive alone. Most research concentrated on gaining opinions about what people would decide about death if they did become demented.

A review of the articles from these sources that are relevant include an English study by Robertson (1993) which sought responses to a series of questions about choices of care in the event of a serious illness. Responses showed that 97% of patients would opt for cardiopulmonary resuscitation (CPR) in their current state of health. In the hypothetical circumstance of having advanced senile dementia only 10% would definitely want CPR, while 75% definitely would not. These findings show that the great majority of patients would not wish CPR if they become demented, an indication that measures to prevent unnecessary prolongation of life might be acceptable.

Nursing homes in Australia generally do not seek resident's opinions about 'not for resuscitation orders', but measuring people's opinion on this subject provides a base for comparing whether people with dementia may 'wish to die'.

Robertson's study illustrates the concern people have about being 'kept alive' if they have advanced dementia. These concerns also emerge from the study from Patrick et al. (1994) who analysed previous research indicating that persons assigning values to ranges of health states consider some states to be worse than death. The authors' emphasis was on the reliability, or otherwise, of the statistical measuring methods that identify and quantify preferences for health states near to or worse than death in a population of well adults and nursing-home residents. In spite of the authors' caution about the reliability of measurement, the findings that most respondents considered that dementia and coma were more often considered equal to or worse than death are significant for the purpose of this study.

This fear of the undignified and degrading results of the dementing process is well founded. Over the last decade the liberalisation of attitudes towards euthanasia is illustrated by the findings of Gallup Poll research which has asked the same question for the last thirty years. The question is:
If a hopelessly ill patient, in great pain with absolutely no chance of recovering, asks for a lethal dose, so as not to wake again, should a doctor be allowed to give a lethal dose, or not?

The results were:

<table>
<thead>
<tr>
<th>Year</th>
<th>1962</th>
<th>78</th>
<th>83</th>
<th>86</th>
<th>87</th>
<th>89</th>
<th>90</th>
<th>91</th>
<th>92</th>
<th>93</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give dose</td>
<td>47</td>
<td>67</td>
<td>67</td>
<td>66</td>
<td>75</td>
<td>71</td>
<td>77</td>
<td>73</td>
<td>76</td>
<td>78</td>
</tr>
<tr>
<td>No dose</td>
<td>39</td>
<td>22</td>
<td>21</td>
<td>21</td>
<td>18</td>
<td>20</td>
<td>17</td>
<td>20</td>
<td>18</td>
<td>15</td>
</tr>
<tr>
<td>Undecided</td>
<td>14</td>
<td>11</td>
<td>12</td>
<td>13</td>
<td>7</td>
<td>9</td>
<td>6</td>
<td>7</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

(Ilunt, 1995)

Although the responses do not show a totally consistent rise, the change in acceptance from 47% to 78% is extremely significant. If this liberalisation of attitude continues, future studies such as those conducted by Patrick et al. (1994) could be expected to show an increase in the percentage rate of people choosing to die rather than living with severe dementia.

The issues of death and dementia are also examined in a study by Dewey et al. (1993) who correlate the 'wish to die' with mortality. In a three-year period 1063 community residents aged 65 and over were interviewed. Expressed wish to die was confirmed as a predictor of mortality. The study did not go on to discuss whether an 'expressed wish to die' is a justifiable choice that can or cannot be met by the current American health system. For those in Australia who support the concept of Social Role Valorisation and right to life 'wishing to die' is a condition that people should be 'talked out of' (Runge and Beaton, 1994).

A closely related issue to this concept of 'wishing to die' is the choice of limits to care. Fried and Gillick (1994) undertook a retrospective study to record the type or types of care patients (or, in the case of incompetence, their families) and their doctors chose to limit during the last episode of illness preceding death and during previous episodes of illness. They did this by examining those instances when therapy other than that considered 'standard' was given. The results showed that a choice to limit diagnostic tests or treatment was made by the patient or surrogate in 40% of cases during the 6 months before the patient's final episode of illness, but the presence of dementia was not a significant deciding factor in this choice. In most cases respondents chose not to undergo diagnostic tests, surgery or hospitalisation for purposes other than surgery. During the final episode of illness 89% of the patients chose limits to care. CPR and intubation were the most common treatments to be withheld. Unfortunately for application to this study this work was carried out with a
sample of patients living in the community. The authors concluded that there are multiple points in the course of an elderly patient's illness at which choices about level of care can be made.

This kind of research supports, but is tangential to, the work in this study. Fried and Gillick's (1994) research is indicative of the work that has been undertaken about restricting care which focuses on removing life support systems that are technological, not ones that rely on care given by human beings. Lynne (1992) has edited a series of articles dealing with the debate about limiting food and water. Lynne is a physician and leads the debate herself, arguing that the topics such as eating and drinking are the 'little things' (Lynne, p.1) that get lost in the major debates. She clearly outlines and supports the limiting of nutrition as a way towards a peaceful death. I use her work in outlining the ramifications of this approach within the culture of a nursing home in the conclusion to this study. Her book gives differing points of view about the legal and moral issues that pertain to the decision to limit sustenance, with some small discussion about the physical effects. Volicer (1986) discusses the idea of a hospice approach for people with dementia, which he and his colleagues (Volicer et al., 1986) do not clearly define as being different from mainstream hospice care. Volicer is also a physician, but he concentrates on measuring the effects of minimum intervention for people with dementia after defining different levels of care, the choices of care usually being based on decisions from family members. Results are presented from a quantitative research perspective. Lynne (1986) is critical of Volicer's (1986) work, indicating that the ambiguous and difficult nature of the deaths of residents with dementia do not lend themselves to this kind of empirical inquiry. Nevertheless, the title of Volicer's article put the question of a palliative approach to the care of people with dementia on the research agenda. However, only a little work seems to have continued since this initial foray into the area. The bulk of the work that has emanated from the Geriatric Research Education Centre, under Volicer's guidance, appear to be small studies such as those measuring the effect on fever of treating or not treating people with dementia with antibiotics (e.g. Fabiszewski et al., 1990; Hurley et al., 1993). Whatever the limitations of this work with the paucity of data available all these studies are useful in analysing the results of this study.

Another area of research that touches on the question of death and dementia is the question of living wills or advanced directives. Two names which refer to a variety of methods by which choices of medical treatment can be anticipated. A hypothetical situation is imagined, such as becoming demented, and a person can then leave instructions about how they wish to be cared for.
Molloy and Mepham (1992) have introduced and monitored the use of Advanced Directives in an aged care complex and they show that, with a great deal of support and opportunity to change choices at regular intervals, older people can choose their own limits to care. On the other hand, Clarrett, in discussing the use of Advanced directives says 'As a clinician working with old people who often die I know that many of these are incapable of discussing these complex issues in a rational fashion' (1994, p.7). High (1993) has demonstrated that the take-up rate for the use of advanced directives is very low in the older aged group, in spite of the enforcing of the Patient Self-Determination Act, 1990. After the passing of this Act medical facilities in the USA who were receiving federal funding were required to 'give written information to each newly admitted resident explaining right-to-die and other treatment options under state law' (Madson, 1993).

Opinions of the elderly and health professionals will gradually change this situation. Most of the general public, including the elderly, gain their knowledge from and form their opinions about such marginalised subjects as death and dementia from the media.

The condition of dementia as presented in the media

The media plays a large part in framing and reflecting the moral attitudes of society measured against prevailing standards of rectitude. It is effective in shaping attitudes and providing knowledge about ageing as Gibb indicates:

The media constitute an important source of social views about aged people. They also make a major contribution to the construction of social opinion... the media is one way through which society both represents and reproduces itself to itself. In this feedback loop the media picks up and represents dominant or acceptable representations... feeding them back to a community which can in turn use these media representations as a means of validating existing values or ways of thinking. (Gibb, 1990b, p.1-p.3)

The power of the media has also been acknowledged by Friere (1972) who says:

In mass society, ways of thinking become as standardized as ways of dressing and tastes in food. Men begin thinking and acting according to the prescriptions they receive daily from the communication media rather than in response to their dialectical relationships with the world. (Friere, 1972, p.80)
For this study, therefore, an analysis of the information that has been found in the media over the last decade is important. This study is about, and for the use of, members of the general public, and there can be no denying the influence of the media on the values, beliefs and needs of this audience.

The media tends to lean towards good story telling rather than clear analysis in the presentation of the issues surrounding the care of people with dementia. The most effective influence in the media is television coverage. The series on ABC television, *Mother and Son*, is sometimes portrayed as illustrating a person with early Alzheimer's disease, but it is not at all realistic and this kind of comic portrayal will not be dealt with in this study. Only coverage of the human interest stories associated with dementia will be discussed and only the print media and some television programs will be reviewed. Radio programs such as the ABC's *Life Matters* or *The Moral Map* may present deeper analysis of the subject matter but are not the kind of programs which influence the majority of the lay public, or staff who work in the sort of nursing homes that are the focus of this study.

Moving portrayals of the degeneration of Alzheimer's disease were shown on television in the drama *There were times dear* (Hope, 1991). The focus was on an idealised married couple, with money, friends and supportive children, the story ending with a scene where the person with dementia dances in a blank manner with his still attractive, young and unharrassed looking wife before being admitted to a nursing home. The difficulties of adapting to the degenerative nature of the disease were clear, but end-of-life issues ignored.

Goldie (1992) showed the joyous side of getting old and adapting to new life patterns as well as the devastating effect of becoming chronically ill, including the ravages of a dementing condition. In an ABC documentary daughters who were caring for their dementing mothers at home were shown indicating that they were at the end of their tether, at times 'wanting to put a pillow over her face' and then feeling guilt and regret a moment later. Again the institutionalisation phase for people with dementia was not followed through into care. While the issues of death and dementia are not raised by the media, and therefore not opened up to debate, there is a limit to the progress any scientific publication or research can make to empowering consumers of health care to make choices about themselves if they become demented.

Newspaper and magazine reports concentrate far more on the 'living death' aspect of SDATs and the need for loving care and rarely discuss the actual physical decline into death. These stories romanticise the condition of dementia, by avoiding the unpleasant issues like people passing faeces on the floor, or falling over and
sustaining fractures or severe bruises. Instead the stories concentrate on the loving relationships between the person with dementia and the carer. There is no doubt that these relationships do exist, and can have mutually beneficial effects, but the disproportionate concentration on them further obscures the difficulties inherent in caring for people with dementia and their death. Three articles published over eight years (Hutton, 1986; Kennedy, 1991; West, 1994) are remarkably similar. They all demonstrate an emphasis on 'loving care'. Each discusses a mother/daughter relationship. One starts:

_The old woman's eyes light up as she recognises her daughter coming towards her, arms outstretched. The daughter bends to kiss her forehead, and they slowly walk together, arms wrapped around each others waist ... out of the locked ward at Wilsmere where Ellie Harvey is spending her last years._ (Hutton, 1986, p.29)

The story goes on to explain how Ellie's daughter cared for her at home until life became a 'nightmare'. Ellie is now in the late-stages of SDAT but her daughter still takes her home on a regular basis where 'she wanders in delight from room to room, staring at herself for a long time in the mirror'. It does not describe what life in the locked ward of a large psychiatric institution would be like for Ellie day after day.

The second story also tells of a daughter, in this case a nurse, supporting her dementing mother and aged father at home until they could not manage any more. The reader is told of various events that happened in the nursing home and then, after a fall and a fracture, how new medication improved the mother's condition to the point where visits could be 'full of healing and full of love, love shared and spoken' (Kennedy, 1991).

The third story is one of badly managed medical care and the resulting strain and frustration for a caring daughter. The story ends on a sentimental note as the mother finally has a room of her own in a pleasant environment and is now 'home'. None of these stories makes mention of the physical or behavioural manifestations that often signify the end-stage of Alzheimer's disease. For example, skin breakdown, the lack of bowel and bladder control and contractures are all missing from this account.

The sentiment in these stories is repeated in a book co-written by a person who was, at the time, Executive Director of the Alzheimer's Association of Victoria (Naughtin & Laidler, 1991). This book further reinforces this sentimental notion that 'loving care' is the essential ingredient required for care of people with dementia. The back cover says 'This book is about courage' and it opens with the claim that 'This book is about human goodness'.
There are some powerful messages in this kind of media coverage. They are based on presumptions that the present study will question, namely the expectations that 'loving care' may and should be given with endless patience.

In reality, care for people in the late-stages of dementia can be a continuous struggle - physically and mentally exhausting. For nurses the strain of trying to meet the expectations created by media stereotypes - to display unfailing 'goodness' and be a source of continual comfort and care - perhaps contributes to the distress nurses feel when caring for a person who display behaviour which is difficult and beyond the point when anyone else can cope. To think of the person as a 'loved one' or to display goodness in these circumstances is not easy and certainly not without cost.

On the other hand this critique of the popular press needs to be balanced with those pieces of reporting that have investigated SDATs in order to make strong social comment that is comprehensible to the general public who may have no direct knowledge of the subject.

A report which appeared in The Age in March, 1986 (Van Ulzen) tells of the institutionalisation of the reporter's grandmother who was suffering from SDAT. Victoria had (and still has in some places) large public hospitals set aside for care of the elderly. This article did not begin with sentimentality - rather it began with a description that is familiar to all nurses who have seen elderly people admitted for long-term care.

*When we first took my grandmother to the hospital, she cried and begged to be taken home. We lied to her saying 'Later, Gran, when you get better'.* (Van Ulzen, 1986)

She then goes on to describe the situation when her grandmother had been in the hospital for eight years:

*It's as if the blankness of her life has taken hold of her face. Her head falls to one side and she blinks like an owl. She fiddles ceaselessly with the hem of her dress, sometimes pulling it up over her head and showing her nappy underneath. She barely moves from the chair all day.* (Van Ulzen, 1986)

Van Ulzen then goes on to mount a plea for people with SDAT to be allowed to be left at home to die and is critical of the Westernised form of family structure that
almost always prevents this. She then goes on to express thoughts that reflect the
issues about which society is becoming increasingly concerned.

*There is no doubt that senile dementia is a degrading, hugely
debilitating disease that ends in death if left to run its course, simply
because the patient ceases to function in various essential ways. The
hospital constitutes an artificial life support system, serving the same
purpose as technological equipment. It maintains life where it
otherwise would have finished ... It seems the old mind/body duality
implicit in Western thought renders us incapable of understanding
that the disease is a physical one, affecting our mental powers. If that
health has declined so much that self-consciousness no longer exists,
can that person reasonably be said to be alive? (Van Ulzen, 1986)*

This piece of reporting highlights the fact that there were, and are, no simple or
pleasant answers for her grandmother. Deciding the best form of care for people with
dementia remains a matter of uncertainty.

Murphy (1988) linked together the ageing of the population, chronic illness and the
right to die. This article discussed a survey that had found that the things older people
most fear about getting old were poor physical health and being unable to care for
themselves. There was no specific discussion about SDAT but Murphy predicted that
the euthanasia debate would gain momentum and the use of living wills would
increase substantially in the coming years. He was right.

In 1989 *Time* produced a cover story about SDAT, with a comprehensive history of
the growth in our understanding of dementia, the latest scientific facts about cure and
treatment, discussion about the increase in the ageing population and the prevalence
of dementia, the functioning of support groups, the frustrations of day care, the
emotional pain of caring and the difficulties of admission to a nursing home. The
article stopped there, that is, coverage did not go on to the death process. This article
provided accurate information for public education but the nature of the magazine
means that it would only reach a limited audience. Nevertheless, it is an audience with
above-average influence, a public who may well be demanding a different type of
service from aged-care practitioners in the very near future, for their parents and
themselves.

The kind of information surveyed above, both sensational and factual, is absorbed by
staff and relatives and forms the subconscious knowledge from which feelings and
actions spring when faced with the realities of caring for people with SDAT. Some
practitioners in the nursing home have knowledge of the professional health literature
covering the condition of SDAT, but these are the minority.
Publicity from the Alzheimer's Association can also be considered to be media coverage as this is where carers and the general public turn to find support and information. The Alzheimer's Association is a voluntary self-help organisation and is therefore more concerned with supporting carers in the early stages of the disease than with the difficulties of institutional care. The national and international conferences of the organisation are opportunities for dissemination of information, but most of that is to health professionals in senior positions and those undertaking research.

It is usually well before late-stage onset of the disease when many family or friends of the person with dementia seek help in caring for that person. Eventually the person is 'handed over' to a nursing home and the reality is that that is where they will stay for the rest of their lives.

The institutions in which the majority of people with dementia end their days

The development of institutions to care for the sick and elderly in the Western world has a long and complex history that impacts greatly on the difficulties being experienced in today's version of them. So it is necessary to briefly turn to history to put into context the place of nursing homes in Australia and the background of the culture to be examined.

Since European settlement Australia's changing social and economic conditions have imitated Western culture, including trends in health care. Australia followed the direction of England, and later America, resulting in the technologically-based health care system that exists today. Throughout history and up until the present time provision for the care of elderly persons who became chronically ill was problematic within this medical based 'cure-oriented' system.

Today, many charitable organisations retain the primary role for care of the aged, a role which has evolved from roots buried deep in the past. For example, nursing homes are direct descendants of the poorhouses or almshouses of eighteenth century Britain, America and Europe. Norton (1990) traces the genesis of the marginalised status of gerontic care and this linking together of the poor, old and ill to the introduction of the Poor Law system in Britain in 1601. This legislative change marks the beginning of the State's assumption of the responsibility for those who reach the point, for whatever reason, of being unable to care for themselves. Each stage since has had its reformers and its contemporary reformist notions, sometimes more popular and influential and sometimes less so, addressing the implications of public policy regarding care of those seen to be in need of it. Among the issues that
reappear from time to time in the dress of the period are the links between public measures and private troubles, the costs of care and the priorities of need, the supposed efficiencies of institutional care versus the wide-spread preference for care in the home, of the problematic connections between bodily health and general well-being, the increasing recognition of the individual's entitlement to dignity in his or her distress, the associated question of social stigma and finally the training and status of the growing workforce engaged in staffing the institutions of care.

While it is not the purpose of this work to examine the history of care, it is worth briefly noting the impact in this area of the main forces that have shaped modern western industrialised societies and which impact on the culture of nursing homes. Among them we may number the growing domain of the modern state, the concomitant rise of the large bureaucratically organised institution, the ever-growing power of technology and the less steady rise in the public's faith in it, and the usurping of the sacred by the force of ethical relativism.

The early stages of this modern phase, after the entry of the state, were marked by a failure to distinguish among the groups in care according to the source of their dependence. The very poor, the helpless aged and the mentally incapable were treated together by much the same method, with confinement as the story's *leitmotif*. One of the indicators of progress, it might almost be said, has been the gradual remediying of that oversight by the attempted targeting of different regimes of care for the specific groups in need.

Commentators refer to the medicalisation of health as an upshot of the growing power of the health sciences and medical technology. As the moral righteousness and paternalism of the Victorian era gave way to the social security reforms of Beveridge's time the medicalisation of old age began to occur. The 'chronically sick' old quickly became seen as a problem in hospitals, blocking beds for those acute cases considered more worthy of attention. The term 'bed blocker' still remains in colloquial use today by many health professionals who see the elderly as being in the way of the 'more needy' acutely sick younger members of society.

Two wars saw an enormous increase in the 'curing' ability of the medical profession, but for the elderly little improved. The Nissen huts of the Second World War, relocated to the grounds of acute hospitals, became the Nightingale wards for 'extended care' where I began my gerontic nursing career. Reforms since that time have been instituted to replace the infirmary concept of care with one that has an emphasis on quality of life and respect for the particular physical and emotional changes that occur in old age. The future for those aged in Australia who are not able
to stay fit and active, lies in progress through that part of the health system set up to
care for ailing elderly people. Nursing homes were, and still are, the last resort when
behavioural difficulties, incontinence or lack of mobilisation reach the point where a
person needs twenty-four hour care.

By the 1950s some nurses, often widows 'with little business experience, but with
confidence in their nursing skill' (Durdin, 1991, p. 114), were setting up small
nursing homes to provide a service for the aged and a source of income for
themselves. These women were able to set up and own private nursing homes by
purchasing or leasing large houses. One nurse working in aged care today remembers
the nursing home her mother ran as being:

*The days of the horsehair mattress, feather pillows and eiderdowns,
red rubber mackintoshes, monstrous commodes with heavy china pans
and, in the sluice room, the inevitable enamel enema can with lengths
of rubber tubing.* (Durdin, 1991, p. 114)

She concludes that these conditions reflected the prevailing mores of the day, or
maybe were a little behind, due to the isolation of the Matron and the residents from
the rest of the world. Although this isolation still exists for residents in nursing homes,
and, some would have it, in the ghettos of hostels, boarding houses and retirement
villages, today the unwanted effects of seclusion are acknowledged and perceived as
unhelpful for a full and interesting life for elderly people. (Durdin, 1991)

In Australia focus on the particular problems of the aged and of the role of nursing
homes received very little attention until the late 1960s (Howe, 1981). At that time the
lack of nursing home care was the major consideration, rather than the quality of that
care. The injection of large amounts of government funds resulted in an increase in
nursing home beds from 25,000 in 1963 to over 72,000 in 1983 (Clare and Tulipule,
1994). At that point the growth was slowed and the present phase of consolidation
and regulation began. When, by 1986, provision of institutional beds had risen to
make 104 beds available per 1000 persons aged 70 years and over the government
called a halt to growth and indicated that it would now adopt as a target lowering the
ratio to 40 nursing home beds and 60 hostel beds per 1000 person aged 70 and over
(Brown & McCallum, 1991). This process of deinstitutionalisation was the start of the
enormous increase in frailty of people in nursing homes. The push to keep people in
the community became foremost in public policy planning. Research about the
connections between institutional care and community care for people with dementia
pushed the status of nursing home care further into the background.
A study by Brodaty et al. (1993) attempted to determine which variables best predicted prognosis and time to nursing-home admission and death in patients with dementia. The sample was drawn from a group of patients and their caregivers where the caregiver was participating in a training program that would assist them to manage at home. A follow-up study five years later found 76% of patients had entered a nursing home and 42% had died. Severson et al. (1994) studied 275 patients from The Mayo Clinic Alzheimer's Disease Patient Registry and found a high rate of institutionalisation for patients with dementia. Half of the sample of patients with dementia were institutionalised within two and a half years of enrolment in the patient registry. A total of 72% of the patients with dementia who died over the course of this study had been placed in nursing home care prior to death. The mean length of stay was 2.8 years. This finding corroborates the anecdotal evidence of Hudson and Richmond (1994) who discuss the difficulties of the long-term nature of nursing home care for people with dementia. Severson et al. (1994) also concluded that social and disease-related variables, especially marital status and cognitive and functional status, are related to risk for institutionalisation. The Brodaty et al. (1993) study found that dementia severity and rate of deterioration, together with the ability of the caregiver to cope without getting depressed or ill, significantly influenced rates of nursing home admission and death. Aneshensel et al. (1993) investigated difficulties experienced when caring for an impaired elderly relative, including decisions to place this person in institutional care. Three annual interviews were conducted with 555 caregivers to parents or spouses with Alzheimer's disease. All patients were initially cared for at home, but 192 were subsequently placed in institutional care and 146 died. These authors state that:

The odds of patient death increase substantially following institutionalisation, even when health status is controlled. These results illustrate that in-home care may be beneficial for care-recipients, but increase role-related stress for the care provider. (Aneshensel et al., 1993, p 70)

These findings give the impression that nursing home care is 'bad' - it kills the residents - and home care is 'good', apart from the fact that it leaves carers depressed and ill. An unfortunate side-effect of these kind of investigations, where the generalisation of findings has limited use due to the very individual nature of the progress of dementia and the effect of interrelated factors, is that they appear to imply that institutionalisation is the last and worst resort for care. If someone has a diagnosis of dementia the 'norm' and the expectations of health professionals and society is that they will be cared for at home, because it is detrimental for the person with dementia to go into a nursing home as they will die. This contrasts to the support
that is received if someone receives a diagnosis of cancer. This loosely-linked body
of evidence, opinions and assumptions may also appear to support the common
misperception that nursing home care is inferior care. On the other hand the Brodaty
et al. (1993) study did at one point suggest that 'Nursing home admission per se does
not seem to hasten death once allowance is made for the interaction between NHA
(nursing home admission) and rate of deterioration' (Brodaty et al., 1993, p. 647).
For reasons not clarified in that research report this finding was not included in the
authors' conclusions.

Hudson and Richmond (1994) reflect the feelings of many nurses that figures
indicating that people's death is hastened by admission to a nursing home may hide
the facts about the population that does not die. They say:

\[ \text{National statistics indicate that a high proportion of persons admitted}
\text{to nursing homes die within the first three months of transfer ... Our}
\text{figures at Melbourne City mission Nursing Home reflect that}
\text{phenomenon. From April 1991 to April 1992 there were 19 deaths ,}
\text{50\% of whom were resident for seven months or less and 23\% for two}
\text{months or less. But this does not represent the whole picture.}
\text{Although many deaths occur soon after admission (as the Department}
\text{of Health, Housing . Local government and Community Services}
\text{found in nursing homes for the aged 1993), other residents adapt to}
\text{their changed environment, enjoying a long and stable relationship}
\text{with their new friends and 'family'.} \] (Hudson and Richmond, 1994,
p.169)

The studies reported, nevertheless, support the need for resources to be poured into
community care, to reduce carer burden and to maintain quality of life for the person
with dementia as long as possible. A side-effect of this need for community support is
increasing competition for health resources between the institutional and community
sectors of the health service. Nursing-home care is seen as the last resort, a place
where people are cared for by their 'family' as Hudson and Richmond put it; care
which only requires funding and attention at a level commensurate with an ordinary
standard of human kindness.

The promotion of physical fitness, preventive medicine, dealing with pain and
extending life are all part of the new primary care concept. An offshoot of this
change is that, by emphasising quality of life, death is made less visible and, even
perhaps, less acceptable. Invisibility increases the disempowerment that has been
endemic in aged care. A brief overview of the history of geriatric nursing will give
some understanding of the prevalence of this disempowerment in geriatric care.
The background and conditions of nursing home staff

Nursing, as a profession, has been following the same trajectory of development of many other specialties; that is, attempting to gain legitimate power by a process of credentialism which would move the profession up the organisational and social status hierarchies.

The history of nursing contributed to this situation. In 1976 the nursing profession's decision to move nurse education into the tertiary sector was outlined in the Goals in Nursing Education Policy Statements (Goals in Nursing Education, 1976).

The move into the mainstream of university education was implemented slowly. Hospital training continued alongside tertiary education for almost two decades. Feminist ideology began to have a strong influence and many commentators would make the point that nurses had been:

*socialised in a patriarchy which acknowledges and supports the dominant culture that of white, middle class men. ... As part of oppressed group behaviour women and nurses are undervalued, perceived as second class citizens, and the dominant culture with its greater prestige, power and status [has] exercised control over nurses.*

(Glass, 1992)

Critics have seen this domination as a negative aspect for care. In discussing the influence of the scientific model in asylum nursing Chung and Nolan point out that nurses had neither the professional training nor the social standing to question the dominant model. The pervasiveness and unquestioned acceptance of the medical model limited the opportunities for nurses to contribute creatively to progressing the cause of the mentally ill (Chung and Nolan, 1994).

The move to tertiary education and the development of nursing as a profession was intended to change this situation, but, for gerontological nursing, the move could be seen to further marginalise their already invisible and humble position within the nursing profession. As the undergraduate programs came to be dominant, the gap between the geriatric practitioner, usually a hospital-trained middle-aged female, and the new university-trained graduate widened. The historical attitudes of obedience, service, conformity and task orientation, which were firmly entrenched by this historical progress of nursing, continued to be comfortable as 'good practice' in aged care settings while these were beginning to come under question elsewhere.
The development of gerontology allowed this situation to continue. As a separate nursing specialty, gerontology did not develop in the same way as others such as psychiatry and midwifery. Adams and McIlwraith (1963) suggest that culture and practice in nursing of the elderly retained much of the heritage of early Victorian days. They say:

*Nursing in general hospitals is one with the image of Florence Nightingale, but geriatric nursing is associated in too many ill-informed minds with the image of Sairey Gamp.* (Adams and McIlwraith, 1963, p.xvii.)

On the other hand, while these old-fashioned virtues may seem to some to be suitable for the kind of work to be performed in nursing homes, they were not producing effective care or work satisfaction. Adams and McIlwraith (1963) presented evidence that most nurses held negative attitudes towards elderly people, whether they worked with them in the main or not. Other work at that time demonstrated that much care of the elderly, especially the mentally impaired elderly, was degrading to the human spirit for both parties involved in the interactions (Robb, 1967).

The critiques of the reform movements in the late 60s and early 70s were a spur to the growing field of gerontology which had flourished since the founding of the American Geriatrics Society in 1942.

By the 1960s the Australian Commonwealth Government had, amongst its health and welfare reforms, provided legislation for nursing home benefits. For the first time Matrons began to see themselves as managers, dealing with the bureaucratic machine and associated paper work rather than primarily as clinical nurses. Organisations such as the Church, rather than private individuals, began to be responsible for providing institutional care for the majority of the aged.

In 1964 the inaugural meeting of the Australian Association of Gerontology was held. The Association was essentially formed for and by doctors. Although still dominated by doctors, nurses are now the largest professional group within the society. The goals of the society were to promote research, to eliminate the handicaps of later life and to improve the quality of life for the elderly (Sax, 1985).

Geriaaction, the professional organisation that mainly represents nurses working in the aged care area, was born in 1967. It began as a section of the Australian Trained Nurses Association, becoming an autonomous organisation in 1971. It was at this time that the term 'gerontic nurse' began to be used. Gunter (1980) explains the debates that ranged around the feeling of pretentiousness of the term 'gerontological
nursing' and yet the difficulty of trying to find one term that would be used instead of a variety of terms, all meaning the same thing, such as nursing care of the elderly and geriatric nursing. Gerontology is still seen as an uncomfortable word by many clinicians but there seems to be no other choice and it is now widely accepted as the word which describes 'the knowledge base and research focus for the area' (Gunter, 1980, p7).

Credentialism was spreading throughout nursing but had little impact in the gerontological area. At that time, and it is still the case today, many of the registered nurses in the aged care arena hold only their primary qualification gained perhaps 10 or 20 years ago. The lack of qualifications found amongst nurses in the gerontic area (Abbey, 1987) contributed to the view that specialist education was required if geriatric nurses were to be capable of contributing to finding solutions for the many-faceted needs of aged and dementia sufferers. The ready availability of employment in established fields in the 1980s was not conducive to attracting highly qualified staff to the area. There were too many other jobs with higher prestige and better salaries.

Graycar (1987), the then South Australian Commissioner for the Ageing, advised the responsible State Minister that:

There is an urgent need for suitable and effective training of all nursing home staff. If present care standards are to be maintained then staff will need to have a keener appreciation of older people's needs, hopes and desires, as well as a better knowledge of direct care techniques. (Graycar, 1987, p.55)

In spite of the reforms, training and standards that have been achieved, calls for more education for gerontic nurse practitioners as the solution to the many faceted problems of aged care have continued. Stevens and Crouch (1992) and Burdekin (Human Rights & Equal Opportunities Commission, 1993) were critical of care of the elderly suffering from cognitive deficiencies and suggest education of care staff as one way to make improvements. The Alzheimer's Association also called for funds to be provided for this purpose as there is a need for greater opportunities for education on dementia for all staff working in residential care (Alzheimer's Association Australia, 1993, p.53).

One of the reasons that investigators conclude that education is needed is that gerontological nursing content has been largely absent from undergraduate programs until recent times. It is still limited. Even though Brown (1989) acknowledges Wullis's (1982) point that gerontological nursing is emerging with a new image, he says:
A substantial increase in gerontological nursing efforts is needed, especially at the tertiary education level, including a review of gerontological nursing theory and clinical opportunities in the new college-based nursing programs. Almost all gerontological nursing knowledge is untapped or untested in spite of all the impressive and extensive clinical problems which abound ... (Brown, 1989, p.6)

Nay-Brock, a long-time observer and writer about gerontological nurses, says that nurses working in the field have often not made themselves responsible for their own professional advancement because:

... nurses generally have not chosen to work with old people as a positive career choice, but because they could not get into anything else, or because the hours suit them. Skills and knowledge are seen as relatively unimportant in this area. (Nay-Brock, 1988, p.16)

The continuing emphasis is for nurses, careworkers, family and friends to be educated to a level of knowledge where they are able to understand dementia and can therefore take a legitimate and important place as advocates in an inter-disciplinary team (Alzheimer’s Association Australia, 1993). At the present time there is some increase in opportunities for post-basic gerontic education. Australian Government policy encourages and extends these opportunities but does it by ‘one-off’ Commonwealth grants, so that often all that happens is that distance education packages and videos are produced, but not used effectively, and short courses are run to fulfil training levy conditions. It is still too early to say with confidence whether the demise of the training levy legislation will lead to any change in this.

Education also has many gaps at the senior management level. In 1987 a South Australian Ministerial report stated that many people who undertook gerontic nursing courses often became Directors of Nursing and thus spent more time on management than clinical issues.

Education or training for care of people with late-stage dementia does not seem to be able to take into account the lessons of history or keep up with the present. The lack of attention paid to education and the changing nature of gerontological work may have contributed to the frustration and tensions surrounding gerontological models of care that have been observed before, and since, embarking on the study. During the development of the profession, nursing has been struggling to articulate frameworks of care that fit the patterns, traits and products of a particular category of work. These do not fit easily with the models that exist because of the dominant
forces throughout history and the effect of public policy. The clash between the medical model of care, a holistic nursing approach and the social role valorisation ideal is another factor worthy of consideration in the analysis.

The models of care that guide and institutionalise policies

Modern-day analysis of the models of institutional care began with critiques such as Foucault's (1967) *Madness and Civilisation* and Goffman's (1961) *Asylums*. Their work in raising issues and questioning accepted routines gave impetus to exposes such as *Sans Everything* (Robb, 1967) and Wolfensberger's (1975) *The Origin and Nature of our Institutional Models*. One difficulty with this analysis was that de-institutionalisation and normalisation principles were transferred from the care of the insane, criminal and the disabled to the care of the aged, and therefore the habit of linking the old with other socially devalued groups continued.

Social Role Valorisation arose from a model of care developed by Wolf Wolfensberger in the 1930's which he called 'normalization' (Wolfensberger, 1932). The thrust of the movement at that time was to change the 'asylum like' institutions in which young people with a disability lived into places that were more like a normal household. The idea of normalization was a world-wide success and the principles on which it was based became the accepted criteria for care planning for disadvantaged groups of all kinds. Australia was no exception. In 1987 normalization was explained to Australian health care providers using the following definition:

*Normalization is the utilisation of culturally valued means in order to establish and/or maintain personal behaviours, experiences, and characteristics that are culturally normative or valued* (O'Brien, 1987)

This generalised statement was useful in providing a broad base in order for normalization principles to be introduced into all settings, but it was also open to very wide interpretation. Normalization found its way into in to aged care in Australia through the application of the "Outcome Standards" devised by the Commonwealth/State Working Party in 1987 and set out in the publication *Living in a Nursing Home* (Commonwealth/State Working Party, 1987). These ideas were expected to be implemented through an emphasis on the architecture, physical environment, language, meals, activities and nursing care planning mirroring, as much as possible, the day-to-day life we all lead. Nurses, along with most other health care
professionals, saw these principles as being fair and equitable and a positive advantage to those they care for. However, as time progressed and the absurdities and difficulties of a rigid application of normalization principles began to be apparent, criticism of the movement appeared and gained momentum. The normalization protagonists responded to the critiques of the movement by re-naming normalization as 'Social Role Valorization' (Wolfensberger, 1981). This change was to indicate that valuing the role of a person in society was the central tenet of the ideas to be implemented, rather than an emphasis on the environment and architecture.

As the social role valorisation movement was gaining influence over aged care policy the medical model was in its ascendancy in the health care sector generally.

There is a considerable body of literature which has discussed the medical model over many years (Illich, 1976a & 1976b; Navarro, 1978; Taylor, 1979; Preston, 1981, Fitzpatrick et al., 1984; Turner, 1987; Preston, 1981; Bates & Linder-Pelz, 1990; Short et al., 1993). The Cartesian mind/body split is seen to be the basis of the medical model as Turner's description suggests:

*Disease is regarded as the consequence of certain malfunctions of the human body conceptualised as a biochemical machine. Secondly, the medical model assumes that all human dysfunctions might eventually be traced to such specific causal mechanisms within the organisms; eventually various forms of mental illness would be explicable directly in terms of biochemical changes. The medical model is reductionist in the sense that all disease and illness behaviours would be reduced causally to a number of specific biochemical mechanisms. Furthermore the medical model is exclusionary in that alternative perspectives would be removed as invalid. Finally, the medical model presupposes a clear mind/body distinction where ultimately the causal agent of illness would be located in the human body.* (Turner, 1987, p.9)

Popkin et al. (1981) suggest that Descartes should be blamed for having created all the problems that arise from the concept of seeing mind and body as two totally different types of entities. This reproach seems especially deserved when we try to grasp the complex nature of dementia. The reductionist model has contributed to the marginalisation, since Nightingale's time, of any nursing models of care that have concentrated on a holistic view of health and the contextual nature of care. The following summary of the ideas of nursing theorists through history demonstrates how all are aiming to encapsulate this view of care one way or another.
<table>
<thead>
<tr>
<th>Theorist</th>
<th>Meaning of Nursing</th>
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<tbody>
<tr>
<td>Florence Nightingale, mid 1800s</td>
<td>A calling; discover and use nature's laws regarding health.</td>
</tr>
<tr>
<td>Hildegard Peplau, 1952</td>
<td>Significant, therapeutic interpersonal process.</td>
</tr>
<tr>
<td>Ernestine Wiedenbach, 1960</td>
<td>Four elements of clinical nursing, philosophy (way), purpose (why), practice (what), and art (how).</td>
</tr>
<tr>
<td>Ida Orlando, 1961</td>
<td>Helping to meet patient needs through nurse-patient relationships.</td>
</tr>
<tr>
<td>Virginia Henderson, 1960s</td>
<td>Assisting individuals in performance of those activities contributing to health or its recovery</td>
</tr>
<tr>
<td>Dorothy Johnson, 1960-1980s</td>
<td>External regulatory force to organise and integrate client behaviour and assist in maintaining balance.</td>
</tr>
<tr>
<td>Dorothea Orem, 1969-1990s</td>
<td>Helping service that assists individuals toward designing, providing and managing systems of therapeutic self-care.</td>
</tr>
<tr>
<td>Imogene King, 1968-1990s</td>
<td>Process of action, reaction and interaction where nurse and clients share information to assist clients to maintain health and function in their roles.</td>
</tr>
<tr>
<td>Sr. Callista Roy, 1970s-1990s</td>
<td>Goal is to promote adaptation in regard to the four adaptive modes (physical, self-concept, role function and interdependence).</td>
</tr>
<tr>
<td>Martha Rogers, 1970-1990s</td>
<td>Exists to serve people. Committed to maintaining and providing evaluative, therapeutic, and rehabilitative services.</td>
</tr>
<tr>
<td>Betty Neuman, 1970s-1990s</td>
<td>Reduction of stress factors to affect optimal functioning through primary, secondary and tertiary prevention.</td>
</tr>
<tr>
<td>Madeline Leininger, 1970-1990s</td>
<td>Culturally based profession involving professional caring actions made to assist, support or facilitate another person or group with a need to improve or ameliorate a human condition or lifeway.</td>
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(Doheny, Cook and Stopper, 1992, p.52)

Some more contemporary theorists not mentioned in this summary are Levine (1967), Watson (1979) and Parse (1981). Watson used a humanistic viewpoint from which to analyse caring, which she saw as the essence of nursing. The 'carative' process, she says, aims to help people 'attain (or maintain) health or die a peaceful death' (Buckenham and McGrath, 1983, p.72). Parse concentrated on an existential analysis while Levin outlined a theory that was based around the notion of health depending on the conservation of body energies. These are holistic views far removed from any connection with the Cartesian ideology.
When the Australian authors Buckenham and McGrath (1983) summarised the state of nursing theory they concluded that most of it was rhetoric. This rhetoric suggested that nursing practice was holistic, multi-factorial and focussed on the patient, but the experience of nurses in the social world of the hospital was one of learning to be deferential and subservient, fitting in with the medical model and treating the patient as if they were the most inferior part of the whole health team process. Buckenham and McGrath used acute hospital settings for their exemplars as it was and is the dominant culture against which nursing measures itself. Today Australian nurse scholars such as Lawler (1991), Pearson (O'Brien, & Pearson, 1993), Taylor (1994) and Lumby (1995) are calling into question some of the rhetoric of the past and suggesting that a closer connection between theory and practice is necessary. These scholars are suggesting that nursing needs to be seen as it is practised recognising, as Taylor sees it, the reciprocal and therapeutic nature of the nurse/client interaction. She says:

*Nursing is what happens between nurses and patients in contexts of care, and it is facilitated by the humanity of both parties, as they negotiate the illness experience together.* (Taylor, 1994, p.241)

or as O'Brien and Pearson say:

*Nurses develop relationships through proximity to the people they care for with an associated awareness of individual behaviour patterns that are frequently invisible to people not in such close contact.* (O'Brien, & Pearson, 1993, p. 122)

Gerontological nursing theory has had much less academic focus and remained less well developed. Nurses working in the area were far more concerned with reforms for aged care in general and trying to make conditions even slightly attractive so that committed nurses would work in them. Theoretical rhetoric had little part to play; it just dribbled down in the hierarchical nursing system.

Norton, perhaps the first gerontological nurse theorist, worked ceaselessly for reform in aged care following her role in the 1962 research team that undertook the first large-scale study looking at the care of older people. She insisted that:

*solutions to the practical nursing problems are not concealed within practical nursing experience (as it was supposed) nor are they to be found in a concerted attack upon specific practical difficulties (as it was hoped). They lie in the treatment of the environment.* (Norton, 1967)
Norton (1967) commented that only saints or fools would want to work in that present aged care environment and that reforms for improved working conditions for the staff must parallel reforms for the care of the patients.

Norton (1954, 1977) had developed and was refining a model of geriatric nursing care with an emphasis on the therapeutic role and function of nurses and the milieu in which they worked. Much of the care of the elderly in the UK, where the literature was emanating from, took place in long-stay wards attached to acute hospitals. This environment was questioned as being suitable for the special and different kind of care needed for the elderly suffering from chronic conditions.

Rudd's book, *The Nursing of the Sick Elderly*, which was first published in 1953 and reprinted up to the seventh edition in 1972, details practical nursing care of the elderly with very little theoretical base except that the elderly are not to be neglected. He states that even though the old are economically unproductive they should not be allowed to die off unobtrusively because 'such thinking is inconsistent with the experience of the great civilisations, both of the East and the West and with the tenets of the great religions, Christian and non-Christian' (Rudd, 1970 p.15).

The fact that the concept of holistic care as expressed by nurse theorists was only rhetoric could be shown to be true as this view has remained unchallenged. The view that old people should 'not being allowed to die off unobtrusively' has been translated into the concept that they need to be 'valued'. This valuing has then been further translated within the dominant medical model, so that 'valuing' equates with being kept alive by the latest technology available. Holistic models contained within nursing theory have not challenged this and have actually had the effect of contributing to a state of confusion in the aged care sector. Miller and Gwynne (1972) suggests that this results in nursing homes delivering a 'mixed' model of care, care which is both medically based and encompasses holistic principles. Miller and Gwynne (1972) define two different models of residential care - the Warehousing and the Horticultural model. They suggest that under the Warehousing model the:

... primary task becomes to promote physical life. It represents an attempt to translate the model of the hospital into the setting of the residential institution. The intake into the system is a resident defined in terms of physical malfunctioning ... The resident is expected to become dependent on, and grateful for, the ministrations of nurses and doctors. (Miller and Gwynne, 1972, p.85)

Under the Horticultural model:
... the intake into the system is conceived as a deprived individual with unsatisfied drives and unfulfilled capacities ... The primary task is to develop these capacities. (Miller and Gwynne, 1972, p.87)

Gibb (1990b) also suggests that these two models coexist in gerontological care. Following research on the first nursing unit in the UK Professor Alan Pearson describes two differing models of care, the 'caretaker nursing' model and the 'professional oriented nursing' model (Pearson, 1983). His emphasis is on the difference between care that protects and limits people and care which promotes independence and rehabilitation.

Current aged care policy, according to the argument advanced in this thesis, can be most easily identified by reference to the horticultural model or the professional oriented nursing model. On examination we find a large degree of overlap between these two models and the concepts variously referred to as Social Role Valorisation or a holistic model of care. Throughout the thesis I refer to this phenomenon as SRV or 'normalisation', because this is the name most commonly used by staff throughout the culture I am discussing.

There is another model of care, that of palliation, that exists in health-care institutions. For those with a recognised terminal illness with a reasonably predictable journey towards death, such as people with cancer and AIDS, palliative care is usually offered in a hospice as death draws near. A hospice is a medically-based unit with a doctor always available and staffed at very high levels when compared to nursing homes. Comparing a hospice standard of 45.5 nursing hours per week per patient (Hunt & Maddocks, 1994) to the 27 nursing hours per resident per week for a person in a nursing home who is categorised at level 1, the highest rating possible (Commonwealth Department of Health Housing & Community Services, 1992) indicates the disparity in public resources committed to these modes of care. A hospice model of care is based on totally different principles to either SRV, holistic nursing care or the medical model. It is a model of care that concentrates on offering assistance to relieve suffering, both physically, mentally and spiritually.

Palliative care principles seem to fit exactly with the same humanitarian approach that has guided health care reformers for decades. Dame Cicely Saunders explains Peabody's 1927 philosophy on which St Christopher's Hospice, the oldest and most famous hospice, was based, when she says:

*The secret of caring for the patient is caring for the patient* ... *What is spoken of as 'clinical picture' is not just a photograph of a man sick in bed; it is an impressionistic picture of the patient surrounded by his
home, his work, his relations, his friends, his joys, sorrows, hopes and fears. (Saunders, 1990, p.v)

Although this statement seems to reflect a holistic approach to care, it sustains the assumption that the patient will still be 'whole', that their world will still be intact. This is because palliative care has developed with its main focus to care for people with cancer. In general, palliative-care protocols fit care for people with advanced cancer but need to be adapted for other kinds of care.

Dr Ian Maddocks, the first Professor of Palliative Care in Australia, says the terms palliative care, terminal care and hospice care are generally used interchangeably but distinguishes them 'to give each a particular emphasis'.

Palliative care when cure is no longer possible, aims to control symptoms and sometimes also to prolong life (eg. palliative radiotherapy).

Hospice Care no longer hopes to prolong life, but emphasises symptom control and the quality of remaining life.

Terminal care refers to the last stages of an illness when support for the family may become especially important.

(Maddocks, 1993, p.5)

This study will link the phenomena of SDAT and the concept of 'terminal illness'. This linkage may be met with the objection that SDAT can not be described as a terminal illness in any medical sense at all. The plaques and tangles of AD do not 'kill' in the orderly, easily measured and well researched way that cancer does.

However, this semantic distinction unduly privileges a specific approach to health care and, from a holistic perspective and certainly from a nursing perspective, hinders rather than helps understanding. Cancer cells cause organs to stop functioning; so do the plaques and tangles of AD and the thromboses of MID. The plaques and tangles of AD invade the brain with consequences as damaging as invasive cancer cells, but in a much slower and more insidious form. They do not 'kill'. They do not affect the mechanical mechanisms that keep the heart pumping and the lungs exchanging oxygen. It is other complications of the ageing process, immobility or the iatrogenic consequences of institutionalisation that result in the physical, as distinct from the spiritual, death of these people. The increasing frailty of nursing-home residents, questions surrounding quality of life, changing views about death with dignity and the economic impact of caring for so many dependent people is beginning to produce a focus on the issues surrounding palliative or hospice care in nursing homes (Hunt & Maddocks, 1994, Abbey, 1994, Hudson & Richmond, 1994).
In the last decade public policy has given little attention to palliative care connected with chronic conditions of the elderly. Instead, policy guidelines have concentrated on practices which do not stigmatise or stereotype the aged and concentrate on quality-of-life. This emphasis on individual rights is meant to ensure that the elderly are offered the same level of service that the medical profession can give to any citizen, that is, assistance to live as long as possible and be as well as possible. If a chronic condition becomes overwhelming to the point where an elderly person cannot care for themselves, or be cared for in the community, then he or she will also have the right to be cared for in an environment that will value them. Policy is closely connected to public opinion and the social and legal forces in play at the time it is formulated. The connections between aged care policy and the moral and legal debates in Australian society today are also important for an understanding of the nature of nursing-home care.
Chapter 2

Policy, laws and moral standpoints, emotional work

Public policy

Attention directed to government policy is generated by various forms of public pressure, one of these being a marked demographic imperative. AD and associated disorders are conditions most common in the aged, a section of the Australian population that is increasing as a percentage of the whole.

The proportion of the population aged 65 years and over is projected to increase from 11 percent in 1991 to over 22 percent by the year 2051. The increase in the proportion of those aged over 80 will be even more marked, with a projected rise from around 2 percent to around 8 percent of the total population. (Clare & Tulpule, 1994, p.72)

Life expectancy has been growing since the last century, with those 85 years and older being the fastest growing group. This population increased from 55,000 in 1966 to 152,000 in 1990 (Clare & Tulpule, 1994).

This forecast is particularly significant for South Australia, because it has a higher proportion of people in the age groups 65 years and above when compared with the other states and this will remain the case until at least the year 2021 (Office of the Commissioner for the Ageing, 1993).

This is an important demographic shift as the prevalence of dementia increases exponentially with age (Jorm & Henderson, 1993). People over 80 years of age have a one-in-four chance of developing dementia. Burdekin (Human Rights and Equal Opportunities Commission, 1993) estimates that by the year 2001 there will be 200,000 people in Australia suffering from dementia. The situation is of even more concern when one considers that, on average, four other people in the community are affected through being in some kind of supportive or involved role (Potter, 1994), often at a cost to their own emotional well being. The requirement for 24-hour care and the difficult nature of that caring is the reason that people with dementia are the greatest users of nursing home care.
Nursing homes in Australia accommodate approx 75,000 people (Office of the Aged, 1995). An estimated 60% of the resident population in nursing homes suffer from dementing conditions (Commonwealth Department of Community Services and Health, 1991). The figure is higher than this if RCI (Resident Classification Instrument) questions are used as indicators. In March 1995 data from the Commonwealth Department of Human Services and Health show that '74% of nursing home residents score highly on at least one of the four dementia related questions'. Translating this into numbers, a review undertaken by the Alzheimer’s Association Australia found that:

... there are over 50,000 people with moderate or severe dementia living in residential care facilities in Australia, including an estimated 43,800 in nursing homes, at least 5,700 in hostels and 3,000 in psychiatric hospitals and other mental health facilities. (Alzheimer’s Association Australia, 1993, p.1)

Women are more likely than men to need nursing home placement for two reasons. Women live longer than men and men have a greater chance of being cared for in the community until death or until they exhibit unmanageable behavioural problems.

With the ageing of the population the projected increase in health care expenditure is expected to rise from $29 billion in 1994 to $126 billion in 2051, an increase in the fraction of GDP devoted to this purpose from 8.4% to 11.1% (Clare & Tulpule, 1994).

This means that economic considerations are likely to have an increasing impact on care that will be available to the proportion of our people in our nation who will suffer from a condition which leads to dementia. Politicians and health bureaucrats have acknowledged the growth in the numbers of people with the potential to develop SDAT as part of the greying of Australia, and have instigated policies and procedures to be followed that reflect their ideas of how the situation should be managed, both from an economic and moral stance. The recent thrust of public policy affecting the care of the aged has revolved around value positions that uphold the principles of rights and choices from seemingly altruistic and individualistic motives. In various government reports (McLeay, 1982; McDonald & Bates, 1988; Ronalds, 1989; National Action Plan for Dementia Care, 1992; Braithwaite et al., 1992 & 1993.) or journalistic exposes (Hailstone, 1988; Hogben, 1990) there have been instructions to health-care administrators and professionals about what should be done from the standpoint of this moral framework. These instructions were consolidated into the Outcome Standards. Other changes were not mandatory but became expected
behaviour, for example, people who were admitted to nursing homes were to be called residents, not patients, under the rubric of valuing the chronically sick elderly, a philosophy that, prima facie, must be applauded. Recommendations from many of these official reports related to the need to educate staff so that 'attitude change' would occur. Another theme that emerged from these reports was an increasing emphasis on individual rights and the freedom, even with the uncertainty of an action being safe. This argument became jargonised in nursing home language as the residents' rights to 'dignity of risk'. Also a lot of emphasis was given to the standardisation of quality of care, staffing numbers and staffing mix.

A study to:

* determine the impact of staffing mix on nursing home residents' quality of care and life as measured against the standards set out in 'Living in a Nursing Home'.* (Department of Community Services and Health, 1990, p.xiii)

was undertaken in 1990 by Deakin Institute of Nursing Research (Pearson *et al.*, 1990 ) This report analysed the debate amongst policy makers about the basis for staff provision in nursing homes, that is the question of whether skilled nursing care is required, or whether care is only needed at a level which would be satisfactorily provided by untrained workers of a kind and caring disposition. The analysis of a comprehensive literature review showed that experts were divided on this issue. The main findings of the skills mix report were that, in Australia, enrolled nurses were the least satisfied members of nursing home staff, that the numbers of diversional therapists needed to be increased; that registered nurse levels should remain as they were as increased levels did not have a significant impact on quality of care; and that in-service training should be encouraged. The role and attitude of the Director of Nursing (DON) was found to be pivotal in relation to quality. Nurse assistants rate nursing home work in much the same way as registered nurses when measured on various attitude and satisfaction scales. Satisfaction or quality of care as perceived by residents could not include those residents with dementia. So, as with many other studies, the needs or desires of people with dementia could not be measured or analysed. If the same study had been undertaken using some kind of 'satisfaction' measure for people with dementia the results may have been very different. However, these findings would seem to be well supported by the evidence found in this study.

In all these various reports the culture of care itself is rarely treated as being important or subject to much analysis. Henderson and Jorm (1986) reported that:
... no one showed an interest in the problems encountered by staff in what is indisputably a demanding task. ... Nursing home and hostel staff are presently a lynch-pin for the care of the elderly with dementia; yet little is known about the conditions under which they work, the problems they endure and the satisfactions they obtain. (Henderson & Jorm, 1986, p.48)

In response to these and other challenges the McLeay (1982) and Giles (1985) reports were commissioned and the recommendations from these resulted in the appointment of Dr Rhys Hearn to undertake a consultancy (Rhys-Hearn, 1986) about quality of care in nursing homes. The results of this report led to the legitimisation of the quasi-legal 'Outcome Standards', the Care Aggregated Module (CAM) and Standard Aggregated Module(SAM) funding model and the extensive government controls which flowed from these. CAM funding provides the money for the staffing of nursing homes and SAM funding provides the money for infrastructure costs.

By 1987 the federal government had taken over most of the responsibility for nursing homes and introduced a totally new way of assessing their suitability to receive government funding. The old system of State government and local-council public-health inspectors checking and monitoring matters mainly concerning hygiene and safety gave way to a monitoring process using 31 Outcome Standards (Commonwealth/State Working Party on Nursing Home Standards, 1987) designed to measure quality of care. This change has had an enormous impact on the culture and style of nursing home care and has been part of the focus of the study.

Another shift during the last 20 years, due to a combination of change in philosophy as well as the increasing demand for institutional care, was the move from the situation where a General Practitioner (GP) had the power to admit people to a nursing home to the systematic, bureaucratic rationing process that exists today.

Today in order to be admitted to a nursing home, a person has to be assessed by an Aged Care Assessment Team (ACAT). The Mid Term Review of the Aged Care Reform Strategy indicates that the Aged Care Assessment Teams (ACATS) have a vital role at the interface of acute and long-term care for the aged (Department of Health, Housing, Local Government and Community Services, 1993). These teams are made up of nurses, doctors, social workers, occupational therapists and other health professionals in different combinations at different places. If the person with dementia is not considered to need nursing home care the ACAT will assist in arranging community care or hostel care. Reassessment can take place as the dementia worsens. To be able to be admitted to a nursing home a form known as the NH5 must be signed by the person being admitted. For people with dementia this is
sometimes either impossible or meaningless and so a close relative has to shoulder the burden of signing the form which they often see as 'putting away' their mother, father or spouse. For a person with dementia who has no relatives or advocate an application has to be made to the Guardianship and Administration Board for the NHS to be signed.

Once a person with dementia is admitted to a nursing home their care will be affected by the values, philosophies and presuppositions of public policy, of the controlling body of the nursing home and of the staff themselves. This moral and intellectual framework will be the one which shapes the context in which people with late-stage dementia begin their journey to death. The customs, practices and social conventions that will inevitably impact on nursing home staff's capacity to identify distress and suffering in others and their view of the right or wrong ways to assist in relieving it, will be shaped by the widely held ethical conventions of the time.

**Moral framework**

Differing ethical arguments about end-of-life decisions that are culturally relevant to the Australian context are discussed amongst bioethicists, church representatives and palliative care specialists. Helga Kuhse and Peter Singer from The Centre for Human Bioethics at Monash University and Brian Stoffell of Flinders University are outspoken Australian philosophers who openly support voluntary euthanasia. Peter Singer takes a radical, but logical, point of view, arguing the need to identify 'a person' to set the margins for when killing is wrong. He suggests that the intrinsic dignity of a sentient being can be demonstrated in such attributes as rationality, self consciousness, language at some level of sophistication and the ability for abstract reasoning. If these are then taken as measures for the meaning of 'a person' this term can be extended to animals such as the great apes, dolphins and to a limited extent some other animals extending down the evolutionary scale (Singer, 1994). It is clear that, on Singer's view, we need to see beyond the physical form of the living object, to go deeper than merely recognising its species, to determine how we should treat that life-form in various circumstances. Species membership, for Singer, is not irrelevant, but neither is it conclusive. He explains his views in these terms:

*If we compare a severely defective human infant with a non-human animal, a dog or a pig, for example, we will often find the non-human to have superior capabilities, both actual and potential for rationality, self-consciousness, communication and anything else that can plausibly be said to be morally significant.* (Singer, 1994, p.201)
This mode of argument has not been, but could be, extended to a person with late-stage dementia. The attributes of rationality, self-consciousness, language at some level of sophistication and the ability for abstract reasoning were all but lost to the residents in this study. This is not to say they are no longer to be regarded as sentient beings as Singer would understand that term. Nor is it necessary to contradict Megan-Jane Johnson's (1989) view of sentience as the ability to be either benefited or harmed, which means an ability to feel pleasure or pain. She says, and Singer would certainly agree, if one has sentience then one has interests, and can make claims. This is not in question. What must be questioned is the nature and extent of the claims late-stage dementia sufferers are entitled to make and the definition of the obligations we continue to bear in respect of them. If this position was accepted as a logical moral argument, it could provide a starting point to discuss the implementation of palliative care for people with dementia.

Without claiming to do justice to the complexities of Singer's argument we may approach it through his claim that:

\[
\text{a being that is not a person does not have the same interest in continuing to live into the future that a person usually has, but it will still have interests in not suffering, and in experiencing pleasure from the satisfaction of it wants. Since neither a newborn infant nor a fish is a person, the wrongness of killing such beings is not as great as the wrongness of killing a person. But this does not mean that we should disregard the needs of an infant to be fed, and kept warm and comfortable and free of pain, for as long as it lives. Except where life is at stake, these needs should be given the weight they would be given if they were the needs of an older person. The same is true, with the necessary changes for its different needs, of the fish. Fish can surely feel pain. The pain matters as much, in so far as rough comparisons can be made, as similar pains experienced by a person. We do infants wrong if we cause them pain or allow them to suffer, unless to do so is the only way of preventing greater suffering.} \\
\text{(Singer, 1994, p.220)}
\]

This argument is persuasive and highly relevant to this study.

Tobin attacks Singer's view by arguing that the essence of being a human being is 'that they are united in a certain kind of fellowship with others' (1994, p.6) and therefore 'killing' or 'letting die' a person is a very different case to killing a fish. Tobin goes on to describe this fellowship as one which exists because of choices people make, the ability to reason. As people with late-stage dementia have, as far as we can tell, lost the ability to reason Tobin's view excludes these people. The status of
'personhood' for someone with dementia has still to be resolved. At some stage in the dementing process it could be argued that this 'person' has lost rationality and is now no more, or no less than, a sentient being.

The basic premise put forward by Singer's study is simple. He maintains that it is morally correct that we should not cause suffering and should relieve it where we can. What constitutes 'suffering' and 'relief' then become the issues to be debated. Stoffell's view is that this decision needs to be taken by the person themselves. He maintains that it is morally correct to act in a person's best interests and that we must respect their individual judgement about what they would consider to be 'suffering'. That suffering is very individual has been movingly written about by those who have faced the prospect of death (Dunlop, 1990 & Keenan, 1993). Stoffell also maintains that we are capable of making predictions about how we would want to be treated if we became demented, and that this choice is a right to which we are morally entitled (Stoffell, 1995). The argument against this view is that no-one can have insight into what they may wish as a 'demented-self'.

These ethical positions are increasingly being supported in law.

A recent landmark judgement in Britain about the treatment of Tony Bland has led to new moral arguments and legal decisions about the 'death with dignity' debate. Tony Bland was a victim of the Hillsborough soccer disaster where 95 people died when they were crushed against a fence. Tony Bland did not die, but was left in a permanent vegetative state. When it seemed clear to the treating doctors that Tony's condition would never change, permission was sought to withdraw the treatment which was keeping Tony alive. This treatment was not a respirator - Tony needed care of his body through, for example, assistance with nutrition, elimination and movement. This body maintenance is similar to that carried out in much nursing-home care. The Bland case went to the House of Lords whose judgement allowed the body maintenance for Tony to be withdrawn.

As Singer (1994) reports it:

*On one level, the British approach is straightforward common sense. As Lord Mustill said in the House of Lords 'the pitiful state of Anthony Bland and the suffering of his devoted family must attract the sympathy of all'. No doubt this sympathy was a powerful factor in leading all of the judges, in each of the three courts that considered Bland's case, to the same conclusion. No-one who reads these judgements can be in any doubt about the fact that all the judges are searching for a solution that brings an end to a tragedy that is*
already terrible, and threatens to be drawn out, in the most grotesque way, over decades. Nevertheless, when we recall the pronouncements of judges in earlier cases about life and death, the judgements in the Bland case do break new ground, in two crucial respects. They allow considerations of the quality of life to enter into a decision whether life should be prolonged. And they accept as lawful a course of conduct that has as its aim and object the death of an innocent human being. Putting these two points together, it is no exaggeration to say that the Bland case marks the moment at which the courts ceased to give effect to the traditional principle of the sanctity of human life. (Singer, 1994, p.64)

Singer, Kuhse and Stoffell maintain that this move towards rationality and honesty in facing death and discontinuing life support when there is no benefit is a positive and logical step.

The ethical arguments of these three philosophers do not convince everyone. They have been met with much opposition. So other arguments and views must be canvassed.

The Roman Catholic ethicist Nicholas Tonti-Filippini and his supporters see the stands taken by both Kuhse and Singer as wrong. They see these attitudes as the precursor of the 'slippery slope', forming attitudes that will further break down the already disintegrating moral fabric of our society (Glover, 1977; Tonti-Filippini, 1994b).

In accord with their Church's position they do not believe that relieving suffering which results in ending a life is wrong. However, they see a very distinct difference between acts of omission, letting die, and commission killing.

The law in Australia is clear on this point. Active euthanasia, the ending of a life is illegal. However, increasingly, this is being widely discussed in legal fields. As this study was being completed the Consent to Medical Treatment and Palliative Care Act 1995 was assented to in South Australia. This Act supports the concepts of good palliative care orders and advanced directives. At the same time the Rights of the Terminally Ill Bill was passed by the Northern Territory Parliament, although it is now likely to be challenged by a Private Member's Bill. If this Act is proclaimed it will allow a medical practitioner to assist a patient to end his or her life. The illness must be 'causing severe pain and suffering' and the patient must be predicted to die within 12 months. The definition of 'assist' contained in the Bill is:
'assist' in relation to the death or proposed death of a patient, includes the prescribing of a substance, the preparation of a substance and the giving of a substance to the patient for self administration, and the administration of a substance to the patient.

This changing moral and legal framework has differing acceptance amongst all sections of the population, including the elderly. Answering an opinion poll question is very different from facing individual decisions about death and very different answers may be forthcoming. The elderly can fear that the legalising of euthanasia will mean that they are further marginalised. In Action Network, the Australian Pensioners and Superannuants' Federation's newspaper, the following comment was made with regard to the Northern Territory Bill while it was still before the House of Assembly.

Passive euthanasia - allowing people to die by not giving them further medical treatment - has much support among older people, as has active euthanasia which the Northern Territory Bill would allow. ...

... [we must, however] make sure that, for older people on the wrong end of pervasive ageist attitudes in the health system, euthanasia laws won't just be a way of denying them decent health care for the last time. (Editorial, 1995, p.2)

When this study began none of these issues was being discussed in such a wide forum. As the study progressed it was clear, however, that issues of 'letting resident die' were emerging and would need to be a major part of the analysis. One of the difficulties with discussing any form of care for the elderly that does not put its primary emphasis on curing, or assisting the elderly person by raising his or her 'quality of life', seems to be the fear that this would be the start of the 'slippery slope'. Mitchell and Lovat call the 'slippery slope' debate the 'give an inch and take a mile argument' (1993, p.56). The essence of the argument is that once 'killing' is legalised then the line between those who choose to be killed, and those who will get killed without their clear and explicit consent and possibly for other reasons, will eventually get blurred.

Roger Hunt attacks the 'slippery slope' argument by saying:

Doctors have the responsibility of protecting the rights and interests of their sick and vulnerable patients - we are not in the business of abusing them. But opponents of euthanasia tend to portray doctors as untrustworthy or incompetent, and prone to a lust for killing. This is an insult to Australian doctors. It is also a ridiculous claim that Australian governments and doctors would conspire to produce a Nazi holocaust. (Hunt, 1995)
There seems to be a presumption that euthanasia for the aged would be the marker for the start of the slippery slope process. No counter argument has appeared in the literature putting forward another point of view, that to leave the elderly out of the debate denies them natural justice. They are being denied choices that the rest of society are demanding. No societal group is homogeneous and opinion will be just as diverse amongst the elderly as in the rest of the population, but new legislation will primarily assist those suffering from illness with a predictable pattern to death, not a feature of the chronic illnesses that the elderly suffer.

A recognition that the public are wanting to be informed and involved in decisions about their death is shown by a slow increase in publicity about the 'death with dignity' debate over the last decade. Examples of sensationalism abound, however, such as the story titled 'Bending euthanasia laws in the name of mercy' (Levy, 1987) which begins:

For a moment their eyes met like a final embrace. The pretty young woman tightly holding the hand of her teenage son gazed down the length of the hospital bed at her husband. A priest and a nurse stood by in the private room. The vast bearded figure of Peter Admiral gazed at them all. They were ready. He plunged the hypodermic needle swiftly into the patient’s arm and even before he had withdrawn it the young man’s eyelids were closing on a last look at his family. (Levy, 1987)

This melodrama is far away from the reality of death in a nursing home, yet these images make the readership aware that assisted death is possible. This report was of one incident in Holland that became a test case, but the image that stays with people is that there are opportunities available for a 'choice' of death when life becomes unbearable. This is only the case in very particular circumstances in Holland. It is not a possible scenario in Australia. Headlines such as 'When a doctor is asked to turn killer' (Ragg, 1990) are also typical of the overstatement of the kind of decisions that can be made when someone is suffering greatly before death. This use of drama limits opportunities for sensible discussion of the issues surrounding limits to care, the value of advanced directives, dying and dementia.

This situation has been happening for over a decade. A 1982 headline reads 'Boy chooses to die' (Anon. 1982). A year later an article covering the passing of South Australian Natural Death Act in 1983 is headed 'SA to get first right-to-die law' (Debelle, 1983). When the Dutch parliament did eventually support the concept of voluntary euthanasia even the conservative ABC News bent the truth enough to make the situation emotional. They reported:
The Dutch parliament has effectively legalised euthanasia, the first western country to do so. Doctors will be allowed to practice mercy killing, in some cases without the consent of the patients. (Warburton Media Monitoring, 1993)

By 1994 media coverage of end-of-life issues had increased quite dramatically. One example was a Four Corners program (ABC Television, 1994) which was advertised as discussing the issues surrounding 'a way to go'. They did this by concentrating mainly on a story of a person with a diagnosis of terminal cancer who had chosen not to have chemotherapy or radiotherapy treatment, who had elected to die in her own home and who had made an arrangement with her doctor that she could choose to control her pain relief at the end to a level which would cause her death. The reporter started the story with the fact that 'one in four people will die with cancer', keeping the discussion about palliation, limits to care and euthanasia in the cancer arena. Two nursing home residents had been interviewed for the program about end-of-life issues for the elderly and those suffering from dementia. None of this footage was included.

There has also been extensive media coverage surrounding the publication of the Kuhse book Willing to listen, wanting to die and the review undertaken by Baume and O'Malley (1994) which surveyed doctors' ways of complying with patients' requests to die. This coverage resulted in a public debate between those doctors who support euthanasia and those who don't. The differences between Helga Kuhse and Nicholas Tonti-Filippini were aired. Kuhse headlines her comment in Opinion 'Let patients die with dignity', and Nicholas Tonti-Filippini entitled his opposing view 'Euthanasia undermines rights of sick' (Tonti-Filippini, 1994a).

Kuhse points out that the Baume study demonstrates that:

many doctors will, at a suffering patient's request, take direct steps to end the patient's life. Compassionate doctors will occasionally take this step, even though voluntary euthanasia is clearly unlawful and may attract the charge of murder. (Kuhse, 1994a, p.11)

Kuhse goes on to indicate that it is time to stop debating the issue of voluntary euthanasia and take steps to legalise the process. Tonti-Filippini links the support of euthanasia to economic rationalism and the devaluing of life. Here he links his views about the slippery slope argument with care of the chronically sick, the majority of which are the aged. He comments that:

We are rapidly approaching the stage when the only care available to the chronically ill is care that terminates the need for care: killing.
Euthanasia would certainly improve the throughput rates - in the door and out to the morgue. (Tonti-Filippini, 1994a, p.11)

Pollard, another long-time opponent of Kuhse, supports this side of the argument by quoting figures from Holland that '27 percent of doctors admitted killing patients without request' (Pollard, 1994, p.7). This evidence emanates from the Remmelink report (Van de Maas et al., 1992) which found that 1000 people had received euthanasia without requesting it, according to one translation of the facts. This, according to the opponents of euthanasia, is evidence of the dangers of the 'slippery slope'. Kuhse calls this 'dancing with data' (Kuhse, 1994b). Her argument is that:

_to demonstrate the existence of a slippery slope, one would need to show that society is worse off after introducing a new practice. In other words, one would have to prove that there are now more unjustified deaths in the Netherlands than there were before doctors could openly prove direct aid in dying._ (Kuhse, 1994c, p.259)

There are more and more Australian doctors revealing that they practise a form of covert euthanasia, and Kuhse's point is that this was most likely the case in Holland before the euthanasia legislation. Therefore it is not possible to say that this is any different from the situation beforehand.

Nevertheless those who support voluntary euthanasia are making progress and with this progress questions about what is good palliative care and how consumers can get their wishes met are being highlighted.

Clarnett, another outspoken opponent of euthanasia, says that the Baume survey is:

_at best a superficial snapshot of doctors' opinions. ... The study made no attempt to ascertain doctors' knowledge of the legal constraints regarding treatment decisions or their training and knowledge of modern palliative care techniques. These are questions that need to be answered before we start legalising euthanasia._ (Clarnett, 1994, p.7)

In making this criticism he does raise some issues that may have validity, and are worth exploring.

This thesis discusses acts of omission (letting die) under the rubric of palliative care, not because it rejects the view that acts of commission (euthanasia) may be more humane and appropriate, but because of the cultural and historical framework in which these questions are to be debated. The essence of this thesis is to gain an understanding of the issues surrounding the deaths of nursing home residents with
late-stage dementia and to contribute to any process that may improve this care. Therefore any moral position will need to be pragmatic enough to be acceptable as a working tool for present-day care. To this end Max Charlesworth’s (1993) approach is useful. Charlesworth (1993) helps to bring the previous absolutist moral positions together. Max Charlesworth sees a growing scepticism about the differences between the arguments put forward from either Kuhse, Singer, Stoffell or Tonti-Filippini.

Charlesworth (1993) takes an approach that he considers is culturally relevant, discussing ethical argument within the framework of present political and economic forces. He says:

Above all, in a liberal democratic society we must keep the community debate over health issues open and tolerant so that the various parties to that debate can all contribute to the complex and often lengthy process by which some kind of liberal consensus on how to approach the basic ethical issues can be achieved (intelligent, well informed and balanced media commentators - extremely rare specimens to date - are essential for this public discussion). In a liberal democratic society that is the only process - clumsy and fallible as it may often be - that we have at our disposal to reach such a consensus. (Charlesworth, 1993, p.154)

It is hoped that this study will contribute to this debate. Conclusions extrapolated from the data will be controversial and need to be couched within a much more complex moral debate than has been, or can be, presented in this study. This study aims to answer questions about nursing care. The present moral debate as it impinges on that is important but to debate these matters further is not the purpose of the study. Conclusions from this study are presented within a context where moral answers are not simple. But they are conclusions which have emerged and appear to have merit within my chosen and explicitly stated conceptual, analytical and ethical frameworks. The issues and the stories presented will benefit from extensive frank and open discussion and further research.

Debate about the ethical issues surrounding end-of-life issues in nursing homes is being taken up by some nurses, not yet in detailed research studies but in the form of stories. Stories are an important source of information for nurses. It is well to recognise what practical experience clearly shows: stories are usually much more relevant and believable to a nursing audience than the results of statistical social science studies. Two very important pieces of current Australian knowledge that are directly relevant to this study have been published just as the writing for this thesis draws to a close. One is a book written by two nurses, the Director and Deputy
Director of Melbourne City mission nursing home. The book aims to reflect on the 'lives and deaths of ordinary nursing home residents' (Hudson and Richmond, 1994, p.1) and describes the uniqueness of each instance.

Before taking over the nursing home Hudson and Richmond were senior staff members of a ten-bed hospice. When this closed down due to lack of funds and the hospice beds became nursing home category instead, Hudson and Richmond, who were very sensitive to and knowledgeable about palliative care issues, were in a fortunate position to collect stories of the difficulties of life and death in the nursing home context. The staff who remained and worked in the nursing home were also trained in palliative care and had specialised knowledge. In spite of this not all deaths were dignified or handled well. The authors conclude that 'Regrettably, residents' needs for palliative care are not matched by available resources and, short of placing further demands on caring staff, it is not clear how that gap is to be filled' (Hudson and Richmond, 1994, p.13). They go on to tease out many useful practical suggestions for nursing care but finally conclude that 'the field is wide open for the kind of research that will influence practice and enrich the lives of dying residents and their carers'. They continue:

statistics, documentation, research and quality control have a significant place, at best they are only a guide to care and not a guarantee of the resident's safe and dignified passage to death. Such objective data can be effectively applied only by means of sensitive, reflective interpretation. Many of the stories and their reflections signify the importance of attitudes. When there is an attitudinal change away from the notion of custodial care to that of advocacy, then our residents will benefit. (Hudson and Richmond, 1994, p.169)

Another recently published book, edited by Helga Kuhse, relates stories about people who 'want to die'. In one chapter Harper (1994) discusses terminal care in nursing homes. She describes the trauma of one resident, described as 'senile', which may mean she suffered from SDAT,' (Harper, 1994, p.106) being kept alive year after year in spite of repeated requests to die. Harper repeats the feelings expressed by many of the students in the Adelaide gerontological course discussed later in this study. In Harper's story the resident is Amelia, but the dilemmas are typical of those that surround the residents in this study. Harper tells her story.

I live with the knowledge that I failed Amelia when she was most in need. She should have been able to die when she (emphasis in text) wanted to die - not when a doctor, mindful of her repeated requests to die, decided that the time had come to provide 'comfort care only'. (Harper, 1994, p.106)
As it is nurses who are responsible for 'comfort care' the fact that they are now speaking out on this issue indicates that they may be ready to use their experience to begin working out both when palliative care is appropriate in nursing homes and how it might be applied.

That these books have been published attests to the fact that they are now likely to find a market, that the community is becoming aware of the issues that surround being 'kept alive'.

Surveys have shown that the attitudes of both doctors and nurses have moved towards a majority in favour of limiting or withdrawing treatment if quality of life is compromised (Stevens & Hassan, 1992).

The Royal College of Nursing, Australia (RCNA) has published a discussion paper about euthanasia outlining the positions of The Royal Australasian College of Physicians, The Australian Medical Association and The World Medical Association. The RCNA suggest that the time has come that 'the assumption that because it is possible to intervene to sustain life, life must be sustained, is challenged' (Royal College of Nursing, Australia, 1995, p.1). In essence the medical views are that a doctor's role is primarily to preserve life but where curative treatment is in conflict with a comfortable and dignified death, or is futile, doctors are not prevented from 'respecting the desire of the patient to allow the natural death process to follow its course in the terminal phase of sickness' (Royal College of Nursing, Australia, 1995, p.7).

The International Council of Nurses (ICN) position is very similar, but couches their argument around the 'double effect' scenario. The ICN takes the view that the:

- fundamental responsibilities of nurses are to: promote health, prevent illness, restore health and alleviate suffering. However, some nursing measures used to relieve symptoms in the dying patient may entail substantial risk of hastening death. These measures are designed to relieve suffering and pain not the death of the patient. If the patient does die while these measures are being used for his care, the nurse is not morally responsible for his death. (Royal College of Nursing, Australia, 1995, p.3)

Ethical, legal and policy opinions have changed considerably during time the study was taking place. The fact that debate about euthanasia has escalated so quickly in Australia during the course of this study has meant a constant re-thinking of the use of the findings.
The final section of this part will bring together knowledge from my own experience of 30 years involvement with gerontic care and information from the literature searched to begin to understand the present nature of nursing home work as perceived before the study commenced.

The nature of nursing home work: alienation, emotional labour, and the control of care

Present clinical guidelines for nursing care coping with death and dementia

So long as there is no easily available or widely accepted treatment or cure for dementia then managing symptoms will remain the basis for care. In 1981 Mace and Rabins produced their book 'The 36-Hour day' which became a widely accepted text on which to base this management. It has also provided the basis for educational programs and policy development.

Mace and Rabins's message, which they convey in summary form as 'six R's', is written for carers of people with dementia at home, but the principles are still considered relevant as a coping strategy for the early and middle stages of the disease in aged care settings.

Restrict. The first thing we often try is to get the person to stop whatever he is doing. This is especially important when the person might harm himself or someone else. But trying to make the person stop may upset him more.

Reassess. Ask yourself: Might a physical illness or drug reaction be causing the problem? Might the person be having difficulty seeing or hearing? Is something upsetting him? Could the annoying person or object be removed? Might a different approach upset the person less?

Reconsider. Ask yourself how things must seem from the patient's point of view. People with dementia are often unaware of the extent of their impairment. When you try to bathe or dress someone who does not understand that he needs help, he may get upset. The person's anxiety is understandable when things are going on that he can't make sense of.

Rechannel. Look for a way that the behaviour can continue in a safe and non-destructive way. The behaviour may be important to the person in some way that we cannot understand. One man who had been a mechanic continued to take things apart around the house, but he could not get them back together. His wife had an old automobile carburettor steam cleaned and gave it to him. He was
able to enjoy taking it apart for several months, and he left the household appliances alone.

Reassure. When a person has been upset, fearful, or angry, take time to reassure him that things are all right and that you still care for him. While the person may not remember the reassurance, he may retain the feeling of having been reassured and cared for. Putting your arm around the person or hugging him is a way of reassuring him. Take time to reassure yourself as well. You are doing the best you can with a demanding and difficult job. Give yourself a pat on the back for surviving one more challenge. If possible, find some time away from the person to regain your energy.

Review. Afterward, think over what happened and how you managed it. You may face this problem again. What can you learn from this experience that will help you next time? What led up to this behaviour? How did you respond to it? What did you do right? What might you try next time? (Mace & Rabins, 1991, p.117)

The ways of caring for people with dementia continues the 'loving care' milieu that has permeated most of the literature reviewed so far. The use of techniques such as alliteration to aid memorisation of the message gives an indication of the thrust and level of general education considered acceptable for aged care workers. Ebersole's work is similar, using the word 'dementia' as an acronym to provide directions for practitioners when making an assessment.

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(Adapted from Ebersole, 1989, p.111)

Carers and nursing home staff are often regarded as having an educational level of a year ten secondary pupil (Deakin University, 1989). This approach focussed on the obscure but powerful value term 'caring', laden as it is with the need for emotional labour, has become totally entrenched as the ideal for coping with the behavioural difficulties of someone with dementia. It is the approach constantly referred to in the publicity pamphlets re services for the family and friends of people with dementia which are provided by both the government and the Alzheimer's Association.

Jones, (1992) in a text specifically dealing with care-giving in dementia, takes this caring approach further but retains the simple and uncomplicated framework by
describing a nursing model for people with dementia based on Maslow’s hierarchy of needs. This model seems amazingly old-fashioned and simple in contrast to recent discussions about the theory of nursing care in acute settings. The model relies on the filling in of forms, which are provided, and continues the 'being nice to the elderly' framework of Norton's day. The assumptions underlying this model are that all the residents needs can be related back to their life history and can be discovered and met. This fits well with the SRV philosophy of Australian institutionalised aged care.

This concept of caring being a simple, instinctive task continues in present day publications. In the latest edition of a basic nursing text, for example, Mildred Hogstel's (1994) Nursing Care of the Older Adult, we see that only a little assistance can be gained in sorting out the tangled dilemmas surrounding deaths of people with dementia. In turning to the section called 'Death: The End of the Aging Process', passages such as the following are to be found.

... every death trajectory is individual. There seems to be no pattern, and little can be predicted. It is hard to die, because dying means giving up life. (Hogstel, 1994, p.236)

and

The concept of death with dignity is used freely with few specific criteria that are largely undefined. (Hogstel, 1994, p.242)

This last statement is perhaps the most honest and, again, indicates the lack of information on which this study can draw. The geriatric texts give little clinical guidance in coping with the death trajectory of late-stage dementia. Work by Kubler-Ross (1970) and Hinton (1972) has outlined the various stages a dying person is expected to go through - denial, anger, depression and finally acceptance. Whether or not this conceptualisation is applicable to people with dementia is not known, but serious doubts have been raised by Robert (1989). This leaves a practitioner in a knowledge vacuum.

A model of palliative care does provide protocols for nursing care of the dying patient but little is relevant to the demented elderly, especially to the Australian situation where nursing homes do not anticipate that residents with dementia will receive parenteral nutrition or naso-gastric feeding.

Hogstel discusses four factors - pain, respiratory distress, loss of control and body image - that she considers 'interfere' with a dignified death and gives clinical guidelines as to how they can be cured, rather than managed, relying heavily on a
medical model of care. No guidelines are given for care that is oriented to a palliative approach.

Miller’s (1990) book *Nursing Care of Older Adults, Theory and Practice* was given the accolade of being chosen as the AJN Book of the Year and is also cited as a basic text for gerontological practitioners being ‘written for undergraduate, graduate, and continuing education students’ (Miller, 1990). Death is mentioned here only when it happens to someone else - there are guidelines for the older person to cope with the death of a friend, relative or spouse. There are no references to hospice care and the small section on dementia, although useful, is mainly applicable to the acute care settings and does not deal with late-stage dementia or the death process. The author refers the reader to other texts and the Alzheimer’s Association for further information about appropriate interventions for caring for people with dementia. Another well-used undergraduate text, by Eliopoulos (1993), does not add anything to our understanding of these neglected topics.

These basic American texts reflect the fact that gerontological nurse leaders, as well as public policy bureaucrats, have marginalised death and the dilemmas surrounding caring for people with late-stage dementia.

Jacques, an English author, indicates that:

> despite the lack of curative treatments, we can approach the care and treatment of dementing people rationally with some hopes of alleviating the problems experienced by sufferers and their families (1992, p.308)

Jacques’s view of ‘treatment’ for people with dementia is that it should take the form of assistance with aids to daily living and drug therapy to keep people physically well and to control behavioural difficulties. The book is based on and limited by its belief that ‘dementia sufferers’ only need ‘simple help at home’ (Jacques, 1992, p.342). This book is an up-dated and somewhat more academic version of Mace’s text, with no new ideas, paradigms or frameworks. The patient is still an object on which the carer performs their tasks with unlimited compassion, time and patience.

There are few Australian books which relate to clinical care of the aged. The first Australian book that was produced as a basic text was Shaw’s *Challenge of Ageing* in 1984. It has retained a very high usage rate in education. In the second edition (1991) hospice and palliative care are discussed but, again, not in a way appropriate for use for people with dementia. The chapter indicates that only a few guidelines can be given because ‘at present it does not seem possible to do more than indicate a
starting point in hospice care' (Ryan, 1991, p.194). Therapy and activities for people with dementia are outlined, but no discussion about their death.

Barbara Sherman (1991), an Australian social worker whose husband suffered from dementia and died in a nursing home, has written a very clear text called *Dementia with Dignity*. This text indicates that it deals with the 'advanced stages' (Sherman, 1991, p. 5) of the disease but the emphasis is still on 'niceness' - this time an emphasis on looking for the person behind the disease. Again this book is written in a very simple form and at a lay person's level of understanding because it is for carers. The late-stages of a dementing illness are not dealt with beyond advice on how nursing home staff may console relatives at the time of death.

Mintchelillo *et al.* (1992) the most recent Australian gerontological text, is written as a multi-disciplinary approach but has little practical nursing clinical detail. The authors do discuss quality-of-life issues, but not those that deal with decisions about palliative care rather than conventional treatment. In discussing such issues as restraint these authors indicate that the aim must be to provide the greatest freedom possible for the resident if that is what they and/or their advocates wish. On the other hand the authors indicate that the health professional must be careful of litigation in the case of accident. Once again the nurse is left with the dilemma to solve on a day-to-day basis.

The dearth of directly related literature about death and dementia reflects how marginalised the subject of death for the elderly is. The actual physical death of the person with dementia is even more so. Present paradigms of care contribute to this situation. One reason for the gap in knowledge and subsequent lack of clinical guidelines shown above are the taboos that surround the moral dilemmas attached to the subject, the lack of status and resources for aged care and the lack of research effort put in to understanding the nature of nursing home work. Added to this the nature of nursing home work is highly bureaucratic and regulated. Occupational subordination (Friedson, 1970) has been shown to lead to alienation. It would lead us to hypothesis that many aspects of alienation might be present within the nature of nursing home work.

**Alienation**

Although scholars interested in the history of ideas can argue about the fundamental roots of the concept of alienation, it is widely accepted that, in his early writings, *The Economic and Philosophical manuscripts of 1844* (Marx & Engels, 1958) the young Karl Marx was the first to use the concept of alienation to explain the links between the nature of work under capitalism and the deleterious effect this had on
workers' morale and spirit. Observation of the industrial revolution led Marx to
develop the theory which Ollman describes in these words:

_The theory of alienation is the intellectual construct in which Marx
displays the devastating effect of capitalist production on human
beings, on their physical and mental states and on social processes of
which they are a part._ (Ollman, 1971, p.131)

Self-alienation occurs when the worker is separated from the results of her/his labour,
when that labour provides no fulfilment or satisfaction and is 'only a source of
physical exhaustion and mental debasement' (Jordan, 1971, p.17). In his middle years
Marx saw the results of alienation as economic, rather than as emotional, when
developing his theory of surplus labour. All of Marx's work has been subject to
widespread critique and the concept of alienation has been no exception. Nevertheless
it spread into the modern English speaking world, in an altered form, through the
work of scholars such as C Wright Mills, Eric Fromm and Herbert Marcuse (Israel,
1979). Social psychologists have re-examined and redefined the concept of
alienation and continue to use it to analyse social conditions and their psychological
consequences within the highly technological and industrialised western societics of
today. Consequences such as powerlessness, which Seeman (1959) identified as the
principal element in alienation, arise from lack of reciprocity and control and
subordination. These themes arise repeatedly in nursing literature (Fitzpatrick et al.,
1984; Turner, 1987; Bates and Linder-Pelz, 1990; Short et al., 1993). Alienation
forms the basis for the sociological concept of emotional labour, originally identified
and labelled by Hochschild (1983). Hochschild's (1983) work brought the translation
of alienation into the modern world of women's work, and is especially applicable to
the world of nursing.

**Emotional labour**

Hochschild begins her work thus:

_In a section in Das Kapital entitled 'the Working Day' Karl Marx
examines depositions submitted in 1863 to the Children's Employment
Commission in England. One deposition was given by a mother of a
child labourer in a wallpaper factory 'When he was seven years old I
used to carry him to work on my back to and fro through the snow,
and he used to work 16 hours a day .. I have often knelt down to feed
him, as he stood by the machine, for he could not leave it or stop'.
Fed meals as he worked, as a steam engine is fed coal and water, this
child was an 'an instrument of labour'. Marx questioned how many
hours a day it was fair to use a human being as an instrument._
(Hochschild, 1983, p.3)
Hochschild went on to examine the contemporary nature of the cost of being an 'instrument of labour' in the new and burgeoning service industries where the display of contextually and commercially appropriate emotions form a key part of the required work effort.

She gives examples of people engaging in emotional labour:

_The secretary who creates a cheerful office that announces her company as 'friendly and dependable' and her boss as 'up and coming', the waitress or waiter who creates an 'atmosphere of pleasant dining,' the tour guide or hotel receptionist that makes us feel welcome, the social worker whose look of solicitous concern makes the client feel cared for._ (Hochschild, 1983, p.3)

She argues that this kind of labour, in being expected as part of a role employees must play, has become a tool of management. 'Emotional management' is the 'management of feeling to create a publicly observable ... display' (Wharton, 1993, p.205) and emotional labour is the work of producing these feelings in order to be rewarded with a wage.

Following Hochschild's work other authors took up the notion of emotional labour and applied it to nursing work. James and Smith have been most influential in this. Smith (1992) outlines the effect of the managerial style of nurses in senior positions on the perceptions of quality of care and also the effect of emotional labour in nurse-patient interactions. She questions how care can be defined and describes how this has been attempted by sociologists, rather than nurse theoreticians. The effect of smiling, holding, talking and loving from a nurse was found to be positive and therapeutic. Patients did make links between the emotional and physical aspects of their care. They did feel supported, relieved and cared for when nurses displayed what the patients believed to be appropriate emotion.

James (1989), following participant observation in a hospice, examined the role of emotional labour in the care of the dying. It was found that the use of emotion was of great value in assisting patients and family (James, 1989). Smith calls the care of people who are dying 'the ultimate emotional labour' (Smith, 1992, p.96).

Both Smith (1992) and James (1989) found that the concept of emotional labour has not been clarified in the same way as the positivistic nature of medical care. It still has connotations of weakness and femininity and consequently it is not valued or rewarded in the ways and to the degree which might be expected.
Taylor's (1994) work on *Ordinariness in Nursing* take these notions closer to the bedside and further expands our understanding of nursing work, but she does not take a critical approach or link the work with politics or public policy. She does, however, use thick description and metaphor in a way that begins to give shape and form to these ideas.

The focus in this study will be limited to a critical examination of nursing care and the constraints and dilemma involved in the combination of physical, clinical and emotional work. Some understanding of the outcomes and costs of emotional labour and the experience of alienation involved in nursing work during the death process of elderly nursing home residents with dementia is essential to the present day analysis of care and the likely impact of any paradigm shift. The task of teasing out much of the invisible nature of nursing work will be put to one side in favour of a discussion of reforms of work practices and nursing care plans that are urgently needed. Echoes of Norton's (Norton, 1967) work in this statement are deliberate. The need to force practical change, rather than dwell on a complete analysis of the nature of work, demonstrates that gerontological praxis holds the same relative historical position in the hierarchy of progressive change as it did in her time.

**Control of care**

One of the areas where we can see tensions between the requirements of nursing work and the dominating and alienating effects of socially imposed models of care and lack of clear clinical guidelines is in the relationship between doctors' and nurses' explicit or implicit models of care. Stein describes (1967) some of the common coping mechanisms employed. He says:

_The nurse must be bold, have initiative, and be responsible for making significant recommendations, while at the same time she must appear passive. This must be done in such a manner as to make her recommendations appear to be initiated by the physician ...the major disadvantage of a doctor-nurse-like game is its inhibitory effect on open dialogue which is stifling and anti-intellectual. (Stein, 1967, p.699)_

A decade-and-a-half later Stein and his colleagues were contending that this relationship had significantly changed (Stein et al., 1990) because one party, the nurses, had unilaterally decided to change the rules. These authors base their views on observing nurses in hospital settings where they are seen to be increasingly challenging doctors about patient care decisions and taking responsibility for care that they consider is in their domain, without consultation.
It is not only the doctor-nurse relationship that contributes to and results from frustrations. Due to workload pressure and the historically marginalised and oppressed position of geriatric practitioners, nurse-nurse interactions suffer too. This surfaces as 'horizontal violence' where '... violence is perpetrated by frustrated members of an oppressed group against their peers and becomes the institutionalised oppression of nurses by nurses' (Street, 1992, p. 45). Street argues that this behaviour results from the rejection by nurses of their own characteristics such as warmth, sensitivity and nurturance as they have attempted to adapt to and assimilate the norms of the medical model. This leads to negative feelings about themselves as individuals, and to others who display the same devalued characteristics.

It may be a valid extension of this argument to suggest similar roots for the phenomenon of patient abuse in nursing homes which has been documented by Pillemer and Moore (1989). They claim that abuse in nursing homes is extensive. The authors are critical of studies and literature in the area of gerontology on the grounds that they often have 'relatively little to do with the actual experience of staff and patients' (Pillemer and Moore, 1989, p. 319). These authors conclude that nursing home work is difficult, stressful, marginalised and a neglected area of research. Understandings and analyses developed by sociologists are useful frameworks to develop contextual understandings of work which contains these elements.

The sense of who is in control of what is not only based on the face-to-face personal relationship between doctors and the nurses, or nurse and nurse, but also by the nature of a bureaucratic system which emphasises division of labour. That nurses' positions within this hierarchical structure create conflict is recognised by Short et al. who observe that:

*Bureaucratic organisation is not always fair or democratic, and it is not always efficient as there are flaws that impede realisation of the organisation's goals. A bureaucracy can be in a state of conflict, which has unanticipated consequences, including the creation of intolerable frustrations for those who work in them. Nurses who are frustrated or dissatisfied with aspects of working in bureaucracies need to see this as a structural problem in the organisation, not an individual problem or failing in themselves.* (Short et al., 1993, p. 39)

One common feature of bureaucracies is a heavy reliance on written records. This is very much the case in the aged care area and causes immense frustration and difficulties for nursing. Other features are regulation and rules. The fact that these have been imposed in the aged care area by public policy initiatives in recent years and been given strength by the sanctions attached means nurses are thwarted even if
they do 'see' the problem as structural. The growing reliance on the symbols of bureaucracy, written records, rules and regulations appears to have increased the feeling of powerlessness for workers in the aged care area. Certainly, the effect of the visits of Standard Monitoring Teams and RCI validators are reported in this study as causing a negative and distressed response in staff.

If the need for standards to protect residents seems to be universally accepted, the difficulties of managing the measuring of these standards in a flexible manner is more problematic. This attempt to unravel the culture of nursing home life is not immune to the frustrations and limitations arising from the complexities of the nature of bureaucracy, and other factors which impact on care.

Conclusion

These two chapters have sought to suggest that the power structures, the values, the implicit understandings, the force of history and habit and the emotions that surround the nature of nursing-home work will have an impact on the care provided to residents with late-stage dementia. The culture of care will be affected by the still-dominant medical model, manifested in research outcomes and recommendations; by social attitudes exemplified and disseminated by the media and embodied in law; by expected behaviour and attitudes from nurses as postulated by nurse theorists and academics; by policy, institutional and employment expectations and by models of care as outlined by gerontic experts.

It has also shown that there is a large knowledge gap in the area in which this research is taking place. So profound is that gap that we may almost speak of the subject of this research as being invisible in three senses. Gerontic nursing is invisible and marginalised within the nursing profession; body care has only just been named and recognised as a legitimate subject for discussion; and the study and death is ignored by a society that fears it.

In consequence the limitations of this study will be great, but the need for it to be undertaken were correspondingly clear. The paradigm shift suggested at the conclusion of this work will be supported by some philosophers and ethicists and opposed by others, and the same will be the case amongst public policy makers, the media, consumer groups and those in the aged care industry.

This introduction also demonstrates that a perspective is required which is formed not only by a close knowledge of the medical aspects of the condition of dementia but also of the practices and approaches of day-to-day nursing care, the legal and ethical frameworks governing treatment and the public policy context. The complex and
sometimes contradictory relations between the various epistemological viewpoints and the dynamic nature of the changing social milieu requires an analysis that will draw on these various bodies of knowledge and the work of those who have attempted to forge connections between them.
Chapter 3

Undertaking the study

Conceptual framework

Research is a social and intellectual activity, and inescapably a political one, which responds to the needs of the time as perceived by the research community or, less commonly, the individual researcher. Nursing is implicitly/necessarily humanistic, holistic, open to complexity and directed at people. In contrast science, in its narrow, modern sense, is mechanistic, deterministic, focussed on typical/average cases and directed by laws. Historically, for at least the last 100 years, this scientific approach has been popular as a basis for social research methods as it purports to be able to demonstrate the cause-effect link and thus create predictability and the possibility of control. Qualitative research methods, based on the interpretive skills of the researcher and aimed at understanding rather than measurement, emerged to challenge this approach. There is much debate about how each view contributes/impedes the understanding of nursing and how accurately and adequately the different epistemological and ontological bases illuminate the human condition. There is, on the other hand, increasing acknowledgment that as Minichiello, et al. (1990) put it, the choice of method is 'influenced by the assumptions that the researcher makes about science, people and the social world. In turn, the method used will influence what the researcher sees' (Minichiello et al., 1990, p. 6). So next I will briefly contextualise my social world.

The idea for this study began with my experiences as a gerontic nurse and educator. During the period in which this idea was taking shape nurses were being encouraged by their professional body, The Royal College of Nursing, to contextualise nursing knowledge. The college was suggesting that researchers needed to:

... formalise and extend the knowledge for nursing practice in the context of changing community needs, ongoing technological development and increased competition for resources. (Royal College of Nursing et al., 1991, p.3)
The results of a CD-ROM search have been reported, indicating that there is a scarcity of published research dealing with the questions this study asks. On the other hand, there was a great deal of literature supporting the usefulness of an holistic approach to research about the difficult questions surrounding care of the aged. For example, Gubrium, in commenting on a collection of new research studies, says that he is heartened to see 'the health care of the elderly considered from qualitative perspectives' (1993, p.131). Cameron tells us that ethnographic methods 'assist the gerontological nurse researcher in discovering the type of information needed to identify and meet the health care needs of older adults' (1990, p.5).

A method that attempts to uncover hidden patterns of meaning operating within a particular culture was needed to tease out understandings of nursing care during the death of people with dementia. Emancipatory alternatives to taken-for-granted structures of behaviour and discourse were also objectives of this study. Qualitative research, especially the work of Glaser and Strauss (1965; 1968; 1970) and Kübler-Ross (1969), has been shown to be effective in shaping new paradigms for handling the experience of death. Glaser and Strauss altered the perception that hiding the knowledge of impending death assisted people when they were dying. By studying the social environments of hospitals where people were dying they found that, instead, this secrecy left people lonely and frightened. Kübler-Ross (1969) was able to build on this kind of work and through her talking to people about dying was able to raise the awareness of the issues that surround the process and describe stages that people may go through.

For any qualitative researcher understanding our own history and prejudices before we begin is important (Kleinman, 1991). In a very real sense the researcher is, in Wolcott's (1975) much-quoted observation, her/his own 'research instrument'. It behoves any researcher to be aware of their own biases. As Minichiello et al. (1990) says:

\begin{quote}
Methodologies and methods are not constructed or chosen in isolation from ontological and epistemological positions. Rather, the manner in which we gain access to knowledge and our choice of techniques for collecting evidence are directly related to our image or reality and the way we think we can know it. (Minichiello et al., 1990, p. 214)
\end{quote}

Inevitably, however hard one attempts to put one's own views and ways of seeing the world on one side, the question of bias will arise. Various researchers have identified different ways of dealing with bias, introduced in the course of qualitative data collection and analysis (Stevens et al., 1993; Burns and Grove, 1993). Koch (1994)
outlines the need for careful collection of data and reflective analysis in her
description of the decision trail as a way of establishing rigour in qualitative research,
but finally states that her 'own mode of thought and experience are things that cannot
be eliminated' (Koch, 1994, p.985). Kleinman (1991) says 'we all know the rule-
examine your emotional reactions to the setting, the study, and the participants'
(Kleinman, 1991, p.184). We should begin a study by knowing who we are and why
we chose to study a certain problem and population.

To this end, before tackling other ways of achieving accuracy, I must set out some
salient parts of my view of the world, state where my interest has come from and
outline the forces that have shaped my ideas at this beginning point.

Street (1991) indicates that reflective processes inform practice in the real world of
nursing. She encourages nurses to feel confident in their own descriptions and from
that find ways in which they oppress themselves, or, alternatively engage in good
practice. Reflection on critical incident/s or influences in our lives or our practice can
uncover the causes for our actions and feelings. Three of these had a profound effect
on my motivation for undertaking this study.

The first influence was being brought up in a house where party politics was a large
feature of our lives. This left me with an interest in political and policy issues and an
admiration for elderly people who were often around organising fund-raising
schemes and being involved in meetings. They were usually very interesting people
with strong views.

The second was being involved in an accident at age sixteen where I fell off my bike
and rolled under a car. The doctors thought I was 'almost dead' and the memory of
hearing what they were talking about while to them I seemed totally unaware, gave me
a first-hand account of how little we know about unconscious understanding.

The third generative event that I remember as the trigger for my interest in the death
of old people happened 28 years ago when I was a recently qualified junior
registered nurse working on night duty in a large aged care complex. I was involved
in an incident where, on reflection, an old man was kept from a dignified and
peaceful death due to the inexperience of myself and a young doctor, neither of
whom adhered to the unspoken custom and practice of the hospital where the
incident took place. On becoming aware of the patient's rapidly worsening condition
we promptly instituted acute care procedures which, although viewed as 'successful'
by the criteria used in a medical model of care, actually seemed cruel and
inappropriate for this person when events allowed time to take stock. This incident
happened at the same time as the reformers of the 1960s were gaining ground, and, at the time that I was reading 'sans everything' (Robb, 1967). In retrospect, the experienced gerontic nurses of the time were much kinder in their efforts to hasten slowly, than I was, with my naive reformist enthusiasm.

This experience of keeping the old man alive, when neither his body nor his spirit would allow him even a basic minimum standard of dignity, was an unforgettable first-hand illustration for me of the effect of the taken-for-granted nature of nursing practice, and its often inhumane consequences for those at the edge of death. The episode left me frustrated, sad and confused about the meaning of 'good' nursing care, emotions which have continued to fuel an interest in and commitment to the debate surrounding end-of-life-issues for the elderly. The social, legal and political climate surrounding these issues has changed considerably in the last two decades, and the difficult questions which attach to them are today being widely debated and legislated for in a variety of forums.

Added to these incidents and influences were a series of experiences where capable, mature women whom I had taught in a geriatric course would break down in my office and sob out traumatic experiences when they had attempted to improve nursing home care after gaining knowledge and empowerment through education. I was powerless to assist apart from listening. One of the dilemmas they faced was the inhumanity attached to nursing home care of the long-term chronically ill residents.

All this experience was useful background to the study for the reasons Leininger (1985) suggests:

> Researchers who have some general knowledge about a culture become better discoverers if they take their cues from people and listen and observe rather than having no general knowledge of the culture. (Leininger, 1985, p.41)

There may in this work be a discernible sympathy for those who, because of their position or characteristics, get less of the power and other privileges which our existing social structures allocate. This study is for gerontic nurses and those they care for. My background as a gerontic nurse may have contributed to bias in this study but it was also my greatest strength.

The last personal view I must put forward is one of ideology. I am an agnostic, I believe that we do have the capacity to anticipate and plan for predictable health-care situations in spite of the fact that I do not have any idea of what, for example, my 'demented' self may be. I do not believe that futile curative care is worthwhile. On the
other hand I do believe in equal rights for all, so that the old and demented have as much right to claim an equal share of resources, attention and interest from society as any one else. Many times I have heard the remark from nurses 'I love my dementias'. Although I do not applaud the way this sentiment is expressed I know what these nurses mean, and I feel the same way.

The use of the first person throughout the text fits in with the approach of this research and is based on the reasoning of Harry Wolcott (1990) who says:

*In quantitatively oriented approaches, and among the more self-consciously 'scientific' qualitative types as well, researchers typically desert their subjects at the last minute, leaving folks and findings alike to fend for themselves, seemingly untainted by human hands and most certainly untouched by human hearts. One of the opportunities-and challenges-posed by qualitative approaches is to regard our fellow humans as people instead of subjects, and to regard ourselves as humans who conduct our research among rather than on them... Science may be better served by substituting the observer for I, but I have yet to be convinced that our highest calling is to serve science. Perhaps a compelling case can be made on behalf of matching the formality of the writing with the formality of the approach the more critical the observer's role and subjective assessment, the more important to have that role and presence acknowledged in that reporting.* (Wolcott, 1990, p.19)

Other authors have supported Wolcott's view, for example Savishinsky (1991), Street (1991) and Atkinson (1992). All report their research using 'I' or 'us' rather than 'the observer' or 'the researcher' in order to make their stories more meaningful and closer to the social context from which they are drawn. As well as their own descriptions the authors let the words of those they interviewed tell the stories as much as possible. This approach fits the critical ethnographic methodology chosen for this study.

**Research methodology**

The deaths of residents with late-stage dementia that will be studied take place in the sub-culture of nursing homes. Critical ethnography allows the researcher to investigate sub-cultures, to seek out links with the larger social and political environment and to tease out from the tangles of customs, values and concepts some emancipatory alternatives.

Quantz (1992)says of this methodology that:

*... critical ethnography is recognised as having conscious political intentions that are oriented toward emancipatory and democratic*
goals. What is key to this approach is that for ethnography to be considered 'critical' it should participate in a larger 'critical' dialogue rather than follow any particular set of methods or research techniques (Quanz, 1992, p.448-449).

Depoy and Gitlin say that critical theory is a 'world view that suggests both an epistemology and a purpose for conducting research' (Depoy and Gitlin, 1994, p.137). These authors acknowledge that a vigorous debate exists as to how soundly critical theory rests on its epistemological and ontological underpinnings, but acknowledge that there is agreement that its purpose is to discern the character of relations within social structures, to assess these against some set of social relations and to promote emancipatory change. A critical approach is appropriate when research is multifactorial, when it needs to acknowledge the dynamic nature of the subject matter and be sensitive to the sociopolitical context of the moment. The importance of the contextual nature of this inquiry makes it efficacious to use an ethnographic approach within the conceptual framework of critical theory.

Perhaps the closest definition that is useful to this study is Simon and Dippo's (1986) comment that:

For ethnographic work to warrant the label 'critical' requires that it meet three fundamental conditions; (1) the work must employ an organizing problematic that defines one's data and analytical procedures in a way consistent with its project; (2) the work must be situated, in part, within a public sphere that allows it to become the starting point for the critique and transformation of the conditions of oppressive and inequitable social regulation; and (3) the work must address the limits of its own claims by a consideration of how, as a form of social practice, it too is constituted and regulated through historical relations of power and existing material conditions. (Simon and Dippo, 1986, p.197)

In order to meet these fundamental conditions it will be useful to separate the concepts of ethnography and critical theory in order that, when they are brought together again at the conclusion, the groundwork has been laid to move towards the methods needed to achieve this type of analysis.

Ethnography

The increasing popularity of criticisms of the positivist orthodoxy redirected attention to disciplines and schools of thought which had never entirely succumbed to the positivist fashion. Prime among such disciplines was anthropology. The earliest modern work in anthropology tended to focus on the study of human anatomy,
physiology and the biological bases of behaviour. The development of anthropology took place during the great age of European colonialism and there were disputes among the scholars involved about the relationship between their scholarship and the spread and penetration of colonial power. Some scholars became concerned as to whether such research—observation, recording and re-interpretation into European terms—harmened or helped the peoples among whom these observations were carried out. Critics maintained that the findings often served merely to facilitate manipulation of the less-industrialised cultures by the western industrialised imperial powers.

Ethnography, which developed within the ambit of anthropology partly as a reaction to this concern, moved away from anthropology's early physical focus and instead adopted culture, in the widest sense, as the principal phenomenon to be investigated, seeking insights into customs, rights, relationships, systems of rules and the roles of individuals as cultural actors and thinkers.

With the passage of time the traditional association between anthropology and remote locations and exotic civilisations has faded. In the last four or five decades the concepts of anthropology and ethnography have been blended by sociologists such as Spradley (1980) who see research into 'the native point of view' in a very broad sense, citing work by himself and his students who have studied sub-cultures such as those created by quadriplegics and skid row alcoholics in the USA. In the same way, nursing homes can be considered as sub-cultures. This broadening of scope prompted questions about the senses, if any, in which such widely disparate societies and sub-groups could be comprehended by any one body of knowledge or set of approaches. The debate continues with the argument ranging round how best to search for meanings, the principles underlying the ordering of those meanings and how to arrange them in larger cultural constructs.

Nurses and those who write about nurses have been influential in recent times in embracing new qualitative research methods, such as ethnography, and adapting them to fit the kind of questions that they seek and indeed need to answer. Ethnography has many offshoots such as Leininger's (1985) ethno nursing method and the methods of ethnology and ethnoscience described by Field and Morse (1985).

Ethnography is particularly vulnerable to critiques due to the fact that the researcher becomes immersed in the day-to-day lives of people belonging to the community or group being studied and is the one who interprets, classifies and renders intelligible to outsiders the meanings and actions of what is observed. Agar (1980) considers that bias cannot be avoided by ethnographers; rather they have to indicate how biases may have influenced their research. Qualitative researchers believe that for research to be
'valid' it must reflect the milieu and understanding of those being studied and be meaningful to the subjects of the research. This is dependent not only on the interpretations of the researcher but also on the rigour and methods used in obtaining data. For ethnographic research to be acceptable and useable it must, according to many basic texts (Spradley, 1979 & 1980; Ellen, 1984), understand another way of life from the native point of view (Ember & Ember, 1988).

The traditional anthropological approaches did not undertake studies from this point of view. They studied cultures and drew conclusions as if the 'White Western' view of the world were the norm. As contemporary ethnography developed there grew up two different explanations of how culture was to be viewed. When a culture is viewed and analysed in its own terms, from within the culture it is described as coming from an 'emic' perspective. It relates to the insiders' view of society, using explanations and concepts that those within the culture are familiar with. An 'etic' perspective is one viewed from the outside and one which examines similarities and differences across cultures or in different situations. It is an outsider's view, i.e. using the observer's concepts and scientific explanations.

Critics of the ethnographic method can be scathing. For example one writer quotes a colleague who sees ethnography as:

little more than subjective interpretations based on casual observations, lacking in systematic controls, and incapable of generating hypotheses or 'scientific' understandings. Ethnography, after all, is little more than 'hanging out' and writing up some narrative, an interpretation that provides an 'account' without addressing how better accounts are justified. (Thomas, 1983)

Because an ethnographer is considered to be a 'human instrument' (Sanday, 1979) this kind of critique has the danger of researchers becoming bogged down by questions of bias and acceptability. Nevertheless attempts to eliminate bias, or correct for it, must be made if the results are to be as accurate and useful as possible. Ways in which this study has considered the matter of bias and how the focus on cultural patterns through experience, inquiring and observing were undertaken will be outlined after considering the other important element of critical ethnography, the meaning of 'critical'.
Critical theory

The origins of critical theory were closely linked with Marxism through the work of the Frankfurt Institute of Social Research. Established in 1923, the personnel in the Institute had left-wing political orientations and because many members were Jewish chose to migrate to America at the time of the Hitler's rise to power, gathering again in New York and continuing the Institute's work until the 1940s. Some of the famous theorists numbered among the Frankfurt School were Max Horkheimer, Herbert Marcuse, Theodore Adorno and Erich Fromm. Horkheimer returned to Frankfurt after the war while others such as Fromm stayed in America. Jurgen Habermas was Horkheim's successor in the chair of Sociology and Philosophy at Frankfurt and is the most influential representative of the 'second wave' of the Frankfurt School, departing from 'classical' critical theory, although building on it and synthesising its ideas with those of structural functionalism, hermeneutics and theories of cognitive and moral development.

Many nurse researchers use Habermas's work as a basis for their view of how critical theory applies to the health arena and their own research findings. Grbich (1994) offers an explanation of the relevance of his work to health professionals:

*Habermas is particularly concerned that there are elements of our social structure and culture which deny individual freedom and growth by imposing unnecessary forms of social control. He views medical control as one of these elements.*

*Habermas asserts that capitalism is in a state of crisis. In a recession there is conflict between the owners of capital, who want to make more profit, and the demands of the increasing numbers of people on social welfare. The role of the Government is to provide a suitable climate for the achievement of capital gain while maintaining harmony in the wider population. In order to support the capitalists, Governments have pruned back both social welfare and support services. The cutbacks in welfare payments will ultimately force people into the labour market in search of other sources of remuneration which in turn will give greater power to employers resulting in punitive employment practices and greater conformity of behaviour of those who do gain jobs.*

*One of the major service sectors experiencing cutbacks is the health area and the implications from Habermas' views are that the major challenge for the Government would lie in an attempt to gain a proper balance between the needs of the system (which are negotiable) and the needs of individuals who require information,*
choices, alternatives, legal recourse, strong health institutions and an informed public in order to create effective resistance. (Grbich, 1994)

To deal with the difficulties that arise within this economical-rationalist approach, Habermas (1973) focuses on individual and group emancipation rather than change in the wider political process. He concentrates on understanding through personal reflection so that people can gain knowledge and awareness and take control of their own lives. Street (1992) based her critical ethnographic understanding of nurses within this framework and it has been immensely useful for the nursing profession. However, it also has limitations. Personal freedom within the confines of a nursing home, for both staff, residents and relatives may come at great cost. This study, therefore, will use the 'classical critical theory' of the Frankfurt School as a basis for analysis. Although Habermas's views have been developed from this original framework they have moved quite substantially from its Marxist origins.

Giddens, a sociologist with his own version and opinions of critical theory, says:

Most Marxist authors see Marxism as part of a 'package' of sociological analysis and political reform. Marxism is supposed to generate a programme of radical political change. Moreover, Marxists put more emphasis on class divisions, conflict, power and ideology than many non-Marxist sociologists, especially those influenced by functionalism. (Giddens, 1989)

Critical theory perspectives that move away from the original work of the Frankfurt School tend to also shy away from the 'grand questions' that can be answered by Marxist approaches. The work of the Frankfurt school was an openly ideological and committed response both to the dominant positivist tradition and also to:

the rise of Fascism, the irrationality of Hitler's charisma, the quietude of the postwar global Pax Americana and the proliferation of popular culture. (Langman, 1991)

In support of the idea that 'classical critical theory' has a different role to that of the 'second wave' or Habermasian adherents, is the argument that much nursing research, by moving away from the traditional view of critical theory, is unable to answer 'grand questions' (Giddens, 1989). Giddens suggests that typical of these kind of questions are those such as 'How do societies hold together?', or 'What are the main conditions producing social change?' To answer big questions, to challenge the status quo, it is appropriate to return to those fundamental Marxian ideas of being fundamentally critical and to state the need for nursing research to enter the political arena. Holmes (1993) points out that:
Even amongst recent nursing references to critical theory (e.g. Allen 1988, 1990) there is a reluctance to openly state the political ideology on which it is founded (a recent exception is Campbell and Bunting 1991) and certainly no explicit commitment to it qua political ideology. More often than not critical theory is exploited by nurses purely for its attractive research methodologies, which are harnessed to individualistic emancipatory aspirations... trying to maintain an appearance of ideological neutrality. (Holmes, 1993, p.10)

This study was attempting to answer the big questions connected with difficult ethical dilemmas embodied in a very dynamic socio-political context. Given this aspiration, the use of the classical view of critical theory as a framework for analysis may be justified by outlining a number of the distinctive contributions it can make.

Values and philosophy

Perhaps the first mentioned ought to be the values base of classical critical theory. Flatly denying the positivist's belief in the possibility of gathering or analysing knowledge without allowing human values to influence the process, critical theory uses emancipatory and democratic human values in critique of the status quo. The nature of emancipation is that it frees society from intellectual, legal, social economic or other restraints and is based on the fundamental democratic principle that all have equal political rights. Critical theory believes that these are expressions of the natural order of human affairs but that societal constraints and manipulation may prevent people from realising this. It recognises that this is importing values but does not shy away from holding this view. This notion of rights is substantially different from the sentiments of present aged care policy which are based on attenuated individualistic versions of the values of dignity and freedom.

Theory serving practice

Associated with this explicit value commitment goes a view about the purpose of social theory. Revealing the marks of its Marxian origins, critical theory sees social theory as an instrument to be tested against the demands of practice. Holmes (1993) says:

*That theory must be an expression of practice is a central plank of orthodox Marxist doctrine. As part of his onslaught on idealism, Marx consistently derided the intellectualism of abstract theorization and insisted that theory was only important to the extent that it was grounded in, responsive to and directed towards, the realities of practice.* (Holmes, 1993, p.10)
The critical approach wishes to go beyond understanding how a situation comes into being, beyond watching and recording what it means to the individuals or sub-groups who are the subjects of the study. Critical theory seeks to portray that situation in a way which makes problematic the taken-for-granted concepts and structures which participants use to order their experience.

**History and the dialectic**

Another distinctive contribution is the Marxian insight that development and change comes about due to the interplay of opposites over time - the historical force of contradictions. An example of this could be the postulate that inside all living things are the seeds of its own destruction. That is, it is impossible to give a definitive, exclusive answer to the question of whether a person is living or dying. Each of us is doing both things simultaneously and the relationship has to be understood over time. So the way you look at this changes what you can see. Seen through a dialectical perspective life and death are viewed as entwined parts of a parallel process - they are seen historically, they cannot usefully or accurately be described as static or fixed states. Rather they are processes in constant interaction, each shaping and directing the other and each helping to give meaning to the other. A critical theoretical position accepts that what constitutes change and continuity is inevitably somewhat problematic, and that paradox, inconsistency, irony, contradiction and discontinuity are part of the human condition, rather than necessarily evidence of dissolution or disorganisation of a society or culture. This stance can assist in coping with the problems associated with the ‘slippery slope’ argument. If this study contributes to a change in nursing-home care, which, in turn, becomes problematic if it is not implemented with humanitarian and well executed processes, then a new wave of reform, challenges and paradigm shifts will inevitably occur, reflecting the needs of the culture and the societal structure of the time.

In spite of all the debates surrounding critical theory it can be seen as a framework for welding together an amalgam of diverse theoretical positions with a central theme being a willingness to enter various literary and political arenas on behalf of peoples caught up in struggles for autonomy or more satisfactory economic, political, social or cultural circumstances. This made it eminently suitable for this work. So now we can return to the amalgam of these ideas - critical ethnography.

**Critical ethnography**

One use of critical ethnography is that it concentrates on:
research accounts sensitive to the dialectical relationship between the social structural constraints on human actors and the relative autonomy of human agency (Anderson, 1989, p.252)

This distinguishing feature of critical ethnography, as distinct from mainstream ethnographic studies and other interpretive approaches, is its insistence on the role of social structure, especially on the power relations which both sustain and operate through the structures. It is true that social phenomena are the result of human interaction but it is equally important to see that each generation and each subgroup conducts its culture-producing interactions within an inherited framework of more-or-less established and more-or-less fixed patterns of behaviour and discourse which limit the choices apparently open to it. Gary Anderson, an American specialist in critical theory, says that the methodology:

is the result of the following dialectic: On one hand, critical ethnography has grown out of dissatisfaction with social accounts of 'structures' like class, patriarchy, and racism in which real human actors never appear. On the other hand, it has grown out of dissatisfaction with cultural accounts of human actors in which broad structural constraints like class, patriarchy and racism never appear...

... And so it goes. (Anderson, 1989, p. 249)

This exploration of the relationship between structure and human agency in this study has been undertaken with the double intention of linking those concepts and structures to basic political and ideological issues in the wider society and thus showing the new uncertainties as large political opportunities. According to the critical theorists these patterns embody and conceal distributions of power and prestige, an aspect which is hidden in normal times and seen clearly for what it is only when challenged or exposed by the critical imagination.

Quanz (1992) is careful to point out, however, that the need for emancipation must not influence the collection of data. All evidence observed must be:

observed, described and analyzed, and that which appears to counter researcher assumptions must be revealed. But keep in mind that all evidence, supporting or refuting, must be considered within historical/structural conditions and pointed toward emancipatory possibility (Quanz, 1992, p.473)

It would be very tempting for the researcher to take the view that an expose from this study could lead to a sharp policy change that would promise social action to improve the quality of life in the last stages of a demented person's life or to assist in releasing either demented residents or gerontological nurses from oppression. But it
is important to be aware at the outset of the distance which lies between socially
critical research, or social science research of any kind, and policy. A significant
body of literature has been produced to document and explain the tortuous path
which links research to policy, and to explain why it is rare for any idea or proposal
to complete the journey without enduring great delays or loss of identity. It is also
important, however, to recognise that the value of critique does not lie solely in its
potential short-term usefulness to policy makers. A fine line between utopianism and
premature compromise has been attempted.

It is by examining and describing the institutional culture in which the deaths of
people with dementia take place that the study was able to gain insights into the ways
in which a process of death is 'chosen' for people with late-stage dementia and
who/what was most influential in making that choice. The study also describes the
connections between formal and informal policies, how they impact on institutional
practices and link with the political/economic/moral framework of today's society.

Research method

Data collection

Field work within a sub-culture is the foundation of an ethnographer's work.
Participant observation, interviews and collection of documentation were used to
obtain the data for this study as follows:

1 In-depth and field interviews were conducted with nurses, significant family carers,
   administrators, doctors and ancillary nursing home staff.

2 Participant observation in the nursing homes occurred at regular intervals, before
   and after the death of the residents included in the study. I attended at 'handover'
times, meal times, at night, or when a significant event occurred in the life of the
resident. I did not directly observe the actual death of any resident, but either
visited the nursing home or interviewed care staff and family as soon as possible
after the event. Photographs were taken in and around both nursing homes. Some
aspects of the care of some of the residents in the study was also recorded by
photography.

3 Data was collected from nursing histories, including the prescription and
   administration of drugs, social history, and comments from nurses, doctors or
   allied health staff.

4 Data which relates to the institutional policies of each nursing home was collected.
An observer requires an efficient system of record keeping to be as effective and accurate as possible (Spradley, 1980). The recording systems used for this research were a voice-activated cassette used for taping interviews, a camera to record details of degenerating bodies, a lap-top computer used for field notes, a computerised pocket note book for informal jottings while walking around the nursing home or working with the staff, and a diary for written material.

Gaining entrance

The collection of field work for this study began in January 1992. By July 1995, when this research was concluded, 14 of the 15 residents had died.

Unless this study was to be undertaken in a large institution then there was likely to be some difficulty in obtaining enough suitable residents in one nursing home. Although findings from a study such as this cannot be generally extrapolated in the way that experimental or survey data possibly can it was hoped that the choice of average size nursing homes would produce more 'typical' data than that from a very large institution. Residents with dementia survive for many months, sometimes years, in a severely demented state. Therefore finding residents who were considered to be in the 'terminal stage' was likely to be fraught with problems. A sample of ten residents was considered to be a suitable number for the study and as many nursing homes as necessary would have to be visited to get this number. In fact, fifteen residents were identified as suitable for the study in the first two nursing homes that were approached. The nursing home administrators kindly agreed that the study could be conducted in their institutions if the DONs, who knew the residents and families, felt they would be comfortable about being approached for permission to be included and to give consent on behalf of their relatives. An example of the consent form used is reproduced as Appendix 1. These two nursing homes were chosen initially due to location close to what was my home at the time and the knowledge that both were run by charitable organisations with a commitment to high standards of care. The first approach to each institution was a personal one as I and the members at the appropriate level of management in each organisation were known to each other. This was invaluable in providing an atmosphere of trust in which to work.

As Fetterman points out:

\textit{A strong recommendation and introduction strengthens the field worker's capacity to work in a community and thus improves the quality of the data.} (Fetterman, 1989)

I did not know the particular nursing homes or staff in them before starting the study.
Permission to undertake the study was sought both verbally and in writing and the replies were positive and encouraging. The DON in each particular institution was then approached by phone and an appointment made to meet. Beachdale and Bayside were pseudonyms I chose for the two nursing homes in which this study took place.

Before starting the data collection in one nursing home I spoke to two meetings of staff, one of them an RN meeting and the other with all other staff, at which I outlined brief details of the study. In the other nursing home, information about commencement of the study was written in the communication book and filtered through via informal information sharing between staff and phone calls from me to the careworker seeking information about gaining the permission of relatives for residents to be included in the study. The plain language statement (Appendix 2) which was given to anyone who consented to be interviewed also supplied some background to the study.

**Ethical considerations**

It is a moral imperative that ethical aspects of collecting data must always be at the forefront of the researcher's mind. In a project such as this it was vital. Formal requirements were met through the process of gaining permission to conduct the study from Deakin University Ethics Committee, management of the nursing homes and residents or their advocates.

I gave assurances of treating all residents in the study with dignity and being sensitive in my recording of their deaths. Each person who consented to be interviewed was given a plain language statement and consent form. Verbal emphasis was given to the confidentiality of the data by highlighting the comment about the identification of any person being kept separate from their responses. This was particularly important in enabling staff to talk freely. It was also made clear at the initial meetings and communications with staff that all participants would be given an opportunity to see the completed study. A promise was made that a draft of the thesis would be left in each nursing home for a month before final submission in case there was anything in the writing that would be considered inaccurate, offensive or distressing for any participant. This exposure period would also allow any participant to make any criticism of the analysis offered. In addition, all relatives who had agreed on behalf of the resident with dementia to be included in the study, and/or been interviewed themselves would be informed that the draft of the thesis and any photographs taken would be available at the nursing homes if they wished to see them. A copy of the
letter sent to relatives at this time is attached as Appendix 3 and a copy of the note inserted at the front of the draft of the thesis left at the nursing home is Appendix 4.

There were much more difficult ethical considerations attached to the participation of incompetent residents. As Rapp et al. (1994) suggest the identification of potential subjects was undertaken by key informants in the nursing homes after being given clear parameters. The key informants, the DON and the CNC (Clinical Nurse Consultant) were also important in increasing my ability to be sensitive when seeking permission from the closest relative who was exercising, formally or informally, power of attorney for the person's care. They were also important in ensuring that no-one who may feel uncomfortable was asked to participate. Levine (1993) states that in the cases where research is to be undertaken with a population of vulnerable subjects, such as the residents in this study, the principles of 'best interest standard and substituted judgement standard' (Burns & Grove, 1993, p.97) should be used. 'Best interest standard' is based on balancing the risks and benefits to the individual and the 'substituted judgement' standard is concerned with trying to determine what course would have been preferred if the individual were able to make a choice. These were the principles that were followed with relatives making comments such as 'she would be pleased to be helping' during discussions about permission to be included in the study. Consent forms, in all but one case, were signed 'on behalf' of the resident. Consent, as far as was possible, was gained verbally from each resident. A description of my attempts to do this are described, in some instances, within the case studies themselves. The right to withdraw at any time was offered, as was the right to view any documentation, including photographs, and to require their destruction.

Woods (1992) indicates that covert versus overt research is the most difficult ethical problem for ethnographers. He says:

\begin{quote}
Participant observation has, on occasion been likened to 'spying' or 'voyeurism', activities more in keeping with intelligence services and perversion than academic research. There is an unsavoury feel to such a role so conceived (Woods, 1992, p.378)
\end{quote}

It is possible to conceive that the observation I undertook of the residents was a form of covert research. They did not understand my reason for being there, for observing them, writing notes and taking photographs. Various arguments for and against covert research have been put forward (Woods, 1992) and I have soul-searched for answers as other researchers have in the past. In the final analysis, the urging from relatives and staff that the dilemmas they were facing needed to be revealed, the
history of marginalization of women, gerontic issues and the elderly and the suffering I observed left my conscience clear.

Another ethical issue, that of confidentiality was met by the use of fictitious names. The terms of address - by title or first name - are included in line with how residents were addressed or referred to in the nursing home during the study. Some residents were addressed in both ways, sometimes called by their first name, sometimes their surname; others, for example Amy, were always referred to by first name. The case histories reflect the particular patterns employed. All staff, except the DONs, were always addressed by their first name. The precise geographical location of the nursing homes is concealed to further ensure confidentiality.

**In-depth interviews**

Minichiello et al. (1990) indicate that in-depth interviewing is appropriate to use by itself or with participant observation when an understandings of a broad range of relationships is sought. The intent of the in-depth interviews was to explore feelings that were not at the surface of people's conscious awareness. In-depth interviews were always conducted in private, some in family homes, in doctors' surgeries, in private rooms of the nursing home or outside in a quiet corner of the grounds.

In in-depth interviews it is expected that the researcher will know what they are going to talk about - there is a purpose - but it is a conversation. The intent is to ask questions meant to draw out the interviewee's thoughts.

To have some order and structure in the interviews an interview guide (see Appendix 5) was used for in-depth interviews in the first instance. The purpose of the questions was to gain some contextual understanding of the lives of the informants and their ideas and feelings about control in the nursing home. Moving from questions on this guide to discussing general aspects about care, death and decision making during these interviews was very easy as most of those interviewed talked easilly and eagerly.

Most relatives were interviewed where and when it was convenient to them and these interviews did not follow a format because the questions related specifically to their own situation. During most interviews there was much evidence of the emotional power of these issues. The transcribed interviews cannot capture shouting, hand waving, tears, chain-smoking and numerous apologies when words would not come. I soon learnt to carry a tape recorder, a 'do not disturb' sign and a box of tissues to all interviews as so many were punctuated by tears, mine as well as those of the person being interviewed.
At the start of the study appointments were made to interview relatives to undertake in-depth interviews. After two interviews I reflected on the process and was concerned that these had the potential to cause distress, especially for elderly people left alone to mull over the questions I had been asking. Moreover, in return for these risks, I was getting little pertinent information. I realised that for a stranger to turn up to their home and start asking questions about the death of a parent or spouse was just too difficult for most people. Therefore, for the majority of the study, I only interviewed those relatives who visited the nursing home regularly or were spending long periods of time at the nursing home because their relative was close to death. This gave some limitations to the study but, on the other hand, ensured that questions about nursing care and the management of death were directed to those relatives who had had an opportunity to form judgements based on their own direct observations. This self-imposed restriction was also in accord with my sense of my own ethical responsibility to the sensitivities of those who were also suffering because of the devastating effects of dementia on someone they cared about.

The language of staff and relatives was recorded verbatim as often as possible and notes made about the way information was presented. Debriefing at the end of interviews consisted more of ensuring the return of both the relative's or staff member's equilibrium, and mine, rather than clinically summarising what is learned from the informant as is suggested by authors on this subject.

Holding onto the emotional force of what transpired in the interviews was important because it changes the force of the actual words as they appear, cold and stark, on paper. The use of data triangulation (Burns & Grove, 1993, p.277) had been decided before embarking on the collection of data, but the need to capture the complexities of the emotion surrounding the long-drawn-out death of people with severe dementia forced a more adaptive, less tidy approach than is normally recommended in the textbooks. The idea of the use of photographs stemmed from this need to reflect as accurately as possible, but from another vantage point, the dimensions of the deaths that were observed. Watching the flesh fall off a person you love and with whom you have shared 60 years of your life is probably indescribable. Neither the actual words used in the interview or a description of the sobbing that went with those words would be enough. But they are essential parts of the picture. George and Louise Sindler (1992) observe that taking photographs is 'important for documentation' (Spindler & Spindler, 1992, p.79) and meaningful in ethnographic work.

Field interviews took place when a significant incident occurred to a resident in the study. In the first instance a schedule was used for these incidents (Appendix G) but
often in practice they became so long that the difference between in-depth interviews and field interviews became blurred. Also, as I got to know the staff and relatives well, this process became informal and interviews became incorporated into field notes which took more account of the emotions of the moment. The use of tape recordings during emotional moments increased as the study progressed. I came to rely on tape-recordings to capture these discourses, including the tone and manner of them, as accurately as possible. I noted that staff became used to me working with equipment in my hands all the time and began to ignore me turning the tape recorder on and off or tapping away at the computer.

The language - or verbal sounds - of the demented themselves, and their behaviour was also part of the culture which was examined. Recordings were made of screaming, babbling, grunting and confused speech. This cannot be presented in this thesis, but was intended to be used when presenting findings from this research in conference settings.

Fifty-five formal interviews were recorded, 37 with nursing home staff, 13 with relatives and five with doctors. The discussions and observations recorded resulted in 52,730 words in computer field notes as well as hand-written diary notes.

**Participant observation**

Participant observation refers to research characterised by a period of intense social interaction between the researcher and the subjects in the milieu of the study. I chose to engage in moderate participation as described by Spradley (1980). He says moderate participation:

... occurs when the ethnographer seeks to maintain a balance between being an insider and an outsider, between participation and observation (Spradley, 1980, p.60)

As I hold a current practising certificate as a registered nurse I could have engaged in complete participation, that is, I could have been an employee while studying the institutions. One reason for not doing this was to maintain a sense of distance. Distance was needed for the constant questioning required in order to be aware of taken-for-granted situations which exist in the culture under study. The different environments of the two institutions made it possible to check the validity of assumptions against the data. One nursing home would be considered 'state of the art' accommodation - a purpose-built nursing home with only single rooms, all with en-suites, blending into the local community so that every building looked like normal housing and where the principles of SRV were enshrined. The other would be
considered to represent the 'community average' - an old converted house where managing with what one had available was the overriding task.

Engaging in moderate participation involved shadowing RNs and Careworkers on some shifts to familiarise myself with the staff and residents. At the same time this provided a base for establishing opportunities for further data collection. I used a portable computer for participant observation in conjunction with tape recordings of field interviews. The material had to be 'tidied up' on my main computer each day when I returned from the field as the typing was so hasty and inaccurate in my attempts to be fairly unobtrusive or to record fleeting or tea-room conversations that happened spontaneously. However, it enabled me to get a lot of data into the computer quickly.

Establishing trust with participants was essential to the success of the study. There was a need for sensitivity, knowing what to say and when - and when not - that will achieve this end. In fact, establishing trust owed more to the calibre of the people in both nursing homes, than to subtlety or thoughtfulness on my part. Often in my rush to get away to make notes, so as not to forget material, or to get to another interview, I was insensitive. The staff, used to being tolerant to a wide range of people and behaviour, did not criticise me for this or let it affect their willingness to assist with the research. I lived in the local community during only part of the collection of the field-work data and so did not get to know staff outside the work environment. They did not become friends in the sense that Oakley (1981) describes. The staff extended support in a most generous and professional manner. I did not encounter any defensiveness; only a willingness to support a study that might assist with the difficulties of caring for people with dementia and might bring to the attention of policy makers and institutional managers a nursing perspective on the half-hidden pressures which, whatever policy enjoins, do much to structure day-to-day life in a nursing home.

During periods of observation I was sometimes uncomfortable about recording personal aspects of the residents' lives. Where I was hesitant, for example, in cases where I took photographs, I took values and clues from the staff. An explanation had been given to the staff that I wanted to capture changes to the residents' lives due to the progression of SDAT as closely as possible. After a while staff would prompt me about a suitable aspect of the resident's condition that they felt warranted recording. For example one resident, Amy, was becoming stooped and her appearance changing quite considerably. I had previously taken a photograph of her for which she posed very cheerfully, seeming to love it. The staff then were keen for me to continue
recording her decline. In Amy's case it meant that she could clearly be identified. This was an especially difficult decision for me as Amy so clearly loved having her photograph taken and the attention it gave her. The family had asked that she give consent to the study in the first instance which she had, but I was not sure that it was given with understanding. This presented a dilemma but I decided that enjoyment amounted to consent on her part, as she perceived reality at the time. Other photographs, focussing on the declining body, were taken. Anonymity can be preserved in these as only body parts are shown. Processing was undertaken confidentially at a laboratory specialising in medical photography. Examples of photographs and explanations of their purpose are included throughout the thesis.

**Examination of case notes and policy documents**

Case notes for each resident contain records of daily nursing notes, medical notes, medications, pathology results, social history, financial transactions, incident reports, and other incidentals such as bowel, bladder and behavioural charts. These notes were read and extracts from them used in conjunction with recorded incidents and observation over the time period of the study. Some quantitative data were gathered from these notes but is only meaningful in connection with other data collected. This enabled a 'case history' (Glaser and Strauss, 1970) approach to be taken with respect to each resident within a critical ethnographic framework. It is acknowledged by expert researchers that case histories provide rich descriptive data and stimulate insight (Wilson, 1989). Glaser and Strauss (1970) see that case histories provide readable imagery that can be used to demonstrate human experience.

Policy documents from each nursing home were collected and have been used as a reference to check the accuracy of staff's stories.

**Credibility of findings**

Ethnographic research is said to be valid if it is meaningful and understandable to the people involved, and if it reflects their own understanding of reality (Roberts & Burke, 1989). Validity is also assisted by 'checking the representativeness of the data as a whole and of coding categories and examples used to reduce and present the data' (Sandelowski, 1986,p.28).

Categories were coded from the whole of the data collected and themes selected from interviews, observations and notes by hand. Each section of the relevant information that had been coded was marked and entered into the Non-numerical Unstructured Data Indexing (NUDIST) software package. This allowed systematic management of
the large amount of data collected. Extracts relating to each coded theme from all data were then available in an easily accessible form for writing up and analysis.

The representativeness of the data was also checked by the process of leaving the first draft of the work at the nursing home for comment. Although the study did not 'involve' participants, as in an action research approach (Kemmis & McTaggart, 1988) the commitment to seek opinions from a variety of sources about interpretations in the study and the likely consequences of applying them in practice had the effect of checking validity as well as satisfying an ethical obligation.

At the end of the month when staff and relatives had had an opportunity to read the draft of the study an informal gathering was arranged with tea and cakes in each nursing home and I had an opportunity to let anyone speak to me about difficulties they may have about the analysis. Some staff members and relatives availed themselves of this opportunity and others wrote notes throughout the draft. Only one relative expressed any discomfort, feeling the term 'body maintenance' was harsh - 'like talking about maintaining a car really' but then, sadly, said 'but I suppose you are right, that is what it is isn't it?' . Other staff provided further information about residents telling them that they had expressed a wish to die, while another indicated that the study had increased a feeling of helplessness and powerlessness in their work. There was no doubt, however, that the general thrust of the evidence, that the deaths observed involved much suffering for the residents, was supported and that the cultural observations of nursing-home work were accurate.

Summary

In conclusion this study:

1 Recorded and analysed evaluations and nursing interventions concerning residents suffering from advanced late-stage dementia as recorded on nursing care plans during the final stage of their lives and to their deaths.

2 Recorded and analysed data concerning the life history of the resident and the perceived trajectory of the disease as expressed by all carers and recorded in resident notes and the relationships between this data and the death that is happening.

3 Discovered factors associated with a dignified or undignified death for a resident suffering from late-stage dementia and the decision-making processes that are connected with each.

4 Examined policies available at all levels which are connected with care of a resident suffering from late-stage dementia in a nursing home.
5. Gained insights into ways in which a process of death is 'chosen' for people with late-stage dementia and who/what is most influential in making that choice.

6. Analyzed the social construction of decisions made in relation to the death of residents in the late stages of a dementing illness.

7. Described the connections between formal and informal policies and how they impact on institutional practices.
Chapter 4

The exploration

Beachdale and Bayside

Introduction to environment

The first task of the study was to seek selection of residents and to gain permission for access to policy documents and medical records. After an initial approach to each nursing home one DON arranged to meet me for an explanation of the study in the first instance and made a further appointment when the CNC would be available to assist. The other DON chose to have the CNC present at the first interview and the selection of residents was made immediately.

Both DONs and CNCs were female registered nurses. The authority of both DONs was immediately apparent. On my first visit the DON at Bayside was able to order coffee to be brought into the office. At Beachdale this may have been possible but instead the DON chose to go outside and join the staff who were having a 'morning tea' for a staff member who was recovering from an operation. In this case it was clear from the demeanour and conversation of the staff that 'the boss' was joining them for tea and I was accorded the status of being 'the boss's visitor'. Nevertheless it was a friendly and relaxed occasion with support of all staff to each other being demonstrated. Both the offices of the DONs were very small with a vast amount of paper-work evident.

Both DONs indicated very early in the study that the amount of government regulation in nursing home management was worrying, stressful and difficult to understand and keep under control. For example, in response to the initial discussion about the need to obtain policy information for the study, one DON indicated that internal policy documents were really only cosmetic and the policies that really mattered were those connected with funding. Those policies are a constant concern to all staff, especially her, as she frankly said:

I think the government keeps everyone in line by fear. The fear for me is that if I knowingly, - now who's going to interpret that - knowingly -
make a false declaration that I could go to gaol for five years and get a $10,000 fine. That to me is intimidation in the workplace. I can't do that to my staff and get away with it, but the government is doing it to me, and they put it in black and white... And the organisation then can be fined as well. Now that would mean that I would lose my licence to practise, I would never get a job anywhere else. So what they're doing is ruling by fear and intimidation, and I think that's wrong.

The other DON in talking about the difficulties she has to juggle in her work and maintaining records, preparing for regulators and so on 'they [the government]...say when you accept our funding you have to accept our inspections'.

The reasons for the anger towards government control varied, but frustration due to a pattern of inconsistencies, especially amongst the Standard Monitoring Teams, seemed to be prominent. The effect of government policy on staff was also apparent immediately. The first field note of this study records that, a moment after I had introduced myself to a particular RN, she stopped to give a resident her medication. As she put an arm around her, coaxing her to take her tablet, she said 'here you are love'. At that point she turned to me and said 'I know we are not supposed to call them love but I would like to be called love and it is a soft gentle term'. At this point I was obviously still being accorded the status of 'boss's friend' and so this remark was friendly, but defensive nonetheless. The 'not supposed to' was a clear message that this remark would not gain the approval of the Standard Monitors. At that time this staff member had no notion that public policy was part of the study. As the study progressed it was clear that the kind of comment she made was common and acted as a protective 'mantra' that staff would repeat often. The phrase 'we are not supposed to' was recorded as a routine expression in nursing home language. Other similar reactions, which came so easily, and were later revealed to me as part of the continuing banter against the 'stupid them' [the government] who did not understand the realities of clinical care, confirmed the decision about the necessity to gather data connected with public policy because it was likely to be an important factor in the culture of the nursing homes.

**Selection of residents**

It was explained at the first meeting with the DONs that the case studies would focus on residents who were assessed by the DON and the CNC as suffering from late-stage dementia and/or had a medical complication which caused an expectation that the resident would die within a 12-month period or less. The rationale for this approach was that it is notoriously difficult to predict the progress of a dementing illness (Pitt,
1987). Nurses who are in close touch with the residents are likely to have an intuitive awareness of the past progress of the resident's disease, the present position and likely future. Also it was the intention in the study to focus, in the main, on nursing care for the residents.

Initially when the question of selection criteria was raised there was an automatic presumption by the DONs and CNCs that selection would be by medical diagnosis. When it was indicated that nursing diagnosis would govern selection, meaning that nurses would select residents because of their nursing knowledge, hunches and experience, both the DON and CNC of Bayside became very animated and started talking at once and interrupting each other. They responded to the challenge of using their nursing knowledge and judgement immediately and with enthusiasm, looking pleased that this was being asked for and used in such an overt manner.

At Beachdale the CNC took the greatest part in the selection of residents, putting emphasis on the medical characteristics of the disease. At Bayside a mixture of factors surrounding the residents was far more prominent in the selection procedure.

The following is the outline of the selection criteria given to the nurses as a guideline for their choices in selecting residents for this study.

(i) their own 'hunches'. For example, I have a feeling that Mrs X won't last much longer;

(ii) nursing observations. For example Mrs X has been losing weight, she has become very frail, her dementia has increased markedly and so on;

(iii) medical diagnosis. For example, Mrs. X has been diagnosed as having carcinoma of the oesophagus;

(iv) nursing knowledge gained through experience and/or knowledge of the residents for example, Mrs X has decided to die. I've seen residents go through a stage like this before; or

(v) any other criteria they deem appropriate.

In the process of choosing the resident the intimate knowledge of and involvement with residents that nurses have was apparent. In describing one resident suitable for the study the nurses showed their concern at the family's apparent disengagement. They saw this as evidence that the family was presuming that the resident was easing towards death because she could not respond as was expected in social situations
anymore. The nurses obviously felt this may be true, but to them the resident still needed social stimulation and family contact. Somehow they felt that the family did not want to understand the progress of the disease, that they believed that she only needed to be nursed as a 'dying person', i.e. someone who is very ill. They said the:

... family is very critical of our care. We query if they are ashamed about their mother's condition. We have to ring to encourage them to come. Rang the other day as she [the resident] said it was a lovely day and she would like to go for a drive, but it was not convenient, but they did come and do it a few days later, but usually they never take her anywhere ... She does not go outside the doors.

In spite of the attitudes revealed here there was nothing uncomfortable in the conversations about those who were going to die. In both nursing homes the view came through that the staff knew quite clearly who the residents were who had advanced dementia, and therefore would die in a relatively short period of time, but the individual nature of the person made any predictions further than that very difficult.

At Bayside ten residents out of the 38 in the nursing home were chosen to be included in the study, seven of them female and three male. At Beachdale seven female residents were chosen, five of whom were in the dementia house while two were in another house which considers that its function is to care for the frailler residents who are not demented. However, those with 'manageable' dementia are cared for here too. The total number of residents at Beachdale can be 55: 30 in the nursing home and 25 in the hostel.

After the residents were selected permission for inclusion was sought, if possible from the resident, and from residents' relatives. One resident signed her own consent form. A plain language statement was given to each relative to keep and consent forms were signed for both themselves and on behalf of their relatives. In each of the nursing homes a relative decided, on behalf of the resident and themselves, to decline to participate. This left fifteen residents in the study, twelve females and three males. This proportion is representative of the make-up of the nursing home population where 75% of the residents are female (Department of Health, Housing, Local Government and Community Services, 1993).
Before the study commenced I had decided on ethical grounds that all participants with dementia who were chosen for the study would have the research explained to them, however extensive their neurological damage and however impaired their understanding. In this way consent would be sought from them as far as was possible. I explained the purpose of the study in what I hoped was careful, clear and tactful language to each resident who had been chosen for the study, discussing the fact that I was exploring 'care' rather than 'death'. Most responses when I did do this were grunts, or blank stares or words that had nothing to do with anything I had said. However, there were two residents who did respond more or less directly, albeit with confusion clearly evident.

The first was Amy. Her son had indicated that he wished his mother to sign her own form. I had already talked to this lady, a tiny bird-like person who wandered round the nursing home all day looking rather lost. Any kind of contact seemed to produce a bright, if whimsical, smile. I found Amy in the lounge on the day I was going to ask her for her consent to be included in the study and this capricious look on her face when I spoke to her immediately gave me a feeling of engaging with her in some meaningful way. Yet I had to wonder if the smile indicated that she was happy to leave the lounge with me, or whether she was in a world of her own, living another experience in another place and time? I was aware that Amy's mood could change any moment and, perhaps, wanted to believe that this air of contentment was tacit approval of me.

I guided Amy back to her room, read the plain language statement to her and then explained the research as simply as possible. I told her that I had spoken to her son and he said she would be able to sign the form. The mention of her son produced a reassured look and she said, 'it's all right then but I won't remember'. I replied that that was why I wanted to talk to her and find out about her as I was interested in people who had trouble remembering. She gave me one of her expressive smiles in return and signed the form. Amy's signature was wobbly but very legible. This was 20 months before her death.

Another resident, Lillian, who to all external appearances may have been at roughly the same stage of dementia as Amy, was mobile and able to respond to some questions with some appropriate answers, was not considered by her closest relative to be able to understand well enough to sign the form. Yet for one staff member she was 'not really demented yet - when they get really demented they go over a point and they don't know. She's not there yet'.
Lillian's son had given written permission for Lillian to be included in the study so I asked Bertha, a bright and lively enrolled nurse, if she could tell me who Lillian was so that I could speak to her. Bertha's first comment was that Lillian had recently hurt her arm in a fall, and was beginning to decline. The unspoken message seemed to be that she wanted it recorded by me that the fall was not the fault of the nurses. As we approached Lillian the impression was one of a thin, anxious looking lady with a bruise around her left eye. Her left arm was plastered and covered with a rug. She was sitting in a chair in the corridor, opposite her bedroom. Bertha told me 'this is Lillian'. rather than making any formal introduction of one person to another, then sat down next to her, taking her right hand and leaning over to shout 'hello' into her ear. She then told Lillian who I am and leant back and told me that Lillian was very deaf - there is a confused, anxious response from Lillian. June, the receptionist, went past and Bertha encouraged her to talk to Lillian, explaining to me that Lillian knows June - she saw her going past - 'it makes her feel safe if June is here'. Bertha left us and I repeated who I was to Lillian and that I was doing some research. Helen, a domestic, walked past - smiled - said 'she's a sweetie isn't she?' It was obvious that my talking to Lillian like this was an 'event' in the nursing home, so all who were around got involved in one way or another.

After asking Lillian if I could talk to her and write about her the response was as follows:

J: Do you mind telling me about yourself?
L: No I've got nothing to hide
J: How long have you been here?
L: As long as I can remember. A long time I like to have a bit of a group then you don't scamp around all over the place you know I'll have a wash and a laundry later. and get myself in a good position.
J: Are you happy here?
L: Very happy They have been very good to me really - although I react in the same way you know.
J: What happened to your arm?
L: Is improving Must have got a bit of a twist or something. That's why I wanted to stick around because they know what happened you know.
J: Is that all the news?
J: Have you got a family?
L: Yes I have five sons and daughters accordingly
J: Do they come and see you?
L: One was here. Yes. They come quite a lot to see me. I didn't want to come here and be the only one. You get a bit lonely then.

Got all your good news?

J: Why did you come here?

L: I don't know why. Started off in that direction and kept going. They are very good for looking after you - you know. I'm hoping keeping going a little bit longer, there's not enough time really.

J: Not enough time to do what?

L: Service. As long as they come and give it to me.

J: What do you think is wrong with you?

L: Deafness is the worst - not so bad that I can't add a bit to company, but that's my main complaint. Afternoon tea. If you get where you come from, battle's half won isn't it?

J: Is there anything else wrong with you?

L: Don't know there is anything else you need to put down, but I am hoping they supply me with - what do you call them - iron work part of the business. Don't know exactly.

Bertha returned to the area and Lillian became increasingly anxious, talking about the 'iron works'. Bertha translated this language easily as a need to use the commode and so I concluded the interview at this point. In contrast to Amy, Lillian appeared anxious and distressed and yet her words would belie this. One could glean from this conversation that Lillian had a glimmering of my needs and was trying to assist. In conflict with that of Lillian's relatives and senior staff it seems that because the staff are able to translate Lillian's own particular 'language of dementia' quite easily and understand her needs they see her as 'not really demented yet'.

These two examples illustrate the difficulties in obtaining informed consent or a judgement of needs from people with dementia. In the light of these difficulties people form and act upon their subjective judgements in decision making connected with the care they provide.

All the selected residents' doctors were contacted and raised no objections to the residents in their care being included in the study, which entailed my having access to medical notes, and all the doctors agreed to be interviewed at some time in the future.

**Physical environment**

Nursing homes choose, for pragmatic, architectural, financial or philosophical reasons, to care for residents with dementia in integrated or non-integrated settings.
An integrated setting is one where the resident with dementia will be accepted into a nursing home where the other residents are likely to have been admitted due to a variety of diagnoses such as arthritis or paraplegias. Institutions which create non-integrated settings admit residents who have organic brain dysfunction into a segregated area and these sections of the nursing home are usually called dementia units.

In this study the residents at Beachdale who suffered from dementia were segregated into what was called the dementia house. At Bayside the residents were all integrated. The nursing homes were both in coastal towns of moderate size and within a half-an-hour drive of each other.

The nursing homes varied widely in the physical amenities they were able to offer residents. Both nursing homes are run by church-based organisations which have a reputation for a high standard of care.

My first impression of Bayside is noted as:

10.30 am. I arrived at low slung cream brick building which I found easily as it dominated the streetscape. The name of the nursing home was displayed on a wooden strip at the front of the building. I entered a small lobby furnished with two cane lounges and two higher chairs. To my left was an office type window with a receptionist label on it and a desk with a computer on it facing into it. Lion mints were displayed for sale on the ledge. The receptionist was not in the office. ... A middle aged lady was also waiting. She told me that her 'person had been contacted'. I sat down to wait for the receptionist and in front of me I noticed a display of craft items for sale in the hallway that ran off the lobby. They were rather the same as I have seen in most other nursing homes, crocheted coat hangers and the like. However, the most prominent features in my vision were two large appliances that had to do with fire regulations. One had a notice on it telling what to do in case of fire, starting with 'remove patients, alert the fire brigade'. My attention wandered from reading. I then noticed that next to this appliance was a very large red cupboard containing a fire hose and on top of that a rather tired looking bunch of dried banksias. The lobby smelt slightly of disinfectant, it was pleasant for me. The receptionist arrived and said I would be able to see the DON soon - she hoped.

My first impression of Beachdale was recorded as:
9am. Found the corner of x and y streets [the address I had been given] but could not find the entrance. It looked like an ordinary suburban street with new housing units in it. There was nothing but numbers on each of the houses. I knocked on the door of what looked like one of these ordinary suburban houses because I noticed that the gate was taller than the others and had latches top and bottom. I guessed that might have something to do with the care of residents with dementia. I was greeted by a comfortable looking young woman who was gracious and charming and said she would take me to the DON. She took me down the corridor of what seemed like a large house. I was walking past the bedrooms. On the way the staff member who had opened the door stopped to speak to - what must have been a resident - in a wheelchair, and said - 'Take you up later George' - then turned to me with a 'Needs a shave'. There was no institutional smell at all. We passed what looked like a large country kitchen and then I was taken out of the back door of the house into a garden setting and then into a small office where I was greeted by the DON.

From the start Beachdale had a more genteel ambience about it than Bayside. Bayside had a more 'knock about' feel and a 'we-are-doing-the-best-we-can' attitude. In the first instance this made Bayside seem less intimidating and more friendly. However, after a few visits both nursing homes felt comfortable and welcoming. The environmental differences which were so stark at the beginning faded over time as other elements of the culture took prominence.

The personal spaces allotted to each resident at Bayside were much smaller than at Beachdale. In each of the nursing homes the shared space which the residents moved about in over a 24-hour period usually ranged from an area equivalent to a large house to a space equivalent to the distance between a bed and a bedside chair.

There was a marked contrast in the internal decor of the two homes. There were few colours or textures apparent at Bayside, the predominant impression was of grey and white, with clinical, easy to clean surfaces. At Beachdale there was a much greater mixture. Photographs 1 and 2 show the contrast between the personal space allocated to a resident in each home and the contrast of decor. To the left of the photograph of Bayside was another bed. To the left of the photograph at Beachdale was a private ensuite bathroom; so Beachdale residents not only enjoyed more personal space but also much greater privacy.

The speed in which environments are changing to cope with the increasing population with dementia is shown by photograph 3. None of these locks were in place when the study began. All the locks shown in the photographs have been
THE RELUCTANT SOLUTION
TO WANDERING

Photograph 3
installed during the time this study has taken place. Bayside now has digital coded locks on every exit door, and Beachdale now has locks on every door and gate connected with the dementia unit. The effect of being imprisoned may be overwhelming for a person who is confused, but for safe care of the residents they are seen as a necessity.

The outdoor areas of each nursing home were, in theory at least, available for residents with dementia to wander around but they were not conveniently located, they were difficult to get to, hard to negotiate and would certainly contain many hazards if any if the residents in the study had tried to venture out. In the first weeks of this study the staff at Bayside organised a picnic day out for those residents who could manage it, but, in spite of a stated willingness to continue the practice, the shortage of staff and weariness of work caught up over the next three years and it did not happen again.

The architecture and furnishings of Beachdale would be considered to be achieving the criteria set out under SRV guidelines to a much greater extent than Bayside and this difference in environment was apparent to the staff. Many Bayside staff had never seen Beachdale or seen another nursing home with up-to-date design, but the impression that they had to manage to make what they had got more 'homelike' was very strong.

The most noticeable difference in the culture which seemed to be a direct result of environment was at meal times although this changed considerably at Beachdale over the period of the study. When the study commenced some residents at Beachdale would be able to eat together in the private dining room and those who needed assistance would eat in the large kitchen. By the time the observation and field work data collection phase had finished all the residents were in the kitchen and all but two needed assistance with food. At Bayside there was a large dining room where everyone ate together, whether they needed help or not. In both cases lots of bantering and chatting amongst staff, and residents if they were able, went on while everyone was eating.

The residents in Bayside had, in general, been admitted from the organisation's independent living units or hostel. The population of Bayside was drawn from wherever the DON can find a new resident. The DON has to take 'who she can to fill the beds'. Nevertheless, residents chosen for the study seemed to come from fairly similar socio-economic backgrounds, regardless of the different paths which have brought them into the system. All the residents in the study were white and English speaking, and they gave the impression of ranging from lower middle class to upper
class. Therefore the particular needs of ethnic or Aboriginal and Torres Straits Islander minorities have not been considered in this study.

From the first impressions of the nursing homes it would seem that each one's cultural atmosphere would be unique. The actuality was that many features of the two differing sub-cultures were found to be very similar. The architecture of the nursing homes seemed to make only a little difference to the way relatives viewed the care of the person suffering from dementia or any difference for the sufferer themselves. Feeling proud of the furniture, fittings and private rooms at Beachdale seemed to have a positive effect on staff morale, while, on the other hand, at Bayside the staff seemed to gain strength from being part of a small, intimate community.

The effect of a total commitment to the principles of SRV were immediately and obviously apparent at Beachdale because of the architecture and through conversations with the staff. Probing a little deeper as to how this commitment impacted on the frail demented resident yielded a mixed picture. Many aspects of SRV policy were proving to be dysfunctional. The effect of the architectural environment has not been analysed in depth in this study. There seems no doubt that for reasons of privacy, dignity, comfort and aesthetics SRV principles as applied to some aspects of architectural design are positive. However, the detail of this debate is not a major part of this story. Debates about designs for dementia-specific units and integrated versus non-integrated nursing homes are important but are tangential to this study. The atmosphere created by SRV will be examined only so far as it affects caring during the process of death.

It is into this milieu and against this background that the deaths trajectories of the fifteen residents in the study were observed.
Part 2

The dying
Chapter 5

Resident profiles and synopsis of death trajectory

Each of the following profiles has a different emphasis. There were particular aspects of each death that illustrated aspects of care that can be usefully examined further when considering emancipatory change of practice. Each case history will concentrate on the point which it illustrates best. The aspect of care illustrated by one case is often evident in the others but this will not be emphasised in the course of the case studies themselves.

Some case histories are very short while some are reported in detail, not because one is more important than the other, but simply because of the message the stories tell. Each case history starts with a quantitative summary of some aspects of care that have emerged as important factors in the culture of care. These details are of interest when linked with the qualitative analysis but do not stand as evidence by themselves.

For example, Mrs Fishlock had a fall which resulted in a fractured femur, yet she only has four falls recorded, while Mrs Zampatti, who never sustained a major injury, had 96 falls recorded. On the other hand this data does illustrate the paradox between the 'sameness' of much of the care for people with dementia and yet the subtle and complex differences for each person. It also illustrates how linear the documentation process is, only telling one part of the story of care. Yet this is the 'evidence' used to measure the standards on which nursing homes are judged.

Overall the story that emerges from the case studies is one of a clash of values, language and needs. Doctors, nurses and the agents of government are all working to get their own needs met while carrying out the duties they are paid to undertake. They respond to residents' and relatives' behaviour from an imperative that is steeped in their own professional and personal frame of reference. This is understandable as it is vital for a person to feel a good measure of control over their daily life and work if they are not to feel alienated from it. The product of this work, the body of the person with dementia, is controlled by all these forces. These stories show the struggle over the ownership and control of the decaying body and the remnants of the person with dementia as they die. Each of the three groups who have the major opportunity
for control will interpret the needs of the person with dementia in a way that suits their purpose. These purposes may be well motivated and ethically sound, but nevertheless, they coalesce to form ways of coping with some of the agony surrounding these deaths which lead to the marginalisation and ignoring of tasks that are too hard to solve.

The phrase 'help me' was repeated by many of the residents in this study. I think they meant it in its everyday sense and I saw it as indicating that they were suffering. That that suffering cannot be relieved or avoided within the present paradigms of care comes through clearly in the following stories. Conclusions drawn from these stories are that all the residents suffered in one way or another, some railing against pain and distress, some enduring their illness while others were dying as patienty and bravely as they could. Some moved back and forth along this continuum; some stayed closer to one end or the other.

In the first two case studies, one from Beachdale and one from Bayside, we meet two residents, both of whom died after just over three years in the nursing home and both with signs and symptoms that could, perhaps, have meant that they suffered from bowel carcinomas. Both residents exhibited belligerent behaviour and therefore posed a difficult task when physical needs were being met. These physical care needs are dictated by the atmosphere of SRV and aged care policy. For example, it is expected that residents are out of bed and dressed in their own clothes every day. These case histories raise questions about the morality of a type of caring based on a vague and generalised notion of quality of life rather than one based on palliative or comfort care principles.

The first case history, that of Mrs Zampatti, is spelt out in the most detail to set the context of the triangulation process that has been used for all case studies, the combination of field notes, observations, interviews and the use of case notes.
Mrs Zampatti

A painful death ignored or nurses not wanting to let go?

- 88 years old at time of death
- In nursing home for 37 months
- No transfers to acute hospitals but visits to gastroenterologist for investigations eg barium enema
- Incontinent before admission to nursing home.
- 3 courses of antibiotics during time in nursing home.
- 96 falls recorded on incident reports.

The first case study illustrates how the progressive decline of Mrs Zampatti was resisted by nurses who tried to press medical staff to find ways to 'make her better'. Medical staff could not find a definitive diagnosis for the resident's 'illness' and get frustrated with the nurses' demands of them over indefinable episodes when they were told that Mrs Zampatti is 'feeling unwell'.

This case history provides opportunities to see how a case-managed approach based on clear directions of what 'general nursing care' means may have relieved time, pressure and irritation for staff. A clear multi-disciplinary plan may have meant less upsetting investigations and better management of pain and distress for the resident.

For example the presence of any pain (apart from chest pain which is treated with anginine) is hardly dealt with in the three years of management, even though a carcinoma is suspected and investigated. A comment about this conclusion was made when the draft of this study was left at the nursing home. An anonymous staff member left a note saying 'I did not feel that Mrs Zampatti was suffering pain (abdominal) only distress from constant diaborreat'. This comment could explain why the issue of pain was not raised or dealt with. If staff closely involved with the resident do not assess and interpret non-verbal symptoms as pain then they will not be addressed. As will be shown as the stories progress, assessment of a resident's condition has a lot to do with the values and ideologies of the person undertaking the assessment, although it may also be related to the level of knowledge of the care-staff.

In any event, a philosophy that addressed ways of relieving distress, rather than making attempts to cure the cause, may have been more appropriate for Mrs Zampatti in some of the circumstances described.

In the first notes written when she was admitted to Beachdale Mrs Zampatti was described by a careworker as a rich lady who grew beautiful roses. Mrs Zampatti
spent three years and one month in the nursing home between her admission and her
death. In most of that time she was incontinent and regularly attacked both staff and
other residents. Yet she was constantly presented as a person one should feel sorry for
because 'she has got all that money and no-one to care for her' - the implicit message
from the staff seemed to be 'except us'. The notes reflect the staff's efforts to advocate
for her over and over again, as if acting out the responsibility they felt because,
except for Sally, a friend who called when she could, they were Mrs Zampatti's
'family'.

Mrs Zampatti's early notes say that she was:

... a lady who likes her own company, and on most mornings enjoys
reading the Advertiser and local papers in her room, and often liking
a cup of tea whilst doing so ... Mrs Zampatti loves dining out and
when Sally Jones [her friend] visits every fortnight they go out for the
day either to have a meal or to do some shopping. She also takes her
to the local hairdresser. Mrs Zampatti has visited the hotel for a
Melbourne cup luncheon with volunteer and they both enjoyed the
outing. She also enjoys devonshire teas.

Two and a half years later the following exchange was recorded when observing Mrs
Zampatti being showered by Liz, the careworker:

Liz (the personal care attendant): Time for your shower.
Mrs Zampatti makes some incoherent noises and 'go way' gestures
Liz: You are not really with us today are you
Mrs Zampatti: [shouting]. I don't want a shower - I can't stand up - I'm too
cold don't take the gown off. [shouting]

Liz turns to me and says that she gets very contrary - looks as if she has left
most of her breakfast. Mrs Zampatti shouting over this and objecting to
her shower

Liz, tells Mrs Zampatti that she has the heater on in the bathroom and she will
feel better after the shower. Liz is shouting at her because of her deafness.
Mrs Zampatti is screaming now. Don't be such a beast.

Liz shuffles her over to the shower. Mrs Zampatti has been incontinent of
faeces - she is covered in faeces all over legs and nightdress and smells
awful - Mrs Zampatti screaming - help me help me - her legs are bruised
and swollen yet thin and emaciated.

Mrs Zampatti is hitting Liz now as she attempts to take the nightdress off while
Mrs Zampatti struggles away. Mrs Zampatti is screaming 'Take your damn
hands away' and hitting Liz all the time.
In between these two descriptions is a story of intellectual decline that is typical of a dementing condition. It seems most likely that Mrs Zampatti had multi-infarct dementia, or a mixed dementia. When Mrs Zampatti was chosen to be included in the study seven months before her death I was told that 'She may go if she has a big TIA [Trans Ischaemic Attack] - we have saved her a few times by straightening her airway - she started to breathe again'.

Mrs Zampatti had no close relatives; her husband died about 12 years ago. Her care and affairs were handled by the Guardianship Board. Staff commented that she used to "bash other residents in the dementia unit with her stick". Because of this she was moved out of that unit and was much more settled in another house which was where I first met her.

When I spoke to Mrs Zampatti about being included in the study her reply was a rather incoherent sentence that I interpreted as her asking me for a glass of water. I got her a glass of water and asked her again if she had any objections to me including her in the study which meant that I would get the story of her illness from her notes. Her answer to my question was 'I have not made a mess anywhere - I am deaf'. I repeated my question by speaking into her ear clearly. She replied 'You do what you want to do, I have a pain in my chest'. We continued a confused conversation and when I gave her another glass of water she handed me a banana - almost as if it was a gift. I took it out to the staff as it seemed rude to put it back and as I gave it to Jill, the staff member on duty - she says 'Isn't she sweet'.

This gentle aspect of Mrs Zampatti's behaviour seemed to be her saving grace in the eyes of the staff allowing them to care for her with some affection. They took the moments when she would say something like 'you can take my Mercedes' as an insight into her true character and the aggressive, confused behaviour as an indication of her worsening dementia.

From the medical point of view Mrs Zampatti was viewed a little differently.

On admission, Mrs Zampatti's examination, problem list and directions to nursing staff read:

#1: Widow - no obvious family support - family trustee

#2 Senile dementia - progressive for last few years was only JUST
[underlined 3 times] coping at home, max community support until
recently but was becoming a danger to herself - wandering outside in the
cold - not eating - unable to toilet satisfactorily - leaving stove on etc.
#3: TIA's occ dizzy episode
#4: Blind (r) eye how long and why - suspect secondary to embolic problem
#5: deafness since secondary to childhood measles
#6: UTI's Abdomen (name of local hospital) early '89 with this E coli (the name of the causative organisms) Rx Keflex
#7: Mild macrocytosis in CBP but B12/Folate levels NORMAL (This is indicating that although Mrs Zampatti had a slight abnormality in the size of red blood cells which could indicate a certain type of anaemia, the B12/Folate test results indicate that this is not so, therefore there is no explanation)

A further summary confirms that Mrs Zampatti is blind in her right eye, can count fingers with her left eye, but is 'demented place and time', can walk, coordination OK. She has sounds in her lungs which indicate some consolidation but is not short of breath. Her pulse and blood pressure are within normal limits, but she has some cyanosis of her toes and fingers. Palpation of her abdomen shows no abnormalities.

The GPs notes finished:

**Plan:**
1. General nursing care
2. Urinalysis specimen if suspicious of infection
3. Watch for evidence of TIA's if frequent consider aspirin daily.

These medical instructions put the responsibility for Mrs Zampatti's care firmly in the nursing sphere.

What follows is a precis of Mrs Zampatti's early progress as detailed in medical notes and through nurses' messages. This demonstrates the interactions between nurses and Doctors that occurred over a protracted period.

The first entry following the doctor's admission notes was the recording of nursing action following a phone call from the doctor.

*Lomotil script written for Mrs Zampatti (verbal order Dr Catwright). Loose B/A's (Bowel actions) Faecal specimen also to be collected for lab testing*

At this time daily nursing entries were recording Mrs Zampatti's faecal incontinence and her wandering such as 'found sitting in gutter in road'. There is no record of a doctor visiting or examining Mrs Zampatti. A bowel specimen was collected and
reported on. Nothing unusual was found but no comment was made about this in either set of notes. The bowel difficulties continued concurrently with difficult-to-manage behaviour and fairly frequent falls. For example, one nursing entry reported that Mrs Zampatti:

... accused Mrs Gabb of taking her car keys and was trying to hit Mrs Gabb with stick. Mrs Zampatti also knocked Mr Gabb's cigarette from his mouth saying 'he shouldn't talk to lady with a cigarette in his mouth'. TLC [Tender Loving Care] given to both residents

Later the notes record the same resident returning Mrs Zampatti to the nursing home when he found her wandering down the street, indicating to staff that he had no hard feelings about the matter of the cigarette being knocked from his mouth, but questioning whether Mrs Zampatti's freedom needed to be curtailed.

Since the Lomotil was not controlling Mrs Zampatti's loose bowels Metamucil, a substance which 'provides soft bulk to restore natural bowel function and relieve constipation' (MIMS, 1981) was tried for ten days but stopped as it was thought to be causing abdominal pain. When Mrs Zampatti was examined at this point, it was found that she had a slightly distended tympanic abdomen and the GP queried the need for a barium enema. However it seems that it was decided this was not possible as shown by the following nursing record:

Dr Cartwright will contact a gastroenterologist to advise re loose bowels. For now ensure high fibre breakfast. Barium enema would not be likely to be tolerated.

How this decision was made is unclear as is the basis for the doctor's order linking emotion and bowel movements which read 'As noted patients bowels worse if upset. Try Valium 1mg mane as a trial.'

There is nothing in the nursing notes to confirm that they believe the connection between Mrs Zampatti being 'upset' and having loose bowel movements. Lomotil is still used spasmodically although it is noted that Mrs Zampatti began to refuse to take it as she considered 'this is causing the problem'. Nursing staff repeatedly record large fluid bowel motions and faecal incontinence. Other entries in nursing notes refer to parts of Mrs Zampatti's body that are healing after various falls and knocks, and a continuous stream of behavioural difficulties such as the loss of her handbag, keys, jewellery or violence towards other residents. Over the Christmas period
she was treated for a chest infection with Bricanyl syrup, a bronchodilator that also helps to clear mucus, and Amoxil, an antibiotic.

Later that month a written exchange occurred between the CN and the GP.

The nursing entry reads:

? loose B/A's to be diverticulitis related? and if so should we cease daily bran. Loose B/A's not as frequent since Valium was commenced specially since [date]

The doctor's reply was:

Loose bowels probably not related to diverticulitis as usually pain and mild fever would be present and occasionally blood stained loose faeces. Bran is used in cases if diverticulitis. Anyway stop bran and see what happens.

This exchange indicates the different imperatives each profession has. The GP's reply indicates that assisting control of a resident's bowel movements is a nursing responsibility, and that doctors don't really need to be bothered with it, also that it is going to make little difference to the resident's condition.

For the nurses, in contrast, it is an almost daily distressing part of Mrs Zampatti's life, for which they have no remedies, relief or cure. After the GPs' comment the nurses deal with the loose bowel actions, or now the occasional case of constipation, as best they can in each individual instance. A change in bowel habits is a typical symptom of bowel cancer (Spiro, 1983, p.1000) but these kinds of indications are unlikely to be noticed within the complications of caring for a resident with late-stage dementia. There could be so many factors affecting bowel motions.

During a routine review a few months later the doctor's report reads:

Review; BP 140/90 2HS Ejection murmur.

Chest: few basal crackles

fit for age

Moderate dementia Continue same Rx

and much the same in another two months, although there is now some further evidence of heart murmurs and the doctor queries Mrs Zampatti's 'smell' which indicates that a UTI (Urinary Tract Infection) was suspected.
There are no medical entries between these two reviews and no evidence that nurses are connecting changes in behaviour with a UTI.

There are some sharp exchanges between nurses recorded in the nursing notes at this time. One nursing note asks why Mrs Zampatti was not given any analgesia (Paracetamol syrup) because it seemed to assist her abdominal pain. A message comes back that although she had pain it was not 'bad enough' to need analgesia. Also there are messages from one nursing staff member to another suggesting that describing Mrs Zampatti as 'annoying' was a subjective opinion and demeaning to the resident. In the next few days there was a note from one to another staff member saying that to describe Mrs Zampatti's behaviour as co-operative:

suggests a responsibility to you to behave in a certain manner of your choice, thus leaving an impression of restricted choice and demeaning overtones which I'm sure was not your intent.

These exchanges demonstrate the tensions as staff struggle to learn the new language attached to the Outcome Standards when coping with the kind of demands a resident like Mrs Zampatti continually places on workers throughout an eight hour shift. It is more than likely that the reason for the reprimand was so that the Standard Monitoring team did not give them a 'not met' because of this manner of referring to a resident. It also indicates that when things become difficult and the release valve to the doctors has been shut off, the nature of the struggle now takes place between the nurses. If this worsens it leads to horizontal violence between the nurses and an atmosphere of poor morale, alienation and helplessness. Also it seems to have resulted in any resolution of the 'pain' or 'not pain' problem being forgotten.

Over the next 2 months the GP visited Mrs Zampatti because of a chest infection and the nurses returned to their requests for assistance in managing Mrs Zampatti's distress and 'unwellness'. This pressure resulted in an X-ray being requested. The report indicated that Mrs Zampatti may have a lower bowel obstruction.

Mrs Zampatti was then transferred to the local hospital for a barium enema. When she returned the nurses showed their pleasure at her obvious relief to have it all over and be back 'home'. They say that Mrs Zampatti '...had a cup of tea and lots of biscuits, also had a large meal at tea time'.

The barium enema showed no abnormality. The specialist suggested that the problem was probably a pseudo obstruction secondary to Lomotil. The decision from Mrs Zampatti’s GP was 'Therefore No more' indicating to the nurses to stop giving Mrs Zampatti the Lomotil, as she herself had requested some weeks before.

However Mrs Zampatti’s bowels continued to be a problem. A nursing entry directed to the doctor a few weeks later reads:

*Bowel actions continue to be loose and expressive. Could Imodium be helpful? Also has dizzy spells and TIA’s? Aspirin indicated as suggested by admitting M.O. Please review. Ta.*

The comment of 'Ta' shows how the doctor-nurse game was still operating in these circumstances. The nurses are still feeling out of control and powerless in the situation.

The rather curt reply from the GP was:

1. *Add aspirin for presumed TIA’s*
2. *Bowels same as far as I can see on or off antidiarrhoeals*
3. *Unwell o Chest clear o Abdo bloated as usual MSSU please.*

While there is a good deal of rhetoric about the necessity for multi-disciplinary collaboration to ensure the patient’s comfort when 'general nursing care only' is indicated, there is little forthcoming in these notes to suggest the practice here reflects the injunctions from academic articles or the class-room.

The medicalisation process continued, the MSSU result was 'no growth and few cells' so it seems that a UTI was not the cause of the 'unwellness' which nursing staff had noted.

Now the RNs have turned to another problem and press the doctors to take some sort of action about Mrs Zampatti’s urinary incontinence. They say that *she stands up at night and a steady stream of urine trickles from her bladder. She goes to the toilet at least 4 times a night*. They indicate that staff encourage her to sit and try to ensure her bladder is completely empty.

There seemed to be no way of resolving the problem so nurses request another MSSU on their own account because 'past negative routine tests have proved positive'. However this did not happen, either because the specimen could not be collected or it was not ordered by the GP. A month later after many nursing entries recording that
Mrs Zampatti stayed in bed because she reported feeling 'unwell' or 'her stomach was out of order' she was referred to a specialist with a note in the file from the doctor saying 'still has abdo problems' The CN wrote the following referral letter in the medical notes.

Thank you for reviewing Mrs Zampatti. She often has days when she feels unwell in the 'stomach'. On those days when she is unwell she usually has one or more 'explosive' fluid bowel actions. For sometime she was having Lomotil following each loose explosive bowel action - which they generally are - but no improvement came from this. In fact I think she is having slightly less problems since it has been ceased. Metamucil was tried a long time ago [date] but it caused subsequent abdominal pain, therefore ceased.

Apart from Mrs Zampatti's problems above I am also concerned about her urinary incontinence. She retains urine after voiding, has hesitancy, post-void dribbling and only voids small amounts - a large void for Mrs Zampatti's being about 200mls which is usually an overnight void- dribbling occurs during the day and she is unable to hold on at night and probably during the day. Staff have noted that she voids frequently when she is feeling 'unwell in the stomach'.

frequent tiny voids. Could you please consider any relationship the GI tract may be having with Mrs Zampatti's urinary problems and suggest further action. Please see also the letter from Mrs Zampatti's MO and her Xrays (and fluid balance charts opposite) Thanks and regards CN

The reply from the GE specialist was:

Partial obstruction probably due to tight anal sphincter. She may benefit from anal dilation but I doubt if she would tolerate it she certainly objected to me stretching the anus with my finger.

One can easily imagine that behind this comment was the confused screaming of Mrs Zampatti that would make the idea of further treatment seem pointless for a specialist dealing with acute problems in otherwise healthy people day after day.

These exchanges give the impression that the GPs are trying to assist nurses to cope with the problems Mrs Zampatti is having, while nurses are looking to the GPs for cures. In interviews the GPs indicated that most investigations and implementation of treatments arise from pressure from nurses and relatives, rather than are suggested by them. This case seems to indicate clearly the reluctance of the doctors to be pushed into anything but vague generalisations about Mrs Zampatti's condition. It seemed quite possible that Mrs Zampatti may have a carcinoma of the bowel, but this problem
was dealt with as if it could be disassociated from the complications of her dementia. The pain of a possible carcinoma, irritable bowel syndrome or colitis, for example, and Mrs Zampatti's organic brain dysfunction cannot be separated, but there had been no review of Mrs Zampatti's dementia in the medical notes at all, or an acknowledgment that any management of pain control could be implemented.

A pattern of frustration and difficulty in coping with Mrs Zampatti's decline was beginning to appear in both sets of notes and the lack of any coordinated or planned approach constructed around a shared model of appropriate care was obvious. The conflict between nurses, who are seen as 'making a fuss,' and doctors, who are seen as 'not caring' is perpetuated by this type of case management.

So there was no resolution of the problem. Somehow it is obvious that Mrs Zampatti had some kind of obstruction, but what one could do about it, or how the situation was to be managed, was put back onto the nurses' shoulders. Again we see conflict rising in the following statements amid partial attempts to solve problems via the medical model. A week after the visit to the Gastroenterologist (GE) the medical notes report another potential problem with no known antecedent:

Recent swelling face and legs and SOB O/E swelling down now and chest essentially clear ?cause

The nursing notes continued to report Mrs Zampatti as 'unwell'.

A typical nursing entry reads:

Feeling very weak today. Up and dressed but didn't have the energy to walk from her room to kitchen except at lunch time after, [clearly underlined for dramatic emphasis, and perhaps to show how much time and effort this action took] being persuaded.

A month later after daily nursing reports such as this the doctor wrote:

ATSP and vaguely unwell puffy eyes and SOB at times. Pt denies any of this.

O/E o swelling chest clear good AE JVP NR o SOA

a. ???mild (L) VF

b. Rx trial laxix M 20mg mane PRN only [PRN has scribble underlining under it]
However, that night Mrs Zampatti had an episode of chest pain which was treated by nursing staff with Angininc and an episode of frank blood in her faeces.

It is obvious that both nurses and doctors are feeling that something is wrong, that Mrs Zampatti is 'ill' but no-one can find a specific medical diagnosis. Mrs Zampatti's fluctuating condition adds to the confusion. A few days after the chest pain episode the nurses' report says that 'Mrs Zampatti is extremely well today wanting a ride to Adelaide or on a bus today'.

In the next record we can see the irritation of the doctor surfacing again by the use of 'apparently' to start the record.

\textit{Apparently SOB nocte and SOA}

\emph{O/E} O distress

\emph{JVPNR} chest \textit{clear} good. \textit{[again the word 'clear' is underlined, which seems to be used in much the same way as nurses do - to add emphasis without actually saying what the person means - the emphasis here seems to be that the doctor has reservations about the nurses' story about breathlessness when he can not find any clinical signs of consolidation in Mrs Zampatti's chest.]} Mild \textit{?SOA for regular lasix 20mg mane [and now regular is underlined] extra pillow}

\textit{25:1:91 ATSP 'vaguely unwell'}

\emph{O/E} Looks \textit{ISQ (In Status Quo) although subdued chest clear JVPNR P(Pulse) 84 reg abdo distended soft non-tender.}

a. \textit{????? [Here the GP acknowledges that a diagnosis is not possible].}

b. \textit{Rx wait and see check MSSU.}

The GP rings the GE specialist asking if it is worth trialing Donnatabs. However the answer is, again, negative and no alternative is offered.

\textit{(name of gastroenterologist) phoned noted Donnatabs will not help with tight anal sphincter. We still need MSSU(of sorts) to make sure urine is clear.}

This time the pathology result does show that Mrs Zampatti has a UTI.

Antibiotics are commenced but next a sore tongue and diarrhoea are reported by nursing staff. The medical opinion is that this may be secondary to the antibiotics and the order is \textit{Therefore stop, Start Fungilin lozenges. More}
investigations are ordered. CBR ESR Elects/renal f/u LFT's which are all tests which can be undertaken on blood samples to look for causes of 'unwellness' such as infection, liver failure and so on.

A couple of weeks later the doctor is prepared to hazard a guess that there may be some serious underlying problem, such as a carcinoma, causing Mrs Zampatti's feeling of being unwell. However, no treatment is suggested or orders given. Again, the possibility of pain does not seem to be discussed. In the medical reports there is still no mention of an acceleration of Mrs Zampatti's cognitive decline. However, nursing notes record regular falls and TIAs. For example:

?had a TIA or M.I , lost consciousness for a short time , pulse erratic , pale, sweaty and hot. When consciousness returned she was confused, aggressive. Helped to bed .

This episode is not mentioned in the medical notes of the next day when the doctor reports 'Asked to see because of bleeding pr'. After his examination he reports a tentative diagnosis of diverticulitis underlying Ca colon and suggests that Solprin is stopped because it is unnecessary. Again, a couple of weeks later the 'unwell routine' is repeated and more investigations are ordered. The doctor reports:

Non specifically unwell Needs : MSSU, CBP (Hb 9.9) ESR (normal) CRP (normal) ALP (essentially normal)

This indicates that Mrs Zampatti's haemoglobin (Hb) was found to be below normal limits, and further tests were ordered to investigate the cause of this. The GP indicated that the matter would be discussed with a specialist gastroenterologist but there is no written report from this discussion.

By now, in the eyes of the nursing staff, Mrs Zampatti's agitation is getting to be the biggest management problem. They report a phone discussion with the doctor about Mrs Zampatti's breathlessness and agitation. Mrs Zampatti is re-commenced on lasix 40mg 1 mane 9 and Valium 5mg 1 bd to build up then to be reviewed daily by RN for prn dose only. The nursing reports are repeatedly saying that Mrs Zampatti is breathless, distressed, restless, confused and record further falls and TIAs.

At the same time Mrs Zampatti has days when she is - seemingly - well and somewhat orientated, or at least aware of her confusion such as the day this
report was written. '... read social history notes today and asked about what she had done in her life'.

Observations and reports about Mrs Zampatti show that her condition was - as reported by staff - 'up and down'. This erratic pattern between 'being well' and likely to be dead any moment was illustrated by the comment recorded from a staff member returning from holiday. She says as soon as she comes on duty, 'Is Mrs Zampatti still with us?'. This illustrates the constant underlying tension and perception that surrounds Mrs Zampatti's care. At handover there was a discussion about Mrs Zampatti 'maybe having another TIA' - Jill says 'She stopped breathing - no pulse - hate it when she does that - then she did a big motion and then there was that big breath. She hasn't had any more falls after the 3 falls in 2 days episode. [which had been discussed previously ]

After handover Jill comments that she thinks of Mrs Zampatti is slowly deteriorating. She tells me that Mrs Zampatti's '...mouth is slack and her teeth are showing - you can see it when she's asleep in the chair.'

A month later Mrs Zampatti is reported as being 'just the same'. An overway is purchased for her bed as she is now having difficulty sitting up to eat meals. Diarrhoea is still a problem and Lomotil PRN is tried again as well as Metamucil. Next Mrs Zampatti's eye becomes sore. A diagnosis of conjunctivitis is made and it is treated with Chloromycetin.

Either Mrs Zampatti's dementia is worsening or her poor general health is causing her distress. In the nursing notes it is recorded that:

Mrs Zampatti is always looking for her car and keys. Has been awfully aggressive towards Mrs x for no reason that I can see referring to her as 'The Bitch' Even hit Mrs x with her walking stick.

and on the same day it is recorded that Mrs Zampatti has been 'quite nice this pm'.

This epitomises reports received when asking about Mrs Zampatti or when she was being observed. Any description would have an 'at the moment' attached to it or a 'has been OK' with a tacit acknowledgment that everything could change in an instant.
By now the nursing and medical notes have settled into a new pattern. Nursing notes are recording comments such as 'all care given' indicating Mrs Zampatti's inability to dress herself, and sometimes to eat unaided. Her increased confusion is described in actions such as 'inappropriate disposal of pads'. The daily episodes of incontinence are also recorded. The anxiety about how 'ill' Mrs Zampatti is seems to have settled and now she is in, what is described as the 'total care' phase. Doctors only came to see her at the regular 6 weekly review and record entries such as '6/52 review Demented no new problems ... Continue' or '6 weekly review BP 135/85 P 70 reg alert but confused . Chest clear . Reluctant to cooperate '.

Things were settled in this kind of pattern for about 4 months. The description of a showering episode at the start of this story took place during this time. Towards the end of this period nursing notes begin to record such episodes as being almost continual. Mrs Zampatti was continually described as being 'aggressive' and 'calling out'. Behaviour was now reported in the medical notes:

*Behaviour worsening upsetting other residents calling out and shouting but not for any reason - in fact doesn't realise she is doing it when confronted - try Neuraxil 2.5mg nocte please report on success/sedation*

Nursing notes change quite dramatically following the commencement of the Neuraxil (Pericyazine) with comments like 'speech very slurred today' , 'slept all shift' . Jill reports that the 'pills are knocking her out, but what can they do, she is getting impossible to deal with' but then a bad fall and an episode of aggression 2 days later resulted in a verbal order from the GP for an increased stat dose of Pericyazine although it's also recorded in the medical notes that the drug would take two weeks to get to an effective level, perhaps trying to tell the nurses that just increasing the dose may not assist. Mrs Zampatti only lived for 11 more days. The day before she died she was:

*found at commencement of shift upside down in bed, in foetal position, with part of her head through the rails. Please ensure bedrail covers in place when in bed. Spat out medication and threw toast across room. Calling quietly and tiredly 'Mummy'. Shortly afterward had a ?TIA lasting a good 10 mins. Unable to find pulse or hear B/P. Needle fluctuations indicated systolic of approx 75mmHg*
The GP was called and diagnoses a 'hypovolaemic episode' which describes a state of shock after quickly losing a large volume of fluid from the body. Mrs Zampatti died the next night.

Elesa, a careworker who had cared for Mrs Zampatti, told me what had happened as she viewed it.

In past few days Mrs Zampatti was very calm not agitated, not on any medications. Mrs Zampatti had been hallucinating last week talking to three people. We could not work out who they were. We were with her for nearly an hour and watching her, one of them was Lorna. 'Mrs Zampatti was sitting in chair counting two people in front of her and one behind - 'three' she said turning round. The next day she was disorientated, her speech was very slurred - yesterday she had bowel action about 9am on the bathroom floor. It was very dark - we did not realise that it was blood in the bowel action, she had bowels open in the afternoon and vomited blood at night.

This story illustrates the confusion about the medication regime for Mrs Zampatti. There has been a great deal of literature about the use and misuse of psychotropic medication in nursing homes which has been summarised by Harrington et al. (1982). Perhaps at this point the use of morphia to provide a level of comfort and peace, which may have been considered using a palliative care approach, instead psychotropic medication, would have been more appropriate.

The way in which the end of this story is told is very similar to other stories about other residents. It is as if, despite her death, Mrs Zampatti is still in their care. I frequently observed that it takes a certain amount of time for staff to 'let go'. This may be an indicator of the level of emotional involvement which staff develop in their relationship with residents like Mrs Zampatti; and, further, could provide the motivation to sustain the intensity of care and the degree of forbearance required of staff coping with residents in the late stages of dementia.

The story from Sheila powerfully reveals this quality of commitment. She told me:

When I was handing over to Petra (night duty RNJ) said Mrs Zampatti had had a turn - a seizure - Dr Prendergast was here when she had it - he examined her and thought it was a hypovolemic attack. ... She had large bowel action - you know that old blood smell. At 7pm she was rousable and did have a cup of tea. We gave her a shower because the bowel action went everywhere and it was the only way we
could clean her up. We put her back in bed and she was not rousable then, she went into deep sleep. Petra said what do I do if she dies in the night --- I had no vision of her dying that night I just had a feeling that her unwellness was medication induced - last week I commented in notes to ask if she was unwell or was it medication induced - I wanted people's feelings ... About 2am she [Mrs Zampatti] had another huge bowel action in bed and also a blood stained vomit. The girls cleaned her up the best they could - she was virtually in a coma and the next thing when they did their round she had passed away.

I went home and thought about what Petra had said Sally [Mrs Zampatti's friend] had been to Darwin and only just come back I was lying in bed thinking and I thought has anyone rung Sally - when I get to work I'll ring Sally. When I got to work in the morning she [Mrs Zampatti] had passed away and I felt terrible, I was shocked - when I was lying in bed I thought the time would be there for me to make that call and I felt sad she died alone - we have so many sickies - we have two people on nights - I felt really sad that she died alone but they do not have the time to just sit there. ...that night when I said to Gaynor [careworker on night duty] that I was sad about Mrs Zampatti dying I could tell in Gaynor's eyes that she would like to have been with her. Gaynor is a very spiritual person. She always sits with them to the end if she has dying people in her house [the various wards, or parts of the nursing homes are called houses in this nursing home].

This example of Sheila worrying at night demonstrates how seriously she took her responsibility towards Mrs Zampatti, and how much she cared about the feelings of the person Mrs Zampatti left behind.

The careworker who was on duty the morning after Mrs Zampatti died gave yet another insight.

I was not surprised at Mrs Zampatti's death after the day before it was a good thing - she was a lady who tried to hold herself together, even with the dementia, she used to blame the incontinence on the children - she used to say who did that - it must have been the children - when she was incontinent all over the floor. And the fact that she was a well-to-do woman - she still spoke like a well-to-do woman and I do not think she would have liked to have gone like that - it would have been worse if she had gone on.

As in all the deaths I observed, the staff seem to feel a sense of loss, yet a sense of relief for the resident being out of their 'misery'. There is no explanation of why a
person died - it is as if the death is totally expected and yet unexpected and worrying at the same time.

However, there is not a sense of peace nor is the death seen as having been well managed. The expectation of death, coupled with the denial of death, leads to an atmosphere where staff have to get on with the job, but feel alienated because of the residual feelings of a job not handled well, and out of their control. The concept and the production of a 'well managed death' which might serve to resolve the tensions is missing.
Mrs Hilda Watts

Is this comfort care or still untreated pain?

- 87 years old at time of death
- In nursing home for 52 months
- No transfers to acute hospital
- Incontinent before admission to nursing home.
- 5 courses of antibiotics during time in nursing home and fluvax yearly
- 6 falls recorded on incident reports.

When Mrs Watts was admitted to Bayside her daughter, Helen, was suffering from the shock of finding out that her mother suffered from dementia. The discovery occurred because Helen’s father had been admitted to hospital and Helen had her mother to stay with her for the weekend. She describes the impact of the unfolding realisation about her mother’s condition.

I did not really discover it until Dad had a severe heart turn at home and he was looking after my mother at the time and he had to go hospital, and I said to the doctor who was there at the time I think we better do something about Mum because it is getting too much for Dad and they never let on to me what they suspected and I think it was Dr Churchill at the time looking after Mum and Dad, and ummm - so naturally we had to bring Mum home because she couldn’t stay in the house by herself and Dr Churchill arranged that she go to the [local acute care hospital] hospital and stay there for respite care until we could get her into a nursing home, whichever had a bed, that happened to be over the weekend and Mum was going into the nursing home on the Monday. When we had her home here over the weekend she seemed a bit strange, more so than usual, she was very disorientated, she thought she was in her own home instead of here and so when we put her to bed at night -- OH!!! that was terrible (almost laughing sadly, ruefully) she complained about the bed, you know that is just part of the complaint but we didn’t know at the time - and I had to take her to the toilet and she didn’t know how to wipe herself and I thought gee!! if Dad had to put up with all that Ahhhhhhh!!!! and I couldn’t get her to shower, I had to wash her, I was beside myself ( more rueful laughter) I really was, ‘cos I didn’t know what to expect, Dad didn’t let on anything and tell you the truth by the time Monday came I was glad she was going into hospital, I really was. And I said to Dad ,after when I went to visit, him , why in the heck didn’t you tell me what I was up for (putting on a voice) ‘Oh I didn’t like to worry you’

On admission to Bayside Mrs Watts was assessed as mobile but confused and disorientated. Her admission diagnosis was described by nursing staff as Senile Dementia. and by the GP as Severe Alzheimer’s Dementia.
Mrs Watts's nursing history from the early days of her admission describes 'aggressive outbursts,' 'restlessness' and 'shouting.' Parallel with this is a history of abdominal distension and discomfort and alternating constipation or loose stools. Early in her admission nurses record that Mrs Watts was passing 'soft faeces and constipated' (sic) and the stools were blood stained.

In contrast to Mrs Zampatti care, Mrs Watts's bowel problems were not investigated or discussed in the doctor's notes. Yet three years later, Mrs Watts also died after a large bleed from her bowel. The emphasis on normalisation - on valuing people, which was so prominent at Beachdale - seemed to result in management where residents were subjected to far more investigations and 'cure' oriented behaviour. The emphasis on maintaining a valued social role for the resident translated into keeping them alive when no other course was available. In an environment where less emphasis was put on this notion, keeping them comfortable was more to the fore. Comparing these two case histories it becomes a value judgement to say which person was less or more valued or, perhaps more to the point, suffered most. The descriptions of their lives over the years in the nursing home, however, must lead us to ask how much both Mrs Zampatti and Mrs Watts suffered and this is the question that needs to be debated.

Mrs Watts's bowel problems seemed to be perceived as a nursing problem, part of the 'difficult' person Mrs Watts was. This perception of being hard-to-please may have been due to the effect of dementia on her personality that was apparent by the time she was admitted. Staff reported that they were not able to establish any rapport with Mrs Watts from the time of their first encounters.

This would seem understandable if one notes the kind of behaviour that was being exhibited. Illustrations from an early behaviour chart read:

<table>
<thead>
<tr>
<th>Action of resident</th>
<th>Action taken by staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>pinching and trying to bite</td>
<td>turning</td>
</tr>
<tr>
<td>aggressive, flinging out arms at nurses</td>
<td>TLC and reassurance</td>
</tr>
<tr>
<td>threw face washer at nurse</td>
<td>reassured we would not be long in the shower</td>
</tr>
<tr>
<td>pinching and abusing nurse</td>
<td></td>
</tr>
<tr>
<td>verbally abusive. Would not let us wash or change her</td>
<td>left her alone</td>
</tr>
<tr>
<td>aggressive. Hit nurse in the face when combed</td>
<td>put back to bed</td>
</tr>
</tbody>
</table>
On the other hand, moments of empathy and connecting with Mrs Watts as a person do appear. When Mrs Watts's husband died an entry in the nursing notes reads:

_During evening meal Mrs Watts asked where her husband was and why he hadn't come to see her. When reminded that Helen [daughter] had visited and told her he had passed away a few weeks ago, she appeared to understand completely and said 'It's sad, I'll miss him. We had some good years together.' She asked to see her daughter. Helen contacted ..._

This entry further illustrates the difficulties for nurses in relating to residents with dementia when on one occasion they can be kicking and screaming and the next talking like this.

Once again the signs of a bowel cancer (Spiro, 1983) or some bowel pathology continue, with entries from the nursing notes such as 'some loose EA but 3 constipated stools amongst? if overflow. PR done no faeces in lower bowel.' and a day later 'passed constipated lump with bowels as well as loose offensive. To have senokot granules tonight.'

At the same time Mrs Watts was described as agitated and difficult. In spite of the fact that this may have been due to her being in some pain from a colon carcinoma no connections seemed to be recorded.

Another nursing entry reads:

_BNO x2 glyc supps given with no result. Seems agitated about something, but cannot communicate. - nursing intervention - sitting and talking and trying to understand._

Mrs Watts also had TIAs in the same way that was reported with Mrs Zampatti. The GP was contacted after one TIA. Otherwise doctors do not seem to be called, although there is a record of some pressure from nurses to get Mrs Watts's a course of anti-depressants as they felt it may help her 'moodiness' and 'aggression'.

Some months after this TIA episode one of the first field notes recorded about Mrs Watts shows nursing management and responsibility for Mrs Watts's bowel difficulties was still paramount. At handover there was a discussion about Mrs Watts having an enema because it was thought that she may not have had her bowels open for 9 days. It was queried whether this was because it had not been recorded or if it was true. Charmaine said that there was nothing in Mrs Watts's lower bowel and that she had had enough aperients to 'make her explode'. The discussion then went onto the fact
that the nurses felt she was in pain, but that this was probably arthritic pain. It was hoped now that the doctors would prescribe anti-inflammatory medication.

Charmaine says Mrs Watts is in a lot of leg pain and although she can walk and bear weight on the leg the staff 'don’t have to push her to do so'. It is not clear whether this leg pain follows some damage from a fall, or if it is a worsening of her arthritic condition. The analgesia given is 2 Panadol. One staff member comments that she thinks Mrs Watts is in agony.

During the observations in the same week when Mrs Watts’s hands, face and groin were being washed, in preference to getting her out of bed for a shower, she says 'I feel awful'. There is a sympathetic 'there, there' type response from the staff. Bertha comments that Mrs Watts is getting very frail. She goes on to say - 'she’s really lost everything since that fall'. From the time of the fall Mrs Watts had been totally dependent on the nurses. If she was out of bed she was restrained. There was a general feeling amongst the nursing staff that she was now dying, and she was left in bed if they felt she was in pain or felt 'unwell'. By now Mrs Watts has a pressure sore on her heel.

Within a week Mrs Watts was being left in bed for most of the day and nurses would talk about her ‘deteriorating’ and the ‘peripheral shut down of her feet and legs’. Nevertheless Helen organised for her to have a flu vaccination. The GP ordered an x-ray for severe left leg pain and a vaginal swab is taken to investigate a discharge. These all occurred in the two weeks before Mrs Watts’s death.

Ten days before Mrs Watts died, as Bertha and Kelly are sitting her up for lunch, Kelly says ‘She’s just given up’ and Bertha replies ‘She’s tired Kelly, she’s old - her husband went so quick. He was lovely. She’s just given up’. In the next week comments recorded from staff reveal Mrs Watts as:

... not being well, ... Mrs Watt’s had a pr bleed ... We expect her to go every time we turn her. But that’s just us. We’ve had them like this before and they last two or three days.

Mrs Watts’s condition was not reported clearly in the notes. Comments such as ‘daughter notified of her mother’s present condition’ are euphemisms for saying that she is dying. Three days before Mrs Watts died the doctor visited and ceased all medications. The night staff wrote ‘all palliative care given including spiritual support’. Flowers were put on Mrs Watts’s overhead table. She looked calm and comfortable. At handover on the day that she died the comment was made that:
Mrs Watts has deteriorated even further. Refuses to have anything by mouth. Fluid or food. Frank blood. Bowel ooze. Nothing to be done. Family informed. Still try her, even on a teaspoon. No pain. Looks peaceful.

At this point the symbolic nature of care is epitomised by the continuation of offering food, even when an acknowledgment of death is clear. This was expressed in the encouragement to 'still try her, even on a teaspoon'.

Mrs Watts died about 3 hours after this comment was made.

This case study shows a much greater emphasis on nursing care versus medical care. Yet Mrs Watts lived in the nursing home for a year longer than Mrs Zampatti and the staff had similar behavioural difficulties to deal with.

The staff were not able to develop a rapport with Mrs Watts as had been the case with Mrs Zampatti. Perhaps this lack of emotional involvement is the reason why there is no sign of pressure on the doctors to investigate the bowel condition. There is far more indication in this history that the nurses blame themselves for not 'managing' Mrs Watts's bowels well enough.

The staff did not express a great deal of grief but rather a degree of relief at Mrs Watts's death. Bertha expressed what seems like a consensus staff view:

... sad that no-one can be with people when they die. But Mrs Watts had never been happy since her husband died. But she always knew Helen. If she wouldn't eat all week she would eat the chocolates that Helen would bring in. Her husband used to bring her in peeled fruit and sweets.

Robyn, another staff member, expressed the difficulties in not being able to form a reciprocal relationship with Mrs Watts - 'she wasn't a person you could get close to' - and it seems that for this reason the death did not make such an impact on the staff as some others obviously do.

Helen acknowledges that the actual death of her mother was a relief in the end. She says:

I wasn't all that cut up about it because I was expecting it. I've been expecting it for a long time and Mum wasn't Mum as far as I was concerned because once she lost her memory that was it for me because it just didn't seem like Mum

She also acknowledges that for her mother it was:
A blessing in disguise. For her and for us. She couldn't go on like that she was no good to herself either. No, Its a pity she couldn't have gone a bit earlier really, but still that's how things go isn't it?

This comment - 'it's a pity she couldn't have gone a bit earlier really' - seems incongruous from a person who ordered and paid for flu vaccine every year for her mother. But then perhaps Helen's imperative was to indicate that she was doing something to ease her sense of powerlessness and to indicate that she cared for her mother. This may or may not have been a factor in Helen's behaviour and the care experienced by her mother. A comment from staff about this conclusion was to ask me how I consider that flu vac is 'life lengthening'. In theory a flu vaccination may be exactly that. Flu vaccination for debilitated people is designed to limit the complications, such as a life-threatening pneumonia, which may result from a bout of flu. Whatever the rationale was for giving the flu vaccination is not clear and any speculation can be only that, as I did not ask Helen for her reasons. But this reflection reminds us of the need, especially pronounced in the case of people with severe dementia, to look outside the actual condition of the resident - to government institutional policy, to the predilections of a profession or the pain of a family member - to find explanation(s) of the treatment given.

Much caring provided to assuage guilt could be avoided if values and feelings could be sorted out, if possible, with the person who has dementia, or at least between caring staff and families. Perhaps for Mrs Watts, doses of morphia could have been a much kinder intervention than flu vaccine. But the acceptance that 'that is how things go' stops this comforting intervention. The emphasis on 'caring' for people with Alzheimer's disease rather than treating it as a terminal illness needing palliative care further confuses the issue of providing a culture in which a peaceful death can occur.

In contrast to the last two histories the following case seems to demonstrate an approach to the problem of dementia by the resident that is calm, but determined, private and accepting. Nurses accept this to a certain extent, but are left with the difficulty of feeling responsible for keeping the resident clean, comfortable and not hungry or thirsty. These basic dignities are railed against by the resident and raise moral questions about the manner of care.
Mr Small

Was this a good death?

- 90 years old at time of death
- In nursing home for 16 months
- No transfers to acute hospital
- Incontinent before admission to nursing home.
- 7 courses of antibiotics
- 25 falls recorded on incident reports.

Mr Small was admitted to Bayside on 29 May 1991 with a diagnosis of Alzheimer's disease and renal calculi. He was 89 years old and had been living in his own home after the death of his wife and caring for himself. Recently his confused behaviour had been increasing and causing some dangerous situations. The final decision to admit him to the nursing home was taken after a bout of pneumonia which involved admission to the local general hospital. A judgement was made that he was not well enough to return home and manage with community support. His previous medical history was described by the nursing staff as follows:

*About 4 years ago had his first small stroke. Has had a series of them since and has also developed dementia*

This description is most strongly indicative of a multi-infarct dementia, but the medical history states the diagnosis as Alzheimer's disease. He also had a history of bladder stones and urinary tract infections. Mr Small had his urine tested for a urinary tract infection 10 times in the 16 months that he lived in the nursing home.

On admission Mr Small could walk by himself, although slowly with a shuffling gait. It was indicated on the nursing care plan that he was deaf, needed assistance with showering and dressing and 'vigilant supervision of meals'. Mr Small's lack of appetite, or reluctance to eat, remained a difficulty for staff throughout his stay. He was occasionally incontinent. Mr Small's confusion increased throughout the next year. In the early days of his stay the staff worried about him because he left the home, wandered around, turning lights and televisions off and often fell due to giddy spells. The staff say a characteristic of this time was that he alway wanted his hat on but, as soon as he got it on, he was 'off - out of the nursing home'. The police used to bring him back but he always wanted to go home. The staff's way of dealing with this problem was by hiding his hat except when his son came and could take him for a walk or drive. Eventually wandering from the nursing home was dealt with for all
residents by coded locks on all doors, as shown in the photographs, so that no-one who did not know the codes could get out.

By early 1992 Mr Small was becoming increasingly incontinent. At this point Mr Small was selected as a possible resident who would be suitable for this study. The staff certainly felt he was within a year of death.

_They usually say it takes 5 yrs from diagnosis to death. He's been with us a short time, but had it [a dementing illness] long before he came here._

The 'short time' Mr Small had been in the nursing home had been a year. This sense of time was typical of the culture of both nursing homes. Residents were still referred to as 'new' even when they had been at the nursing home for some weeks.

Staff report that Mr Small 'had became a recluse after diagnosis', and it was indicated that he was a very 'private' man. It was obvious that the staff were very fond of him but perhaps not close to him in the way they were with other residents. One example of this was represented when there was a reallocation of rooms. The comment made at handover when it was reported that Mr Small had been moved was 'Poor little man - fancy shifting him.' Although the response was kind, if matriarchal, it was distant.

The 'private' nature of Mr Small, obvious even against the background of his dementing illness also seemed to prevent that close, pseudo-reciprocal relationship sometimes noticeable with other dementing residents. One of the many paradoxes to be found in this study is that the residents were endowed with distinct personalities up to the moment of their death. These personalities may have been totally different to that of the person before they were ill. They were the demented-self personality. These characteristics continued to be attributed to the person while at the same time many staff and relatives were saying that at a certain point in the process of the dementing illness had been reached which was equivalent to that person being dead.

One example of the power of habit or personality that seems to remain in many afflicted with dementia was demonstrated clearly by Mr Small and Amy in the early days of the field work.

I was leaving the RNs office after handover with Petra. Mr Small's son, Bryan, came down the corridor with Mr Small. Petra introduced me to Bryan and we shook hands. Amy, as she usually did, had followed us up the corridor, and she watched the introduction. As Bryan and I exchanged pleasantries Mr Small gave a big grin and put his hand out to be shaken too. Amy came up, indicated that she wanted to be
included and smiled excitedly. I did then introduce both Mr Small and Amy, inwardly reproaching myself for my bad manners in automatically ignoring Mr Small and Amy as people to be included in the introductions. It was a most humbling and touching moment. It was also a reminder of the major area of concern about trying to recognise suffering for people with dementia. This recognition needs to take account of the fact that they could well have far more insight or awareness than we know about, which might mean that they do suffer badly but are unable to communicate this to their carers.

I was also made aware by the incident of how much I acted like the staff as soon as I entered the culture of the nursing home in treating the residents with dementia with a certain distance in order not to get trapped by their demands. Also I found it impossible not to think of both Mr Small and Amy as seeming like young eager children pushing in and wanting to be included, yet the instincts and knowledge that prompted the action were obviously adult. The child-like image presented no physical incongruity as both these residents were short and frail. In Mr Small's case this child-like status was often reinforced by staff in subtle ways, such as a comment at one handover. 'Mr Small has had a hair cut - looks like a punk rocker'. Again, it was an affectionate, slightly distant remark with motherly overtones.

Over the following months the kind of comments regularly reported in Mr Small's nursing notes were 'incontinent and unsteady on his feet', engaging in 'odd behaviour today', hopeless at taking tablets'. Mr Small used to object to being showered, the staff putting the reasons for this down to his private nature. The staff learnt ways to manage, one of which was telling him that he was going to church each time they were getting him ready for the shower. Bryan had given them this 'tip' and seemed happy that the staff went along with it. Certainly Mr Small would often be more co-operative when this message was used.

Mr Small's urinary tract infections continued. The difficulty for staff of getting Mr Small to take his medication raises the question about how effective the courses of antibiotics were. Georgina indicated that in a conversation with the GP about Mr Small's urinary tract infections he commented that Mr Small had 'a chronic problem and there isn't much we can do about it.' She reported that, because Mr Small would not take his tablets or eat, 'he girls were worried'. Georgina puts all Mr Small's 'uncooperative behaviour' down to the fact that he is a 'very private little man - does not like his personal space invaded - makes up his mind he doesn't want to do something'.

Mr Small seemed also not to want to eat. On one occasion I record that Mr Small looks very grumpy - or distressed - when the careworker is trying to persuade him to eat. On another occasion when the RN is trying to give him his antibiotic Mr Small rejects it very firmly and clearly. The RN attempts to persuade him saying it tastes all right and then asks if he would like bread and jam. She then tells him that he likes bread and jam. He spits out a little bit of his tablet but the RN seems to choose not to notice. Another day I observe that Mr Small will not eat lunch and he seems quite distressed at being pressed. When left alone he just coughed and dribbled sputum and let the food fall out of his mouth. The staff try to persuade him to drink or eat. He says he will, but then does not touch either his food or drink.

A few months later Mr Small is moved from his room again because a new female resident is being admitted. The nursing home policy is that beds are changed around so that males do not share the same room as females. Georgina says it wouldn't make any difference to Mr Small as he does not know anything from one minute to the next. For example, she tells me that he greets her like he's never seen her before although she has seen him 5 days a week for the 'last two years'.

Mr Small continues to deteriorate and has a bad fall - nursing staff now say these falls are due to him getting giddy in the mornings when his blood pressure drops. The GP had been contacted after his fall. After visiting Mr Small the doctor said nothing was broken and ordered pain relief.

More and more incidences are being reported of Mr Small's behaviour changing, 'rather aggressive'; 'would not eat lunch'; 'shaky and uncooperative today; refused tea and fluids; needs lots of prompting to eat; incontinent, bowel ooze.'

One day Mr Small has a day in bed because of a productive cough and runny nose. After this whenever he is out of bed he needs two nurses to assist him and is very shaky on his feet. He is continually refusing to eat, but the staff press and encourage him and debate the kind of things that might tempt him. They agree that it does not matter what he wants to eat as long as he eats something. Entries such as 'fully assisted with meals, ate a jam sandwich only' begin to appear. Eventually, but only much difficulty, some staff begin to hint that Mr Small really does not want to eat - that he has 'had enough', as one of them put it to me.
The difficulty of Mr Small’s eating intensified at the time when the DON was expressing strong concerns about residents in the nursing home losing weight, which, she indicated, may demonstrate lack of attention given to the 'feeding of the residents'. The DON herself attempted to get Mr Small to eat so that she could assess the problem he was having. She was not inclined to accept the view that he didn’t want to eat or is past eating, and rather suspected that the nurses were not giving him enough attention or trying hard enough to nourish him.

Her attempt fails. Afterwards she enters in the nursing notes that Mr Small is ‘having severe difficulty swallowing food and drink, points to his throat and says it won’t go down there; no more’. She is indicating that there is a physical obstacle to swallowing. This is not followed up in any medical sense, neither is it discussed as possibly resulting from Mr Small’s further cerebral degeneration. The staff do not think there is a physical problem; they see it as a face-saving technique used by the DON, because she was not able to get Mr Small to eat either.

This discussion of why Mr Small wouldn’t eat was skewed by conventional assumptions. Despite some intuitions among members of the nursing staff, no one seemed able to raise explicitly the question, which a palliative perspective might have prompted, as to whether Mr Small’s apparent wish not to eat should be respected and accepted as a natural expression of a wish to die. To make this point is not to prejudge what might have been the answer. We simply note that the question itself was not readily 'available' within the terms of the governing paradigm.

It ought to be noted in passing that the staff do not talk about 'eating' and 'nourishment'. Common parlance in these nursing homes, as in most others, is of 'feeding' people. Some of the staff in this study, many of whom live on small farming properties occasionally mention the similarities between feeding their stock and feeding residents in the late-stages of dementia. Price and Nay (1995) have objected to the use of the word 'feeding' in government publications, arguing that it encourages a negative view of nursing home residents as it is a word normally used about animals or babies. Their letter received a rejoinder from an enrolled nurse (Stafford, 1995) supporting the use of the word 'feeding' on the grounds that orders from 'superior' officers will not change the words already in people's minds. On the other hand, Price and Nay (1995) say that a concentration on changing language which has negative connotations within a retirement village has been shown to have a positive effect on altering the environment. This debate is part of the larger debate surrounding issues about 'personhood' and what it is to be 'sentient being' as Singer
(1994) understands the concept. The term 'feeding' and its connotations may help us later in an attempt to distinguish the act of nourishing and caring for the person from the superficially similar but truly very different act of body maintenance.

After the unsuccessful intervention by the DON there were no further comments made about Mr Small's eating difficulties. But, perhaps because of the absence of a concept of palliative care as a valid alternative, the focus of attention now moved back to surer ground, querying a further UTI. This was two weeks before Mr Small died. Another course of Bactrin (an antibiotic) was ordered. The Doctor discussed with the staff and the family the fact that he felt it was now time for no further active treatment and this is documented. Staff continued to get Mr Small out of bed, pressing the doctor to visit and still trying to persuade Mr Small to eat. A meal chart was commenced and the achievement of getting Mr Small to eat soup and custard, even though it may have taken one and a half hours, was thought worth noting.

Mr Small constantly had urinary tract infections. During one handover staff were told that Mr Small's urine was very concentrated and that staff were instructed to 'push fluids' even though he was refusing them 'because the Dr thinks that his urinary tract infection was making him miserable because it was so painful'. The imperative to 'push fluids' was made stronger by Charmaine indicating that it would prevent his discomfort, even though it would be an arduous and time-consuming task for the staff and a seemingly uncomfortable and painful procedure for the resident. Pushing fluids is an 'acute care' type response to the situation - to assist in curing the UTI. A palliative or comfort care response in these circumstances would have been a difficult choice. If analgesics was given at a level that would totally relieve the pain of the UTI it would most likely have made it very difficult to get Mr Small to drink very much at all. He would have been, as the staff so often put it, 'zonked out'. The question of intravenous or subcutaneous fluids would not be considered in the nursing home although that may have been considered as a palliative comfort measure in a hospice. A much more comfortable management plan for Mr Small may have been the combination of analgesia with only as much fluid as he seemed to want and could comfortably tolerate. The outcome of an approach that meant the giving of analgesic drugs and a gradual withdrawal of nutrition has been called 'pharmacological oblivion' (Hunt, 1995) and will be discussed further in the conclusion. Would this approach have been kinder here than the futile attempts to force fluids which would almost certainly not be at a level which would assist in clearing the infection? The risk, or benefit, is that this approach may have meant an earlier death for Mr Small.

But by now Mr Small was deteriorating. Helen notes that.
Mr Small is really sick - his son was crying - I reckon he has got pneumonia. Mr Small calmed down as soon as he saw his son but kept asking him 'What is wrong with me?' I have got something wrong with me.' He had two mouthfuls at breakfast but started coughing and choking and dry reaching. Then Georgina gave me senokot to give him, he had one mouthful then dried retched, but he looks nice now he has had a beautiful shave. He has lost a lot of weight.

On the last day of Mr Small's life the entry in the nursing notes reads 'refusing to eat and drink'. Up to the end the staff were still being careful to show that they had done their best to keep his nourishment up.

In tea room discussion of Mr Small's death it was said that:

... he was very alert just before he died, but right up to the last day he still did not like you taking his trousers off - he was the same very private person and he always knew his son right up to the last.

They also comment that he smelt like a dying person. They 'suppose' he had pneumonia, but it is clear that what they believe is that things just wore out.

One person says:

he started wearing out as soon as he got here - but then how often do you see that? The dementias go down really, really fast. ¹

Georgina comments that she thought:

Mr Small went down the hill a good three months ago because of the chronic urinary tract problem, chronic constipation and lack of appetite. I think he had a carcinoma. He had to force himself to eat.

When he got this chest infection three weeks ago, that knocked him off - the last week he had that glassy look and was not responsive even to family.

This is opposite to the impression of the careworkers who felt he knew his son Bryan up to the last. Bertha had been unusually quiet during this tea room conversation and her only comment was that she was sad that he died alone.

A story then unfolds about preparing Mr Small for his funeral. Georgina describes talking to the family who said that they did not want any of his belongings, 'so Cynthia [an RN who was well known as fast, efficient and neat] goes non stop and cleaned out his gear.' Gerald, the handy person, had helped Cynthia to take them to the Goodwill depot. The family then obviously had second thoughts, talked to the undertakers and rang the nursing home to say
they wanted Mr Small dressed in the suit and hat he had during his time at the home. Gerald was rung at home, returned to the Goodwill store and managed to get the suit back, but forgot the hat. Gerald goes back to Goodwill again and finds Mr Small's brown hat and takes that to the undertakers. There was obviously a good feeling amongst the staff due to having been able to do this. This episode occurred at the weekend when there was no one 'official' around and Georgina could organise it all freely. There is no feeling of alienation here. Rather it is a jolly celebration of a moment to be creative, to solve a problem and get on with the job. It is almost as if the episode has been instrumental as a symbolic farewell to a resident whom all staff had liked but to whom none had felt really close.

There is no accounting in any policy program for this kind of voluntary activity in the nursing home. No-one complained for a moment about having to do this. On the contrary they blamed themselves for being too efficient and fast and there was no question that they would take whatever trouble was necessary to arrange what the family wanted. It did not seem to be questioned that the only thing to do when the family's wishes changed was to ring Gerald at home; nor was there any surprise when he immediately attended to the problem himself in his own time and at his own expense. Examples such as this, attending funerals, bringing in talcum powder and so on, do not seem to alter the staff's perception that they cannot 'do enough' with the time and energy they have. This episode served to mark for them one of the odd moments to feel good about the lengths to which they often go, when so often something about the work and the way it is regarded tells them what they do is not good enough.

In Mr Small's case the staff felt pleased that he had a 'good death'. George, the RN on night duty when Mr Small died, said:

_I think it was a very good death. He went down very quickly - no distress - he just gave up the ghost. He had shallow respirations from about midnight onwards. I gave him oxygen for about an hour. He took the mask off - he didn't like it. It made no difference anyway so I left it off. I rang the daughter-in-law - those were the instructions left - and she contacted the other relatives. She seemed upset. Then I rang the funeral directors and Charmaine and Downer [the GP] He breathed a sigh of relief and said I'm glad for him. I rang the undertakers again and said Dr Downer would be coming up there later. I went off duty and Calandra took over the rest. I had done some of it even though it was late because I knew Calandra was very fond of Mr Small and I thought she may be upset._
Calandra reported feeling a certain sense of loss because Mr Small was such a lovely gentleman - but she was relieved that he was not suffering any more. Again, the phenomenon of staff still talking about residents in the present tense shortly after death was present. Calandra said:

he was suffering because he had lost so much independence and self esteem - it showed by his withdrawal and refusal to accept staff help as far as hygiene needs etc

There is present in this instance the notion of a 'good death'; but it seems to the onlooker that a 'good death' is regarded as something which happens or does not happen. When it happens the nursing staff and others - the doctor, the family - are grateful; but when it doesn't there is nothing for it but to lament the suffering of the one who has died.

The next case study illustrate the difficulties for a caring and involved relative, who wanted the very best that was possible for her father during the process of him dying - or being kept alive - depending which way one views the following stories, in order to repay a debt that she felt she owed to him.
Mr Price

A case to answer?

- 84 years old at time of death
- In independent units for 8 yrs, hostel for 5 yrs and nursing home for 19 months
- No transfers to acute hospitals
- Incontinent before admission to nursing home.
- 4 courses of antibiotics during time in nursing home.
- 32 falls recorded on incident reports.

The unfolding story of Mr Price and his death trajectory is tangled up with the close relationship with his daughter, Laura. In this case study Laura's story will be used to demonstrate the disempowerment of relatives by the culture of the institution and the status of people in the hierarchy. It also illustrates the kinds of gaps in communication which may mean that the resident's comfort is not the paramount consideration in care. This story shows how staff, even after recognising that the resident is very near death, are not always prepared to let him go and still instead institute curative measures. This scenario is illustrated in other cases, and, as with those, these actions can be seen to contribute to a situation where a dignified and peaceful death does not occur.

The progress of Mr Price's loss of cognitive function, which was diagnosed as Alzheimer's disease, was complicated by war time experiences leaving him with some psychiatric instability. The first nursing comment made about Mr Price was that:

this family has been through lots of trauma because of the erratic moods of resident. The grandchildren do not visit now.

Laura, Mr Price's daughter, acknowledges these family difficulties but sees her father differently. She says that her father has been the backbone of her life.

Everything good that has happened to me he was the instrument of it, he made it happen for me all my life. Of course at sixty three, [Laura's age] that's a long life of having your father behind you. He was always good, always thoughtful. I mean we have had our moments, but, as I said, every good thing in my life was a direct result of what he did for me.

Laura visits the nursing home every day and had a warm and close relationship with the staff who actually gave the hands-on care to her father.
Mr Price had lived in Bayside's residential units/ nursing home complex for 13 years. As long-serving staff saw it, he and Laura were very much part of the family. Laura talked about her father's lifetime 'illness' and how it changed and developed to the point of his admission to the nursing home:

Well, evidently it started in the prison camp. He had cerebral malaria and apparently in those times it used to affect him. You know, he'd go off his head, and the other fellows used to lock him up in a little hut so that he wouldn't wander off. Well, when he came back he was O.K. He used to have tantrums, what we thought were real tantrums, jump and down and so forth. Two or three times he was in x [the local war veterans hospital] and they used to - they knew he'd had cerebral malaria but they thought there was something else. One time they even asked us did we have pet parrots or cockatoos because they thought there were some sort of germs that were affecting his brain. But he was fairly normal, you know what I mean, it wasn't as though he was a hard case. He was O.K. It's just that he used to - he couldn't, never could stand a lot of noise, and he'd be O.K. for weeks and weeks and then he'd have a real tantrum, threaten to kill us all, and that sort of thing, but never actually did any physical damage, any harm. And that just went on for years and years ... I never could see why - that he was any different than normal - but they decided to put him in and do tests on him and what not.

Anyway, when he was fifty-five they made him retire from work because he couldn't cope any more, and anything harassed him, he'd fly off and that...he was always going to shoot us or kill us or do something when he couldn't get his own way, and flew into a temper.

Comments such as 'they made him retire from work' and 'they decided to do tests on him and what not' show Laura's subservience to the control of the medical profession over many years. This seems to arise from learnt behaviour, born of incomprehension, where giving in and accepting rather than fighting the system allowed a more peaceful life. Laura was a gentle, quiet person who had strong views, but would choose to accept unwelcome outcomes rather than initiate conflict.

The following summary of a report from Mr Price's medical files shows that he was suffering from fairly severe cognitive impairment at least five years before he was admitted to the nursing home. At the time this report was written, from a hospital assessment, he was living in Bayside's hostel units.

He was an elderly man, neat and cleanly dressed. Very Parkinsonian gait, his behaviour was co-operative and he was undistressed. He did not appear to be irritable or depressed and denied any visual or
auditory hallucinations. His short and long term memory were severely impaired and he was completely disoriented in time and place. He couldn't even remember his own date of birth. His attention was poor and thinking was disjointed and incoherent. He had some nominal dysphasia.

Diagnosis: Moderately severe dementia (probably Alzheimer's type) ...

'Mr Price was admitted for observation with no medication prescribed. His episodes of delirium slowly settled and Mr Price became more lucid. There were no signs of depression. Mr Price was later able to give a story of taking Oxazepam in large doses as well as history of memory impairment for 2-3 years to having to write notes to himself and not being able to remember if he had taken his medication. On this basis, any future medication should be dispensed by nursing staff only. It has been explained to the patient that his memory may continue to deteriorate. His LMO has been contacted and has agreed to offer explanation and prognosis to family.

Even with this medical diagnosis of severe cognitive impairment and a history of violence Mr Price was able to be cared for in a hostel for 5 years. The hostel did not then, and does not now, have a registered nurse caring for the residents. This posed problems in fulfilling the doctor's order for medications to be dispensed by nursing staff. The way the staff solved this problem was that the enrolled nurse from the hostel came over to the nursing home. The tablets (for all residents that need prescribed drugs that are not self administered) were put into labelled containers and the task of giving them out delegated to the enrolled nurse. However, according to Nurses Board policy medications can only be given out by ENs (or sometimes Careworkers) under the 'direct supervision' of the RN. All RNs at Bayview knew that this arrangement was stretching the meaning of 'direct supervision' and that they were acting in a way contrary to stated professional conduct. This caused concern for them. The fact that both policy makers and management were reluctant to clarify their position seemed to be further evidence of their low status and leaves open the way for compromise and deception to become entrenched in their professional lives. This situation is not unique to Bayside. It is common knowledge in the aged care industry that the problem of medications in hostels exists, but is allowed to continue as the 'remedy'. Employing RNs in hostels is too expensive.

Laura's memories of her father's developing dementia reveal the typical pattern of gradual realisation by a family of somewhat reluctant recognition.

... Mum died eight years ago. We didn't really realise it, [that her father had dementia] we just thought it was Dad being Dad, but
looking back I think that's perhaps when it started, because I know when Mum died, he, they'd had their name down to come up here, and he very much wanted to come up here. [up here' being Bayside's hostel and nursing home complex]. It was about two years after Mum died that he thought he couldn't cope on his own any more. He was in the units, he could cope, because he had all the help necessary but once they said they'd take him, he started to pack up his stuff. He had cardboard boxes all round and he was selling off his furniture at ridiculous prices to anyone who came in. At the time that Mum died, he bought a brand new car and he rang up the people who sold it to him and said he didn't want it any more, so they bought it back from him - he lost about $2,000. Then, I said to him, you should have kept it, and I would have taken you for drives in your car, because he hated driving in my car, because it was small. I found that... people took advantage of him, people that came into the place helping him, they, well for instance, he had a beautiful red leather settee lounge and he sold it for $35.00.

Laura went on to outline how she felt people exploited her father because he was 'mentally incapable' and this obviously hurt her deeply. She was not concerned about monetary proceeds coming to her. Rather it seemed like a snub from society that those who were meant to 'assist' actually did her father down. She had attempted to resolve one situation where he had virtually given all his bedroom furniture away but no-one from the community services health care area felt able to assist her in taking the matter up.

In the hostel Mr Price's behaviour continued to be erratic with bouts of confusion, hallucinations and delusions. His ability to cope began to deteriorate more seriously and after a painful fall he was transferred to the nursing home. After a period of trying to cope with her father's worsening behaviour Laura seemed glad to 'hand over' the responsibility to the nursing home. She says: 'so I was rather glad when he came up here [to the nursing home] and was looked after ...

Mr Price was prescribed twice-daily doses of Serenace. Laura seemed to have some knowledge of the medication and perceived the move as very positive.

Actually since he's been over here [in the nursing home] it's been a different story all together. It's been so different, so different... he's been calmer, he's been more like I used to know him when he was in his more lucid moments. Then again they thought at one stage that they would lessen his medication, and he got very aggravated then. So he really needed whatever they had given him in the first instance, because as soon as they lessened it, he would get hostile, and aggravated. It was only about three months - he tried to take a wild
swipe at me - it was one of the instances when they had given him less. I was standing talking to Bertha actually, and she reached out and grabbed in his arm, and said, no, Eustace, no. And when I looked round he was oh like this at me [holding her arm up as if about to strike someone] you know. Why I don’t know. As I said I think from the lack of medication at that stage But, since then, you know....

Laura’s voice trailed off as if there was nothing more she could say and gave me a look that silently asked me to understand the incomprehensible pain of watching someone you love disintegrate in front of you.

Mr Price’s care was complex. In the early days of his admission to the nursing home, at the end of 1990, the nursing report read:

_This resident is changeable in his behaviour due to level of dementia. He also has cataracts of both eyes which has resulted in him having peripheral vision only and as he used to be an avid watcher of TV staff need to be aware that at times he may have enough insight to become angry at his situation. He has responded well to nursing home care accepting offers of help from staff when necessary. Occasionally he is found wandering around the nursing home corridors which is like his behaviour in the hostel. Occasionally he needs assistance with meals and/or reminding that his food is there for eating._

_Unfortunately he has had 2 falls with extensive bruising and a cut above R. eye, probably due to poor eyesight and confusion and memory loss. Resident becomes agitated and anxious quite readily and needs ongoing one-to-one intervention. He is incontinent of faeces and urine and needs assistance with dressing, shaving etc. needs assistance to walk to and from dining room, lounge areas etc because of unstable gait._

Within a month of his admission to the nursing home his medication had been reduced and his ability to cope with minimal social contact improved. This report was written a month after the last one.

_Mr Price continues as above with little change. Serenace has been reduced gradually over past 2-3 weeks to 1ml BD + level of awareness and interest in surroundings has increased although dementia remains a problem. Incontinence of urine and faeces remains a problem but continence maintenance programme is effective at times. Constipation has been a problem. Treated Nulax PRN. Bruising from falls has subsided and resident readily accepts help and assistance from Nlstaff as necessary._
As time progressed Mr Price's management difficulties seemed to settle into the areas of falls and continence management. Some connections were made with Mr Price's cognitive deterioration, but only rarely. Medications were more often blamed for the problem.

The nursing notes reflect this, for example:

_Mr Price has continued to have falls even with Serenace reduced he just seems to lose his footing, at times this month he has been quite wandery, continues to have constipation problem ...developed a large haemorrhoid through constant straining. Rectinol supp given with effect, needs aperients daily ....resident quite aggressive refusing to be dressed or washed , residents (sic) needs to be left when this occurs and try 1/2 hr later . Al in all condition has deteriorated greatly_

_Mr Price seems to be settled this past month. Spends most of his day in his room. Becomes restless at times but we have found that its usually when he wants to void. He still does have falls at times but doesn't seem to harm himself . Mr Price still has the problem of constipation and at these times he seems to become more aggressive. ....Falls day and night seem to be Mr Price's main problem (continuing) with minor lacerations and bruises resulting from some of these falls. Constipation. BNO for up to six days continues to require the aid of aperients and suppositories._

One of Laura's first comments about her father was that she did not know 'how any one could fall that much without killing themselves'. However, it seems she had not discussed restraint in any way with the nursing home staff. She accepted their care as doing the 'right thing', that the nurses were attempting to contain the falls while not curtailing Mr Price's right to independence. They were also attempting to keep Laura in touch. One report of a fall reads:

_Found on floor next to bed by Mrs Davies at 1600hrs - Injuries, (l) elbow skin tear, abrasions on back ( side.) P84. Disinfected with Betadine, bactigras and Melolin dressing applied bandage for protection. Daughter notified. Daughter pleased about notification. Please put a non-slip mat in front of bed as well as armchair. Floor too slippery. Often he likes to get up to void ._

About six months later Mr Price began to lose weight and his general health showed a decline. His weight loss was treated in the same way as Mrs Zampatti's 'obstruction'. 'No obvious cause' a frequently recurring phrase, leaves us with an unanswerable question arising from a diagnostic curative paradigm; when the same observation
might have been positive and confirming evidence from within the palliation paradigm. A nursing report reads:

*Has lost some co-ordination with walking and independent moving - now needs assistance of 2 person to ambulate. Needs to be assisted fully with eating. Has lost weight (8kg in approx 12 months) ... now 53 kg which Dr feels there is 'no obvious cause' Constipated. Bowels continue to be a problem requiring the assistance of suppositories at times. Falls are less of a problem since his deterioration in mobility Incontinence of urine and faeces continues.*

At the end of the year Mr Price developed a chesty cough and Laura asked the GP to visit. The GP's report said that Mr Price's chest was clear, but he could have Ventolin if necessary. Two days later the nurses called the GP again as Mr Price's temperature was raised. Laura was notified and asked for an Anglican minister to visit her father. Amoxycillin was ordered and Bertha commented that, within a day of getting the antibiotics, Mr Price was 'not dying, or dead, but brighter'. It was very unlikely that the antibiotics would have had this effect, if any, within 24 hours but the fact is that Mr Price did improve and the staff and Laura were happy with this, feeling that he had been 'cured'.

After Mr Price died Laura very tentatively reflected on this time. She said 'I think it would have been better had he died then because I thought [here she hesitates and seems to look to me to say what she means or indicate that I know what she means - before going on to say] ... his quality of life ...' Laura then explained that it seemed the right and caring thing to do at that time, because she could not foresee what was to come.

A few months later it is noticed that Mr Price's leg is starting to contract and give some pain. Panamax is ordered for relief of the pain. Two months later Mr Price is started on another regime of Amoxycillin for a urinary tract infection and 'chesty cough' after Laura had again contacted the GP. Mr Price continued to deteriorate and due to his chest congestion he was being suctioned regularly. By now there was virtually no response from him. On one occasion about two weeks before he died while assisting him to eat, which involved placing food in his mouth and reminding him to swallow, I note that he will perform this act but does not say a word or react in any way and his facial expression seemed blank. He took a small amount of food quite comfortably, but then closed his mouth against any more. The staff have taped music going by his bed. About a week before Mr Price died the nursing
home staff are now saying that Mr Price is very sick and will probably die very soon. The story they report is that:

the doctor had been rung on Tuesday and he came on Friday. He put him on antibiotics. He [Mr Price] is still opening and closing his mouth like a little sparrow but he's not rouseable some times. His daughter is very upset.

The staff tell me that they feel that it is time for Mr Price to die but their actions belie this fact. Bertha asks Georgina to suction Mr Price in order to make him comfortable. In the previous week I had asked the careworkers why Mr Price was being suctioned, to which they had replied that it was the RN's job and decision, they just tell them when they think he needs it. The registered nurse on duty, in response to the question 'why do you suck him out?', had said:

*I just had to. I don't know what it is - it's just gut instinct - he was battling so hard to cough but he was so weak and frail - I helped him and he went from grey to white.*

By the time I arrived at the nursing home in two days time the fact that I had asked this question had obviously filtered through to Georgina, the RN on duty. As soon as I walked into the staff room she said:

*I sucked him out on Saturday morning because he was cyanosed and distressed and I couldn't cope with it - I couldn't just leave him - even though he might have died, must have been awful for Mr Jervois [the other person in the room] listening to the death rattle. No [In a very firm voice - looking me straight in the eye]: the reason I did it was because he was distressed and it's just not fair.*

I reassured Georgina that it was not my place to make any comment or take a position and the question was out of interest only. I reminded her that I understood that the resident's comfort has to be her paramount consideration. Her justification to me was not necessary but reflected the culture of alienation, that someone has a right to comment on whether or not they 'doing a good job'. It also reflects the difficulties for staff in wanting someone to die but not having protocols or agreed structures of care to handle situations as they arise. Georgina had indicated to me that she was a very strong advocate of palliation and leaving people to die peacefully. It was obvious that she felt I would see her actions as contrary to this belief. This exchange also indicated to me that there was a small Hawthorne effect (Burns and Grove, 1993, p.41) creeping into the study. My questions were alerting the staff to my views.
However, as this episode shows, my observations made no difference to the practical care given to the residents. Also it was about this time that I was withdrawing from intense observation and daily visits. As I was around the nursing homes much less this Hawthorne effect began to decrease. Nevertheless by the end of the study there is no doubt that awareness of palliation issues in both nursing homes was vastly increased.

Georgina went on to tell me Mr Price's current condition was no better and he was incapable of responding to anyone. He was propped up in bed, with chest rales and rattles being very noticeable. Music was playing on a tape recorder by his bed. One staff member makes the comment that she:

can only sponge him now, shave him, comb his hair, keep him comfortable and tidy. He's got a lot of mucus but hasn't got the strength to cough it up. I hate it when they get like this. He could go on for weeks. I don't like to see him suffer like that - if it was an animal you would take it to the vet and get him put down. I hate it - I know we are not supposed to be involved but you do.

Her colleague replies:

Poor bugger - and his family just want him to go and I think it would be the best thing for him instead of just lingering.

The concept of helping is only applied to keeping the person alive - there is no mechanism for nurses to conceive of helping him by turning him to be as comfortable as possible, giving him pain relief and helping him to die.

By now there was increasing tension amongst the nursing staff about how to care for Mr Price. It was suspected that a skin break has been caused by the night staff getting him out of bed. Bertha was furious and let everyone know. She shouted the following information at me in the staff tea room, somewhere between tears and rage.

The night duty report showed that they had got him out to use commode in middle of the night. It was about 6 degrees that morning. The report said he had OpSite on a skin break. I had done him the day before and he had a line. I reckon it was a line from the commode. It broke my heart.

Kelly came in with a placating comment that may help her friend Bertha see the night staff's point of view:

On Sunday morning they said something at handover - they said he was wide awake till 2am.
It had no effect whatsoever. Bertha's voice rose an octave:

Why get him out at 2am? They could have done a manual removal - [Referring to the problem of Mr Price's bowel ooze that may be secondary to an impacted bowel] Why didn't they pass on the message? How long did they sit him out for?

Now Kelly had been put into the position of defending the night staff, although she is a mate of Bertha's:

Well you know how long it takes for a suppository to work on him. He never goes by himself. They do manual removals and all sorts.

But this is to no avail. Bertha replied:

They dragged him out of bed, another thing that annoys me - they do all this continence and stuff - he was the main one we did the continence aids on so that a frail sick contracted man did not have to get out of bed, but it makes no difference [shouting]. How much you document it makes no difference but its just her [the night nurse] - [at this point Bertha's voice drops and she gets tearful, realising it seems, that she is taking her upset at Mr Price's near death and her frustrations with the system out on one nursing action] No it isn't - it doesn't matter how much you document - it doesn't make any difference -... I get told off - I am getting too emotionally involved

Kelly was able now to leap back in and defend her friend and turned the attack on the 'them' of administration:

But we are also told you have to be a caring person, so what do they want?

The horizontal violence that emerged as a result of frustration and alienation is clear. Added to this is the grief many of the staff were experiencing. Bertha calmed down and reflected on her grief about Mr Price while at the same time keeping up the complaints about 'them'.

I can see the pros and cons of it but he is a frail old man who has been in bed three days. I agree everyone has the right to use the commode and toilet etc I will swear on a pack of Bibles that that OpSite is covering a skin break - she [the night duty sister] is so obsessed with them being dry.

This kind of conversation indicates a need for a rational approach to terminal care and, just as clearly, some of the obstacles in the way of progress. The judgement of
how near to death Mr Price was varied from person to person and affected their judgement of nursing care delivery. For example, the process of 'manual removal' of faeces is another nursing home dilemma. In most geriatric courses it is taught as being a dangerous and forbidden procedure, that may tear and damage the skin in the anal passage leading to a pre-disposition for fissures, but for these frail, emaciated weak old people the RNs see it as the easiest, kindest solution to make the resident more comfortable. Staff do not like doing a manual removal of faeces and they are not carefully planned. Then tend to be done when staff can get around to it. It is suggested in one text that 'faecal impaction may require manual disimpaction. A pre-medication may be required as the procedure can be painful' (Gray et al., 1992, p.56) but this is academic rhetoric and is not likely to occur in the present day culture of nursing home care. It is not usual for routine pre-medication to be given before a manual removal. It is these kinds of procedures that could be reviewed in a palliative care program.

The staff discussed the erratic progress towards death that Mr Price was making but had no power or processes to make decisions about how to deal with it. Various comments that are recorded as the tea room conversation continues were:

*He was so sick on Saturday, I did not think he would get through the day - he would not eat breakfast and then ate dinner like it was going out of fashion.*

*It's really hard we talked about sucking him out - but he's been a big part of our lives for 18 months. When he first came in he was aggressive, he used to go right off. We had only certain people going in all the time so he got used to them. You get such a big bondage with them all he has done here is smile and be happy. He used to talk about the Japs - we took the television out and put the tapes in and he was better then.*

*...its that thing we got about feeding - force feeding him - they rush him because of the time factor. It's just wrong.*

*They don't reckon he'll get over this one. I remember last time.*

*It's a strain on the heart that cough, cough...*  

As Bertha leaves the room another staff member indicates her understanding of the reason for Bertha being upset. She turns to me with an explanation:

*Bertha reacts 'cos she just adores him - she's too emotional. One sister decided to commode him because he had bowel ooze - so it was callous - here is a man dying - most are concerned about him.*
She then went on to discuss the question about suction and the part it had played in keeping Mr Price alive. She decides that the uncertainty of Mr Price's progression towards death means that life sustaining measures are instinctively the 'morally' right thing for nursing care. Careworkers say that:

*Georgina (the RN) said he's better for it - Georgina says he did this to us last Xmas and then he came good - the bugger.*

So there is confusion about whether this really is going to be Mr Price's death, or just another false alarm. To the registered nurse this uncertainty justified treatment with antibiotics and suction. The nursing notes read:

*Bed elevated, suction prn for congestion, diet and fluids as tolerated. May have pad (gel) for management of incontinence. Small amount of lunch - Fully assisted. Antibiotics commenced*

But this time the hoped-for recovery does not eventuate. One week before Mr Price died the notes read:

*Pharyngeal suction relieved congestion temporarily. Breathing exercises attempted but resident is extremely frail and weak.*

Two days before Mr Price died the registered nurses were still attempting to give him the antibiotic syrup.

As one moves up the nursing hierarchy the technical training of nursing staff seems to make them respond automatically, reverting to the medical or clinical model of care. The position taken instinctively is that you are doing your job 'right' if you do what you were taught. Suction, antibiotics and breathing exercises feel right because there is no alternative planned palliative care.

Mr Price died at 4.40am. Laura came to the nursing home half an hour later. Some staff reported to others in the morning that Laura had 'been there' when Mr Price died. The RN made it clear to me that this was not the case but let the story spread unchallenged, and asked me to do the same, because this made the staff 'feel better'. The story of the staff not wanting residents to die alone is repeated again and again. Yet there are no plans or resources to avoid this happening. Efforts are made at times to find sitters for people who are dying, but residents with dementia may take many days to die, with multiple recoveries from what appear to be the edges of death, and this makes it impossible to find enough people to cover all the hours.
Kelly was pragmatic, but upset that the physical body, the 'thing' she had
cared for over the years, had not been laid to rest in a manner with which she
felt comfortable. She says:

He was not as peaceful as I had hoped. It was his mouth - his mouth
wasn't closed but then he hadn't had his teeth in for ages. We will miss
his cheeky smile.

Bertha and Kelly attended Mr Price's funeral during their time off. Laura was very
grateful for this, telling me that she 'can't speak highly enough of the girls, they're
absolutely marvellous under very trying circumstances.'

After her father died Laura seemed able to talk about some aspects of his care that
had distressed her. Her feeling toward more senior staff was not the same as her close
and grateful feelings towards the nurse assistants. She talked about the charm and
concern expressed to her by senior management before her father came into the
nursing home, and the apparent lack of interest from senior staff once he was there.
Her criticisms did not stop there.

'I sometimes think', she also went on to tell me, 'the doctor's attitude leaves a
bit to be desired.'

As an example she reports her difficulty in getting doctors to see her father:

... in the six years that Dad's been here I have never ever known one
of them to come when they were called, and you know the girls here,
the sisters and that, they don't call a doctor unnecessarily, ever. And
yet, I've known, even last year, four days before the doctor came to
him, and the sister had rung up explained how bad was his
temperature. Four days later, and that was because, in the end they
asked me to ring up. And two sisters have done that. They say if a
relative rings up, they'll be here, but she said, we're just wasting our
time on those things, ringing them up because they ignore it, and on
those two occasions that I did ring, they were down here the same
afternoon. And I rang again this week, because they couldn't get
anyone. The next day the same doctor wasn't available. The duty
doctor was asked to come who didn't roll up at all. Friday I was here
at lunch time, still hadn't been, so I went home and I waited and then
I rang at three o'clock - yes he was here. So then I waited another
hour and rang him at his surgery, and I let him know that I knew that
nobody had bothered... he said, you know it's just a matter of a
phone call if you want to be reassured.

She indicates her wish that:
they [the doctors] would care enough to pop in and to say yes, well
perhaps there is a little bit more we can do just to make the way easier
out.

Through her tears Laura said that all she wanted was for her father to be made
comfortable, just to be made comfortable. The responsibility for easing the death had
been put onto the doctors by Laura, but she naturally does not see the significance of
the fact that it was the nurses who had encouraged her to ring the GP to get antibiotics
to treat Mr Price's temperature. They obviously felt unable to take responsibility for
sponging and comforting him and leaving him to die peacefully.

The nurses' concerns for themselves and Mr Price were obviously
communicated to Laura. She talks about the fact that she had discussed her
father's worsening condition with the nurses

... before anyone bothered to come and see him, ... I know the nurses
were worried, and they'd done all they could.

She felt she had been ignored by the GP and said she had never been
consulted about treatment. She had received what she saw as patronising and
off-hand responses to her expressed concerns. She says:

They've never spoken to me, never ... That's what I often say, if it was
a twenty year old buxom blonde jumping up and down they'd be here
five minutes later. Because he's a very old sick man ....

Her voice trails off in tears.

In the present medical model, for a relative to insist on contact up the hierarchy, from
careworker to RN to DON to GP, is difficult without feeling that they appear to be
making a fuss and being demanding. A planned approach is likely to produce more
satisfactory results and avoid the bitterness found in some of these remarks from a
person as gentle and unassuming as Laura.

There is probably a measure of exaggeration in the charge Laura makes above,
fuelled by a long-contained anger at what she has experienced as condescension.
However it may be true that the relatives of any twenty year old who was dying would
get more support from the medical profession, and more particularly, the acute care
paradigm, than is usually available to the relatives of 'a very old sick man'. The model
of care and its objectives would be clear, it would be applied appropriately and, even
if its efficacy were exhausted, it is likely the boundaries and time limits would be
clearer. We would be much less likely to see the two phenomena we have seen in the
case of aged residents like Mr Price: a confused scenario where the resident and the relatives are caught between the conflicting values, beliefs and needs of health professionals and where the best efforts of all are stymied by the lack of clear models of care.

It is quite clear that Laura did not want to keep her father alive but she wanted to repay him with all the care she could give for all he had done for her during his life.

There is a case to answer.

The next two case studies have at the centre of them residents who 'spit' and 'stare'. These two residents seem to be treated as 'routine' to the point where they are almost invisible within the nursing home culture.
Mrs Letitia Fishlock

One of the invisible residents or a certain resignation

- 95 years old at time of death
- In nursing home for 68 months
- Transfers to acute hospital for #femur
- Incontinent at times since admission to nursing home.
- 23 courses of antibiotic eye ointment/drops during time in nursing home.
- 4 falls recorded on incident reports.

Mrs Fishlock was a resident who seemed to be a routine 'body' for the staff to care for. She was not able to communicate at all, except by spitting or mumbling. Mrs Fishlock's spitting was the most prominent feature ever mentioned or recorded about her. Very early in the times of participant observation I was given the job of helping her with meals. The first impression of being close was recorded as:

_"I offered Mrs Fishlock her food, having to put the spoon into her mouth. She ate her breakfast easily although I was warned that 'she would spit'. This didn't happen until the last mouthful and I took it to indicate that she didn't want any more as her face also looked very cross._"

In subsequent eating episodes, she was often observed spitting out her food. She spat when I was assisting her to eat and I often saw her spit out her food when staff were doing the same. It was not a gentle rejection; it was an aggressive spit, and it seemed to be directed at the person, and not be just a rejection of the food. There was an expression on her face which I interpreted as distaste, misery, frustration and unhappiness. Expressions of unhappiness or misery were a constant feature of Mrs Fishlock. Her notes record that she had Bell's Palsy, but the facial paralysis that is associated with this condition was not clearly evident. However, this may have contributed to her perpetually pained expression. This seeming misery meant that, in much the same as the scenario relating to Mrs Watts, the staff were not able to build up a close relationship with her.

Mrs Fishlock had been a hostess for a catering firm, an indication that her social skills had been well developed and she was described as a 'very likeable little lady' in admission notes. An early photograph shows her as a smiling, apparently charming woman. Charmaine told me that the staff remember her as an attractive woman and so the staff always tried to make her look nice and put on the dresses that suited her best.
Two years after Mrs Fishlock died, while Charmaine was discussing this story with me, she could still describe the blue dress that she thought suited Mrs Fishlock best.

If one believes that there is awareness left for people with dementia then the uncivilised way in which Mrs Fishlock was being kept alive by being 'fed' may have been for her, a person who had spent a great deal of her life finding ways of presenting food elegantly, a form of unbearable suffering.

In the first discussion with the doctor about her his comment was 'all I can tell you about her is that she is bonkers'. This statement did not seem to upset the nursing or care staff although deprecatory comments about residents often did. It seems that it was not considered pejorative - that since she was 'bonkers' it was OK for the doctor to say so - although they were not 'allowed' to say anything like that because of 'policy'.

In spite of the earlier introduction the nursing notes at the time of Mrs Fishlock's admission seem to have a derogatory tone describing her as 'difficult and noisy...extremely 'vocal' at times. Repeats one phrase 'help me'.

After five months in the nursing home Mrs Fishlock sustained a fall which resulted in a fractured femur and from this point on she was much less mobile. The notes for the next four years reflect a pattern of care that was still apparent in observations and comments from staff during the time of the study. Mrs Fishlock seemed to become a 'routine case of dementia'. Her episodes of calling out and noisiness were treated with Melleril or Serenace. Serenace is known to cause extrapyramidal side effects and/or Parkinsonian-like symptoms. Cogentin was prescribed to ameliorate the effects of the Serenace but this may have only been partially effective. Adverse drug reaction could explain the mask-like rigidity of her facial expression and the strange distorted looks that were translated by me and the staff as misery.

Mrs Fishlock's days consisted of being moved from bed to chair, sitting on the commode, being showered with the help of two nurses and sitting all day looking vacantly into space. She continued to spit at people and looked like a person who was unhappy and defeated. Her family had a comfortable but distant relationship with staff at the nursing home and, it seemed, the same kind of relationship with Mrs Fishlock. Interaction with the GP also appears to have been routine. There are only 18 recorded notes from the GP in the 68 months of Mrs Fishlock's time in the nursing home.

At handovers I recorded a long list of 'no change' reports for Mrs Fishlock. The Bell's Palsy contributed to her having 'sticky eyes', as they were called, at regular intervals.
These were treated with Chloromycetin on a regular basis, with little effect evident. Her notes record odd episodes of vomiting which the staff felt did not need any particular attention, and constant mentions of being 'noisy' and 'spitting'.

Mrs Fishlock's decline towards death was quite clear to staff. She began to eat less, she began to lose weight and she had episodes of sudden collapse. In one of these she was described as 'pale unresponsive and cyanosed around lips and eyes'. The staff accepted these as TIAs and accepted too that, at some time, she may not recover from one.

They talk about Mrs Fishlock's decline as part of 'her progression'. They do not say 'the progression towards death'. These words aren't spoken but it is an unspoken and accepted fact that that is what is meant.

The last TIA was 20 days before her death, after which her condition slowly deteriorated. However, as so often happens, the unnerving phenomenon of a rally before death occurred. Two weeks before Mrs Fishlock died staff described her as 'back to her old self again, chatting well with nonsensc language'.

In spite of knowing that Mrs Fishlock was very close to death the problem of knowing whether the actual death would be days or weeks arose to confuse the issue of care once again. Therefore Mrs Fishlock was still treated as if things had not changed. Her bowels were kept clean with suppositories, her body was kept clean by showering her and not until the last three days of her life was she left in bed completely. She then died gently.

The difficult questions raised here are to know whether Mrs Fishlock's personality and spirit were broken by the process of institutionalisation or the amount of brain damage she sustained during her various small strokes. The fact that she had been a heavy smoker left her with peripheral vascular disease and probably contributed to her TIAs and dementia. To smoke or not to smoke was a choice she had been able to make. Would she also have chosen to spend the last five years of her life as this story describes? Was she calling for help and, maybe, in the only way left to her, refusing to be kept alive by spitting her food back. How do we know? How can we interpret the language of dementia? Even if detailed knowledge about the particular effect of certain damage on parts of the brain could give us a technically sound reason for a particular behaviour the thrust of the query still stands as a point to be debated.
Mrs Alice Brown

A will to live at any cost or months of anger?

- 91 years old at time of death
- In nursing home for 61 months
- Incontinent before admission to nursing home.
- 4 courses of antibiotics during time in nursing home.
- 16 falls recorded on incident reports.

The early stories about Mrs Brown as recorded in the nursing notes are full of comments about her 'pinching and punching ... throws tantrums and anything in room.' Three weeks after her admission her notes record that:

Mrs Brown has been very aggressive throughout the day. She was throwing crockery, walking aids etc, anything that came to hand.
When asked why she was doing these things she simply stated that she wanted to die.

In that same week staff attempted to give Mrs Brown a fluvax injection which she refused but subsequently she was given these each year.

When it was suggested that Mrs Brown be included in the study she had been in the nursing home for four years. She was described as 'The Sphinx'. The reason given for this was that 'she used to pinch and so on' but as she can't do that now she just stares.

Charmaine feels that Mrs Brown is full of anger and perhaps not as demented as her behaviour would indicate. Her view is that Mrs Brown is probably not ready to die, although the anger may be because she wants to but, paradoxically, hanging onto that anger is giving her a reason for living. Also Mrs Brown eats well because her family comes in and gives her her meal nearly every day. Staff observe that when they come she brightens up and 'does much better', meaning that she will eat more.

This constant family attention had declined by the time Mrs Brown was selected for the study. I was not able to get any response from her at all. My explanation about the study was greeted with a vacant look as if I were not in the room.

The 'staring' that Charmaine had referred to is confirmed by other staff and recorded in notes. There never seems to be any question that this blankness may be due to any form of disease or damage. The staff feel that she just
doesn't want to be 'here'. There are various opinions about whether she wants
to die or be somewhere where she can get more attention, or somewhere
where she would be 'happier'. Mrs Brown's notes have the same character as
Mrs Fishlock's. They seem 'routine' with constant references to pinching and
aggressive behaviour. Odd episodes of vomiting and diarrhoea are mentioned
as are difficulties with eating.

Mrs Brown was a large woman and her uncooperative behaviour made her difficult to
care for. She constantly sustained skin tears and had pressure areas on her sacrum.
These were continually treated. Some got better and none became very serious. When
Mrs Brown was discussed amongst staff the ambivalence Charmaine suggested, about
whether or not she wants to die, was constantly present. Mrs Brown was the most
'hidden' resident from me in the study. There never seemed to be a staff member
around to ask questions about her when I was in Mrs Brown's room and when I
observed her being nursed, it seemed to be that the staff were more mechanical and
wanting to get away from her. I had not observed this in any other case.

Eight months before Mrs Brown died comments such as 'Mrs Brown is still with us'
were being made and the pressure areas and skin tears on her legs were accepted as
being 'treated' rather than being cured.

It is subtle nuances of tone and behaviour of staff that reflect these changes.
A resignation in the tone of voice, a lack of discussion about trying new
things that may work. Instead comments such as 'they [meaning the skin
tears] are not any worse' indicate a subtle change in staff expectations.

Two months before Mrs Brown died the staff were recording that these pressure areas
were deteriorating and there was no sign of skin tears healing. She was beginning to
lose weight and it was clear that her health was declining. When she developed a 'cold'
as staff labelled it and became 'chesty' it was suggested to her family that 'conservative
treatment' was now appropriate and the family agreed. The GP was contacted as Mrs
Brown's chestiness got worse and concurred with the staff and family's decision not to
treat 'the cold'. It was three weeks on from this point that Mrs Brown died. But still the
process of conservative care was not fully faced. The staff still wrote and talked about
'assisting her with ADLs' although most of Mrs Brown's day is spent in bed in a state
of somnolence. Mrs Brown's death was considered a relief.

This story portrays a strong-willed woman who had her request for control of her life
taken away from her. Did she resent all those who she felt had 'caused' this? Did her
family and staff provide the support that kept her alive, perhaps against her wishes?
The next case history is another example of a resident expressing a wish to die and exhibiting signs which can be interpreted as psychological suffering of the worst kind. Both the following two stories describe morphia being prescribed, but we see staff using the option in a very limited way.
Mrs Lillian Guthridge

Why is anxiety not suffering?

- 90 years old at time of death
- In nursing home for 38 months
- Transfer to acute hospital
- Continent when admitted to nursing home, incontinent at times for last 15 months
- 12 courses of antibiotics during time in nursing home and 1 fluvax
- 7 falls recorded on incident reports.

Mrs Guthridge was admitted to Bayside following a fall in which she sustained a fractured leg. She had previously been living in the hostel. In the early days of her admission it was considered that she may have been well enough to return, but her multiplicity of conditions, her increasing dementia and level of anxiety prevented this occurring. She had already been treated in the local hospital for a severe episode of meleana, she was deaf, had cataracts and was confused. Her anxiety, distress and depression were recorded from these early days and continue to be so throughout her stay. Her calling 'help me, help me' slipped into the routine background noise of the nursing home, lending it an atmosphere of pathos.

The question of a bowel obstruction was raised by the doctor in the early days of Mrs Guthridge's stay at the nursing home, but no action was taken. Her bowel motions were often loose and offensive, but comments from the nurses alternate between 'no apparent pain' and 'feeling unwell' 'distressed' and 'anxious'. A pain chart was commenced but was only completed for five days. Abdominal pain was recorded by the RN who commenced the chart, who also gave analgesia. After that mild pain was recorded twice, although analgesia was not given, then no pain was recorded for the next three days before the chart was stopped.

This was all happening two years before Mrs Guthridge died. Routine nursing care kept Mrs Guthridge as active as possible, she had her hair done regularly and the staff were sure she liked this and was aware of it.

As the weeks go on new words occasionally crept into the reports. Now Mrs Guthridge is reported as 'sad, frightened, nervous'. Other changes are to 'assist with two nurses' and the recording of her incontinence.

This transition was not easy. Mrs Guthridge had the serious fall which resulted in the fractured arm before it was accepted that she had become so dependent.
Calandra explains what happened:

We thought it was Mr Bellini that had fallen but on further investigation it was Guthridge. She was laying face down by her bed, and we noticed there was a cut above her left eye and she was complaining of pain in her left shoulder. We (Calandra-RN) decided that she should go back to bed. Then we assessed the damage. Laceration would need suturing. Severe pain in shoulder and upper arm. She did complain of mild right hip pain. I felt sorry for her because she was so capable of getting herself on and off the toilet. Because of this incident some of her independence had been taken away. Because I was the person in charge there was a certain amount of guilt that it had happened. I was frustrated because it was not a foreseeable incident: there was nothing we could do about it. Its made us more aware of her frailty. I was on the following wend and Mr Guthridge [Son] came in. I spoke to him about the incident and expressed my feelings of responsibility for it. My impression of his response was that to some extent he held us responsible. I was a bit disappointed because I would have thought he would have understood our situation in that.

This extract shows the frustrations of the staff who are attempting to do their best, to implement the principles of dignity of risk, yet still get 'blamed' by the family when allowing the resident to take the risk which leads to a fall. At the same time Calandra was glad that she had acted as an advocate for Mrs Guthridge, persuading the doctor that they could care for her during the night so that she could go to the local hospital with someone familiar the next day and have the arm set, which would be less confusing for her.

I have outlined the conversation with Mrs Guthridge when first I met her. At that time medication seemed to have stabilised her anxiety a little, but she was also receiving pain relief for her fractured arm.

I took Mrs Guthridge in my car for the picnic that had been arranged for the residents by the staff during the early part of the field work. Mrs Guthridge actually looked anxious and depressed most of the time, although she did not speak until we were driving back, when she asked when it 'would be finished'. Feeling safe seemed a paramount need for her as it is with most people with dementia. Yet the staff felt they were really caring for these residents by providing stimulation, fresh air and a change of scenery. The picnic had involved a very large effort and personal commitment of the staff's own time,
but for many of the residents it was clear that it was quite a stressful occasion as all but about two had very high levels of frailty.

Mrs Guthridge's routine was such that she sat by the door of the nursing home where she saw everyone coming and going. She had become very attached to June, the receptionist, who was constantly in and out and it seemed to give her some security to see her. I always greeted Mrs Guthridge as I came through the door and therefore sometimes was requested to do something for her. On one particular day I recorded this incident:

*As I go in [to Bayside] Mrs Guthridge sees me and says, 'What will I do. I feel like the toilet'...I take her to the toilet. Holly is in Mrs Guthridge's room when I get back but Mrs Guthridge is still agitated and Holly cannot calm her. I take Mrs Guthridge round the garden as she is so unsettled then take her to the toilet again. As we are coming back she says 'I just want to go home and lie down and die'.*

Mrs Guthridge had made this kind of comment on other occasions but the staff chose to ignore this. Some comments were explained away as a result of the depression that can be associated with dementia. In other circumstances, nevertheless, staff can translate the language of dementia very accurately and are able to check their understandings of the resident's language. For example, as has been shown they know that the 'iron works' for Mrs Guthridge means commode. It would not be out of the question to think that Mrs Guthridge could sense that I was someone she knew, I was not unfamiliar to her, I had time to be with her and assist her and, subconsciously, she was trying to tell me how she felt. I believed her. I think she was suffering every minute of every day.

At this time the staff still considered that Mrs Guthridge was deteriorating, not because she was going to die, but because of their acceptance that she could not go back to the hostel. A few weeks after the incident with me Bertha commented that:

*Mrs Guthridge is shocking, calling out for Mummy and Daddy, always asking for someone to sit with her, she's beautiful. She is crazy in her own little mind. She is getting worse because she can't feed herself any more, she does not attempt at all. If you give her the spoon she shuts her mouth.*

Mrs Guthridge continues to deteriorate but receives routine care, including antibiotics for a urinary tract infection until a month before she dies. Mrs Guthridge is still calling out constantly but now is fully incontinent, remains in bed for long periods, has a pressure sore and takes very little food and
fluids. The GP contacts the family to discuss Mrs Guthridge's future and they agree to no more treatment. This is recorded in the notes as 'family request comfort care only at this stage. Antibiotics ceased and may have Morphia 5-10mg four times in 24 hours PRN'.

Mrs Guthridge died six days after this decision was made.

Only six doses of morphine are recorded in the notes as being given in that time. Neither the RNs who chose to give the morphia or those who didn't gave very clear reasons in the notes for their choice; One entry reads 'very quiet evening, no medication given'. Another records 'In distress, calling out needs attended 2 hourly, accepting small amounts of thickened fluids, IM morphia 10mgs at 1220'. When staff have discussed giving these drugs they express their interpretation of the difference between being 'distressed' and being 'quiet' in their own value terms such as 'if it was me I would want it' or 'I would not want to be knocked out and not know what was going on' or 'morphia is only for pain and I don't think she is in pain now'.

That a four-hourly order may have been entirely appropriate is not being questioned. The point to be noted is the not-at-all-unusual degree of latitude that the imprecision of the order left for a random succession of different approaches and philosophies to govern the care given to Mrs Guthridge as she died. Again it needs to be emphasised that this is not at all a result of any individual laxity or indifference. Rather it is a possible, indeed probable, result of the lack of a clear guiding model of palliative care able to be articulated openly and universally shared.

Our next case study, of Mrs Corbett, displays the romanticisation of the dying process to which staff are prone to resort in the absence of a clear clinical model of death as the outcome of the dementing process. Mrs Corbett died because she had heart failure as well as suffering from dementia. For the staff, though, she died because her heart was broken by the loss of her husband.
Mrs Corbett

Death from a broken heart?

- 91 years old at time of death
- In nursing home for 17 months
- No transfers to acute hospital
- Incontinent before admission to nursing home.
- 2 courses of antibiotics during time in nursing home and 2 fluvax
- 2 falls recorded on incident reports.

Mrs Corbett was 90 years old when she was admitted to Bayside from the local hospital. Her medical notes record a diagnosis of Alzheimer’s disease, myocardial ischaemia, intermittent dysrythmia and CCF. She had already had several falls and had a skin tear on her left elbow that was being dressed. The doctor’s notes record, like this, in capital letters ‘SHE NOT BE ALLOWED TO WALK ALONE as she easily falls over’. Mrs Corbett was continent and able to eat unassisted. She could speak clearly but her comprehension was poor. A few days after admission she had an episode of confusion and agitation and had become constipated. The staff attempted to clear her rectum manually as there was a lump of faeces stuck in it. During the procedure she commented that ‘this always happens when I’m away from home’. The nursing notes report her as seeming ‘lost and unhappy’.

Within a week of being admitted to the nursing home Mrs Corbett needed full assistance with washing, dressing and meals. The nursing staff commented that she was constantly tired and without any interest in caring for herself. They assessed her as depressed. Her husband requested that the doctor reassess his wife and ‘explain to him what is really wrong with her’. It seems that Mr Corbett could never come to terms with the reality of his wife’s deterioration.

It was about a year after Mrs Corbett’s admission that this study began. The first comment made to me was that her family were very critical of her care at the nursing home. The nurses’ interpretation of this, at that time, was that the family were ashamed of their mother because they did not understand her condition. The staff also seemed to feel that the family’s upper class attitude meant that they did not savour seeking or accepting advice on the matter from the nursing staff, rather than from doctors, who were seen as being not very interested. In this case, as with many others, the recorded involvement of GPs with the residents and their family is minimal. There are 17 entries in the medical notes in the 18 months Mrs Corbett was in Bayside, four of those being in the two weeks before she died and one certifying her death. Since GPs
are obliged to undertake reviews of residents every six weeks it seems that only what was necessary was undertaken, nothing more.

During her stay in the nursing home Mrs Corbett has intermittent UTIs and antibiotics were prescribed for these. She remained confused, although staff reported that 'validation therapy when necessary seems to bring awareness to time and place'.

Although Mr Corbett visited most days to assist his wife with one meal, the staff did not feel that the family 'do enough'. An underlying motive for this appears to be a perception that Mrs Corbett has enough awareness of her surroundings, that she is more frail than many people with dementia because she had some heart failure, and therefore she is unhappy and has 'lost interest in life'. The staff feel that if the family took her out more this would help her. Staff indicated that they felt that, acting as the patient advocate, they must ring to encourage the family to take Mrs Corbett out.

On the other hand, when Mr Corbett spoke to me his interview was punctuated with sobs that were so sad that I felt his heart was breaking in front of my eyes. His tears soaked the front of his very smart business suit. The image is one that remains with me. He was not able to articulate how he felt or his understanding of the condition of dementia. He seemed to be seeking help from me in trying to understand the nightmare he was going through. Yet this was an intelligent man who had been very actively involved in the community to the point of being the president of various local clubs.

In contrast to this one occasion the wider family appeared self-contained with particular values that they seemed reluctant to divulge or share. The staff interpreted this family's struggle to come to terms with changes in Mrs Corbett as not caring. In the early days of Mrs Corbett's stay at the nursing home there is little meaningful communication between staff and family and a vague sense of hostility as they perceived that the Corbett's felt the nursing home was not 'good enough' for their mother. Later, a much greater understanding seemed to develop between the staff and the family.

A year after her admission, Mrs Corbett was beginning to develop some contractures. At handover it was reported that her fist was tight and needed a roll of combine put into it as it could get infected. It was already 'getting smelly'. In a later case study, that of Mrs Davey, I discuss the problem about the skin on a contracted hand being at risk of becoming soft and infected very quickly. This problem did not happen to Mrs Corbett, but only because of constant routine nursing care.
The problem of Mrs Corbett being liable to fall out of bed resulted in an ongoing debate amongst staff about the merits of bed-rails being up or down. The RN, George, changed the care plan, from bed-rails up to bed-rails down but this caused friction with the night staff and resulted in a heated discussion during an RNs' meeting. George attempted to put the argument on a logical basis, suggesting that he would check the latest research about the risk of injury from climbing over the bed-rails, versus the risk of injury from leaving the bed-rails down. He also gave the results of a small study he had been involved in in another nursing home indicating that residents were, in the majority, safer without bed-rails. (Most staff referred to bed-rails as 'cot-sides' but this was crossed out in the draft of the thesis, perhaps in an attempt to show that staff did understand the pejorative nature of this term. To keep consistent with the culture the term cot-side would be correct, but I have accepted the request of staff, as I also accept the rationale, to change the wording to bed-rail.)

The acceptance of leaving bed-rails down was not forthcoming. Instead the suggestion was seen as George trying to get his own way by being clever in using research evidence to prove his point. Petra's advice to George in relation to the argument was 'Bow out of it - too difficult.' and that is what he did. However, the problem festered. The staff who advocated keeping the bed-rails up cited the occasions when Mrs Corbett annoyed the other resident in the room by having her cot side down. The horizontal violence between nursing staff appeared again. The situation was resolved by Mrs Corbett's condition deteriorating.

An erosion of Mrs Corbett's relatively stable condition had begun to appear. About this time when Mrs Corbett was being given her medication she told the RN that she felt 'awful'. The RN replied 'How do you feel awful? Are you tired?' The RN would be aware that Mrs Corbett would not be able to work out a coherent answer to the first question and so, probably subconsciously, supplied her with an answer which she could use. Repeating the last thing that is said is also a very common response from people with dementia. Predictably Mrs Corbett replied 'yes I'm tired' which receives an answer in a kind tone from the RN who says 'It's Sunday today, you don't have to get up in a hurry'.

This kind of flexibility did not seem to occur so often at Beachdale. There, the residents were up and about every day. At Beachdale there seemed little difference between the week and weekends, whereas at Bayside there were quite distinctly different atmosphere. Again, paradoxically, it was these kinds of 'normalities' that gave Bayside a much friendlier and more home-like atmosphere, in spite of less elegant surroundings, than Beachdale. At Beachdale everyone was involved, June, the
receptionist, would wander through the nursing home and chat to staff and residents, Gerald and Charles, the maintenance staff would always be around making dry comments. Jan, one of the housekeepers took a very strong part in the activities of the home, the kitchen, laundry staff and health professionals such as the occupational therapists would be wandering in and out. This contributed to a noisy, much more casual, slightly chaotic, atmosphere with interruptions for everyone going on all the time. At Beachdale the atmosphere was much quieter and routine, with only one or two staff members in a house. The RNs would travel through all houses at very regular intervals, further leading to a much more formal, and slightly intimidating atmosphere. This impacted on the resident’s care because at Beachdale, rules, or perceived rules were far more strictly adhered too. At Bayside, concomitant with the chaotic atmosphere, a certain irreverence towards authority was apparent.

About this time Mr Corbett was involved in a fatal car crash. He was on his way to the nursing home for afternoon tea. No-one was able to explain clearly how the crash happened as he was on his own and ran off the road and hit a tree. Mystery surrounds why he was travelling in the direction he was coming from. As the nurses were telling me about it they used words and phrases that indicate that he killed himself, or at least that it was because he just could not cope with the difficulties of his wife being demented. They discussed the fact that the local gossip reports that he was speeding. Bertha used the words ‘when Mr Corbett killed himself’. There was no argument from anyone around the tea table. There was a general feeling in the discussion that ‘he had had enough’.

The staff also clearly decided that Mrs Corbett understands in some way. Kelly tells me that it is interesting that when she came on duty Mrs Corbett was sobbing. Mrs Corbett did not know anything then, she had not been told about her husband’s death but she said she was upset but did not know why. That sadness went all morning. Kelly said that although she does cry a lot on and off, ‘it was different it was real sobbing’. Kelly thinks it is a bit ironic and comical. The sobbing went on all morning, she just kept saying the same thing: she was upset but did not know why. They say ‘Mrs Corbett is sad but she does not know why she is sad’. Rita also concurs with the view about Mrs Corbett ‘knowing’. She says that she sensed Mrs Corbett was waiting for Mr Corbett to come to afternoon tea on Saturday.

On Sunday morning, before the relatives had come to tell her about Mr Corbett’s death, she was crying. Rita and Georgina went to talk to her and she just said, when asked what was happening ‘something that keeps coming over
me'. This was about 10.30 am, but the family did not come in and told her the news at 11.30 am. Of course, one might say that the extra attention and the general attitude of the staff could have given Mrs Corbett this feeling but an answer from a spiritual dimension is also possible. When the family told Mrs Corbett about her husband’s death they felt that Mrs Corbett did not seem to register the fact. Mrs Corbett's daughter-in-law had talked to the nursing staff and said she did not think Mrs Corbett understood that her husband had died.

It was over this episode that the family seemed to begin to develop some understanding of Mrs Corbett's confusion. They illustrated this by telling the staff that Mrs Corbett's son had asked if she knew him and she had replied that she knew he fitted into the family somewhere. However when he had said that he was the baby of the family she had replied 'Oh it's Roland'.

Charmaine discusses Rita's recommendation that Mrs Corbett attend the funeral but that Dr Harkin is not sure it is a good idea. 'He did not think it would make any difference - but it did not worry him either way.' Charmaine said the family were 'iffy' about taking Mrs Corbett to the funeral. They had originally not planned to take her but asked the advice of the staff. The staff encouraged the family to take her, saying 'she should go'. Mrs Corbett does go and is reported as seeming to understand and 'behaving like a normal grieving widow'. To the staff there Mrs Corbett had insight or some kind of understanding about the whole affair that transcends our understanding.

This whole incident seems to change the relationship between the staff and the family. In discussing the 'eeriness' they all feel about Mrs Corbett somehow sensing Mr Corbett's death they now seem to be understanding this family in a different way. Communication lines open up and remain open until Mrs Corbett's death.

Life returns to normal and Mrs Corbett's room mate returns from a visit to the local hospital. The staff think that the reason that Mrs Corbett becomes a little more depressed than usual is because she has to share her room again. Staff report Mrs Corbett's behaviour as mainly 'grabbing and fighting'. Dr Harkin prescribed IM Valium as 'we do not know if it is pain or cerebral irritation'.

However, the perception of Mrs Corbett 'knowing' about her husband's death continues, and, according to the staff, contributes to her decline. They say that:
Mrs Corbett has not been the same since her husband died - thrown in the towel - decided to go - has not eaten will not open her mouth pushing my hand away like she is saying to me is leave me alone - I asked is she demented away that I force it down - I just left her - Does not hurt if the family are around to try and feed her - it makes them feel better She just wants to be with him - she's dying because of old age - had enough - given up - nothing worth living for.

However, Mrs Corbett does not die. A few days later the report is that she is still:

hanging on - still with us - Daughter-in-law had stayed all night. The family had rung the doctor this morning and asked for something stronger than Valium as her mother had had a restless night. Dr prescribed morphia 'for apparent pain'.

This request was granted and documented in the nursing notes as 'S/B Dr Harkin RX FM Morphia 10mg 4/24 for apparent pain at family request. given at 0930 with good effect'.

For the following two days the staff report that Mrs Corbett seems comfortable. Mrs Corbett does not receive any more morphine for another 48 hours until the staff give her a dose before they give her a bed-bath. Dora speaks sharply to me when I ask how many doses of morphia Mrs Corbett has had and tells me that 'Mrs Corbett is comfortable'.

Cynthia reports that Mrs Corbett was peaceful when she died but that:

she was not the day before. Every time we turned her she would screw up her face in absolute agony - the family would go out of the room when we turned her because of dignity and respect for Mrs Corbett so they did not see her suffer - they watched her die for a week - that's suffering

Cynthia was very pleased that Mrs Corbett had died while they were with her. Her view of the death was reported this way. She and Robyn went to see how Mrs Corbett was and when they got to the room their impression was that:

It was almost as if she was waiting for us to get there before she could go ... we walked in she was lying there quietly - I put my hand on her face and stroked her hair brushed her hair back and she just died.

Cynthia went on to tell me that they had expected the lingering death - Robyn had predicted that Mrs Corbett 'would not die quickly - she had seen calves like that.'
However, they did know she was going to die because 'she was cold clammy - skin action - an unusual odour - the death odour, she had it for the last week - its' a death smell - it's dank.'

They had felt sorry for the family waiting and waiting, expecting every breath to be the last. When the family came in the first thing they asked was 'was anyone with her?'

Francis and Kelly went to Mrs Corbett's funeral. They were upset because, according to their stories, 'not once did they mention that she [Mrs Corbett] was reunited with Michael [Mr Corbett] - they only mentioned that he had gone'. - Both Francis and Kelly had worked the early shift- They came off duty at 2.30 pm and the service was at 3 pm. They say proudly:

_We [Bayside] got a good report -[the Corbett family] thanked Bayside - felt proud they were pleased we were there - Hannah grabbed hold of us and would not let go - the brother came up and said he could not believe we would come- for the last 3 days I was down there [the section of the nursing home where Mrs Corbett's room was] I felt good - I usually go [to funerals] if it is possible._

The comment about the 'good report' seems to put to rest the seeming criticisms this family had of the care at Bayside, and to finish the relationship on an intimate and satisfactory note. The smiles and real pleasure that came through when this comment was made to me were very clear, making another moment of satisfaction because of a rare moment of appreciation. Not that, in other cases, appreciation is not shown. For example, Mrs Jared, the wife of a resident in a later story, constantly said that the 'girls are doing a wonderful job' but 'the girls' were very aware of the terrible strain that Mr Jared's continual hanging onto life was having for her. He had lost his 'personhood' in their eyes and so his wife's appreciation of their work and care was obscured for the staff by the dilemmas surrounding the husband's care.

Mrs Corbett's physical decline from a time when she was sitting in the lounge attending reminiscence therapy and a report that says 'resident spilt a cup of tea over herself' to a condition warranting 'conservative treatment' only took two weeks and Mrs Corbett died nine days after this. Heart failure was cited as the medical reason for her death. For the staff it was heart failure of a different kind. Either way, everyone agreed that it was the right time for Mrs Corbett to die.

According to one of her daughters, Crystal, it was the right time because Mrs Corbett had chosen it. Crystal says:
I think she's realised that this is the beginning of going into her future life ... I just hope that she goes quickly because I think this is the time.

Even this death, which was an early death in comparison to some other residents in the study, was not considered to have occurred too soon. In contrast, the story that follows is one of pain and horror, and of a lingering death which must certainly be considered too long in anyone's judgement.
Mrs Bernadette Miles

An uncivilised experience

- 85 years old at time of death
- In hostel for 37 months and nursing home for 13 months
- No transfers to acute hospital
- Incontinent before admission to nursing home
- 12 courses of antibiotics during time in nursing home
- 5 falls recorded on incident reports.

The first signs and symptoms of Mrs Bernadette Miles's decline are described by Mirabel, her daughter-in-law, who had become the primary carer for Mrs Miles and her husband. The anger and frustration of reliving the experience was clear in her facial expression as she outlined the story below. This anger was not generalised to all health personnel. In caring for her father-in-law Mirabel had received what she describes as 'wonderful support from the palliative care sister' [a community nurse specialising in palliative care] and through that, had become knowledgeable about care methods which contributed to his dying process being peaceful. In contrast, looking back on the experience of her mother-in-law's death was frustrating and painful.

Mirabel starts off with her first recollection of things going wrong with Bernadette.

*She started having pains in her chest and she went to the doctor and he listened to her heart and said, she's going to a specialist and the specialist said to her 'Your heart and your lungs have had it. There's nothing I can do for you so just go home and make the best of it' and she really dropped her bundle then. She was playing pennant bowls and she sat down that night and wrote her resignation to the bowling club and she stopped doing anything. You know eventually she stopped wanting to go out of the house and she was very uncomfortable if she was out. I mean I lived next door to her. She stopped cooking and cleaning, having a roast dinner and having that whole thing, normally she'd stop and help wash up and then we'd sit and watch TV. Then gradually as soon as she'd eat she wanted to go home. She wasn't happy unless she was in her own house and she wouldn't come out. And she started repeating things and I suppose we all do but she got really bad. I mean she'd ask you 20 times in five minutes what day it was - which makes you get very impatient, it's very wearing and you know it's very wearing of her husband too because he would argue with her. I mean I agreed with everything she said because I like peace at any price but he wouldn't. He would argue.*
He'd say 'No. It's Monday' and she'd say 'No. It's not. It's Sunday' and she was really killing him you know - slowly. Did I tell you she stopped cooking? She wouldn't let him go out. If he came into my place she'd follow him or she'd drag him back. She'd be tired. She'd want to go to bed after six at night but she'd want him to go to bed too and she'd keep on walking around. She had a few delusions - like we sent him away for a holiday so she came and lived with me. In the middle of the night she'd be up under the dining room table looking for her false teeth. She once got the cat's meat and put it on the stove to cook for dinner and she lived a lot in the past about - her mother and her sisters and - really strictly speaking it was because she was killing him that we put her in here [the nursing home] which is four years ago, [a query in her voice] four and a half years ago, and then she has just declined steadily since then I suppose.

Mirabel had a strong commitment to 'doing your bit in the world' and an equally strong commitment to family. She says 'we' when talking about decision-making but she was seemingly the only one who took responsibility for care.

When Mrs Miles was first admitted to the aged care complex she was admitted to the hostel.

She was constantly running away and being brought back by locals. Mirabel did not have a problem with this, but feels bitter about what she sees as the hypocrisy of the 'normalisation policy'. She says:

In the hostel accommodation which is open door sort of thing and she never settled. She wanted to go home. So every time I went to see her she'd have all her belongings in plastic bags and she'd be sat there waiting with her coat on. She says 'I'm waiting for John to take me home or have you come to take me home', you know. And often she would go out for a walk but in actual fact she was trying to go home and she'd get lost because we live right up on the sandhills you know and she'd walk right down the road and get lost and people used to pick her up and bring her back here - all the locals knew her and she went to the pub and he'd bring her back up here. I think it was the tourists that used to come back and abuse the staff.

Beachdale's commitment to SRV meant that, at that time, there were no locks on doors or gates - the complex was as much like a home as possible - which meant that people were free to come and go. This rationale was based on the principle of allowing residents dignity and freedom.
When Bernadette had been admitted her medical notes record her being assessed as disoriented in time and with a diagnosis of dementia. Her first episode of 'going missing' was nine months after admission. The notes record:

Bernadette went walking this afternoon on her own. Was missing when I came to work. She turned up just after 5.00 pm with a man and a woman who had found her by the police station. She was happy but hot, saying she new(sic) she would get lost one day.

As Bernadette's confusion increased community support began to crack. The person who was picking Bernadette up and taking her to church stopped doing this as he and the Minister had decided Bernadette was too disruptive to the congregation when she wandered around during the service. The nursing notes from the DON at the time express disappointment.

I personally do not agree with this 'non-acceptance' of a fellow man of this community, however I could not convince him to accept her.

The notes continue with a typical story of increased confusion, and difficulty in management. In contrast to other stories about horizontal violence that disrupts when life in the nursing home culture becomes stressful, the following extracts from the nursing record show the camaraderie that can exist in managing troublesome behaviour. It also illustrates the way the notes can be used as useful communication and support.

Have tried every morning this week to assist Mrs Miles with shower, she states either 'I will have one before I go out this afternoon' or I had one very early this morning or I've got a nasty cold.

Next day:

Bernadette showered this pm. Clothes in washing machine. I just happened to catch her starting to undress and said 'come on shower time' and she walked in without any bother at all. Lucky this time

Next day:

Thanks Sarah. Good timing.

The wandering, difficulty with showering and wanting to go home continued. Two years after her admission to the hostel the medical notes record Bernadette as agitated and wandering out of the complex. Bernadette's behaviour, in the context of the firm commitment of the nursing home to 'normalisation', caused conflict between the DON and the GP. The doctor
feels that it is time for Bernadette to be moved to a secure setting, but neither
the nursing staff or the relatives feel that it is necessary yet. They say:

*Mrs Miles still (as far as staff has seen) has safe road sense and can
manage a lot of ADL's unassisted. She is not in need of N/H
accommodation at present in my opinion.*

Since the situation is at an impasse, medication is resorted to, but not with
much expectation of success. The two subsequent extracts from the medical
notes reveal some tension of a policy nature.

*As documented in other notes - medication does not generally stop
demented wanderers but lets try Haloperidol 0.5 mg mane.*

Two days later, after another report of agitation and wandering the GP writes
a firm opinion in the notes:

*As predicted, medication has not stopped wandering but made her
unsteady on her feet and dangerous. Stop. She needs to be in a
secure house.*

The nurses feel that the Haloperidol was not given a decent trial. They had
not reported that Bernadette had been unsteady on her feet and so a tense
situation begins to appear. Haloperidol, which can have marked extra
pyramidal effects leading to unsteadiness, is replaced by Melleril 10mg, but
this does not solve any of the difficulties either.

Three weeks later Bernadette falls when she had wandered off into the
township again and fractures her wrist. The Melleril was ceased after this and
the nursing staff then had to deal with an agitated Bernadette, with her wrist in
plaster. The increasing tension between nursing and medical staff shows in the
notes in comments such as the one that directs the nursing staff not to give
Panadeine forte, only Panamax for the pain the nursing staff feel that
Bernadette is expressing. Then it seems that the nurses score a point by
writing a note telling the GP that the plaster of paris has been on for six weeks
and didn't he think it was time to take it off?

The GP rallies by repeating the request for a secure place to be found for
Bernadette. The nursing staff are still indicating that she does not need her
freedom curtailed by being in a locked ward. However, the nursing notes do
show that the DON has discussed the continued wandering with the family
and asked for further involvement from them or alternative accommodation
would have to be found. At this time Bernadette is still attending activities outside the nursing home, and has a reputation as the best performer in the exercise classes.

Bernadette was often getting urinary tract infections or colds and these upset her equilibrium, increasing the periods of unpredictable behaviour where she would wander off. For optimum care what was really needed at this point, as is usually the case, was a full time companion. However, there was no one available or willing to undertake this task and so the alternative, imperfect ways of coping, began to cause conflict all round.

That the DON and GP could not agree about placing Bernadette in a secure environment shows through the notes and is confirmed by Mirabel's memories as her story continues:

_They [the GP and the DON] didn't get on and she wanted Bernadette doped up so she wouldn't go wandering off and the doctor did it and she fell over and broke her arm. So he said 'No. I'm not going to do it. You know you'll have to put her somewhere where she can't get out' and she refused to do it. Well things got really bad. Bernadette got very hostile about it all and her husband was still alive - see her husband's died just now - and he came up in tears. He said 'Oh they're going to put her back' and I said x [quoting the name of an Adelaide psychiatric hospital] ... So my husband, John, came tearing around here you know and she said 'Well you know there's nowhere else for her to go. She's got to be locked up. You can't do anything about it' and so he went and talked to the Head of the Homes but anyhow we were going away that weekend and he came in on the Friday and she [the DON] said to him 'We'll try and swap her with someone at [another local nursing home that did have a policy of locked doors] but we can't do it till Monday'. So John said 'Well that's fair enough. We'll be home on Monday'. This was Friday afternoon and I told him about the plastic bags so I said to my daughter, I said 'Look. Go round and take a suitcase round to Granny to put her clothes in to go to the other nursing home. I don't want her going down there with 10,000 plastic bags._

The story goes on to say that when the daughter went with the suitcases she found that Mrs Miles had been admitted to the local psychiatric hospital. Mirabel felt this had been done behind her back and an arrangement broken. After the move, Bernadette became more confused. After assessment at the psychiatric hospital Bernadette was admitted to another nursing home, which, in Mirabel's words looked 'all right' when they went to see it. She felt that there was a lovely dining room, clean kitchen and was
pleased that they cooked all their food on the premises. However, this nursing home was in the city and so Mirabel was not able to visit often. She says this resulted in the nursing staff taking no interest in her mother-in-law. This is her recollection:

they just put her in bed and doped her up. Took her glasses away, her hearing aid away, her teeth and she was covered in bed sores and she was just like she is now. Just absolutely a mess. You know, in four months she was a vegetable. Anyhow when they got us a bed for her here [Beachdale] and the doctor had gone they did tell us we could bring her back and so we did. ...She came back in September and she’s really you know come on since she came here. I mean they got her up everyday and washed her and dressed her and she sits up for her meals.

This scenario of leaving people in bed so that they ‘turn into vegetables’ is the fear of the people who recount the slippery slope scenario when the withdrawal of food and fluids and restriction of mobilisation is discussed under the rubric of palliative care. But had Bernadette’s dementia already progressed to a point where she was no longer more than a ‘sentient being’? If, at that time, Mirabel had been included in a case conference and her mother-in-law’s condition discussed and care planned for, a comfortable earlier death for Bernadette may have been achieved. Mirabel had a good understanding of palliative care and the concept of the double-effect of drugs. At this point counselling for Mirabel and competent palliative care case-management could have been far more humane than the story that follows. If Mirabel had known of palliative care choices at this earlier point Bernadette may have died within weeks. But what are the moral implications here? Was the situation Mirabel described ‘bad’ nursing? Certainly that is the conclusion Mirabel drew. It would probably be considered so by Standard Monitoring teams or any assessor if they were presented with the facts as she tells it.

We only have Mirabel’s story to make a judgement. When Bernadette returned to Beachdale her bedsores improved to the point of being considered ‘cured’ and she was treated in a way which seemed more ‘humane’ to Mirabel.

At Beachdale Bernadette’s care veered to the other end of the continuum. Rehabilitation, mobilisation and building-up nourishment were all introduced. But, in spite of this early success, within months, as Mirabel indicates, Bernadette’s condition became much worse than was the case at the nursing home when they ‘didn’t care’ for Bernadette.
When Bernadette returned to Beachdale she was non-verbal, incontinent and unable to eat without assistance, her functioning consisting only of mumbles and the ability to chew and swallow, pass urine and defecate. None of this ever changes but because Mirabel sees that Bernadette is dressed and out of bed she is much more content. This is thirteen months before Bernadette dies. It could be said then that the difference between 'bad' nursing and 'good' gerontic nursing in Mirabel’s eyes is the difference between a non-functioning body being left in bed or dressed like a human being and propped up in a chair.

A routine began which involved Mirabel calling into the nursing home every lunch time to give Bernadette her lunch and to make her presence felt to staff so that 'neglect' would not happen again. This continued until Bernadette died.

Mirabel felt happy about the care her mother-in-law was getting at Beachdale as Bernadette was always out of bed, dressed and looking comfortable.

Mirabel expresses the fact that "Bernadette is easy to feed as she has a big mouth". The pressure sores on Bernadette's hips and heels improve. There is a discussion about whether Bernadette had or had not sustained a deep vein thrombosis during her time away at the psychiatric hospital and other nursing home. Eventually it is decided that she has and she is given medication to dissolve the clot.

Within five months Bernadette’s care is becoming a clinical challenge again. The pressure sores are beginning to break down again. The RN reports that:

she is grimacing at night - there is a question about whether she needs a narcotic - has been on Haloperidol 5 mg and Panamax and it just makes no difference. PCW is giving her the Panamax and tells me that she usually likes to give them to her before we they start [doing the dressing] but it is not always possible.

Once again there is a great difficulty in sorting out treatment for Bernadette. The GP writes in the medical notes 'does she or does she not need a bloody sedative?' after what seems like mixed messages from nurses about Bernadette’s level of apathy compared to agitation. Haloperidol is ordered.

The careworkers and RNs all discuss the fact that Bernadette often yells out when she is moved, or when people get near her. They begin to raise queries about the cause. The nursing notes document treatment and preventative
measures for the areas of her body that are beginning to break down. A lifter
has to be used to assist Bernadette into and out of bed.

About four months before her death Bernadette's condition begins to get worse.

She screams loudly as she is lifted out of bed. Sheepskins are put under her
heels as the sore on her foot is becoming deeper. There are signs of
peripheral shutdown in her extremities. Madge knits her some special
'bootees' to keep her feet warm and to assist in relieving the pressure.

At this time care-staff are still getting Bernadette out of bed every day, making sure
her hair is cut and washed and recording her awareness with notes such as 'she
enjoyed seeing her great grandchildren today'.

A month later the staff feel that she is deteriorating rapidly now. It is reported
that:

*she is going down - she is losing weight and she won't heal. Now
slumps in the chair rather than sitting straight.*

Another month later the dilemmas associated with a lingering death are
beginning to show in the following remark:

*Bit hard with Bernadette to judge how she is. She seems to be in pain
but then again she screams before you have ever touched her, seems
she's afraid - she has been more sleepy in last week - she tires a lot
quicker now, she is still eating pretty well - still has the odd
c conversation does not really make sense. Lucid sometimes. All of a
sudden she will come out with something quite lucid - I feel surprised.
It does not happen much now.*

This was the beginning of a 12 weeks of nightmare for all involved.

After discussion with the nurses the GP writes 'I concur that Bernadette is for
palliative care'. By now Mrs Miles screams at the top of her voice if anyone
even goes into her room. The lifter is used to enable her to be washed as she
is over the safety weight and now is only able to be nursed in bed. Her room
smells awful and so does her bed. By now, part of her foot has a large
necrotic area on it and she has a large bedsore on her buttocks. These areas
are variously referred to as 'pressure areas', 'bedsores' or 'pressure sores'. The
terms used reflect how they are spoken about or recorded in the notes in
order to retain as much of the feeling of the culture as possible. As the staff
are preparing to do the dressings there is a discussion about Bernadette's
comfort level, in relation to the terrible screaming. IntraSite gel is being used to dress her foot which is also now beginning to break down badly. Fleur reports that the hip was doing well until Saturday - but it has started to deteriorate last week. She has decided that she will put Bernadette on Panamx four-hourly to see if it makes any difference to her screaming and if not she will discuss the use of morphine syrup with the GP.

The RNs discuss the fact that Mirabel had raised some objections to what she saw as the overuse of analgesia, but the staff feel that when Mirabel comes in around lunch times or early afternoons, Bernadette is in her quieter moments. The debate amongst the staff about Bernadette being over-sedated from the combination of Melleril and Panamx is the beginning of an ongoing dilemma where people end up taking polarised attitudinal positions about medication.

Bernadette had been exhibiting some flaccidity in her face and a reduced level of consciousness. As some of this resolved after these drugs were ceased the 'over-sedated' camp on staff felt that this proved their case. This over-sedation is a sensitive issue in aged care as commentators have been very critical about old people being over-sedated, suggesting this is used as a form of restraint or to make life easier for the carers rather than being in the best interests of the resident.

However the screaming and agitation returned and Bernadette was put back onto these drugs for a few days until Morphine syrup was ordered after repeated request from the nursing staff. However debates about pain versus agitation, the meaning of pain, and the level of sedation continued to rage.

Two months later Mrs Miles is reported as alert ...

but still in pain although she is now receiving a subcutaneous infusion of morphine. Her sores are deep and certainly look painful. Bernadette is still screaming in a way inconsistent with generally acknowledged cause-and-effect rationale. Staff report that when Mirabel had visited over the weekend she had asked 'why can't she have a big dose?', meaning a big dose of morphine. In response the RN on duty had called in the duty GP and got a new order. Tca time conversation records that when Bernadette's GP found out about the locum being called and increasing the dose of morphia he is 'furious - he wants to be in charge of pain management'. So it is decided that the question of Bernadette's ongoing care must be discussed at an RN
meeting. However what is going to happen at that meeting seems to be a forgone conclusion. Fleur reports

I know Dr Prendergast will make it clear that he has to be consulted re pain management. Dr Davies increased her morphine and he did not want to.

A difference of opinion about treatment is beginning to appear between nursing staff with a view that Fleur is wanting to conspire with Mirabel and increase the doses of morphine, against Dr Prendergast's wishes. Fleur is convinced that Bernadette is in pain. Ava, who is a friend of Fleur's, has a different opinion and discusses it dispassionately, clearly acknowledging that it is only a different point of view.

I felt she [Bernadette] was displaying her frustration and fears - her yelling did not correspond to what you would interpret as pain so I always thought her screaming was part of her personality. Fleur was always treating her as if she was in pain with Paradex and Haloperidol which did not make an ounce of difference in pain. Only Fleur and one other relieving staff, probably on instructions from Fleur, would give this medication. At that time she [Bernadette] would scream if you got near her but after that she would settle. She at that time would verbalise - she was not bed fast she was in a wheelchair and if you asked her she would say yes or no and if she said yes I would give her Panamax. I would ask the care workers how she was - yesterday they told me she was restless, the site was stuffed [the area where the syringe driver needle is inserted - meaning that the site was swollen because the medication was diffusing into surrounding tissue] - I changed the site and she settled down in half an hour. I feel as if my hands are tied behind my back by the system - she is rotting away - what a way to go. I am not happy about that but what can you do?

In my position as RN I feel I have to keep her as comfortable as possible so I always see her when I go into that house. I always boost it [the syringe driver] whenever I go into the room. I counsel the daughter-in-law She comes in and says over Mrs Miles 'Oh she is still here - what can we do? You just have to reassure her that it is out of everyone's hands and we are keeping her comfortable.

A week has now passed and both the sore on Mrs Miles's buttocks and on her foot have broken down considerably (see photographs 4). Eventually a meeting is called and Dr Prendergast complains that there are conflicting stories from RNs so Mrs Miles's morphine dose goes up and down like a yo-yo. He says the doctors get different opinions about agitation and other possible indications of pain. The DON then tries an approach where
consultation about management can take place with all the staff and Mirabel. The GP's answer is:

*Miles's family want to bump her off - it is illegal it does not matter how compassionate we want to be. The only reason for morphine will be pain.*

There is then a discussion about boosting the syringe driver. All the RNs agree that any intervention with Bernadette needs to be preceded with a bolus dose of morphine, administered via a boost from the syringe driver. The discussion goes round and round about pain versus sedation, discomfort versus apprehension. Prendergast starts getting very firm and says:

*...apprehension is NOT PAIN - apprehension and fear is to be dealt with by Haloperidol not Morphine*

One nurse replies to this *we know she is dying. So she must go with dignity.*

*Does it matter if it is pain and / or agitation?* There is no clear reply to this. Everyone tries to rescue the tense situation by all talking at once and there is no clear leader to take control. Prendergast's views are quite obviously going to prevail as was predicted by the staff member before the meeting started. All the RNs are talking and interrupting each other in what seems like their passion to have their say. Comments directed at the GP range between:

*She's on a lower dose today and just as comfortable:*

*I would hate to err on the side that it is her dementia not pain - she used to say I will scream if you do that to me;*

*Give her the benefit of the doubt - I would want cover I hope there is someone advocating for me;*

*She's getting 5mg of Haloperidol. Why don't we trial an increase of Haloperidol rather than the morphia?;*

*That leg is horrendous. If you cannot increase their life expectancy then surely we should make her comfortable.*

On reviewing this meeting the GP said that at the time he expressed the view that the GPs were intent on treating the patient's pain, not the pain the nurses were experiencing in watching what they viewed as intense suffering. This single-minded attitude may reflect the essence of the Hippocratic Oath but is not necessarily useful in sorting out the complex dilemmas presented by a case such as Bernadette Miles.

Returning to the description of the meeting, we have reached a point where one RN prevails by saying that she thinks Bernadette 'Is still here' [only]
because the syringe driver was leaking and she was getting less morphine than was being prescribed. The same RN maintains that when she debrides Bernadette's dead flesh from her foot she does not scream, but that when she is cleaning new area screaming does occur. This is the first piece of factual information given to the meeting which shows a direct relation between feeling and pain, but no-one takes any notice. The 'all talking together' just continues in a cacophony of voices. Krystina returns to the question of Bernadette's apprehension and everyone stops for a moment and listens to her. Krystina suggests that Bernadette may not have dealt with her life long problems. One RN replies - can we release her apprehension so that her last breath is not taken with that apprehension? Again, there is no follow up to this and it does not defuse the situation. Another RN turns to Prendergast again and says 'It is not a nice death she is going through.' Prendergast gets angry and replies 'Yes I know but I am not convinced it is pain'. The RN then spits out a reply in a tone of disgust 'to stop her being apprehensive you would have to give her enough Haloperidol to kill her.'

The same response to the tension between an RN and the doctor occurs again. All the RNs begin to speak at once:

Who is in pain here? Isn't it us? ...
I feel awful when I go into that room.
They are dying. Does it make any difference - in acute care they give Pethidine every four hours on the dot.
Do we need to do the dressing every day? Do we need to turn her every two hours? Is she religious? Can someone talk to her, holding her hand?
Is it spiritual? Are we treating the wrong thing?
What religion is she? If they [the priest] came every couple of days it might send her off more easily.

Sheila then picks up a theme from this outburst and queries whether two hourly turning is necessary. Prendergast's view is that Bernadette is 'breaking down' and the staff might be doing more harm than good turning her.

The nurses express discomfort with this idea suggesting that if they don't turn her, under Prendergast's preferred regime, it would be 'neglect'. Prendergast 's view is 'what does it matter if her hip breaks down?' Small wonder that there is some sign of cognitive dissonance from nurses at this point. The GP will not budge on the principles of medical care but suggests to the nurses that they
can be flexible about their modus operandi. Again one RN tries to smooth things over, suggesting a compromise.

*It might help by reducing the number of interventions. If you go in and sit and hold her hand not always go in and turn her she might get better but can we leave the foot?*

Prendergast now gets firm and says *'Leave it for ever'* His tone of voice clearly implies irritation with the discussion going on so long and that the matter is closed. There is no more discussion about Mrs Miles and no decisions have been made. So the nurses are left to deal with a resident, as some of them see it *in pain; a foot 'that is dropping off';* and a doctor with no answers but who insists on complete control of medication levels according to his values and beliefs. By now Mrs Miles's body is breaking down and her foot is getting much worse (see photograph 5)

Mirabel sees the situation this way:

... she is in a lot of pain. ... she's got big ulcers on her feet and on her hips. Her skin is all breaking down and it's just too painful for her to shower or dress so she's been in bed all this week and I don't know whether she's dying or she isn't. The doctor came in I think Friday, and he said *'Her heart's very strong and she's making lots of noise in her throat' which they thought might be pneumonia but - no - her lungs are clear. So really I don't know but they all seem to think you know within a couple of weeks she'll be gone and it's just so pitiful and so traumatic for me to come in and see her like this you know. ...*

The tension and difficulties surrounding the care of Mrs Miles continue. Three days after the RN meeting Fleur talks about Bernadette's present condition.

*Today she is restless and showing signs of distress the best she can - she is not screaming, she is too weak to do that. She is showing signs the best way she can. She is still eating and sleeping the rest of time*

Fleur rang the GP to ask for an increased dose of morphine and an order for a stat dose before dressings are done as the constant boosting of the syringe driver inflames the site. The GP queried how often the dressings were done. Fleur reports that they are being done every other day. The GP asks if Bernadette could be turned less often, Fleur asked how often he would suggest. She reports that he did not answer so she suggested to him that it would be the case for anyone that *'if you just lie there not moving then you*
will get cramps and that will give you pain and discomfort'. A phone order is
given for stat morphia to be given before dressings. Fleur muses about the
possibility of judging the wording about the actual status of the order. Fleur
wants to write PRN but the doctor actually said 'for dressings'. She must, and
does, write that in the notes even though she understands that she has not
achieved what she wanted, that is to have the opportunity for the nurses to
close pain as they judge it. She says, referring to staff on the next shift, 'if
they want more [morphia] they will have to ring him'. The GP does not come
in to confirm the phone order, a locum writes up another order three days
later, increasing the stat dose from 20mg IM to 30 mg IM, but does not write
PRN, only that morphia is to be given 'prior to dressings'. When the GP writes
in the notes again two days after this he comments that he has observed
Bernadette while being turned, that the screaming is agitation, not pain, and
that Haloperidol is to be increased.

Another three days go by and still Bernadette is 'hanging on" as everyone
sees it. In a conversation with an RN I am told that Bernadette is:

much the same - night staff said she was not so well - that she was
Cheyne-Stoking more . They think it can't be long now. When I went
in at 7.30 she was bright and alert .

J: Did she speak?

RN: No - she acknowledged me with her eyes. I think she is still
eating a little bit. Dressing due tomorrow. Madge helps and she
likes to do it after she has had her morning tea.

The wound on the foot is breaking down quite quickly now with the necrotic
area increasing in size (see photograph 6).

During the next 12 days the staff struggled to keep Mrs Miles as pain-free as they
could within the limits imposed on them. To the staff, keeping Bernadette clean and
doing the dressings on her hip and foot was their way of expressing that she was still a
person and deserved to be cared for up to the last. Twelve days after the last report
the RN says:

Mrs Miles has declined a lot - greyer, less aware. Cheyne Stoking
more - stiff arms and legs - has had some catatonic reactions - maybe
due to the increased Haloperidol - first time it was threatening- or
staff were surprised when she threw her arms up - but now ok.

On Thursday Mirabel brought in Jane [relative]: they stood at the
end of the bed as we were washing Bernadette. They asked if they
should go but we said no it was OK - we weren't dressing her foot or
anything. They asked do you do this every day - Jane said there is no dignity in this existence. Do you have to put her through this? Look at that hip. Why does she have to go through this? Mavis [PCW] said it is only for a short while and then it is over. We hope she feels better and fresher for it.

Mavis is actually disturbed by this encounter and explains that the belief or the hope that Bernadette feels better and fresher for her wash is their way of 'justifying' what they are doing. She says that Madge had brought in a pot pourri container and air freshener because the smell of the foot rotting was 'getting to Mirabel' which it certainly was. Mirabel says the smell is:

... just rotting flesh you know. I mean when I go home my clothes stink of it, or I imagine they stink of it, I don't know and I've got it up my nose you know. It takes me two or three hours to get the smell away from me. You know I brought a room freshener in, I brought flowers in. I mean it overrides everything and yesterday the flies. You know those humid days, the flies were just queuing up on her roof screen to get in and God knows how they get in but you know there was about 12. I killed four myself. So the smell must go outside and draw them to the screen you know. And I thought that was revolting. Sitting there listening to them buzzing up and down the windows. I mean the screens fit, the screens on the doors. I don't know how the flies get in but I suppose other RNs are walking in and out and letting them in I don't know really

Mirabel also indicated that being alone in the room with Bernadette during this time was very difficult for her. She acutely felt the disadvantages of the privacy aspect of the SRV policy.

Mavis had also rung Mirabel and asked if the nursing home could get a minister in. Mirabel had replied that she had been praying and did not believe the minister could do more. She had not clearly answered the question. So Mavis had rung the church - they got an elder from the church as the minister was on holiday. Mavis reported that she and another RN who had strong church affiliations 'felt better for it'. Mirabel made no objection to this behaviour on the part of the nursing staff.

Another three days pass. While Mrs Miles's foot is being dressed the staff act in ways which demonstrate the dilemmas they face having to confront the suffering Bernadette is going through before she dies. They give her 'permission' to die, they express the view that they are 'thinking for her', by saying 'let go'. Paradoxically, again, their actions belie this sentiment. When
she becomes distressed they also show her how to stay alive by telling her when and how to breathe. This is the scene during one change of dressing:

Dressings have been prepared in a 'normalised' manner, just the materials required collected and brought to the bedside as one would at home. On the way towards the room Sheila had said she was dreading doing the dressing. She says she is going to soak the foot because the pouring action will cause less pain and they just want to clean it up. Bernadette is making jerking movements. Madge and Sheila talk to her. *It is cruel isn't it?* says Sheila Smell pungent - all of us are wearing masks as the smell is 'not nice' although Sheila says the *Standard Monitors would not like it* - which means that wearing masks is not part of the normalisation philosophy. The wound is treated with Betadine strips and lots of combine. Sheila throws away the crepe bandage saying - (to no-one in particular) *Sorry - I am going to throw this away ; and then to me - We stopped using IntraSite because it was not cost-effective. Bernadette has a fit - the staff stop what they are doing and say *take a breath Bernadette, breath, Let go - its ok - breathe slowly* - talking in soft and gentle voices. They then reposition Bernadette and Madge shows concern about marks on Bernadette's back which occur *just from using the blue straps*, - that is the pressure from the straps used to assist in lifting Bernadette round the bed. Bernadette's back and both hips have sores on them, OpSites are changed on all three. As they change the Kylie Sheila holds onto Bernadette, saying *come and give me a hug - its me Bernadette - there you are a nice cuddle*. Sheila strokes Bernadette's face and says *almost eye contact there*. Bernadette's just making small grunts now. Bernadette has another fit. Staff stop what they are doing and calm her down again *try and breathe calm down, calm down*. When they finish they put the cot side up, saying that this is *In case she brings her knee over* then do a mouth toilet. *You like it!* they say to Bernadette as she sucks on the cotton bud. Sheila says that Bernadette is still taking sips of fluid but can only manage this if they are dripped into her mouth. The staff use a syringe to achieve this. Sheila turns the music on as she leaves the room.

The staff tell me that *it is not allowed* to give water with a syringe, but the fact that Bernadette sucks on the cotton bud makes them feel that she is thirsty, and therefore their actions are justified.

Both the sore on Bernadette's hip and foot have got much worse.

Mirabel's feelings at this moment are that Bernadette is:
... just a grieving corpse really. And I mean even her breathing is very staggered. I mean several times I have to look at her to make sure she's not dead because she stopped breathing for quite long periods and she sort of takes three or four breaths and then off she goes again. ... I don't know anything about death really and what it looks like when it comes around, you know the dead. I mean anybody else would have had pneumonia laying on their back for seven weeks. wouldn't they?

Three days later Bernadette died. The actual death was also fraught with tension and disappointments.

Mirabel had gone into the ward to see Bernadette without the staff knowing. Bernadette vomited a little while Mirabel was there and a moment afterwards took her last breath. Mirabel realised that Bernadette had died but could not find staff. There was no-one in the dementia house at that moment. Mirabel walked outside and could see the staff having tea in the garden. The staff report that 'by the time she [Mirabel] came to the lattice doors she was a bit hyped up. We were having our morning tea out there'. Carol went with Mirabel who said 'I think she has gone'. Both Fleur and Carol went into Bernadette's room. Mirabel hugged Fleur at the bedside. As Fleur reports it 'lots of hugs later' she saw Mirabel out to the car and 'we hugged again'. Fleur says it was a shame they were not there to console Mirabel straight away.

Mirabel was very glad that she was there when Bernadette actually died. The staff report that Mirabel was angry about being alone at the death, but did not take it out on the staff, 'she took it out on the funeral lady instead'. Mirabel had seen Bernadettefitting in the last week. Fleur feels Mirabel was angry because of the attitude of the rest of the family. She is hurt that the rest of the family has not been involved. Fleur feels that Mirabel is saying 'Where is there somebody for me?' Fleur tried to raise that with Mirabel but she did not want to talk about it. Madge indicates that the death is a great relief for her and Elizabeth, the regular staff on the unit.

Since the funeral was held in the city it was too far for the staff to attend. I attended as representative for them and as a mark of respect for Bernadette and Mirabel.

Fleur was concerned that the terrible death process Bernadette had gone through would leave Mirabel upset. So she rang Mirabel 'to see how she was going'. She reports that Mirabel was really pleased to get the call and that she was pleased to have their thoughts with her at the funeral. Fleur considers that Mirabel was suffering from reactive depression; she was not eating, not
sleeping, not wanting to mix, wanting to be left alone. Fleur suggested to Mirabel that she was depressed and she agreed. Fleur says she thought taking some Vitamin B might assist because Mirabel smokes and has an odd drink and Mirabel agreed to that. Fleur says she will ring Mirabel again - she has done it for other people who were grieving in the past. ‘It seems a natural thing to do.’

Mirabel stayed angry about this death and, a few weeks later, talked about how she felt, comparing Bernadette’s death with the death of Bernadette’s husband, her father-in-law, who she nursed at home until he died.

_I mean there was nothing that I could do for that woman. I mean you certainly couldn’t go and visit her and sit and talk because she couldn’t talk. She didn’t know you and she talked rubbish anyhow. The only thing I could possibly do for that woman was go and feed her her lunch everyday. Whereas he you know he went ... I had a bed there [indicating a spot under the window in a sitting room of her house] and .... he could see into the streets and the TV . All the neighbours came in to see him, all our friends, all our relations. You know he was still part of our family and that’s really what hurt me the most. I was so terrified that she was going to die on her own and I think that’s criminal ..._

Mirabel went on to indicate that she felt the staff had done their best during Bernadette’s time in the home but that she was ‘just one of fifteen’, so they could only do a certain amount. Mirabel had ended up feeling she had no control and no support; she was just part of the system.

She, like all the staff, was relieved at Bernadette’s death.

As the long drawn out death of Bernadette had had such an impact on the staff of the dementia house the DON obtained permission for the room to be kept empty for four days. A week later the staff said they had ‘managed to cut Bernadette off.’ The new resident’s furniture changed the appearance of the room and that had helped.

Bernadette’s path to death was horrible, for her and for everyone around her. It would be easy to be overwhelmed by the emotions engendered by the story of her last months, and easy too to be drawn into taking sides with this or that group. But that would be to miss the point entirely.

It is particularly important to recognise that the predicament surrounding this death was not the result of errors of individual judgement or indifference on anyone’s part.
Bernadette's story is the product of a policy vacuum. This is not to say that ideas and philosophies did not play an important part. 'Normalisation' was very influential in this case as, it could be surmised, were private values and legal considerations. A confluence of various ideas, values and practices does not, however, amount to a policy; nor, as we have seen, is it adequate to provide a common language, accepted protocols and a clear locus of accountability. A thorough-going re-examination of the circumstances which produced the kind of death Bernadette had is clearly warranted.
Mrs Violet Drake

Alone, after more than half a century of intimacy

- 84 years old at time of death
- In cottages for 11 months, hostel for 2 months & nursing home for 5 months
- Cataract operation at acute hospital.
- Incontinent before admission to cottages
- 10 courses of antibiotics during time in hostel & nursing home.
- 13 falls recorded on incident reports.

Violet Drake was one of nine children. Two of her brothers were killed in the first week of World War I. This is part of the information she shared with staff when she first came to the Beachdale complex early in 1991. Violet remembers that she loved the shop work she did as a young girl because of all the pretty things she sold. She loved dancing and persuaded Bill, who she eventually married, to get to like it too. In return she shared his favourite pastime, fishing. The staff taking this history record that:

Violet is totally supportive of Bill. They spend a great deal of time enjoying one another's company and she seems to be settling into the cottage reasonably well. I'm sure she would be quite happy wherever Bill was.

This comment from the staff at that time sets the scene for the most painful part of this death, dealing with a life partner's disintegration. Bill had to cope with situations such as seeing Violet's hallucinations acted out in public through to the agony of watching the painful slow decay of her body.

Bill and Violet had moved into the supportive environment of Beachdale because of Violet's increasing frailty due to arthritis and dementia. They moved into a small cottage unit. At the time of admission Violet was often incontinent of urine, needed the assistance of a walking frame and was moderately demented. With the occasional help of the careworker in the cottages Bill took care of Violet and assisted her with her daily hygiene, nourishment, orientation and the effects of increasing neurological damage.

In spite of episodes of faecal smearing, increasing confusion and hallucinations the notes indicate that Bill remained constant in his efforts to care for Violet and quickly developed a relationship with the staff to help him cope. It is also clear that the staff
became attached to both of them very quickly. Faecal smearing (scatolilia) is considered to be a sign of constipation and according to Jacques (1992, p167) is a 'medical problem'. However, there is no documentation to suggest that the episodes of faecal smearing were discussed as a medical matter at all, not even referred to the Registered Nurse. It was accepted, however distressing, as part of Violet's dementing behaviour.

Many entries in the notes had the flavour of the following extracts. These notes, written in an informal and conversational style by unqualified carers in the cottages, serve as information for the next carer. There is a remarkable consistency in style of writing, although the various entries are written by different staff members.

*Violent says she called for assistance when she spilt water but no-one answered. ... Violet is obviously devoted to Bill. They seem to have a wonderful relationship and enjoy each other's company.*

*Violet obviously confused today. Said Bill and his mates would go to Adelaide. Bill gestured to me that Violet was confused. He said that she got up quite a few times to go to the toilet thru (sic) night but Violet doesn't want to remember this. Urine on the carpet next to Violet's bed. Bill said he cleaned it up but PCW will treat with soda water this morning.*

*Violet is in a foul mood this morning. When I went to take her mat to be exchanged for a clean one, she told me she's sick of me shifting it all the time and 'leave the bloody thing alone'. This is so out of character for Violet - even though she gets cross, I've never heard her swear before. I asked her if her knees were aching as this often causes her moods but she said no, they were ok.*

Violet's undiagnosed dementing illness progressed to the point where she was often confused about who Bill was, his motives and feelings about her, and his behaviour. Constant urinary infections contributed to swings in the level of her confusion as is evidenced in the multiple nursing entries describing her perplexing behaviour. It is difficult to know if the nurses were hanging on to a perception that when Violet was positive about Bill it meant she was 'well' because that had some medically proven basis, for example, no bodily infection, or whether Violet's confusion was consistent and they were making these inferences for Bill's sake.

Throughout the notes many references are made to Bill and Violet's devotion to each other. If there was any evidence from Violet that this was not the case then it was noted by the nurses that she was very confused. For example one entry reads:
She's cronky (sic) with me because she says I put things away and she can never find them. Bill can't do anything right today - she says she should never have married him. Quite often this morning her conversation doesn't make sense.

Six months after moving into the cottages Violet had a lens implant for deteriorating eyesight due to bilateral cataracts. Violet continued to fall and her confusion increased. In February 1992 Bill and Violet moved into a hostel room together as the strain of caring for Violet was getting too difficult for Bill. Much of their privacy was now stripped away from them.

Nurses, for example, would now help Violet dress and undress. There is a lot of concern shown by staff about Violet's weight loss and many references to her being 'skin and bone'. Violet is also having increasing difficulty with walking and so nurses arrange for her to have a wheelchair.

Rather than this seeming to be a further life deprivation it was received with much satisfaction by Mrs Drake. The notes read:

_Mrs Drake is as pleased as punch about having a wheelchair. She hasn't stopped smiling, wanted to go out onto the front verandah after lunch, says it's a big relief as it had become very painful even to take a few steps and was beginning to dread the walk to the dining room._

However this is the only bright light in the trajectory of losses. Within a month of Violet being in the hostel nurses requested Violet and Bill's daughter to fill in a restraint form because the staff were getting concerned about her falls and subsequent skin tears. It seems that it was perceived by the nursing staff that this further curtailing of Violet's liberty would be too sensitive to discuss with Bill.

The problems arising from the skin tears are outlined time and time again in the short-term nursing care plan. One typical short-term goal entry reads 'to heal lesions on bony prominence of spine'. The lesions often started because of a skin tear due to falls but would then they would not heal. In reviewing this problem as not being resolved the senior registered nurse writes:

_Violet should be allowed freedom and dignity of risk. Reinforcement has been given to Mr Drake to ring for assistance with Violet at all times as he is half the risk problem when assisting with Violet._

It seems clear that Bill is trying to hang onto as much privacy and life together as is possible and keep life as 'normal' for them both as possible. Although the nurses are
sympathetic to this it is now encroaching on physical care which they see as their care domain. Violet's increasingly poor skin integrity begins to dominate the story. Her incontinence also becomes a focus of attention as this is complicating her care. A decision is made to move Violet to the nursing home. It is clear that Bill and the nurses have agreed this together in an informal family way.

After 60 years of married life both Violet and Bill are now apart, each alone. Violet is put in a bed with rails as it is felt that she would be 'safer with them ... being alone at night now and prone to falls' Bill stays in the hostel unit.

By now Violet requires help with every part of her life, she needs to be washed, dressed and have food put into her mouth for her. She is still able to communicate but is confused all the time now. My field notes record one representative occasion:

*Mrs Drake's room is opposite the kitchen. She is saying she is so hungry she wants anything to eat - anything - she looks very, very thin. Her room smells of urine. Jill tells me that Violet goes in to spasms; sometimes she won't talk or help herself. Sometimes she is like this where she will talk and help herself. Jill takes her in some toast.*

Violet has two OpSite patches on her sacral area and sores all around and the checks of her bottom are just hanging folds of emaciated skin. The nurses both comment on the awful bruises on her legs. The nurses talk about her 'going down'. One of the nurses expresses surprise at seeing Violet 'still there' on her return from holiday. The GP's notes indicate that there is a pressure sore which 'is unlikely to heal in the short term and the goals of treatment should be to maintain patient comfort'. Morphine syrup is ordered for Violet's pain arising from these wounds.

Violet's general condition maintains a pattern of inconsistency. The nursing staff describe this in various ways, one staff member saying that in the last week:

... I thought she would not last but she has picked up again and seems to be stable. I thought it might be the morphine putting her down. Don't know what made her pick up again - yesterday when Fleur was doing her dressing she [Mrs Drake] said 'how much longer?'. We did not know if this related to the dressing or how much longer to live. She's not so talkative any more but still has lucid moments. When she is like that it is like a candle fluttering - it is like a spurt from a dying candle that gets a bit more oxygen.
The staff then go on to talk about Bill - he gets 'very emotional, teary - comes out here [into the kitchen where staff write up notes] for half an hour yesterday'. In the way this story is portrayed it is clear that the staff think this is acceptable behaviour on Bill's part and it is their job to listen, but there is also an air of panic about how they will manage if it goes on because while they are spending the half an hour with Bill their routine work does not get done. Jill goes on to say 'it was bedlam all day yesterday'.

When Bill was with Violet he still talked to her as if she could understand and share his life. On one occasion he told her he was going to the doctor for his sore back. He interpreted a garbled reply from Violet to mean she hoped he was OK and replied that he would be. From my perspective Mrs Drake was mumbling and whimpering incoherently, but Mr Drake, although tearful, seemed to want to make sense of her noises. He answered her noises by querying if she was asking when their daughter would come down and asking how he was. In the same breath he reassuringly answered the questions he had supplied by saying 'yes she was' and 'I am OK'. He then began kissing her, seeming as if he just wanted to come back to give her one more each time he was going to stop.

In spite of this affecting tender display, on the way out of the room Mr Drake turned to me and said 'I hope Mum does not last too long in a way - the girls look after her and all that but that is no good for my position'.

The comment seemed to acknowledge the quality of nursing care his wife was receiving but reveal his distress at seeing her so helpless and beyond reach, and his own frustration at the loss of a partner with whom to share things. Up to the day she died he was carefully explaining to her everything he was going to do. At the same time he expressed his difficulty in being settled in his own life 'while he was waiting'. It was as if Bill saw the very quality of care Violet was receiving as exacerbating the different forms of distress they were both experiencing.

Staff continue to view Bill and Violet as parts of a single whole, in symbiosis. But they couldn't fail to see that this relationship was breaking down painfully. They discuss the fact that 'Bill does not come over as much now - he gets tears in his eyes when he asks how she is going - its only natural - he's devoted'.

By now Violet was totally bedbound and when showering her Jill and Beris treat her like a fragile piece of china. At the end of the shower Jill and Beris spray perfume on Violet. The perfume is Chanel No. 5. 'Chanel No 5, your
favourite' they say to her. They comb her hair and dress her in a clean nightdress - as they are doing this they say 'I'm sorry Violet, I'm trying not to hurt you - we will be finished in a couple of minutes' and to each other, 'Oh its just awful'.

Jill expresses her feelings more clearly when she later explains that:

_I really feel very sad for her, my heart bleeds for her. This is where I would have to say I believe in euthanasia because she has got virtually nothing - no quality of life. She is in a lot of pain, she is suffering. I do not like doing the two hourly turns because of the pain ... she's getting regular morphine but I think she needs more ... Her quality of life changed when her largest pressure area broke down which would have to be a couple of months ago now._

_I think every one thinks it will be a relief when she goes. She's not talking at all. I used to run my fingers through her hair and she would say that is lovely, keep doing it. Now it seems like an annoyance because of the pain._

Violet is still eating and drinking although her food intake had started to decrease in the last week. Most of the pain she is experiencing is perceived to come from a bad pressure sore on her hip, but she is so frail her skin has broken down in almost every part of her body. Her skin seemed to come off in the nurses' hands, literally. Photographs 7 and 8 show the condition of Mrs Drake's body eight days before she died. The staff debated and struggled with their own consciousness about whether to leave Violet alone so as not to tear her skin any more, or to keep turning her to prevent further breakdowns. In discussing the efficacy or otherwise of the of this turning, Jill finishes the conversation with a firm statement.

_She is still a human - it has a lot to do with humanity - she is unable to do it herself and therefore we feel we have to take our own discretion for her needs._

Confusing the issue is the fact that when Adele puts forward the view that she thinks Violet now wants to be left alone, Jill agrees. Adele's belief came from her own experiences of having children in a natural way and she remembers that she wanted peace, no interruptions or noise. She says it was if she needed internal concentration to cope with the pain and she thinks Mrs Drake is the same. Although Jill concurs and says she often feels Violet wants to be left alone, that some caring routines seem to be intruding on her and perhaps contributing to her pain, she is still committed to 'doing the turns'.
EIGHT DAYS BEFORE DEATH

SKIN TEARING AS THE SHOWER WATER TOUCHES IT
These were kept up every two hours until Violet died.

The next phase of this death that was hard to manage was assisting Bill to cope with Violet not being able to respond at all.

Bill had come into the kitchen calling out 'Jilly, Jilly are you there?' and expressed his concern about Violet's condition because she was not 'answering him'. Jill assured him that Violet could still hear him. However she feels frustrated and helpless in assisting Bill as she is aware that he does not know what to do when he goes into see Violet now. In her view:

*he probably wants to give her a big cuddle or have a chat but he just can't - It's sad for him.*

Violet continued to take nourishment up to the day she died. Dressings were continued, the OpSites were all replaced the day before she died, and painful two-hourly turns went on and on. The nursing note on Violet's last day of life reads:

*Only sips of fluid today. Resting comfortably between 2/24 turns. This is when she is in pain, being repositioned.*

Violet died in her sleep during the night and it was noted in the nursing notes that when the family were notified they 'have taken it well and seem happy that their Mother/wife is at peace'.

It seems reasonable to say from the evidence of this case that, once again, the introduction of good palliative care measures could have saved both Bill and Violet those last weeks of separation and agony. As in the previous case studies, it is as if we are watching people - the resident, the relatives, the staff themselves - suffer as a result of an implacable force beyond human understanding and intervention. In such situations it is easy to believe that a person may distinguish themselves by the grace, compassion and control they display in the face of the suffering; but that beyond showing courage in adversity there is nothing which can be done. Human agency is not absent in any of our studies; but it is pitifully circumscribed by the framework of unarticulated and ill-fitting assumptions within which the events unfold.
Mrs Mimi Walker

Is there dignity in risk when you can’t understand how to walk anymore?

- 87 years old at time of death
- In hostel for 27 months & in nursing home for 24 months
- 2 transfers to acute hospital
- Incontinent before admission to nursing home.
- 6 courses of antibiotics during time in nursing home.
- 54 falls recorded on incident reports.

Lillian Walker was a farm girl, spending her teenage years lifting rocks and carting hay. After she married one of the many boys who courted her because, as she told it, 'there weren't many girls in the Mallee in those days', she and her new husband moved as her husband got a job on the ferry which ran between the mainland and the island which became their home. Lillian was closely involved with the local community and that contact continued until she became frail and unsure in her mobility, so much so that she was admitted to Beachdale’s hostel. After a CVA and a fall she was admitted to the local hospital, but was able to return to hostel living for a couple of years. She continued to have episodes of dizziness and suffered from high blood pressure. After another CVA and hospitalisation she was admitted to the nursing home. She was diagnosed as suffering from post-CVA depression and agitation. The first piece of information the staff volunteered to me about Mrs Walker was that she 'had tried to overdose. She knew what was happening to her'. This information was given with an air of defeat. It was clear that staff had no choice but to ignore this cry of independence in wanting to engineer her own death and care for Mrs Walker as the system ordered them to.

Mrs Walker had been in the nursing home for 16 months before she was included in the study. At that point the first observation is recorded mid-morning:

Mrs Walker is lying in bed with bed-rails up and there is no response at all to us entering the room or Flur saying Hullo. I record that her 'face is a mass of bruises'. She is, as the staff describe it, 'burbly in the throat' but I am told 'her chest is clear'. The staff think that Mrs Walker is dying and discuss this calmly and dispassionately.

The GP is not called in but a note is left for him to be asked to see Mrs Walker during the next visit. The nursing plan is amended to a typical medical model of care, chest exercises, encourage fluids, sit upright. This
progresses to the ordering and administration of antibiotics and Ventolin. Mr Walker visits Lillian every night to help her eat her evening meal. She is suctioned on occasion and given Panadol ‘for restlessness? due to apparent pain’. Mrs Walker is still being lifted out of bed, showered and sat in the general areas during the day. This acute condition gradually resolves although she constantly seems to have a ‘wet chest’ up to the time she dies. The staff stop talking about her dying.

Due to her restlessness Mrs Walker continually tries to get out of her chair. The SRV policy is not to restrain residents, so Mrs Walker keeps falling over and has constant skin tears and bruises. One entry in the medical notes records ‘Another fall!’ with the exclamation mark indicating the repetitive nature of the event. Mr Walker, in spite of being a quiet and gentle man who knew the routine of the dementia house well, was upset by the constant falls and subsequent damage to his wife. He talks about one fall where Mrs Walker sustained quite considerable bruising.

W: I was a bit mad about that. She was walking with a walking frame on a tiled floor like this. Well she couldn’t walk very much, it just fell away from her. She couldn’t handle it, I’m afraid. So, she hasn’t been allowed to walk anywhere without help.

J: So, you were mad because you felt that they weren’t helping her walk?

W: I wasn’t actually mad, but I thought it was a bit careless. Should have realised that she couldn’t manage on the tiled floor.

A few days later I walk into the office soon after Mrs Walker had had another fall and see Ava, the RN on duty, filling in a form, obviously upset and angry. She tells me that she is filling in a restraint order for Lillian. She says ‘I will restrain her until her face gets better then she can have the dignity of risk to fall over again’.

To prevent further falls Mrs Walker’s bed is put on the floor. A few days later Liz, the care-worker, reports that Mrs Walker gets out of bed and crawls round the floor. In subsequent observations ‘Mrs Walker crawling around the floor’, becomes routine. To deal with this situation a special chair is purchased which effectively restrains Mrs Walker while having the appearance of a comfortable settee. The chair is on wheels so she can be moved around the house. In fact she just moves from her room to the sitting room and then the kitchen.

During the time of the study no residents from Beachdale were observed being taken outside by the staff to experience daylight or fresh air. However,
when staff read this comment they did indicate that, weather permitting, residents were taken outside. On the other hand, a conclusion from my observations would be that staff just did not have time for these kinds of creative ideas or spiritual needs in spite of the commitment to valuing the residents.

Mrs Walker continued to get frailer and lost weight, her skin becoming like tissue paper.

As the months go on staff make comments like 'her old knocks are breaking down' and that she is 'brewing something'. Some days she is sleepy, other days she thrashes about trying to get out of her chair. The staff describe it as 'something not right with her but I don't know what - she grabs your hand as you go past'. In the nursing notes this condition is reflected by staff saying she is 'frail' and 'unwell'. The medical notes make comments such as 'no change' or 'agitated today, chest clear'. The last medical entry before the visit to certify Mrs Walker dead reads 'no change, eating well, not agitated'.

But before we reach this point we must return to the days before her death.

The nursing notes are also still indicating no marked change. A few days before Lillian died there is a note about doing extension exercises under the shower as it is now 'not advisable to try and ambulate' Mrs Walker. She was given some 'small suction'. On the day before she dies the staff indicate that she is pushing food away all the time now.

Mrs Walker was found dead as the night staff did their early round.

The actual death surprised the staff. Zoe, an RN, reports that she had been 'working' with Mrs Walker for six weeks before she died and that she had 'started to feed herself'. She said:

... it's not good for the RCI's but it was nice to see her doing something for herself. She wanted to do it. She had her teeth in and her glasses. Her agitation and aggression settled down - but she went down quickly.

This again indicates the differences between staff views. There are those who think that if you can do more and more for the residents they will stay alive and have a quality of life. Others feel that there is a point reached where it is too late for this, or there is just not enough time to give this kind of attention to every one every day. Caught in the vortex created by these moral dilemmas are the people like Mrs Walker
who ended her days in a painful struggle. There was a consistent feeling amongst the
staff that Mrs Walker had retained enough character or awareness to keep struggling.

Her energy, which led her to crawl round the floor and try to walk, inclined them to
feel that her 'personhood' was intact. In observing Mrs Walker it was difficult to see
more than a very thin behavioural distinction between Mrs Walker's energy and the
agitation and aggression shown by other residents. Whereas Mrs Walker's energy had
encouraged a sense of personhood, other residents who were ceaselessly agitated and
often violent were more likely to alienate staff, and to prompt their own relative
marginalisation. 'Personhood' is conferred on the demented resident by staff and
relatives in varying measure and often unevenly, that is, in respect of some behaviours
and sensibilities but not others. It seems to be important in determining the texture of
care and much besides. The process of establishing personhood and, at certain stages,
modifying its dimensions and expected manifestations, is inchoate, uneven, and, as
several cases have shown, not always irreversible. The importance of this point is two-
fold. First, it drives us back to re-examine the boundaries and implications of Singer's
concept of the 'sentient being'. Secondly we must recognise that, for all its
uncertainty and ambiguities, the concept of personhood would have to play an
important role in structuring the alternative approach to the management of death
which is emerging in the course of this study.

The other point about this story is that Mrs Walker's choice, to kill herself, was
consistently ignored. It seems that this 'personhood' status was conferred on Mrs
Walker because her wandering and agitation seemed to have some kind of demented
purpose. Perhaps all of it was directed at ending her suffering. On reading this story a
staff member left me a note. It read:

*Mrs Walker asked me on two occasions for scissors. The first time I
said 'What for Mimi?' and she said 'to kill myself'. The second time I
told her I didn't have any and she didn't say anything more.*

If there is only a small doubt in our minds that Mrs Walker's suffering was so intense
that she spent the last months of her life trying, in many of her waking moments, to
find ways to end the suffering by ending her life, then there is evidence that it is time
for some new thinking about how we care for such residents.
Mrs Amy Cook

The dilemma of 'late-stage' when habits and personality remain

- 83 years old at time of death
- In nursing home for 22 months
- No transfers to acute hospitals
- No courses of antibiotics during time in nursing home.
- 42 falls recorded on incident reports.

Amy had only been in the nursing home for a few months when she joined the study. Her personality was immediately apparent as she wandered the corridors and continually asked questions. In these early months she was aware enough to request to ring a close relative at regular intervals. The staff let her come into the nursing office to do this and often the talk would reassure her. Amy was 81 years old, small and stooped. Before her admission to the nursing home she had always enjoyed knitting and gardening and attended church regularly. Relatives still came and took her to church in the early days of her time at the home. She had cataracts in both eyes and was a diabetic. By the time of her admission Amy was incontinent. She suffered from confusion and sensory apraxia. For example, staff reported that she was unable to recognise a toothbrush and toothpaste or be aware of their purpose. Nursing reports constantly repeat comments such as 'needs reassurance and someone to talk to - she loves company'. When she was in company Amy smiled, seemed relaxed and happy but within a moment her mood could suddenly change and she would be described by staff as 'aggressive, insecure and anxious'. She was fully mobile and wandered round the nursing home all day.

A lot of effort was put into a continence program for Amy. Staff were trying to work out why there was always urine on the floor of her room - in spite of the commode being next to the bed. In some senses staff were aware of Amy's sensory apraxia but seemed to expect her to realise what the commode was for.

At handover one staff member reports that she felt there was urine on the floor because she felt that Amy 'straddled the toilet [meaning the commode] and so she wets the floor'. Another staff member disagrees. She says 'No I saw her yesterday, she opened the wardrobe and just did it - when I said I could take you to the toilet she said what did I do?'

The staff member sounded irritated with Amy as she told this story. After what the staff describe as a long 'discussion' with Amy they felt they had worked out that she
used to use a chamber pot under the bed when she was at home and that this may trigger recollections. A bucket was supplied to take the place of the commode and, hopefully, to appear like a chamber pot. The experiment had limited success. The staff felt there was some understanding of the use of the pot, but Amy still passed urine on the floor. In retrospect it is easy to see that it would not be easy for an 81 year old person with intact sensory capacity to squat onto a bucket and accurately pass urine into it, but at the time any solution seemed better than none. Amy also had a constant problem with constipation, in spite of regular aperients. The staff put this down to her 'pickiness' with her diet and her reluctance to drink very much. In spite of all these difficulties Amy was kept continent much of the time by the staff often responding to her 'agitation', by seeing if she was 'wet' and, if not, taking her to the toilet. Since nearly all staff were mothers it is not hard to understand that they treated Amy throughout this process as if they were potty training a child.

This childlike image was accentuated by Amy being short, stooped, small and affectionate. The staff often expressed the ambivalence in their feelings. She 'drove them mad' with her wandering and questions but they all said they 'loved her'. It was easy for the staff, and myself, to establish a warm relationship with Amy.

After a few months in the nursing home Amy's relatives stopped taking her to church because they felt it was a waste of time since she often fell asleep. But Amy often asked the staff about going to church and seemed distressed to be missing it. I took Amy to church one Sunday and the story of that trip highlights the dilemmas of an unexpected realisation that a person with dementia may have much more insight than will often be apparent within the nursing home culture.

I did not know the routine of the church service and so when the elders brought round the communion wine I proceeded to help Amy to drink it. I put the glass to her lips. Amy held onto my hand and indicated that she did not want to drink the wine, seemed annoyed with me, took the glass and held onto it tightly. A few moments later it was clear that everyone was supposed to drink the wine all at the same time and when the preacher indicated the time was right Amy drank her wine, just like everyone else. After church Amy said hullo to everyone on the way out and would not leave until she had seen her relatives. Subsequently I took Amy out on other occasions and she would suddenly read a sign correctly or come out with a totally rational remark out of silence. On one of those occasions, when we were walking together near a tourist attraction, a horse drawn tram, Amy went to stop a child she thought was getting too close to the horse.
Staff often told me stories of these moments of lucidity in residents with dementia, as have my students. One such comment I remember clearly from a nurse in seminar audience. She tells the tale of having a quiet moment one evening and spending some extra time with a resident with severe dementia. At one point she asked him if he had pain. He answered clearly 'No, only in the mind'. She went on to say that the experience has never left her. It is easy to see from these examples that quiet, concentrated one-to-one interactions with people with dementia may produce results that show an increase in function or awareness. The researchers then conclude that education for staff and different types of nursing home care needs to be implemented to give people with dementia more 'quality of life'. The reverse side of this supposition is that if that awareness is there then the years these people spend in isolation, imprisoned inside a dimly lit environment, in a confused world where they are given basic nourishment, often having to be fed like children or animals, is tantamount to cruelty of the worst kind.

All Amy's insight, if that is what it is, occurred at the same time that her incontinence was becoming too difficult to control and when she was wandering around the nursing home in a confused condition, often falling and sustaining minor injuries. To provide a stimulating environment for Amy, to maintain a level of functioning where any moments of insight would be encouraged, would involve 24-hour care on a one-to-one basis. It would be impossible to provide this service for all Australians who develop dementia and therefore perhaps we should ask ourselves some questions. Is it much crueler to provide the stop-gap of present day nursing home care than to accept the point at which people cannot function alone? When people have entered a dying trajectory is palliative care, for relief of this suffering, more appropriate than the present day SRV paradigm?

Amy's falling began to be an increasing problem. Nine months after her admission staff report that:

Rita thinks Amy is falling due to low staffing levels - she needs constant reassurance - always seeking someone to be with.

Charmaine informs me that when Amy was assessed last week the doctor said they were to keep her on Melleril and that she is 'now a nursing care problem'. That there was not much more he could do for her.

This conversation is not reflected in the nursing notes at all. The medical notes read:
BSLs have risen as she has been eating and stealing food. Now needs feeding ... Continues to wander at night. Needs continual nursing care mainly.

However, continual care was impossible and Amy continued to fall, damaging her face but amazingly never breaking her glasses or seeming to be badly hurt (see photograph 9).

Six months later Amy's face has completely healed and she is still mobile enough to visit church with my mother and another resident. Photograph 10 shows these three women, all in their eighties, one fully functional in the community, one needing nursing home care because of her limited mobility and one fully mobile but with dementia, only noticeable from the blank expression captured in this image. This picture was taken eight months before Amy died. This photograph was taken as a record for my own journaling, and as a memory of a happy day with Amy as I, like the staff, had become very fond of her. When the photograph was developed the look on all the women's faces highlighted the difficulties the debate confronts. All three of women, who qualify for being considered 'old' had needs. Getting old in any society is not easy. I remembered so clearly the feeling surrounding that photograph. Amy was pleased as she was getting attention, and going to church. My mother and Mrs Myer were pleased to be going out for the day, but, more importantly, they were being useful. They were helping me by allowing me to take the photograph. The sharing of resources so that all older people can be assisted if they have needs impinges on the questions of morally defensible resource allocation. Keeping people with late-stage dementia alive beyond the point where they can have quality of life could be denying these other two women a chance to have their needs met.

Despite the fact that Amy's apparent injuries had healed by the time the second photograph was taken her dementing behaviour was more pronounced. About this time Amy's agitation began to increase and her behaviour became what the staff described as aggressive. She was demanding of their attention every moment of the day. A certain sanitisation of this behaviour in the notes is obvious. One entry reads that Amy was 'punching slapping and pulling nurses' hair, redirected x10. Tried to reason with her with no effect'.

Once again, as management becomes difficult, family and medical assistance withdraws and nurses are left to sort out the intractable problems. They accept this responsibility without question. In an interview a staff member describes Amy's behaviour and the efforts being made to provide distraction opportunities for residents with dementia. She says that Amy is:
SIX MONTHS LATER AMY IS READY TO GO TO CHURCH WITH FRIENDS OF HER OWN AGE. THIS PICTURE SYMBOLISES HOW THE NEEDS OF ALL PEOPLE MUST BE BALANCED BY A JUST SOCIETY.
becoming more aggressive. Starts with whose on. How she has slept. On Serenace. Hates to be hurried. Sometimes just wants to come and hold you. Has a lot to do with approach. Does not like hustle and bustle. Most advanced wandering person. [This means the person with the most advanced dementia in the nursing home who is still capable of wandering.] Charmaine is trying to restructure staff so that 6 nurses can be on plus RN to do dressings between 7.30 am and 12.30 am. Bertha can still be team leader and concentrate on continence. Can get one person in the group to take the dementias outside. Activities which soften and quieten down.

The referral to people with dementia as 'the dementias' is common parlance in nursing home language. It is usually said with an air of affection. I have spent a lot of my educative effort trying to change this particular piece of language, exhorting staff to refer to residents as 'people with dementia'. This study has made me see that this is only one small piece of the puzzle which may not have warranted the energy I have spent on trying to change the language over the years.

Returning to Amy's story, another effort to provide the 'continuous care', care that had been indicated by the GP as being appropriate and which nurses understand is what is really in Amy's best interest, comes from Kate, the hostel activities officer. She would come over to the nursing home, every afternoon where possible, organising a variety of activities such as sing-a-longs and reminiscence groups. Amy's needs were one of the main foci of these groups and they would keep her occupied for an hour or two which was some relief for the staff. Throughout this time Kate and Amy developed a particularly close relationship and the staff felt that Amy knew Kate was 'there' right up to the time that she died.

Amy had another fall and hit her forehead. She has been ordered Valium 2.5 mg each morning but the staff consider that it:

... zonks her out and increases her falls. Serenace is pointless. Makes her more unsteady on her feet. Calandra does not give her the Valium. She is wandering, aggressive. ... Just picked up her stick and bashed Mrs Sutton.

Amy's change in behaviour led to an unpleasant incident. One staff member reports it this way:

Amy is resistive to care at best of times. Kylie found Amy's incontinence difficult to deal with ... Amy hit Kylie - Kylie hit her back. ... Kylie says it was a reflex action. Amy is hitting residents, it's
an escalation of her dementia. Tried some Serenace - doesn't always take it. Now on insulin. Went to see psychiatrist. All they would do ... is monitor the Serenace. Increased to 7.5; suggested some blood tests to see if there is something organic going on. She is now zonked, so she's incontinent - slips over and falls. So we will kill her that way. Perhaps she needs to go somewhere more secure, but ongoing saga.

This incident and comment occurred one month before Amy died. A psychiatric assessment of Amy was ordered which resulted in a diagnosis of 'severe dementia' and a suggestion for an increase in her Serenace dose. The staff member was disciplined and soon after resigned from the nursing home.

Amy was wandering and aggressive until a week before she died.

The situation changes quite suddenly. On Sunday and Monday Amy is reported as 'still hitting out', then sleeping in the chair.

Amy has now clearly moved from late-stage to end-stage in her dementing illness, a dramatic transition missing from most other cases.

By Tuesday she was curled up in a ball. The Serenace was stopped and Amy was assessed by a speech therapist because she wasn't eating. The staff were apprehensive because she wasn't swallowing properly. The speech therapist could not get a spoon in far enough to Amy's mouth to activate her swallowing reflex so she ordered thickened fluids only to be given. The staff were concerned that Amy was 'silently aspirating', as the thickened fluids were just running out of her mouth. The GP told staff that Amy 'would not be here long'.

Relatives are informed of Amy's impending death and come to visit. They express their concern about events leading up to Amy's death rather than the actuality of it happening now. This is a story from one of Amy's sisters which was told outside Amy's room while she was waiting to see if Amy was going to die:

When her husband died she could not cope. She was on her own, and she was very lonely. I've been to her house at the weekend, but she was crying. The [name of local town] people were good to her, but it's not the same as family. They never told her what she was in for. She was in here to get better. She was in [name of psychiatric hospital] for a week - that's when she really 'packed it in'. In the last 12 months she hasn't been able to put a sentence together. She has 'fretted' ever since she has been here. I used to take her up to my place
a couple of days a week. Then she used to say take me back. I'm scared up here. She was scared of the 'woman in the mirror'. I just guessed that she had Alzheimer's disease. All of a sudden she got the lady chasing her. Then she came in here. I used to take her to church. She enjoyed that. But she got to the stage where she would sleep all the time. So I stopped taking her out. Amy was smiling her head off - she has got used to the girls. They are very nice to them [the residents]. As homes go they are ok - but I don't like them. I know it's hard - but I would never want to go in one. I want to die quick. When I see this I think the family should be here - not her on her own. They slip away - but it's still nicer. The girls said yesterday, she needs company, she likes company. For her sake - I would like to see her go, she's got nothing to live for, better off if she did go. You hate to see people suffer. Have they got qualified nurses here? ... With Alzheimer's they can't communicate can they? But it must be left in the Lords' hands. Not give her a needle or anything. Just not eating or drinking. There's no hope for Amy. Her tongue is swollen. Throat looks swollen.

Kate also visits regularly now and discusses her feelings. She visits Amy as soon as she arrives on duty and was sure that she could 'see the relaxation in Amy when I am there'. Kate has the view that Amy's personality lasted up to this point in time. She says:

_The last time I spoke to her- the week before last- I said come and sit down. We were just chatting - then she said 'Don't go ' and grabbed my hand. ... I went back to see her. She was very clear - 'Don't go yet '. But all the other words were just a jumble, but they meant a lot to her and she smiled a lot, and it seemed to clear a lot of baggage._

By Saturday of that week Amy's extremities were going blue, her respirations were quite regular, but very deep. Her radial pulse was too weak to take but the carotid was recorded as 'still about 80'. Amy had not eaten, drunk or had insulin for two days. The staff did not measure blood sugar levels, they felt there was 'not much point'. Two nights before Amy dies the night staff report that she is indicating 'through non-verbal sign' that she is in pain. Morphia 5-10mgs 3-4 hourly PRN is ordered the next day. The day staff say that they gave her some morphia although they were not sure that she was in pain. 5mg, the lowest dose ordered, was given and at much less than 4 hourly intervals. Only 3 doses were given, at 11.30 pm, 1 am and 10.30 am.
Jenny, the RN on duty the day before Amy died, explains why she did not want to give the morphia and how she was feeling. She explains that the previous RN had said the morphia was to be given before turning Amy.

But I did not want to give her too much. In her last day she didn't speak. Even her poor little ear when we turned her was blue/red. Dear old thing. She used to hang around and hold onto your hand. She wanted affection and I think she got plenty from the staff. Only in the last few weeks she changed. We've all known that. ... She went down very fast. All the girls are sad. The girls went and put a big vase of fresh flowers from the garden on her locker. Just after they had done that she had a visitor.

The caring expressed by the flowers and the presence of a visitor showed as pleasure in Jenny's voice. The unspoken message from Jenny seemed to be that she did not want to give the morphia in case it helped Amy to die too soon, as judged by her feelings and values. On the other hand, some staff indicate that they really missed Amy when she stopped wandering. For them her personality had gone at that point, and, like the family's' reactions, that was when she was lost to them. The actual moment of death was just a relief.

This is a story where it is clear that the tragedy of remaining insight is not noticed because of lack of opportunity. It is a story punctuated by unfortunate incidents, staff running out of patience and carers engaging in rationalisation to survive. At the same time, it is a story of endless patience and unconditional love. The stuff sentimental media stories are made of. The times when the balance swings between these two stories is where the most difficult dilemma in this thesis arises.
Celia Davey

A daughter's story

- 87 years old at time of death
- In nursing home for 64 months
- No transfers to acute hospitals
- 4 falls recorded
- Incontinent for 3 years
- 4 courses of antibiotics during time in nursing home.
- 42 falls recorded on incident reports.

Mrs Davey died just as the study was drawing to a close. She was a tiny figure who lay in a foetal position in bed. She was so light that Sheila, the care-worker, could lift her out of bed by herself. Mrs Davey's hands had become badly contracted (see photograph 11) but, once again, expert body maintenance ensures that the palms, where infections and sores could easily appear, were kept dry and clean (see photograph 12). Mrs Davey, like most of the residents in the study, was beginning to have quite severe skin breakdown of her legs as the disease progressed. (see photograph 13).

Mrs Davey's daughter, Colleen, had gone through much learning to cope with her mother's illness, including contributing a chapter to a publication by the Alzheimer's Association and being closely involved with the self-help groups in two states. She was, however, unaware of the nature of these contractures, or that they could be part of the complications of a dementing illness. In fact, with the gradual deterioration of her mother's condition, she had obviously not really noticed them. I asked her:

J: How do you feel about the contractures

C: The shakes do you mean

J: Stiffening

C: You don't like it but just watching it gradually you learn to accept it. It doesn't bother me. I think it is a bit like when I take the ...[children]...recently when my children visited and I took my son down the first thing he said was what's that on Nanna's hands - so - I mean they are aware of things. I tell the kids regularly how Nanna is but I suppose I haven't told them about the hands I see her so often I just take it for granted and I can see that the staff are doing the best they can - they all do, so I don't make an issue of it.
Hand Contracture

Photograph 11

Photograph 12

Inside of Contracture
Opened Up

Photograph 13

At the same time, good nursing such as that which keeps the contracture clean cannot prevent this kind of skin breakdown.
Colleen had cared for her mother at home for as long as she was able to the point of giving up her work and calling on assistance from her family.

She says she felt ‘angry and frustrated’ when her mother had to go to care. She says that when she took her mother to the doctor for a general check-up and he told her that her mother was ready for 24-hour nursing care her heart ‘just went oomph - you know’.

But this was after a long time of giving long-distance support and 12 months of caring for her mother at home. Colleen admits that before her mother was admitted to the nursing home she had begun to have difficulty in coping because:

_I was up all hours of the night and getting very little sleep and I was getting irritable and my husband - and younger son who was home at the time - they were going off to work each day exhausted before they even started and they saw I was the meat in the sandwich. My husband is very good, I did the complaining._

However she said that after the three-and-a-half years that her mother has been in the nursing home she has left all those emotions behind her except a small remaining feeling which is a mixture of frustration and guilt. She has mixed views about the way she has seen her mother’s health deteriorate in those three-and-a-half years.

_Little by little seeing her deteriorate along the way bit more each day you get to a level and you sort of accept it. Then she goes down and my heart goes down too I mean you come to the realisation it’s going to happen [Colleen looks at me and I nod to indicate that I know she means death but neither she nor I mention the word.] Some days I can go in and not turn a hair. Some days I go in and cannot get out quick enough._

In spite of the fact that Mrs Davey seems peaceful and Colleen has come to terms with her care in the nursing home, she indicates that she would not want measures taken to keep her mother alive if she got really sick. She would have accepted a medical power of attorney if her mother had asked her when she was able. She says:

_I would accept power of attorney if they gave her that before. In my heart I am sure she would say to me .... [crying and cannot finish the sentence]_
When Colleen discussed this statement with me at a later date, after her mother had died, she clarified her position by saying that she would have accepted a medical power of attorney if her mother had given it to her while she still had testamentary capacity and if such a document had been legally available at the time.

At the time of the original interview, when her mother was still in the nursing home, Colleen expressed the view that she would consider appropriate care at that stage to be 'conservative'. She says:

*As long as their general needs are met, pain killers, making the bed, that is all that is necessary as you know. It is only prolonging the inevitable isn’t it?*

However, she leaves all medical decisions and choices to the doctors and nurses and accepts that they 'tell her' when her mother 'has an infection or something that they are treating'.

This was in spite of some difficulties with accepting the results of the 'normalisation policy,' as she describes it, when her mother first went into the nursing home and was ambulant. Once 'locks were put on the doors' she had felt happier.

Mrs Davey's life consisted of being got out of bed, having her body washed and cared for, being given food by staff, sat in front of a television, given another meal again, visited by her family who she may or may not be able to recognise, and put back to bed. As Colleen says, it is all 'prolonging the inevitable'. Mrs Davey did not seem to be in any pain or distress up until the last week before her death, in spite of the skin tears and sores on her legs although she did receive Serepax, an anti-anxiety agent, the whole time she was in the nursing home. In reviewing the care Mrs Davey has received one can only say that it has been optimum when measured against the prevailing ideology. Her years in the nursing home could be considered to be peaceful, her privacy and dignity were maintained as far as possible within the bounds of someone else needing to be washed, dressed and fed, she had regular contact with a caring family and she was not in pain. Nevertheless, a question about what quality of life this was for three to four years, and how long our society can afford to offer this to people, remains.

As Mrs Davey drew close to death she began to have difficulty in swallowing - gagging and choking on food. High protein supplements were given instead of regular meals. Mrs Davey's condition began to worsen and she slipped into semi-consciousness. Some staff reported that she was grimacing and seemed in pain when her 'pressure areas were attended to' and therefore morphine prn was ordered for
relief. In spite of this order, only two doses of morphine were given in the week before Mrs Davey died. Those staff who gave the morphine indicated that 'pain was evident on face'; those staff who did not give it wrote that Mrs Davey 'appears comfortable' or 'does not appear to be in pain'.

Colleen had felt that writing about her mother's illness in the early stages had helped her come to terms with it and so I encouraged her to write a diary about these later stages which she could share with me if she wished. Colleen did do this and it is included as Appendix 7. She was very pleased to share this with me. In fact thinking that I was not going to return to the nursing home after her mother died, she had written that she was 'disappointed' that I had not made contact on the completion of my studies. When I did contact her again, as I had promised, she was a keen reader and critic of the work I had undertaken in this study.

Her own story shows a deep love and caring for her mother. In spite of this, Colleen had seemed prepared for her mother's death well before it happened. There are records of funeral arrangements and details of where to contact Colleen 'in the event of my mother's death' from three years before the event. In reading this story it is reassuring to feel that Colleen considers the analysis of this study as 'caring' and as an appropriate response to the difficulties of ending her life as her mother did.
Mr Clive Jared

Who is suffering most here?

- 83 years old at time of death
- In nursing home for 46 months
- No transfers to acute hospitals
- 25 falls recorded
- Incontinent for all nursing home admission
- 5 courses of antibiotics during time in nursing home.

Mr Jared is 86 years old. He was at the nursing home for three years and ten months and has been incontinent all that time. He had periods of striking out at staff when he was first admitted but he settled after being treated with Melleril. At that stage his wife would take him home once a week, but he became too immobile to manage that.

In those early days Mr Jared had a habit of sitting in an armchair with his arms folded. One comment expressed the staff’s view of this: 'Look at him - the king surveying his colony!' This may have been a way of attributing character to the immobile, blank, passive stare he had now developed. It wasn’t seen as being similar to the staring behaviour of Mrs Brown, it had different characteristics attached to it.

In the last months of his life Mr Jared was unable to mobilise independently and could only make incoherent sounds. He was swung from bed to chair and chair to bed in a never-ending monotonous daily routine. His skin was healthy, he had no skin breaks or pressure sores, although he had had them in the past. Charmaine and Jan made a special cream for him and, as seen in the photographs, his skin was unbroken and in excellent condition. This was obviously assisted by Mr Jared’s general circulatory condition being good. His limbs were well perfused and, as this photograph shows, his body looks firm and robust. Photograph 14 was taken six months before Mr Jared died. At this time Mr Jared’s dementia was far advanced. He was not able to have conscious control of any part of his body. His sturdiness survives due to nursing maintenance. Photographs 15 shows the amount and kind of food Mr Jared usually eats. He cannot comprehend how to eat, so staff or his wife assist him.

Mr Jared’s wife said he seems peaceful and not in pain. However, in the same sentence in which she says how much she loved and cared for him, she wanted both of them to be released from this suffering. Mr Jared’s children and grandchildren find it too distressing to visit him anymore. This was not the capable father and grandfather that they loved.
SIX MONTHS BEFORE DEATH
HEALTHY BODY BUT BRAIN BADLY DAMAGED

BODY NOURISHMENT
Mr Jared had a period where he was constantly 'singing', as Mrs Jared and the staff called it, and this noise was disturbing other residents. One advantage of Mr Jared being noisy was that a small resident's lounge room was turned into a bedroom so Mr Jared could be on his own. Mrs Jared discusses how she felt about this move:

_I like it here. We are together half the time. I can give him a kiss and a cuddle and if he wants to grab my clothes I let him. He doesn't know where he is but they have made it so nice here I couldn't wish for anything better. He made so much noise. Now they have brought him out here, here he doesn't make so much noise - [stops to give Mr Jared a piece of chocolate] The fact that he is like he is - and I wish he wasn't - the children won't come and see him anymore because well the grandson was down doing a course and he said do I have to go and see Grandpa? I would rather remember the fun we had together - they used to go round on motorbikes. We had a spare bit of ground up at [local town] about twelve yrs ago. Seven yrs ago he modelled the house right through but I was noticing things by then. When we had a new caravan he made five lots of mudguards and he put wheels on it but he had put wheels on the front that we used to cart furniture on - he used to say he can't remember things then he got to the stage where he couldn't find his bed, he couldn't find the toilet. He went to respite a few times but they would say to me 'he's piddling everywhere' and one day I said 'can't you find the toilet?' and he would say 'I don't know where it is' and people can't understand so I just used to lead him around and push him on the bed. I have got the arthritis and one day we fell over and they said 'It is too much for you.' Then Dr Downer came and said 'Come for a ride Clive', and took him up to the hospital and then he hit me a few times. Then he went to the hospital for a crook stomach. When he had been there as long as he was allowed they rang and said there was a vacancy [at the nursing home] and I said 'no', then I rang ten minutes later and that was it. I can't complain he has been really well looked after if there is something I am upset about I tell the girls and they are out here in a swirl - nothing to complain about._

J: Do you think about him dying?

Mrs J: I wish he would.

This last statement seems harsh on paper but this interview took place in Mr Jared's room and both Mrs Jared and I were there as Mr Jared was lifted out of bed and while he ate his lunch. Mrs Jared was aware of me around the home and she knew me well enough to feel comfortable about sharing intimacies. This comment was made in the context that Mrs Jared knows that I know, and the staff know, that she loves Mr Jared and does not want him to live like this. The family cannot reconcile themselves to what they see as the futility of his continued existence. After a few weeks Mr Jared
was moved out of his private room as his noisiness decreased so even those tiny moments of privacy are now denied Mrs Jared. This, and stories like it, support the privacy component of the single rooms that are found at Beachdale. On the other hand, as time progressed, the interaction Mrs Jared had with the staff, and the support she got from them seemed to be more important than the privacy she could share with Mr Jared.

The GP expressed the opinion that Mr Jared's staying alive is 'killing' his wife. Mrs Jared is crippled with arthritis but gets to the nursing home as often as she can to give her husband a meal.

As Mr Jared's condition worsened he got to the point where he could not sit up, but only lie in bed grunting and screaming. I observed him being bathed in a collapsible bath. It is, again, impossible not to make analogies that the conventional thinking in aged care would say are pejorative and undignified, but it was just like watching an animal being washed. The lifting out of bed, swinging into the bath, the body having water run over it by one person, the soap put on by the other, the body dried, the face shaved, the swinging back to bed, was all expedited efficiently and remarkably quickly. I videotaped this event and, in retrospect, one can admire the efficiency of the procedure, but feel only sadness for the body that is the subject of it. The bellowing from Mr Jared as the bath took place seemed to be either habit or some kind of reflex action. It seemed to have the tone and tenor of a conversation and it did not seem distressed. The staff did not respond to it.

Charmaine tells me that the bellowing is 'better' than usual, which means not as loud and continuous, because she has just given him a suppository. His distress only gets bad if he is constipated so now they make sure that he has 'his bowels open every two days'. At one point the staff thought he probably was in pain, so he was ordered MS Conten. This was given for three months, but staff felt that it made little difference except cause more difficulties with his bowels. So, by agreement between the nurses and the GP, Prothiaden and Mellerill are tried again, which, Charmaine maintains, 'keeps him more peaceful'.

The staff felt for months that Mr Jared was close to death, but 'how close' is debatable. They expressed the view that 'he could go on for ages', adding that 'There is no strain on the heart when they get to this stage'. They were happy to tell me that 'he loves us girls'. For the staff this is their 'knowledge'. After years of care their instincts were telling them he could go on living for a long time yet. The facts have proved them
right in this case. Mrs Jared tries to visit every day in case it is his last. She repeats that 'It is cruel to see him like this'.

Mr Jared then begins to have trouble swallowing and has episodes of coughing. He was assessed by the speech therapist and the nursing care plan was amended so that he had thickened fluids only. He was still noisy, shouting, moaning and reported as being 'agitated'. He then began to have some twitching and fitting episodes. Now his body was beginning to break down and he developed a sore on his hip. This was happening about 4 months before Mr Jared died. There are exhortations in the notes from one shift to another about 'keeping him off affected area as much as possible'.

Mr Jared continued to slowly deteriorate and ten days before he dies intramuscular Pethidine was commenced due to the fact that Mr Jared could not now take his oral medications, and appeared to be agitated and in pain. He is given this for four days. Then there is a comment from one nurse saying 'Resident accepted breakfast and some fluids. Wife visited and felt resident is in need of analgesia. Resident moaning but not as much as before'. Not until after this comment is a dose of Pethidine recorded. He had one more dose the next day and then none was given for another 4 days which was the last dose given. Mr Jared died the following day.

Four years ago both the doctor and the nurses considered that Mr Jared was in the late-stages of dementia. For a long time his wife had felt that it was time for him to die. Have Mr and Mrs Jared experienced unnecessary suffering for all that time? If so, it could also be said that the community has suffered from the futility of wasted resources.

Apart from being deprived of food and water, Mr Jared could have been considered to have been receiving palliative care. On the other hand, to Mrs Jared it was a caring that kept him alive far longer then she could easily cope with. As I finish this study questions of euthanasia are being regularly canvassed in the media. The case of Mr Jared makes questions about euthanasia pertinent.

On the other hand the next story, of Queenie James, makes the conclusions from this study seem harsh, which is what Mrs James's daughter felt after reading the draft of the thesis. These two totally differing points of view illustrate the uniqueness of individual needs and the fact that there are no black and white answers. As far as possible, if choices can be made available and humane and informed decision making processes be put in place, then a 'good death' as seen by each of these families could be achieved.
Waiting to die

There is one resident who was still alive when this thesis was being completed. I will speak of her briefly. She has been 'ill', in fact gravely ill, but has 'pulled through', as the nursing home jargon would express it. In some way Mrs James seems oblivious, or totally resigned to her fate; she has a calmness about her. The reason may be, of course, that different parts of the brain have been affected to that of the residents who have been described as agitated and distressed. This story, like Mrs Davey's, adds a balance to those analyses which have concentrated on suffering as exhibited by perturbation.
Mrs Queenie James

Body maintenance - a lifetime of giving returned

Mrs James was still alive at time of writing. Mrs James’s daughter, Ella, was a registered nurse and a very important part of the unit.

She comes and gives her mother lunch or supper every day; she knows everyone in the unit and helps out when she sees another resident that needs assistance. Her philosophy of caring for her mother is very clear. Her mother looked after all her children devotedly and selflessly all her life and it is now time to return that care and love. The decline of Mrs James has the same manifestations as that of many other residents. Her skin is becoming paper thin, she has skin tears on her legs and the start of pressure sores on her back. She is incontinent, non-ambulant, needs helping with meals and moves from bed to chair, to sit at the table, and back to bed. This routine is repeated every 24 hours. She still speaks or asks questions very occasionally. Her daughter maintains that she can ‘recognise her family when not drowsy’. She is dearly loved by her family. Their body maintenance is an act of love. It would be hard to say that Mrs James is in any way distressed. She is now developing contractures of her hands and is developing a foetal position when sitting in the chair and in the bed.

Ella feels the term ‘body maintenance’ is a very harsh description of what happens to people with late-stage dementia. She spoke to me about this and wrote about it in response to my analysis, but before I could answer, tears came to her eyes and she said ’but that is what it is really isn’t it?’. Ella goes to great lengths to keep her mother alive and well, preparing her favourite delicacies to tempt her appetite when otherwise she is refusing food. She tells of getting the fresh fish her husband brings home from a fishing trip, cooking it immediately and then running straight down to the nursing home with it while it is still warm. She does not want her mother to die.
Conclusion

This chapter has concentrated on describing the last months of the life of each of the residents. The overall impression is one of protracted distress and suffering, caused at least partly by the lack of a coherent framework of care. A picture begins to emerge where staff feel alienated and families feel torn and tormented because of many factors beyond their control. Death is expected, but also denied, so the case management is shrouded in a sense of confusion, marginalisation and fear.

The concept of a 'well managed death' may have allowed the resolution of many of the tensions the nurses and families indicated that they experienced and being able to work within such a framework may have supplied the professional and emotional satisfaction so obviously lacking. This would have required a philosophy and arena within which all those involved with the patient who had lost testamentary capacity could clarify their perspectives and values while reflecting on the wishes and priorities which might have driven the resident had he or she been in a position to express them.

Deepening our understanding of this complex of contradictions requires that we look beyond the actual condition of the resident - to government policy and institutional practice, to the different self-concepts held by the different health care disciplines or the insistent pain of a family member - to find explanations of the treatment given.

At some point, in seeking to go beyond these contradictions, we would need to learn to look at the behaviour of the resident from a substituted judgement approach rather than a 'best interest' approach. The difference between these two approaches is that the 'best interest' approach as, Mr Justice Brennan has stated "depends on the value system of the decision maker" (Creyke, 1995, p.42) whereas the substituted judgement approach rests on the premise that choices should reflect what the individual preferences of the person would have been prior to the loss of testamentary capacity.
These choices may sometimes seem idiosyncratic or eccentric or even objectionable when arrayed against the value system under which the carer works, as demonstrated by some of the responses to those residents who expressed their wish to die. The wish of the person with dementia to die, expressed in confused terms by the residents themselves, and in overt and covert terms by their relatives, was accepted by many (but not all) of the staff; but there was no framework within such wishes could be regarded as worth recording, let alone considered for possible implementation. In such circumstances habit and conventional wisdom, both embodying ethical and legal concerns developed for very different circumstances, provide the only direction. This policy vacuum meant that keeping people alive, clean, comfortable and not hungry or thirsty equated with the nurses feeling that they were doing a 'good job'. As I have said in the illustration of Violet's story, human agency is not absent in any of our studies; but it is pitifully circumscribed by the framework of unarticulated and ill-fitting assumptions within which the events unfold.

In Amy's story I describe my own reflections on a day in her life and the photograph that I took to remember it. The three women in the photograph were of the same age, but all in different circumstances. Research about preferences for older people shows clearly that each of these women would most like to live supported in their own homes, having a role to play in society and with plenty of stimulating company and activities. The findings of this study do not negate the need to work towards assisting older people to continue to have a full life for as long as possible, but questions are raised as to the most humane and respectful course beyond that point.

Those who believe in the sanctity-of-life ethic and would critique this study on such grounds would say that all these three women remain at all times equally endowed with a right to life. It is when this position is confronted with the question about the limits within which such a view remains tenable that the compromises and different opinions start to appear, at least among an increasingly wide cross-section of the community. The case studies do suggest that there does come a time when the process of a dementing illness has such an effect on a person's life, and the family and society's resources are reaching their limit, when it may be appropriate to say that it is time to let a person 'go gently into that good night', in spite of Dylan Thomas's injunction against this, rather than continue a painful struggle to keep them alive.
However, the current uncertainties rest not only on our common unease with the nature of the relationship between life and death. Institutional culture and public policy, as they now stand, also play a part in buttressing the contradictory and frustrating procession we have been watching; and it is to these matters we now turn.
Chapter 6

The context in which these deaths took place

Introduction

The stories and photographs of the previous chapter describe the work of maintaining deteriorating minds and bodies. These bodies are given various characteristics by different people. However, they are still stories of deteriorating bodies being kept alive by a strongly entrenched system of thought and practice with regard to death and dementia.

The care provided in the stories I have recounted is based on workers perceiving that this is the legitimate pattern for care of people with late-stage dementia. The values, concepts and objectives which characterise the system are rooted in the theory of SRV, or the ideas and words that have been extrapolated from that, even though they are not used in the manner the SRV theorists now think of as appropriate. This care is paid for, supported and regulated by government supporting the concept of nursing home care being regulated by standards which reflect a commitment to a 'homelike' environment.

Themes extracted from observations, field notes and interviews regarding the culture of care in the nursing homes indicate that the legitimacy of this theory and practice is being questioned, albeit, in most cases, subconsciously. The marginalisation of death, the increasing sense of accountability felt by nurses, the fear of inspectors and the thrust of aged care policy has led to a situation where the last weeks and months of residents' lives are often spent in a limbo of confusion and unplanned management. The concept of 'nursing care', if introduced, is nebulous. These sometimes obviously cruel uncertainties and frustrations do not escape notice, but too often are the subject of misconceived or misdirected proposals for change. Proposals for change often have a 'more-of-the-same' character, whether directed to yet more training, tighter regulation or a more rigorous application of the tenets of SRV.

This study has instead lead me to a conclusion that a basic paradigm shift in public policy is needed. The most striking finding flowing from analysis of the stories is that
the task which presently is being carried out in nursing homes is set up to fail. It is set up to fail because a society like ours cannot get to grips with the problems posed by an elderly dementing population. Policy makers want to make policies that set out what they consider should be done from a liberal, humanitarian point of view. There is some concept that a workforce full of kind, strong-backed, patient workers, willing to receive low pay, will carry these policies out with cheerfulness for the whole of an eight hour shift, day after day. There is also a perception that those receiving the care want to be kept alive in this manner. This study questions those perceptions.

**Social change**

As has been suggested throughout this thesis social change needs to be approached with caution. There is every reason to believe that a shift in public policy will lead to as many dilemmas and difficulties as the previous direction.

At the same time it must be acknowledged that social change is ubiquitous, it cannot be avoided. These stories can at least suggest a review of the philosophical understandings of institutional aged care and outline a need to set appropriate and workable limits for the aged who are suffering. As Digby indicates this will be no different to the pleas of the reformers of the past:

> The lesson of history is that it does not repeat itself precisely, yet, on a broader front, certain policy issues, dilemmas, problems and choices do recur in social welfare. To forget the past record of these events is to force each generation to relearn what should already be known, and thus make future developments less satisfactory than they might be. (Digby, 1989, p.130)

History provides the context of the deaths that have been observed as does the culture of nursing homes today.

All data form interviews, journalling, field notes and the case studies was analysed. Sixteen themes emerged from the stories and surrounding the lives and deaths of the residents in the study. These themes were anticipation of death, body maintenance, death opinions, education issues, environmental issues, interruptions, juggling care, letting go, normalisation, palliation, personalising, policy intimidation, policy knowledge, staff as people, staff power and views of dementia.

Each one of these themes would be worth exploring in depth and from differing perspectives, but only those that seem important to the main finding of the study will be taken up. Whatever analysis was chosen, the conclusions would be dependent to some greater-or-lesser degree on the theoretical framework within which that analysis
was couched. For example, medical colleagues would be able to show ways in which suffering could be relieved by managing the acute clinical manifestations described in the case studies with greater clinical skills and knowledge, or the Social Role Valorisation advocates could tease out the 'wounding' that the stories demonstrate. The theoretical framework in which this study was undertaken mitigates against analyses such as these. Instead, a paradoxical situation arises where the need for a palliative care attitude, which for some is seen as the slippery slope towards euthanasia, is put forward as an emancipatory conclusion within the tenets of critical theory, as the analysis that will be concentrated in this study. This study postulates that telling the stories of the care of the residents who were dying demonstrates that this is an act of liberation. Material from some of the above themes put those stories into the present day context.

Before going on to discuss the case studies further and the emancipatory action that could be suggested, the culture of the nursing homes need to be further explored. Out of the 16 themes which emerged the ones that were directly concerned with clinical care were anticipation of death, body maintenance, death opinions, letting go, palliation, personalising, and views of dementia.

As more than half of the other themes were about parts of the nursing home culture not discussed during the case studies they need to be discussed, examined, and evidence presented to further contextualise the final analysis. These themes were education issues, environmental issues, interruptions, juggling care, normalisation, policy intimidation, policy knowledge, staff as people and staff power.

Out of these themes it emerged that the two most dominant features which impacted on the culture of the nursing homes were present-day public policy linked with the changing health status of the residents, both individually and collectively, the constant pressure for education and questions of power and personality. The effect of these pressures were evident in the background to the stories. One example that remains very clear is the feeling of guilt from the staff that they were outside the house having a cup of tea when Mrs Miles died. Up to that point the staff had fought for, argued about and worked hard, according to their own values and within the prescribed circumstances, to give Mrs Miles a 'good death'. But they 'failed' at the very crucial moment. The same feeling pervaded conversations when residents fell. Staff often feel 'judged' by these moments of seeming deficiency rather than on their day-to-day efforts. Some explanations for these feelings emerge from the themes about other aspects of the nursing home culture.
Policy intimidation, knowledge and effect

Staff who had worked at the homes for years were very conscious of the changes in public policy over the last decade and the effect this had. One staff member, struggling to get the right words in her effort to express clearly how she felt, gave a passionate answer to questions about policies in the home. Parts of the lengthy reply follow:

... there's been so many policies come out, look honestly, it makes me shudder just to think, like I read one the other day about the dementias and how to make it home-like and how to employ daily living ... and I was really confused by it, I don't even know why the policy was brought out. They change - they, you just do not know which way you are going. There is a new one all the time... some contradict others as you read them I find that they contradict, but also they make the girls so confused that they really don't know. A lot of them would use their own self-discipline on how to care for someone but now they are too scared to use their own common sense and that is - to me I find that very hard to accept. Then again there's not guide-lines for care - do you understand what I mean?

This fear and alienation, of losing power within the workplace, and therefore 'doing things by the rules' rather than employing compassion and common sense was commonplace.

The confusing quasi-legal status of the Outcome Standards seemed threatening for many staff, especially those who are entirely dependent on their nursing-home job for the main income either through being a sole parent, being the bread winner of the family due to the rural recession or the family being dependent on two incomes. These staff were in the majority.

In trying to feel secure and hold onto their jobs by understanding and complying with the Standards they were further confused by the seeming impossibility of meeting them. There were few strategies to solve the difficult dilemmas presented; only the expected outcomes of regulations. The language of the Outcome Standards was seen as autocratic with little, if any, practical guidance about implementation.

For example Outcome Standard 5.6 states:

*Residents wishes concerning their terminal care are carried out*  

The documentation supporting this says that:
Residents should be given the opportunity to express their wishes concerning terminal care, funeral or cremation arrangements and the person nominated to take responsibility for their property pending finalisation of their estate (Commonwealth/State Working Party on Nursing Home Standards, 1987, p.37)

The stories presented in this study make that kind of direction a nonsense. By the time potential residents with dementia are ready for nursing home care most are not able to make these kinds of decisions. Details of preferred funeral directors are asked for on the admission forms at both nursing homes, but, as the staff say, pressing potential residents or their families further by asking about their wishes in regard to terminal care is neither not kind nor appropriate. This would just add another burden to the trauma that admission to a nursing home can be, as Colleen has indicated in her story. As has been shown, some consultation did take place with families at the end of residents' lives, to seek permission for conservative care, but in many cases the wishes of residents and their families are ignored because they cannot be met under present paradigms of care.

This dilemma is worsened because of the fear of the regulators. Sheila bitterly reports the results of one particular criticism of the dementia house from the Standards Monitoring team after their visit to Beachdale.

...they [The Standard Monitoring Team] felt that there wasn't enough variety of activity for the residents to do. They were from the old school where they're sort of more into 'the group', the buses and the big outings and our philosophy isn't really that. We believe our philosophy is good where we work to a one-on-one basis so we try and meet individual needs rather than grouping people together and they're a bit slow at coming at that philosophy. I believe they tend to think that if everyone in the group's doing things it's all very well but really you know there's probably people in that group that aren't really thrilled about doing what they're doing. They're just doing it because it's a group and they're told to do it and they specifically mentioned the Dementia unit and didn't seem to be a lot going on in the Dementia unit as far as activity is but we explained that two years ago when they were here those residents - a lot of them were still there - two years down the track those residents are a lot frailer and are unable to do a lot of things they used to do and Madge actually explained to them that they've got in-house videos - we've got musicals, comedies and other videos, and music and some of the relatives take the residents out for a walk with weather permitting. In the wintertime it's been a bit hard. I must admit not a lot of things happen. They go out to singalong, the ones that are able to go. But generally they thought that more activity could be done in that house.
and it was suggested a big board or quoits and [we both stopped and laughed. At that time there was certainly not one resident in the dementia house who had the remotest possibility of playing quoits.] yeah we raised our eyebrows and we thought well we're not into this, that type of activity which we see as a bit demeaning to the residents even though they have dementia and so consequently we're not going to act on that because we believe we're doing the right thing.

This illustrates the out-of-date nature of the present regulations with the reality of day-to-day life in the nursing home. Most workers accepted, indeed welcomed, the fact that quality-of-life and care standards are set for nursing homes to prevent unscrupulous owners or organisations abusing the system or residents suffering through lack of adequate care. That monitoring teams needed to be established to ensure the standards were upheld could also be accepted. However, as so often is the case, bureaucratic organisations do not work as intended. Policy makers do not take into account the enormous changes this process made to nursing home culture, to the role of the DON and to the working conditions of all staff. Policy has fallen behind the realities of a culture of care in nursing homes that is changing rapidly as the population becomes frailer.

This does not negate the work that is being undertaken to support quality-of-life for people as they become frailer and action to prevent, or delay, admission to nursing homes. The Rosewarne report (Rosewarne, et al., 1993) demonstrated that dementia programs, where additional funds were received to provide for 'dedicated staff focusing on dementia care', made it 'easier to care' (Rosewarne, et al., 1993, p.xv).

This is an interesting but nebulous concept that can be understood only in the light of a knowledge of the culture of nursing homes. The report goes on to say that:

... staff had a clearly defined job role directed unambiguously to the hostel residents with dementia. Staff became attached [emphasis in text] and felt directly responsible for these residents. They adopted a type of advocate/case manager role which impacted positively on the capacity, approach and attitude to care [emphasis in text] across the internal hostel system. (Rosewarne, et al., 1993, p.xv)

This finding, in contrast to those that discuss the need for education or other interventions, shows the benefits of care from staff with clear responsibilities, a positive job role and some power.

In the nursing home, the paradoxes and dilemmas that thrust themselves through the fabric of day-to-day life in the nursing home both impair the effectiveness of care and reduce the work satisfaction for staff.
This study found an acute awareness among staff in both nursing homes of the
niggling ever-present conflict between, on the one hand, regulation, which are
perceived as rigidly prescriptive, often rather trivial, and, on the other hand, the
exigencies of providing care on a budget to numbers of people with severe late-stage
dementia. For example a comment follows a visit from the Standard Monitoring
Teams who gave the nursing home a 'not met'. Sheila tells the story:

It was noted on the day when the team were there that there was one
care worker assisting two residents with a meal. She was sitting in
between the two but they both had separate meals with separate
cutlery and we explained that on some days we have a lot of
volunteers, a lot of relatives that help and it's usually done on a one
to one basis but on some days with the staffing level it's not possible
so we have to ... you know everyone's got the right to eat at the right
time of day. We shouldn't have to make people wait longer than
others for meals and that's how we do it and they still believed that we
shouldn't, that that's an action required there that we should stop that
happening.

This prompts staff to start thinking of how they could circumvent the monitoring
process, next time the nursing home knows the Standard Monitoring team are going
to visit - should they make sure that extra staff or volunteers are around? Meanwhile
they must do the best they can, having to patch up the problem in the immediate
future in order to get their 'met' on that Standard.

Once again the intractable problems connected with the maintaining of bodies in an
advanced state of breakdown are discounted in favour of requiring that people have
available a range of stimulating activities and are enabled, for example, to eat in a
'dignified' manner, that is with one-to-one attention. For people with late-stage
dementia 'living' and 'dignity' are reduced to little more than providing enough safety
and sustenance to avoid death by accident or neglect. One staff member for fifteen
residents with dementia cannot give one-to-one care. How compromise is achieved
carved tensions and sometimes antagonism between the monitoring teams and the
nursing home staff and, as has been illustrated in the case studies, between the staff
themselves and between the staff and the GPs.

While sustained observation has shown us the difficulties created for residents and
staff alike by the inappropriate application of SRV principles for the care of residents
with severe dementia, the value of the SRV model in other cases is beyond dispute.
Yet even in appropriate cases the conflicting goals of different sets of regulations may
often add to the confusion and frustration experienced by staff. An illustration
involves a resident who was not in the study but is an important and significant person within the culture of Bayside.

Audrey was a 56-year-old female resident who had Parkinson's disease. She had indicated that she wanted to live her life fully and take any risks to do that. She was prepared to sign any kind of indemnity form to do so. Fortunately she had formed a relationship with a gentleman in the hostel who cared for her and took her out every day. I observed an incident as the nurses were listening to an Occupational Health and Safety lecture. Audrey, hanging onto the back of her friend's gofer, was wandering down the middle of the road and went past the window of the lecture room. Bertha, looking out of the window of the lecture room, saw that Audrey's shoelace was undone and left the room hurriedly to run after her to do up the shoe lace so that she wouldn't trip over it. On Bertha's return the lecturer commented about the need for all shoes to have velcro fastening. However, for Audrey, who was trying to retain the last semblances of her appearances as an attractive woman, this would not have been normal or attractive. Audrey's attractiveness was something the staff tried very hard to preserve, taking her shopping regularly, applying make-up for her, arranging a hairdresser and so on.

Bertha got very upset about the implied criticism from the lecturer because of the care she gives to Audrey, and because of her attempts to be a strong advocate for her freedom. She asked in reply to the criticism 'Are we geared to look after this lady?' The lecturer answered, abstractly and somewhat evasively, 'You have got to prove that you have provided the best climate'. Bertha then went on to say: 'How can we provide that here? To this there is no reply. Bertha then became passionate, and I could see that she was going to seize the chance to get assistance from the 'expert' and to air her feelings in front of the CNC and DON.

Bertha went on to say that Audrey wanted her own gofer and that the police had said she was OK to get permission to drive one, but nothing had happened. There was then a lot of confused talk from other staff about 'something in the post'. I later found out that Audrey's licence for a gofer was being 'held up', the gossip being that it was being stopped by some kind of non-spoken arrangement between the DON and the police to let Audrey have the feeling that the licence was being processed, but it had really been stopped as it was felt that it would be too 'dangerous' for Audrey.

This incident prompts several observations. The first concerns the potential for conflict between different regulatory regimes, in this case health and safety considerations and SRV principles. Unlike the people with severe dementia who are the focus of this study, Audrey could only benefit from the freedom the new
libertarian, freedom-of-risk policies should have allowed. Not only was it not used, however, it was condemned by an authoritative expert and believed to have been thwarted.

The second observation reveals that once again it is first-line nursing staff that bear the brunt of the contradictions. When issues of freedom and safety clash nurses are left with the dilemmas to sort out. It is not surprising that they will choose the option that is likely to provide the least possibility of risk that is 'foreseeable', when experts cannot answer the difficult questions but constantly warn about duty of care. Audrey never did get her gofer and Bertha remained angry about it.

Braithwaite and his colleagues (1993) do acknowledge that a shift in focus of nursing home regulation is needed. They say:

**Recommendations**

1. Australian regulatory policy should continue with its focus on maximum achievement of outcomes rather than a 'balanced' approach of specifying structures and processes that are necessary to achieving outcomes as well as outcomes themselves.

2. However, there are circumstances where exceptions must be made to this determined focus on outcomes. These circumstances are where:
   - there is solid evidence of a consistent association between a particular input and an uncontroversially undesirable outcome, and
   - the outcome is difficult to observe (for example, because of low frequency or visibility) while the input is readily verifiable.

The consultants only see these circumstances are consistently arising under the rating of standards 7.3 and 7.4, and probably 7.2, though rarely under other standards. In short, the consultants recommend continuation of a radical outcome orientation tempered by an exceptions approach when inputs are accepted as posing the potential of poor outcomes. This is a preferable strategy to a 'balanced' approach to structure-process-outcomes which poses too great a risk of slavish insistence on inputs when they fail to deliver desired outcomes.

3. Outcomes should be defined in the regulatory process through a dialogue about what outcomes are subjectively important to residents in a particular nursing home. They should not be defined by objective outcome indicators.
4 Standards monitors must be mindful of intimidation or other circumstances that leave some residents incapable of complaining. Sometimes standards monitors must make the judgement that intimidation is the reason residents are failing to complain about conditions of which any reasonable citizen in that situation would complain. Here, dialogue within the team followed by dialogue with stakeholders should be the source of flexibility. It is essential that teams critically examine any assumptions that because no-one complains there is no problems.

5 Notwithstanding the centrality of the discussion of subjective resident preferences in reaching ratings, fundamental research on objective outcome indicators should be actively encouraged. This research will inform the ongoing validations and refinement of the standards and may provide a complementary educational and enforcement resource (Braithwaite et al., 1993, p.17).

These types of recommendations are quintessential bureaucratic writing not easily comprehended by nursing home staff. On one hand these recommendations seems meaningless because of the convoluted sentences; on the other hand, terrifying. The kind of message that is taken from such conclusions is that the emphasis is placed on the fact that 'complaints' are to be carefully extracted from residents, or at least, one presumes, from the 26% of residents who do not score highly on dementia related questions under the RCI categorisation process (OFTA, Aged and Community Care Division, Department of Human Services and Health, 1995). This leaves the usual unpleasant taste in workers' mouths. The department is seen as trying to find out what is wrong, rather than what happens in nursing homes. When they find out what is wrong they then have grounds to apply further pressure for more documentation and education.

The two panaceas - education and documentation

Documentation

In order to measure and regulate nursing home care bureaucrats seek accurate documentation from nursing staff. Often this documentation is not presented in the amount, style or manner which satisfies set criteria. It has been reported by Sue Macri that the introduction of the RCI:

highlighted a unique set of problems for nurses in aged care

...a lack of appropriate knowledge and skills relating to documentation and nursing process
a lack of (nationally) good clinical records designed to facilitate documentation requirements

a lack of knowledge and expertise relating to the area of clinical records, collection of data, storage of information ...(Macri, 1993, p.5)

Macri acknowledges that nurses see infrastructure cost arrangements as punitive and one which concentrates on finding fault rather than rewarding best practice (Macri, 1993, p.40). The increased responsibility for staff to document residents' care in a way that will justify a resident's classification to the RCI team has increased negativity from staff. Another unfortunate effect is that of increased depersonalisation. Every resident is a 'one', 'two' 'three', 'four' or 'five'. Again, as with the Standards, this language has pervaded the nursing home culture. Much education has taken place which attempts to change institutional depersonalisation by being careful about the use of language, but now, in tea room chatter, different jargon is used. The conversation at both nursing homes was often punctuated by statements such as 'she's a four but she should be a three'. The fight against depersonalisation has taken a big backward step; residents are now referred to by their RCI categorisation.

Although nurses were aware that the RCI was the method which, if handled badly or well, would mean the loss of or retention of their working hours the documentation involved was constantly complained about.

How this impacts on the quality of care and death processes of the residents with dementia is a major part of the culture of the nursing homes. It is quite clear that all this documentation only reflects part of the nuances and reality of daily care. This has been evident in the stories presented. This fact is consistent with the findings of Parker and Gardner who say:

*Documentation emphasises the body as an object of our interventions rather than the more personal, involved human dimensions of our caring. Perhaps shyness or embarrassment stops us; maybe we do not want to expose for general consumption something that is privately shared between patient and nurse. Perhaps there are no words that can capture these experiences.* (Parker & Gardner, 1992, p. 8)

The case study of Bernadette demonstrates her painful and dilemma-filled last days. The nursing notes at 0600 hrs on the day she died read:

*Appears more relaxed and comfortable, possibly due to Valium (which had been requested the previous day) only slight seizure this morning 0600 lasting 30 seconds. Swallowing reflex slightly*
improved, marking easily. Full body sponge 0615, linen changed, infusion site okay.

This is a technical explanation of care given to Bernadette. It does not include the care given by such actions as stroking of her head, the dribbling of fluid into her mouth, the fear of the staff, the questions that surround the care and so on. Staff are documenting in a mechanical manner because that is the only thing that is safe and rewarded.

In 1993 the Macri report (Macri, 1993) the Braithwaite report (Braithwaite et al., 1993) and the Gregory report (Gregory, 1993) all attempted to deal with aspects of policy implementation that seemed to be dysfunctional.

Macri was appointed to investigate and report on Commonwealth documentation requirements for the RCI. Braithwaite et al. evaluated the Standards and the Gregory reports were a summary of the monitoring of the Aged Care Reform Strategy and a review of the structure of Nursing Home funding.

In general their conclusions led to the inevitable kind of outcomes; introduce manuals, educate staff, integrate services and increase resources. They are full of bureaucratic speak that nurses in the aged care arena now recognise and ruefully laugh at. Gerontic staff translate the reports into their own language. For staff in the aged care area the implications of comments in reports such as 'a rigorous analysis of residents records' (Braithwaite et al., 1993, p.77) is translated into gossip that the Standards teams are going to get tougher. When this is linked with details of how the nurse on the team is now going to inspect bed sores (Braithwaite et al., 1993, p.77), then the fear of body breakdown being misinterpreted as 'bad' nursing care rather than the inevitable result of a terminal illness where a person cannot maintain their normal body functions produces more alienation and paralysis in the staff. This bitterness grows from on-going experience and the recommendations from these reports are received with resignation.

**Education**

Macri, who is very supportive of nurses and shows a clear and realistic understanding of their concerns, still recommended that they must upgrade their 'skills and knowledge' (Macri, 1993, p.40).

With few professional nurses regarded as knowledgeable and up-to-date in the gerontic area, when measured by standards of a modern industrialised world, a vicious circle has developed of aged care being seen as unprogressive and having attached to
it the diminishing view of tasks considered unimportant in our capitalistic and competitive society, that is those tasks such as cleaning, caring, mothering and nurturing. As these tasks are devalued so caring for the aged and demented becomes devalued. Although it is important that education is seen as an assistance in reversing this trend it will not be enough without cognisance of the political and societal dominant forces that produce and shape it. It is important to educate for reality. The day-to-day care of old people can be demanding, physically hard work, boring and unrewarding. Multi-skilled personnel are needed, not only for the tasks to be done, but also so that there is enough variety in the work routine for staff to remain interested, motivated and productive. None of this was being achieved at any level of staff education and training in the nursing homes studied. The linking of education and changes in work practice and conditions has been sadly neglected in the aged care area. There was a large heap of untouched educational literature in the office at Bayside produced by consultants appointed by the Commonwealth Office for the Aged. Charmaine told me there just wasn’t time to do anything about using the resources. The In-service educators who came to the nursing home on an ad hoc basis did not refer to, or use, this literature at all. Also, coordinated and in-depth gerontic education has not occurred within the academic main-stream.

The anger Bertha showed at the lecturer who could not solve the real life dilemma that was going on outside the window has already been illustrated. What follows is a precis—a representative, account of other parts of that lecture. The impact and reception of this ‘training’ portrays many reactions that are integral parts of nursing home culture. It illustrates the number of dilemmas that are left hanging with different points of view attached to them, the basis of gossip and fear spread by ‘stories’ or examples from nursing homes where things have gone wrong and the teaching that is exposed as theoretical and impractical. This lecture is similar to many others I have observed or attended. It was an average kind of lecture arranged in response to the initiatives that suggest that educating workers who care for people with dementia will improve care.

Before this lecture was given a note had been put in the communications book which read ‘Reminder that Rosita Abbott’s lecture is compulsory’. This means that any staff attending would be paid and that all staff were expected to attend.

The lecture was held in the residents’ dining room at Bayside and a large proportion of staff did attend, many in off-duty time. Rosita began by discussing competency. To illustrate her point she told a story about an enrolled nurse who had been working in the a nursing home for two years who was found to be dyslexic, and she was
illiterate in reading and writing. But the other staff had 'cocooned' her. Rosita indicated that this kindness on the part of the staff in protecting someone who was not competent was a breach of common law - of their duty of care. This set a negative atmosphere amongst nurse attendants for whom written expression and issues such as spelling often worried them. No-one asked why the nursing home staff were now the problem rather than the educators who let this person become enrolled in the first place. Rosita's next point was that the most widespread breach of common law occurs when RNs are administering medication. She emphasised that a careworker is not allowed to give medication. Enrolled nurses can be delegated the task but are not allowed to do drug rounds. [I noticed a few wriggles in the seat, I knew, as has been outlined, that RNs delegated the task of giving medications in the hostel to Careworkers, but no-one spoke up about this] Rosita went on to say that there must be a medication dispensing system where residents are easily identifiable, e.g. photos taken every six months. [I had previously recorded an agency nurse going round with the medication trolley saying the photos did not look anything like the residents] Next Rosita reiterated the five Rs of drug administration. As the audience began to get restless at what I perceive they saw as routine and basic information Rosita changed her tack and began asking the audience questions. The first was to ask if anyone had seen a recent television program on Hinch where 'a 16 yr old lad burnt a resident in the bath'. She then asked the staff 'how do you test the bath water for residents?'. Bertha replied 'With my elbow' which drew a rejoinder from Rosita of 'what's the temperature of your elbow? Could you stand up in court and say I use this?' gesturing with her elbow. One staff member then said a thermometer is needed, which was obviously the right answer, although Rosita then said she had never seen one in use in any nursing homes. Another staff member then said 'ask the resident' and the reply from Rosita was 'what about the demented souls?'. Before anyone else could come up with suggestions Rosita informed the staff that a suitable range of temperatures had been documented and was available from a local Government authority. She acknowledged that 'these kinds of things did forget the humanities', however 'common sense doesn't work'. The staff looked as confused as I was at the outcome of this discussion and there was a pause and a ripple of grumpy sounding whispers in the audience. The staff had been told the 'official information' but it was a totally pointless piece of knowledge which gave no answers but left a threatening atmosphere.

In what seemed like an effort to bring some reassurance to the group Rosita then began a discussion about the benefits of working in 'this' organisation which was more likely to provide a safe system of work than others, such as private industry. She indicated that this was to show that her next topic, about orientation of staff, was
not directed against 'this' organisation [who, after all, were paying her]. Rosita indicated that many residential care facilities say that the introduction of an orientation program is too hard and therefore give 'on the job' training instead. In the case of the boy in the Hinrich program he was off the street. The staff interjected and said 'we take them off the street', but the subject was then changed back to the way of avoiding the problem of someone getting burnt in the bath. If everyone followed the 'policy' it should not happen. Rosita asked 'Is there a policy here that someone must stay in the bathroom at all times?' The staff's retort was to ask her 'Isn't it the resident's right to ask you to leave?' No discussion of this point ensued. At that point in the meeting residents who were in the room began to cause interruptions and people were coming in to ask staff questions. It seemed to be accepted by all that these interruptions were inevitable. Interruptions are a constant in nursing home work and this was just one other example of how they are tolerated and work goes on around them.

Rosita paused until matters seemed to be settled and then began a story about a depressed resident of ethnic background getting burnt in another nursing home. This resident had indicated that she wanted to kill herself. During handover she set fire to her room and herself. The care plan had said she needed to be assessed at 15-minute intervals. Rosita commented that was ludicrous. If that was the case she should have been in an acute hospital or be having one-on-one attention. The resident died from her burns and the Coroner found negligence. The message the staff were to take from this was that 'Families may be angry and sue you in a court of law, we all know that after a fall the resident deteriorates. Families may think about this and sue you after the resident dies. One way of dealing with this issue may be a policy change.' General discussion and more interruptions ensued and while Rosita waited a careworker asked 'because of the way the law is going - how will it effect legality of un-trained staff?'

Rosita answered, 'This organisation has policy of employing enrolled nurses - but before we devalue nurse assistants - they can be efficient .... ENs will require further training. RNs will need re-training as they have been thought of as 'medical model stereotyped nurses' in the past.'

The lecture continued with much discussion about occupational health, a safe work environment and the penalties that are awarded if shortcomings are found. Rosita indicated that 'You can be fined $1000 for blatant disregard of policy and procedures' [In South Australia employees are covered by the Wrongs Act which gives them protection from being directly sued for negligence, but this was not outlined].
The RN who worked night duty at that time was asked by Rosita what she did if she was needed in the Hostel. The RN replied that in an emergency she would have to go because of duty of care but she is aware that she then breaks the law by leaving the nursing home because the Nurses Act says RN must be "on site". No solution is offered but the comment is made by Rosita that it is "an unfortunate exercise" that the hostel is next door.

More stories are told about difficulties that occur in nursing homes that end up in court and then warnings are given about the grounds for instant dismissal.

There is a then discussion about GPs signing medication sheets. Charmaine says that two of the doctors insist that they only have to write scripts. Rosita said she did not know how to answer this but that the new drug legislation says phone orders must be taken by RN and 'responsible person'. Giggles from audience - the comment 'get a resident' is made. A discussion about safe system of work is interrupted by the incident with Audrey. The audience is getting vocal and emotional when discussing dignity and risk. One RN then raised the question of a resident that refuses to take medication. The resident demanded that she should take her medication when she wants to. Rosita suggested that they can give her the tablets to self-medicate but the staff question their liability if 'she takes the lot'. Rosita's reply was that you cannot contract out of liability. Your assessment will count that she is capable of self-medicating. Any risk forms are 'useless, worthless bits of paper'. The staff are getting more and more agitated. Neither Charmaine nor Rita get involved in the discussion. Everyone was talking at once so issues got confused. The conversation drifts back to the resident who is refusing sedation. Someone calls out 'Night staff should be evaluating her'. Night staff then shouted out 'We are not allowed in her room. Do we wake her up?' Lots of discussion and staff begin to argue. Rosita interjects with 'This is ridiculous, there is always another point of view.'

No-one takes any notice so Rosita tells a story about a person with a fracture and dementia being diagnosed with a fracture of L4 and probable fracture of L5. The resident was sent back to a nursing home to be nursed conservatively. Rosita expresses this as 'In other words - in brackets - they didn't want to keep her'. The story continues about a male EN - with a difficult personality - who lifted this resident, injured his back and will win his case against the nursing home because RN had not changed the care plan since the fracture. A further
discussion breaks out about care plans. Again everyone talking at once because the session is raising questions that worry the staff but all they are getting out of it is intimidation and generalisations such as 'duty of care' and 'documentation'. One staff makes the comment that 'if we are going to do weekly progress reports the mind boggles!'. This refers to the extensive documentation needed for the residents when they are going through an assessment period. At this point the lecture/meeting just broke up, with people getting their bags and standing up. Bertha lead the charge.

Staff were commenting to each other as they walked out of the room 'It's really scary isn't it?'. When I go into the staff room Bertha is talking about Audrey. She is obviously really upset and nearly in tears. I had rarely before seen Charles, one of the maintenance staff, join in any conversation or express an opinion but this time he animatedly participates in the heated debate to tell a story about a resident who did not get his driving licence renewed and says 'He cried when he was telling me'. Bertha said Audrey should be a test case for the RCI. 'They should see the kind of care she needs. She'll be in that room on her own for hours. The girls won't go near her till 8 o'clock tonight... Government tells us to give holistic care. This is my dilemma, every Monday to Friday.' [Bertha gets Audrey up and showers her every Monday to Friday morning] Audrey will sign the risk form - its freedom for her.' Bertha shouts out the word 'freedom'. Then she leaves to have a cigarette in a flurry of anger and emotion.

This illustration shows the difficulties in using the rhetoric of education as a panacea for change and the uselessness of an insistence of documentation as if it is antidote to unsafe practice or protection from the law.

This synoptic demonstration also highlights the ethical stress for geriatric nurses that arises from imposed rules and regulations, without acknowledgment of the reality of care. Rosita did no better or worse than any other educator trying to do the same job. Staff are trying to do the thing right, but is it the right thing? Present policy and the education that is linked with it is not facing the reality of nursing home care. Much that is present in today's care has benefited from the reforms of the past, and therefore it is imperative not to move too fast or too far along another trajectory. For example, many of the ideas contained in the SRV philosophy are highly suitable for assisting older people to maintain an interesting and vital life in spite of deteriorating health. For those who want to 'let go' of life the philosophy can seem cruel. For those
who want to hold on to life while suffering from debilitating chronic conditions and seek care to do so. Shared responsibility for risk will need further clarification.

**Environment, power, staff roles**

Beachdale is an example where, on the surface, the best outcomes of SRV are apparent. Medical equipment is disguised. For example the medicine trolley looks like a cabinet and the nursing notes are kept in what looks like a chopping block. Each resident has their own room and familiar furniture and belongings around them. However, in probing a little deeper these environmental considerations have both positive and negative outcomes. The negative aspects are particularly noticeable for the frail and demented residents. For example Bernadette’s suffering was increased, rather than decreased, by the isolation of her mother-in-law during her dying. Staff at Beachdale had to constantly pressure for equipment, such as the Q-chair Mrs Walker was given, for the safety of the residents and their peace of mind. Chairs such as this and items such as lifters are considered inappropriate in ‘normalised’ settings.

Bayside had tried to ‘normalise’ the environment by hanging plastic flowers in baskets in the corridor and putting a frieze halfway up. The DON and staff were very pleased by this but did not want this commitment to ‘normalisation’, as they understood it, to go too far.

The SRV protagonists, who are very vocal in South Australia, are, like its main advocate, Wolfensberger, male. Gilligan (1982) suggests that a policy position, that of rights and justice for the aged, would be an ethical position generally dominated by men, but attached to that position would be the inherent power positions that society favours. There was a perception amongst the senior nursing home staff that the role registered nurses can play to balance the merits and limitations of both the medical model and this ethically held position is frustrated by the fact that it is males who hold the power. The gender balance problem surfaces in the following kind of comment from one of the staff discussing the question of control in the administration of the nursing home:

> men, who don't really have the same role, and don't have the nurturing, caring mothering role, and they haven't been brought up with that, make decisions for women.
This perception of the lack of nursing influence is not new, and is not only a feminist matter. The question has been analysed and documented widely. As Enid Jenkins says:

...despite a large knowledge about and skill in delivering nursing care, nurses have been unable to influence health policy and implement changes to improve patient care. (Jenkins, 1989, p.193)

She goes on to indicate that this is changing with nurses' desire and determination to be more autonomous in the work setting; to exert greater control over nursing practice and to participate equally in decision making about patient care especially as it affects nursing practice, nurse work loads and the quality of nursing care services. (Jenkins, 1989, p.194)

The staff at both nursing homes indicate that this is the case for them. They see both public policy, patriarchal medical practices and the restraints of SRV philosophy as impacting on their inability to practise nursing as they desire.

It is clear from the view of registered nurses, careworkers, other staff and residents' families that an emancipatory intent of this study should be to change both the perception and practice of patriarchal power and public policy to allow nurses more autonomy and control. However, this needs to be in consultation with medical and para-medical staff. Nurses are very important in the death process of a resident with dementia and can be pivotal, but this study would support the need for a team approach as the optimum in quality care. On the other hand, the illustrations of the staff meeting about Bernadette and the educational session at Beachdale shows how this will fail if consultation is not planned and organised and a philosophical position clearly articulated. Also the examples of horizontal violence amongst the staff need to be dealt with before any collaboration can be truly effective. The present role of nursing home work and the needs of frail residents with dementia will also need to be clearly identified. Concurrent with this the present powerless position of the workers will need to be reversed. All this will require further research that concentrates on the contextual nature of clinical challenges.

**Present social/economic context**

The bulk of the field work for this study took place in South Australia from February 1992 to July 1993. This was a time of recession and high unemployment. Many of the careworkers in the study were sole parents, or had partners who were out of work. This had a marked effect on their behaviour, reaction to policy decisions, education,
motivation and the subsequent outcomes in caring for the residents. Much the same
could be said of the RNs. Those who wanted to implement progressive ideas,
challenge the status quo or put into practice ideas learnt during their studies were
often frustrated. The syndrome of 'not rocking the boat' because of fear of losing
their job, or being the one to get their hours cut, was evident.

Staff's perception was that the need to reduce nursing home hours was deliberate
government policy. For example it was stated as fact by a senior staff member that:

the SMTs have a certain number of hours in mind that they are going
to cut down each nursing home.

The day before this staff member made this comment she had been to a seminar
where, she reported, a staff member from another nursing home had said that:

things were going to get worse. New RCI coming in sometime in April.

The spectre of a new RCI rating led the staff to anticipate further staff cuts. The fear
of unemployment was further fuelled by newspaper reports such as this one which
said:

There are more than 1000 qualified nurses registered as unemployed
in South Australia - and nursing authorities say this number is only
the tip of the iceberg. Nurses fear that further funding cuts to SA
health services will boost the level of unemployment in the profession.
(Hailstone, 1992)

This economic imperative for the staff became an important background issue to the
cultural milieu. Hours were cut regularly and the despair this caused took a lot of the
staff's energy, which meant less was available for the care of the residents, who may
well have felt the tension and anger in the staff as they worked. After an episode of
hours being cut the first thing I would hear when I walked into the nursing home was
that 'it [hours being cut] had happened again'. Information about 'the cuts' was saved
for me. Staff would talk to me about it as I was visiting residents or walking with them
as they did the medicine-round and so on. The anger and frustrations sounded in
their voices and they would complain more of backaches, tiredness and feeling
stressed. For people with dementia these underlying moods have a great effect on
them. It is not possible to give quiet, calm, patient care when you are worried about
putting food on the table for your children or paying the mortgage. Gaynor, a
personal care attendant, explains what the insidiousness of the threat of reduction of
hours meant to her and how she is able to cope with that by putting into context. In
spite of the personal hardship for her she had attempted to rationalise why it was happening.

G: Well the shift that I'm on for instance, the 3 till 9, it was 3 till 11 and now it's 3 till 9 and so there's two hours gone in the last 2 or 3 years. I lost a half an hour earlier on this year to 9 o'clock, 12 months ago it was at half past 9, before that it was at ten o'clock - so because my shift by and large isn't as intense as the morning shift, - from 7 till 3, because they've got 2 meals to prepare and it's more to get residents dressed, showered and breakfasted and all of that than it is to do the reverse, - so I guess when the system is under pressure and funds have got to be made to go further then they've got to cut time.

J: Where do you think that comes from, what explanation are you aware of?

G: Oh well, you get all the explanations and I accept them with a degree of salt.

J: What explanations do you get?

G: Well, that there's no money, that there's no funding, so therefore the nursing hours are cut so your time is cut.

J: Why do you accept them with a grain of salt?

G: Because that's only the small picture, the bigger picture's a lot bigger than that and sort of starts getting into my views on politics and the economics of the country, that's outside of this.

J: But just give me some idea of what you mean by that

G: We're only a small population, nationally, there's only about 17 million of us and we're not all workers, some of us are aged people, some of us are too young, still at school, some of us are parents that are not working, so there isn't a lot of people earning a living that are paying the taxes to support all the things you see. I mean Australia doesn't have the population that one of the major cities of the world possesses, I mean a city like New York or London absorbs us as a population. And I think we lose sight of that a bit. We sort of think that there's a lot of people in Australia, but we're hardly one city, if you put us all together on a national . . . if you look at us internationally with some of the biggest cities in the world, so we don't have the funds and when we are going through economic times that we are and the social security bill is getting so big that the government can't fund it. And I think, and this is probably my tunnel vision, aged people are not the only people that are in care these days, its not just the type of support they need a lot of other people are needing because of car accidents and injuries like that and they're a lot younger and I
think there is still this perception that because you are in a car accident at thirty and you now are in need of care you have more time, you are going to be around longer, you've got to be made more useful whereas for someone who is 80 odd or 90 odd it's just keep them comfortable.

J: How do you feel about that?

G: Well, it's true I suppose to a point but some people are young at 80 and some people aren't, but then I guess the ones that are still relatively young at 80 probably aren't in here. But, you know, you can be young in your mind.

Many other staff were far less pragmatic and more concerned about the here and now rather than the larger picture. Also, often the way the cuts were implemented caused anger and frustration as it seemingly took no account of their own personal lives.

At one tea room conversation when the workers are discussing another cut in hours they say they have been told on Saturday that the change would take effect from Sunday. Francis, a care-worker, had made plans to leave at 1pm but when she came on duty there was a note in the communication book which says the change will start on Monday. Francis therefore had to stay the extra hour and keep her family waiting.

The staff discuss these matters with the Union representative, but there is no strong push for action. Again the fear of being singled out for punishment if you make a fuss was prevalent in conversations. A story is told that Rita had called all staff who were on duty on the Monday in question together and says that 'with regret hours must be cut again ...'. She goes on to indicate that if she had had a crystal ball and known about 'the deaths' she would have been able to budget differently and not cut hours so drastically. Rita left the point hanging that the unexpectedness of recent deaths of residents meant that hours had to be cut as the beds were not immediately filled with new residents who had the same RCI weighting.

As I am being told this story one staff member explodes and says 'what does she think this place is for? Fancy not expecting deaths.' The story teller goes on to report that Rita had said that if there were any more deaths she will have to put off more staff. A response to this is that both Kelly and Francis, who had recently attended an in-service training course say 'what was the point of that course if we are going to be put off and what is the point of doing anything else?' [meaning more education].
This analysis leads to the conclusion that the band-aiding responses of more education, better documentation and integrated care are not enough to solve the new ambiguities facing nursing home care. A structural approach is needed which takes into account the changing pressures on nursing home staff.

**Perceived effect of policy changes on care**

A further analysis of the themes 'policy intimidation' and 'juggling care' demonstrate that lack of time and the coercive effects of policy have the greatest effect on the culture of care in the nursing homes.

**Time**

Workers find lack of time to be the most troublesome in fulfilling the 'shoulds' and 'musts' that pervade government reports. The theme was repeated over and over but the people who perhaps felt most strongly about this were staff who had been in the nursing home for many years and had become attached to the residents, to the work and to the nursing home.

For example Sarah, a careworker who had been working at the nursing home for nine years, discusses the changes within that time:

*Time's the biggest one. I mean I can remember when I first started there [the nursing home] that we would have, the residents were actually divided into groups of either five, six or seven residents and each nurse and at that stage there was six nurses on the floor - each had an area (A, B, C, D, E, F, G) so you were responsible for those X amount of residents and the amount of work that we used to do or the amount of care we provided for those residents was a lot more than what it is now. I mean we used to soak their feet everyday you know. Make sure their feet were washed and cleaned and toes were cleaned out between everyday but on a sponge now they would not get their feet washed and we used to set their hair as well. We don't, well we just don't have the time. I mean the breakdown of the ... [here Sarah stops, seemingly finding it difficult to articulate what has broken down] ... the amount of time that has sort of been cut down since the RCI instrument came in I think. It's horrendous. I mean it's not only the nurses either that have been cut down on time, I mean because the nurses don't have time and certain chores have gone onto the domestic side so their times cut down as well and I think perhaps the nursing home isn't as clean as it used to be. Because I can remember when I first started here the cleaners used to wash the walls, where the lino goes up the walls. They used to be washed every week but I haven't seen that done for quite some time, just those little things but*
I'm sure it's since the RCI classifications came in that the time was dropped.

Many workers discussed issues like not being able to clean and cut fingernails or set people's hair. Perhaps more serious were other comments such as this one following a meeting in which the DON tried to discuss the issue of what she perceived as some instances of poor nursing care. The comments in quotation marks are those reported as being made by the DON at the meeting. I attended the meeting that is being discussed in this interview and know that these are an accurate records of the DON's comments. The staff member being interviewed took extensive notes at the meeting as she is the union representative. The staff member is expressing the collective responses of the workers.

She said [The DON] 'Care is declining because of lack of time. Pressure areas are more prevalent in recent times'.

We never had pressure areas, never, never. They came back from hospitals with pressure areas but we never caused pressure areas.

'Extra fluids are not given enough'. That's not a problem when the WorkCover girls are there because one of the WorkCover girls does that but then she's only there two days a week so what happens the other five and that's going to be a problem with summer coming on.

'Two hourly turning and toilet prompting is not carried out.' We used to be fanatical, I think that would be the word, about turning people - absolutely fanatical. Two hours, or hour-and-a-half, whatever hour, on the dot. I remember years ago we had a lady we used to turn every hour because she was just skin and bones and she never got a pressure area, but if we had her today oh I dread to think what might happen actually.

'Hygiene's failing.' I think probably nurses aren't washing their hands perhaps as often as they should. The residents are rushed because of the time factor. Things are getting forgotten i.e. catheter bags being emptied and nurses therefore are stressed because they want to give better care and are not able to because of the time factor.

Time was also used as a rationale for a spate of thrush infections that occurred in Beachdale and a few incidences of non-specific eye-infections causing what were referred to as 'sticky' or 'gluggy' eyes.

J: there have been thrush infections. Can you give me some examples of why you think that might be?
S: Well it should never happen. I mean if you've got the time to do things probably a cross infection shouldn't happen - it shouldn't happen.

J: So the sticky eyes are just accepted as....?

S: I don't know about 'acceptance.' Yeah, I suppose accepted is the right word because and see that's another thing we used to do. We used to do their eyes everyday as well but we don't do now because of the time factor again. And ears that was another one. We used to do ears every week. When you think about it there's a lot that we used to do and don't do.

On the other hand time was not always used as a rationale for falls. The policy of dignity of risk was often the dilemma. The damage that may occur to a resident during a fall is one of the most stressful parts of a nursing day. If someone did fall, then, regardless of how short of staff the nursing home was, or if they had been with the person a few minutes before, the staff blamed themselves for the accident.

Responses from the staff about falls mirrored comments such as these expressing guilt when Mrs Guthridge fractured her arm in a fall.

The careworker says:

I suppose we really should have checked her. Mrs Guthridge is one we don't check on the last round she always got out by herself - commoded herself at night time. I don't know whether that night she was a bit more confused or stuff - I don't know.

The RN had the double burden of blaming herself and feeling blamed by the relatives, as was illustrated again in Mrs Walker's case study. Yet in these difficult situations there is no support for the staff. This is where emotional labour, the keystone of service industry, shows most strain.

Another comment from a careworker expresses her commitment to SRV policy at a cost of personal discomfort to the resident.

Oh I feel terrible that she's fallen and sustained such injuries but that's her dignity at risk of even though she has dementia and is unsteady on her feet, she's ambulant with a frame when she remembers. She's had many a fall. I'm not happy about it but there's nothing we can do really to prevent her falling let alone to restrain her further which wouldn't be very kind to her.

It is clear that when falls are linked with policy it is so that the blame can be shifted to 'them', the bureaucrats who do not supply enough money to adequately staff the
nursing homes. On the other hand it seemed accepted that in no circumstances would there be enough time to prevent all falls while the SRV perspective was dominant.

One difficulty with this perception of time is the changing population in nursing homes. Ten years ago much of the nursing home population who had dementia were able to give and receive the kind of unconditional love that is usually associated with children or animals. Residents could be cared for by a gentle steering to the toilet, a hug, a leading by the hand and a few jokes. Now many, like the residents in this study, are in the later stages of dementia where they cannot walk without falling over, cannot control their bladder or bowels at all and, if they are not hitting, spitting or screaming, have no ability to reciprocate at all, becoming non-verbal as they move towards death.

Lack of time (or perceived lack of time) and control over a workload can lead to burnout in workers. Burnout amongst people who care for people with dementia has been positively correlated with reduced empathy and less positive attitudes towards the people who are cared for (Astrom, et al., 1991). One reason given for burnout is the 'reality vs idealism' dilemma (Nash, 1989, p.443). A lack of reciprocity or reward within a working environment also contributes.

Reciprocity

This lack of time together with the increased level of dementia and frailty of the residents sometimes led to a lack of reciprocity with the residents, an unsatisfactory situation for both parties. The need for attachment and reciprocity leading to optimum care has been discussed by Kitson (1991).

In a study that explored the factors influencing the care-giver (in this case a family) to continue living with and caring for an old person with irreversible senile brain disease, Hirschfeld (1983) found that it was in those situations in which a mutually reinforcing relationship existed between the dependant and the carer that the patient was cared for and coped with at home. More significantly, in situations where low mutuality or no mutuality existed between carers and dependants, Hirschfeld reported that the relationship was in jeopardy and disintegrating under the strain. (Kitson, 1991, p.14)

At Beachdale every visit, for myself and every other person who went into the dementia unit, meant meeting Peter, a resident with dementia not included in the study, and being asked by him where his wife was, if she was coming to see him and where he was. At Bayside it would be Amy who would wander up and seek attention. Amy would stand and look at strangers, but would constantly ask staff questions. Anyone looking at either of these people without knowing their history could think
they were well looking and fit. Both have an engaging manner and winning smiles and their initial conversation, taken out of the context of a nursing home, could seem like that of a friendly, slightly confused, lonely old person. This confabulation type behaviour can lead to very strong bonds being formed between these people and staff. Staff often act in protective, rescuing ways, as a mother does with a child. That this aspect of care is 'forbidden' by policy is constantly referred to by staff. Field note recordings demonstrate one aspect of this.

 Madge calls Celia sweetie and darling - says she knows she is not supposed to - that RNs are always telling us not to call them sweetie and darling - SMTs don't like it - RNs tell us it is OK in the room but not when any people are around.

Many similar recordings show that this aspect of demonstrating affection seemed to represent a reciprocal kind of relationship the staff had with these residents. A great deal of cuddling, kissing and physical affection was shared between residents and staff in both nursing homes. However I also recorded occasions when this reciprocal relationship was not present and people were treated and spoken to sharply, as if they were a nuisance. On the other hand, when there were frustrations with the residents of whom staff were particularly fond their irritations were expressed in a gentler way, usually encouraging and cajoling as one would with a child. An instinctive contact seems to often occur between staff and residents with dementia. Staff feel the resident needs love and comfort and unconsciously give that by physical and verbal means at the same time. On one occasion as I was taking a photograph of Amy after a fall I also took one of Kelly with her. The photograph shows Kelly hugging Amy and I record that as it was happening Kelly says to Amy 'we love you don't we? Come on give us a cuddle too'. On another occasion I asked a nurse assistant who had called in with her grandchild on her day off why she had brought the child in. I received a look which indicated that I was a bit slow on the uptake and a surprised reply: 'because the residents like it'. For her this was so obviously the reason she would do it that my asking the question seemed strange. This kind of 'loving' is translated into a special understanding where the staff have a certain knowledge of the language of dementia which outsiders cannot understand unless they are prepared to learn it.

Residents, relatives and staff have various ways of coping with the behaviour that emanates from the deteriorating brain function that the plaques and tangles of Alzheimer's disease bring. For one worker it is a challenge that she enjoys but as she is describing these feelings she reflects on her own words and wonders about her motives:
I get a lot out of the work here. I like aged people, I like the type of people that we get now, the dementia type and I know a lot of people working in aged care find that difficult but I could have all the people here dementias and it wouldn't worry me in the slightest.

... I think probably because dementia quite often brings out an exaggeration of characters that we would never see in a normal life, our characteristics that we hide away from other people because society might think they're a bit strange. When people become demented, even in some of the earlier stages, these characteristics come out and sometimes they're the nicest characteristics we have and even though dementia people will sometimes go quite off the bend, become aggressive or whatever, if you can understand what dementia is which I think is where a lot of nurses fall down or the nurse assistants fall down is because they don't understand the nature of dementia then you don't take it as a personal thing, you take it as the disease acting out, not the person acting out and you're always aware that this will happen at the drop of a hat. Someone who's been very nice to you will suddenly hit you or something but I don't find that a problem but I think because some of their nicest characteristics come out and because if you're nice to them then you can see the difference, you can make their mood for the day. I suppose that's a bit of a power thing isn't it?

What is being talked about here is a feeling of reciprocity. For this staff member the person with dementia provides an opportunity for her to see rewards if she does her job well. This was not the case for all staff.

Turner (1987) has discussed the issues of reciprocity and the movement of people from one side of the exchange relationship to the other throughout life. Reciprocal relationships can break down when people have dementia. If staff can establish or maintain a relationship through some kind of reciprocity such as Mr Price's smile, Mr Small's need for privacy, Amy's clinging or Mirabel's screaming, there is some reward. It is difficult in those cases where residents appear to the nurses to be deliberately making life difficult for them, whether the residents are demented or not. Comments like 'she's a sphinx', or 'didn't get to know her well', mean that that person may well have been left for hours every day with virtually no human contact and when there was contact it was unsatisfactory for both parties. Sometimes if a reciprocal relationship cannot be established with a resident, the relationship staff make with their relative may, instead, provide the satisfaction that reciprocity gives.

The reciprocity that is present contributes to staff satisfaction and a feeling that they are doing a good job. In both nursing homes if staff became intimate with a resident
they would often do small things for them if they felt they needed it. One example is Madge knitting booties for Bernadette when her feet first began to get cold and her heels sore. In other cases no contact or sharing seems possible. As one staff member put it:

You know there's some people, I mean not all old people are nice sort of people, and some are very self-centred because they're scared that if they're not self-centred no-one's going to look after them but they really genuinely care about how the nurses are feeling and how they're being hurried or their times being cut, and they care about their families and you can tell because they like to hear about the families and also because they do little things for the nurses

... I don't keep a track of who does what but I know that nurses take, not everybody's, but certain nurses will take certain resident's jumpers home and wash them, other girls take certain residents' things home and mend them, other girls bring in things like handbags and jewellery and whatever that they may have and they don't want, either their Mum gave them or they brought it for their mother and she doesn't want it so they bring it in and give it to somebody else rather than, you know and things like perfume and that. If they know someone who particularly likes it and its usually the people whose relatives don't visit and we've got an awful lot of residents whose relatives see them on a very, .... hardly see them, maybe its, you know, special occasions type visiting and the girls look out for them ... the smokers make sure that the people that do smoke - and we've only got the two of them - that they have always cigarettes. It works both ways. There's some residents who breathe a sigh of relief when they know one particular nurse is on. You know a different nurse for a different resident. They do that ... it must be a benefit to both.

For relatives this attachment by nurses to what they see as the shell of the person they once knew is either a source of comments such as 'the girls are wonderful' or a reason to leave the person 'in their hands' so that they can remember their relative as they were, or because they see 'no point' in visiting as the person 'does not recognise us'. For those who believe in the sanctity of life at all costs the answer to these dilemmas is not to implement palliative care but to find a new role and life for these residents who are incontinent, non-verbal, non-ambulant, not able to eat by themselves and failing any longer to recognise their family or friends.

Somewhere there is a point of balance between all these conflicting opinions and habits of mind. Defining and maintaining such a balance would involve, first, regarding people with dementia as sentient beings who deserve not to suffer rather
than deteriorating bodies with an absolute right to continued life. We will be required, in the process of achieving that balance, to define comfort care in a positive light and to acknowledge that such care may require our understanding of the 'limits to treatment' approach. The word 'limits' will have negative connotations and an alternative language will be useful. It will be important to develop a regime of care within which staff could enjoy a feeling of control, well-being, equality and reciprocity. This allows the difficult work of emotional labour to function at its best.

When looking at the reality of care for residents with late-stage dementia from a new perspective, money to provide services will be dependent on society's attitude to the worth of such care. As the quality of life movement and casemix come into being the regulators will have an even greater control and, if the workers in the field don't do it first, economic rationalists will determine, albeit de facto, quality-of-life. The scenarios I have described in two nursing homes may well then be repeated in various forms over and over, but will be worse because some of Wolfensberger's (1987) fears will be manifested. Care will deteriorate and people will be neglected before they die.

**Intimidation**

The fear generated by present-day policy and the effects of the economic depression have impacted on the accountability procedures of nursing home staff. When staff are dependent on an income that relies on the hours that can be squeezed out of the RCI funding there is not a climate in which whistle blowers flourish or good advocacy practices are encouraged. Dealing with the present realities of nursing home care would assist in not putting staff in the impossible positions they find themselves today, struggling to advocate for residents' rights. Part of this struggle is also an unarticulated and subconscious cry for their own needs and rights to be met, to be given the resources to do properly the job they want to do, the job expected of them.

One staff member describes the intimidation she feels within the present policy guidelines:

> We get threatened by - if you don't get all the documentation right, you will get a letter to say that this is your first and last warning and you will be out the door, now people can't give that care if all the time they are getting threatened, they can't do it, we are looking after people, we are torn into three or four different things, we have got the government, the SAM team, the GAT team, we've got RCIs we've got everything if there's all those teams that are coming to get us, to
I have already described the fear felt by the senior members of staff and this filtered down through all aspects of the nursing home culture. The background of intimidation meant staff perceived that if you did not comply with policy you would be fined, lose your job, lose hours, lose your registration or end up in court. This stifled creativity and had a flattening effect on any efforts of educators, trainers or administrators who would attempt to redress this. If a change in care moves towards a hospice or palliative care approach the need to redress the fear of staff, if they acted as whistle blowers, is imperative in preventing the protagonists of the 'slippery slope' argument being correct.

Within the nursing homes there was little awareness of the implications of new legislation surrounding issues of euthanasia and palliative care and the changed societal moral stances flowing into and from this. The staff were still coping with the last wave of social pressure, that is the move towards a 'homelike environment', the implementation of the Outcome Standards and the new system of classification of care. It is on to this culture that the new expectations and law will be imposed. Any debate about the emancipatory outcomes of this study will need to recognise its limitations and potential for abuse.

New policy directions

Social movements becoming dysfunctional

The Aged Care Reform strategy, originally a social movement which gained much support from all sections of the aged care community, has moved from revolution to bureaucratisation to routinisation to oppression. The fact that imposed order or directed social change can become a weapon of oppression is not new.

Kuhn's view of scientific change is rather like Marx's view of social change. According to Marx a new socio-economic order (for example, feudalism) emerges and holds sway for a time; then it develops 'contradictions' within itself until the prevailing order cannot any longer cope with them or contain them; it eventually collapses and a radically new social order, discontinuous with the old one but bearing certain of its features, emerges out of this revolutionary situation (Charlesworth, 1982, p.35).

Similarly, Kuhn sees the dominant paradigm in any knowledge-based endeavour as going through revolutionary change from time to time when it becomes obvious that
the old paradigm's rules about problems, evidence and answers are no longer adequate to encompass the shifts in and acting on the field.

It is certain that the contradictions of this revolutionary change are emerging. Both nursing homes can be described as total institutions (Goffman, 1961). Within total institutions the power is manifested in those who control their functioning. This must not continue to be the case if an environment of consumer choice and right to choose a mode of death is to be the case.

In spite of the present-day rhetoric about rights and choices both workers and relatives felt that the top people in the nursing home hierarchy made the decisions and they were not made in a spirit of consultation.

One worker says 'I'm sure that what I think doesn't matter, doesn't make any difference at all' while two different relatives have the same view. One says 'They never ask me. They never say,' meaning both nursing and medical staff. In response to a question about having opinions about treatment for their relative another says, in a tone of surprise at the question, 'No, no, we just leave it to the people here. I didn't think we had... couldn't interfere, I don't know.' The fading off of this remark at the point of 'I didn't think we had' was fairly typical of the difficulties some relatives had in considering they may have any opportunity for opinion or control within the nursing home culture.

Any new policy will need to be discussed within an environment where quality and accountability measures are going to be greater than they are today. Public policy will need to move into the realm of publicising and encouraging people to think about Advanced Directives, or indications of death choices, in a progressive and sensible manner.

**Advanced directives**

Whatever position people hold within the euthanasia debate or the debate about whether people with dementia do suffer or not, it seems clear that there is consensus now amongst ethicists, lawyers, physicians and nurses that if a person has left clear instructions in the form of an advanced directive about limits to treatment then those wishes should be honoured (Binstock, et al., 1992).

As Ronald Dworkin says:

*Making someone die in a way that others approve, but he believes is a horrifying contradiction to his life, is a devastating, odious form of tyranny* (Dworkin, 1993, p.217)
Staff at both nursing homes are ambivalent about how families can cope with such decisions and how much they just really want to go along with what is suggested by the GP. One says that a GP may say to the family:

_You know this is the situation. What do you want us to do? These are your options, do you want us to be active in our treatment or should we be conservative and let nature take its course? I mean the relatives have the decision and they sort of... the other day... this chap had CCF and he [the GP] said you know 'What do you want us to do? I can give him an injection of Lasix and it will ease it off but other than that he has to go down to the hospital and have this, this and this done. Now how do you want us to go?' and the family decided I mean he had emphysema and obviously it really wasn't going to help him that much. So he had his injection of Lasix and stayed with us and he'd gone in a couple of days._

Both nursing homes recently chose to include a copy of the South Australian _Natural Death Act 1983_ in the folders that relatives of prospective residents receive when they make enquiries about the nursing homes. However, taking the process further to actually getting any opinion about attitudes towards limits to care in order to provide comfort is difficult. As Charmaine says when discussing both staff and relatives' attitude towards the question of the inclusion of the _Consent to Medical Treatment and Palliative Care Act 1995_ and the change it may, or may not bring:

_I don't think it will change care. It certainly won't change my attitude to care because I think now I see sometimes with the nurses that residents who've been here a long time and they hate to see them get sick. You have to keep reminding them that people here are in their last stage of life and that's why they're with us. That's probably the hardest thing they have to cope with but they also have this other side that you know you shouldn't be antagonistic to that idea that they shouldn't be put through any unnecessary traumas. They don't want them to get sick and die but they don't want them to be, you know they don't want to shift them off to the hospital to have great things done to them to make them uncomfortable so I don't think it will have any great bearing on them. I think it will scare relatives with it being given out because we put a Natural Death Act form in our resident's file now and all the papers are there. I go through some of them to say you know this is what you are entitled to be provided with in the nursing home and this, this and this and I don't touch on the Natural Death Act too much but that's there for them to see and to take in and then perhaps later. There's not very many aged people that are that definite except they will in a vague way say 'Look you know I don't want anything, I don't want too much done if I get sick' but none of_
them are really that strong that they say 'Give me that paper to sign please'.

But this situation is likely to change, and plans will need to be in place for those who have left firm instructions that they want 'not too much done if they get sick'.
Part 3

Conclusion
Chapter 7

Changing the focus of care

Introduction

If aged care policy continues with the present underlying principles then the purpose of nursing homes within the next two decades will be to maintain the deteriorating bodies of people with dysfunctional brains. This thesis has argued that all the residents who are suffering from late-stage dementia in this study, who are not dissimilar to many other residents in nursing homes, were cachectic, certainly from the time they entered the study, and probably from the time they entered the nursing home. It also maintains that cachexia, described as a 'a profound and marked state of constitutional disorder, general ill health and malnutrition' (Miller and Keane, 1978, p.160), is an inevitable result of the condition of dementia unless another person is prepared to give their life to the 24-hour care of that person, or society is prepared to tax the rest of the population heavily enough to pay for continuous 24-hour care for people with dementia at a level that will prevent this happening.

This thesis presents an argument for policy change that leads a movement towards palliative care practices for people with late-stage dementia. It has postulated that it will be important to take into account choice by the person with dementia in the form of an advanced directive and the implementation of that choice by their advocate, accurate diagnosis, democratic decision making and questions of morality, but most of all, the culture of the institutions in which this dying will take place. This final chapter will discuss methods of palliative care that may be particularly suitable for residents with late-stage dementia in nursing homes. These are very preliminary conclusions arising from this study which will need much further exploration and investigation.

Dementia palliative care

Only some of the ideas and techniques of the palliative care movement are transportable to other terminal illnesses, such as AIDS and dementia. Both Saunders and Maddocks, leaders in the palliative care scene, still emphasise cancer as being the primary reason for the use of palliative care. The first sentence in Saunders' (1990)
book, reads 'Helping people with advanced cancer calls for more skills than any one individual can command' (Saunders, 1990, p.3). The book goes on to outline palliative care from a team approach. Much can be learnt from these approaches and the experience that practitioners in the palliative care movement have gained over many years of practice. As the euthanasia debate gains momentum some practitioners are being open about the limitations of palliative care. Hunt (1995) says:

Surveys indicate that 50-80% of terminally ill patients have concerns or troubling thoughts about death, and that only a minority achieve an untroubled acceptance of death. Hopelessness, futility, meaningless, disappointment, remorse, and a disruption of personal identity are frequently experienced. Unfortunately, there is very little research showing the extent to which these problems can be ameliorated with professional intervention. I suspect that many of the psychological and existential problems of dying patients are resistant to palliative intervention.

The hospice ideal, to provide a painless and symptom-free, comfortable death with dignity, is usually unobtainable and should not be promised. It is a rhetorical myth that hospice and palliative care can relieve all the suffering associated with the advance of diseases like cancer, AIDS and motor neurone disease.

An approach to palliative care for people with dementia will need to be different from that of a conventional hospice. When a cancer cannot be cured it is accepted that it will become terminal, yet even with access to optimum palliation, Hunt (1995) indicates that relief of prolonged suffering may not be completely possible. SDAT cannot be cured yet it is still not accepted as terminal and therefore those who suffer from it are not eligible for palliative care. I argue that the only differences between cancer and SDAT are timing and types of symptomatology. We may not be able to assist with all aspects of palliation for people with dementia, but much more can be done than is at present.

There does come a point in the trajectory of a dementing illness when decisions could be made to change to palliative care, rather than care based on principles as outlined in the Outcome Standards (Commonwealth/State Working Party on Nursing Home Standards, 1987) or accepted within established nursing routines. However, it will be hard to implement a less interventionist role without a change in policy. In their guide to duty of care in relation to the Outcome Standards, McDonald and Bates pose the question 'Are staff and proprietors legally responsible if residents refuse nursing home services which are necessary to their well being'.
Their answer is:

Provided the person refusing the services has an understanding of the consequences of such decisions ... health maintenance services cannot be forced upon the resident ... Documentation of the details of the situation is essential ... The primary reason is to provide continuity of care for the resident in the hope that through nursing care she will not suffer skin breakdown. (McDonald and Bates, 1989, p.21)

In the present context the practical effect of this kind of analysis forces a philosophy of body maintenance on staff. If staff do not comply with the Standards 'this may well be a breach of their contract of employment, and be grounds for dismissal' (McDonald and Bates, 1989, p.5). Since a person with late-stage dementia cannot make an informed decision, and the role of advanced directives is still in the formative stages, the only way towards the change I propose, at the moment, will be the creation of an agreed position by government bureaucrats, GPs, nursing home administrators, nurse clinicians and family. Although I have long been an advocate that the nurses in the Standard Monitoring Teams look under the bedclothes rather than at the books, the comment in the Braithwaite report that:

If there are residents with pressure sores, the nurse on the team should always observe the treatment of all those sores that occur during the day of the visit (Braithwaite et al., 1993, p.77)

is likely to lead to a new set of confrontations between nursing home staff and government inspectors if nearness to death continues to be marginalised.

The stories of the residents in this study show body breakdown notwithstanding nursing care that was exemplary within the confines of the resources available to them. These traditional methods of nursing care that keep bodies functioning so long after the mind has gone warrant examination.

In contrast to the well-ordered world of hospice care there was no consensus as to what 'conservative care' or 'nursing care only' meant when alluded to at Bayside and Beachdale, either verbally or by writing. The sentiment and attachment to residents that has been described is often a paradox, contributing to care that can be fragmented and disorganised rather than consistent and holistic. The illustrations of the spasmodic giving of morphia is a case in point.

Before we can go on to talk about how to relieve suffering for people with late-stage dementia it is necessary to outline the parameters within which this subject will be discussed. The findings in this study challenge the accepted routines of geriatric
nursing care that have become cemented in place since Marjory Warren's pioneering work in Britain in the nineteen thirties (Norton, 1990), through the reforms of the sixties (Robb, 1967; Norton, 1967; Goffman, 1969), the effect of Social Role Valorisation (Wolfensberger, 1975) of the seventies and the involvement of government reform and regulation of the eighties and nineties (McLeay, 1982; Senate Select Committee on Private Hospitals and Nursing Homes, 1985; Ronalds, 1989; National Action Plan for Dementia Care, 1992; Department of Health, Housing, Local Government & Community Services, 1993; Human Rights & Equal Opportunities Commission, 1993; Clarc and Tulpulc, 1994).

The conclusion to this thesis will propose that a program of 'dementia palliative care' which can be defined as:

*care which is based on the relief of agitation, belligerence, indignity, distress and pain rather than on life-supporting nursing care* (Abbey, 1994)

is more humane than present styles of nursing home care for people with late-stage dementia. This study cannot fully answer the question about how this care is best implemented. It can only raise an argument that if, as I contend the evidence shows, people with late-stage dementia have enough awareness to be suffering horrifically, then a program that investigates new methods to relieve this torment rather than simply keeping people alive in a homelike environment must be found.

Palliative care has been open to the suggestion that it is passive euthanasia disguised within a medical model of care. Roger Hunt, a leading physician within the hospice movement, suggests that the rejection of the idea of euthanasia within the palliative care movement has been slowly moderating and that now 'palliative care has expanded to include forms of slow euthanasia' (Hunt, 1994).

But once this principle is applied to people with Alzheimer's disease then the 'thin edge of the wedge' or 'slippery slope' arguments, often fuelled by the race-memory fears of the horrors of the Holocaust, rise to the surface of many people's mind. In the literature review I have outlined the connection between the 'slippery slope' argument and societal attitudes. It is immoral attitudes that might drive care that was intended for good to deteriorate into care that was intended to harm. The debate about the 'slippery slope' argument will be determined by history. Today we can only work within contemporary knowledge. If, in the future, harm arises due to the application of these palliative care principles, it will have arisen from the power exerted by those in control. I believe that the three parties who are the main decision
makers in aged care today, government bureaucrats, GPs and nurse clinicians base their interventions on motives that are in the best interests of the residents and this can be expected to continue to be the case. In the future it is to be hoped that the control of care will have passed to a much fuller extent to those who are receiving it, the consumers. The clinicians who cared for the residents in this study demonstrated a level of professional commitment to the residents which was consistent with present public policy. This judgment does not support the belief that they or the public will let dementia palliative care practices become a 'slippery slope' where people with late-stage dementia are killed.

This does not negate the fact that vigilance will be needed; but community opinion moving towards the prevention of unnecessary prolongation of life (News in Brief, 1994), legal confirmation of the right of consumers to seek palliative care, and for health practitioners to deliver it, is likely to result in palliative care practices being introduced into nursing homes (Hunt & Maddocks, 1994; Abbey, 1994).

Before any model is constructed to regularise the present confusion and give it sense, form and direction, a consensus will need to be reached on the answers to some very important issues. What will be needed is an examination of nursing practice to extrapolate those routines that are life-supporting, rather than comforting, and emphasise those which concentrate on relief of distress. At the moment, in spite of efforts to use music therapy, massage, aromatherapy, and the like, the reality is that, with limited funds leading to a dearth of staff, only a certain amount of such care can be given within a 24-hour period. In many cases it is a myth that the medical model of care has been superseded by alternative nursing or sociological models. This was shown by a recent English study (Reed and Watson, 1994) and by this study. When struggling to cope with a resident who, for example, is screaming, crying or hitting people; or has diarrhoea or seems to have a pain in their leg, nurse clinicians revert to a model of care which seeks to cure these ailments and which shows care by an emphasis on sustaining body functions.

Dying in different ways needs different nursing care. Care of people with late-stage dementia who are dying is a gerontic nursing skill to which the concepts of hospice care can be grafted. This will enable those nurses who have a relationship with the resident to maintain holistic care up to death. Hogstel indicates that 'many nursing homes now provide hospice care, with hospice staff managing part of the dying patient's care' (Hogstel, 1994). This was not the case at Beachdale and Bayside.
Communication with GPs, pain relief and antibiotic therapy

An examination is needed of nurses' expectations when they request GPs to visit nursing home residents with late-stage dementia who show distress. Why do nurses seek curative or relief measures? Some of the reasons that nurses call GPs to visit the residents in the study were to deal with a resident's unwellness, agitation, shortness of breath or the result of a fall.

Whether the GP was called or not depended on the personality and beliefs of the nurse on duty at the time and the outcome usually depended on the same attributes in the GP. Many decisions depended on the relationship between nurses, the resident and the family, rather than the nature of the problem, but were most influenced by the culture of the nursing home and expected standards of care.

In spite of seeking medical solutions, paradoxically, the situation was that nursing home staff would often be reluctant to give medications, including analgesia, if they felt that the effect will 'zonk the resident out'. How much analgesia a resident gets was dependent on a particular nurse's interpretation of the language of the person with dementia. Since pain, discomfort or distress can often only be interpreted through body language, grunts, screams or calling out there is much room for judgements based on values and guess work.

One study has estimated that 71% (Ferell et al., 1990) of nursing home residents suffer from pain, another that only 8% of non-verbal residents with potential painful conditions received analgesia. (Marzinski, 1993). In this study half (seven) of the residents received morphine. In two cases there was considerable anguish from staff that it was not given in sufficient doses to give pain cover and in another case it was only administered once due to nursing staff feeling it wasn't needed. Yet it has been recommended, by nurse researchers caring for people with dementia, that to promote comfort:

*low-dose morphine by mouth should be considered as an analgesic because it has few side effects and addiction to narcotics for patients with late-stage DAT is not an issue (Hurley, et al., 1993)*

It may be the case that morphia will not relieve more of the symptoms in dementia than many other drugs that have been trialed. However, it has been shown that doctors and nurses do not give morphia because of the fear of addiction or of the 'double effect', the morphia relieving pain, but depressing respirations so that death is hastened. Those fears have been examined and considered as unsustainable if good
palliative care is to be practised (Interim Report of the Select Committee of the House of Assembly on The Law and Practice Relating to Death and Dying, 1992).

The diagnosis of pain in the general older population is often missed, even more so for those who are cognitively impaired. Sengstaken and King (1993) demonstrated that 34% of communicative residents in a nursing home did not have their pain detected by treating physicians and that pain was identified even less frequently in the non-communicative cohort. Marzinski (1993) found that 26 out of 60 non-verbal patients within a dementia unit had chronic conditions which had a potential to be painful, but only three of those received routine analgesia. Literature relating to ways of diagnosing and dealing with pain in the population suffering from dementia is very limited (Onley, 1992).

This situation is not equitable or tolerable. Staff and carers interpret grimacing, withdrawing, moaning, crying, screaming, agitation, aggression, not eating and a variety of other activities as being associated with pain. However, in spite of pain being acknowledged as 'always subjective' (Iclinc et al., 1993), when staff express the view that the resident is 'distressed' or 'unwell' the possibility of this being a result of pain was rarely discussed. For example one remark at handover given in a voice weary with frustration and sadness was:

Mrs Guthridge, seen by Dr O'Connor. Discontinue Panadeine Forte. Ordered Panadol 4 hrly. Half a Valium at lunch time today. All he wrote was three words: For regular Panadol.

This was at the time when Mrs Guthridge was recovering from her broken arm, therefore the need for reduced analgesia could be justified in a medical sense. But her agitation and calling out 'Help me, help me' in a very distressed voice means that the she was 'in pain', pain meaning distress according to the subjective and contextualised view of the nurses. Panadeine forte may not have assisted the distress, but for the staff, the fact that she may have been having physical pain caused by the plaster on her frail arm, as well as being distressed by her dementia and institutionalisation, left them feeling powerless in their care for her.

In their study of the problem of pain in the elderly, which included problems relating to diagnosis, Sengstaken and King came to the conclusion that:

Among those who are non-communicative the identification of pain is much more difficult and, as yet, there is no solution to this problem.
(Sengstaken & King, 1993, p.544)

Julienne Onley puts the same point differently. She says that:
the question of how to assess pain in the demented population, especially the severely demented, is vexing. (Onley, 1992, p.12)

But these negative responses to the view that solutions are too hard rest within the present paradigmatic framework. Onley's attempt at a solution for diagnosis of pain in people with dementia depends on observation of factors such as blood pressure, diaphoresis and pallor, and/or observable behaviours that can be interpreted as pain. She suggests that nurses could do well to emulate the diagnostic capacity of vets. Nurses frequently used the same analogy. 'We would treat an animal better than this' was one direct quote but variations on this theme were frequent. Often these remarks were made when the tape recorder was off or the computer not in evidence. These kinds of remarks were made to me when staff perceived me as 'off duty', when I was not recording verbatim, or they would say to me 'please don't say I said that'. This demonstrates the ambivalence of separating care for a sentient being from care for what is seen as a person. Again, paradoxically, it may be kinder to think about diagnosis and care as Onley (1992) suggests, in the way that one would for an animal. Objective measures of what is happening to the resident may then be more easily separated from the needs and emotions of the carers.

If a different paradigm were to be used, that of a well-developed approach to dementia palliative care, then individual solutions to pain could be worked out in a much more effective way than at present.

Analgesia or sedation may not always be the best solution for relief of suffering. Leaving residents in peace may reduce the need for pain relief. Many of the residents in the last days of their lives only seemed to suffer pain when they were being showered, got out of bed or turned. The tensions that arose between the nurses and one GP over this kind of situation have been described in Mrs Miles's case study. The GPs wanted the nurses to stop doing their job so that he did not have to over-prescribe morphine. The tensions that inevitably arise in these situations are described by Liashenko et al. (1991):

When death is the enemy in any circumstances, heroic interventions interfere with care, practice breaks down and moral outrage or disengagement ensues. (Liashenko et al., 1991, p.261)

While this situation exists, the residents will continue to suffer. If the observations and perceptions of nurses, care staff and kin were accepted as diagnostic criteria within a philosophical framework of individual case-study palliative care management they may assist in framing an appropriate care plans for the resident. If nurses and GPs
could see palliative care as a well worked out and caring option for residents with late-stage dementia then some of these tensions could be relieved.

However, to develop these care plans without a shift in attitudes and power will result in continuing to ignore pain in the people with dementia and will result in a continuing failure to recognise and treat the particular pain of the demented.

To establish a protocol of palliative care in nursing homes a redefinition of words such as 'dignity' and 'pain' will be needed in terms of what those concepts mean to an individual person. Debate about issues surrounding the dignity of the job of caring for these people and the way staff can feel valued will also be needed. If the thrust of the argument of this thesis could be accepted then nursing criteria which could act as a basis of agreement that body maintenance was to be reduced could be developed.

Concurrent with making requests from the GP for pain relief is the question of administering antibiotics. Many residents with late-stage dementia spat out the tablets they were given and so in fact receive an incomplete course. For 14 residents in the study who died, all but one, Amy, is reported as receiving multiple doses of antibiotics over the course of their time at the nursing home. The average number of courses during a stay in the nursing home was six. This raises two issues. Firstly, how effective is the treatment for the resident? The comfort of the patient may be far better served by administration of oxygen, sedation and narcotics.

Secondly, how much is the routine administration of antibiotics contributing to the spiralling increase of resistant bacilli? Nursing home residents have been described as 'biological amplifiers' (Gaynes et al., 1985) of resistant strains of bacteria, bringing these with them when admitted into acute care facilities. Presumably these resistant strains are also being carried into the community by staff and visitors and pose a health threat to the staff working in the nursing home.

Yet antibiotic therapy is seen as routine care in the medical literature. A recent medical article says:

*Antibiotic therapy must be a basic clinical skill for all primary physicians for whom infectious diseases are 'bread and butter' practice.* (Yoshikawa & Norman, 1994)

and this is reflected in the remarks made by the GPs who work at Beachdale and Bayside.
There are two issues to be considered here. One is a utilitarian approach, that is balancing up the common good against individual needs. The question of routine administration of antibiotics in nursing home is being questioned. Yoshikawa and Norman say:

... it [the ageing of the population] behoves us to address the problem of infections and the use of antimicrobials in N.H. [Nursing Homes] ... We must look at the problem as a multi-faceted one, viewing it not only from the microbiological perspective, but also from an ethical, societal, and financial viewpoint, since limited resources may force the medical profession into a triage situation of rationing care to those most likely to benefit from it.

... When a patient is admitted to a N.H. [Nursing Home], it is imperative that the patient's physician (and the NH physician if they are separate individuals) explain in a compassionate but detailed manner the choices that a patient and/or family must face in terms of advanced directives, living will, and durable power of attorney for health care. (Yoshikawa, & Norman, 1994)

On the other hand the primary ethical consideration of a physician, many would say, is to his/her patient and therefore maintenance of life and/or comfort is paramount. This is the prevailing medical model of management.

In discussing the options of whether or not to treat with antibiotics one of the GPs felt it was a subject hardly worth considering. The trauma that Laura went through with her father's illness was remembered by the doctor as follows:

I can't remember it particularly, but I think I did give him antibiotics, and the reason that I did was because his daughter was really keen that he was treated, and I personally don't have any problems with that ... obviously he was demented and he was very ill. He'd just had cardiac failure, and his daughter would ring up quite often saying, what are you doing? I said, we're giving him some antibiotics and that's all that we can really do ... The next step would be to put him into hospital and give him intravenous antibiotics, do chest X-rays, and blood tests, and blood cultures, and catheterise him, and that sort of thing not justified, and I think she could see that. That's not warranted because, - but it's very hard to wait and watch, but if you do something simple like that, you know if you give them - like what's going to kill most people is infection - if you give them a simple antibiotic and some Ventolin, and then I think everybody feels better about knowing - it looks as though you're not doing anything. If it's a serious infection they'll succumb to it, but if it's a simple thing then they'll get better.
J: If the daughter had said I don't want antibiotics given to him, what would you have done?

GP: Well I think I probably would have talked to her because I think it's a matter of degree. It's quite a simple thing to give, it's no different to giving - it's a bit different to giving a vitamin tablet but it is a simple procedure which is not really doing anything.

J: It could never be called extraordinary measures?

GP: I couldn't call it extraordinary measures. So what I would do, if a family really didn't want to do that, then I would say to them, well I think this is appropriate that we do this because it could be treated, and if we don't do it, well it's unlikely that it would get better. If we do it, well, it may help, it may not. I usually find that people can respond to that sort of thinking. People, I think usually can tell when someone is really, really sick and whether they've got just a cold or just something - I think they can differentiate.

J: So treatment would in fact be exactly the same whether the family pressed you or not?

GP: Yes.

J: Would you differentiate between people who have a severe dementia and/or anybody else ..

GP: I don't think so. I don't think it really makes any difference. Obviously, it would be quality of life, ... - a simple measure like that I don't think I would differentiate.

Another doctor had a differing view:

GP: ... don't see the normal run of new antibiotics ...as something that's overly aggressive. Perhaps using the magnificent new cephalosporins and things like that which are super expensive might be going a bit over the top. It's very hard decision so I suppose you make it at the time. I think the crux of it often in those situations is deciding whether they are worthwhile sending to the hospital for intensive therapy and we might make that decision in conjunction with the nursing staff and there are a number of patients who have left the nursing home and subsequently died.

J: Now in relation to residents with dementia. .. about late stage care? Exactly the same?

GP: I think if someone's severely demented and you know they've got pneumonia, I'd really be in two minds whether to put them on antibiotics at all.

Both doctors and nurses varied widely between these two types of opinions. The most frequent comment was that antibiotics were justified because they would make the patient more comfortable, even if at the same time people expressed their view that it
was better not to subject people with late-stage dementia to treatment that would keep them alive.

However, it is well-accepted policy and practice that residents are moved out of bed, turned, walked where possible and generally kept physically mobile, all factors which will reduce the likelihood of chest infections and eventually pneumonia. It seems from this study that treatment with antibiotics is accepted in the same way, as absolutely inviolable and routine, except in the last few days of life, when bed rest and withdrawal of virtually all treatments can be accepted.

This notion is perpetuated by medical literature which suggests that nursing home residents with pneumonia 'should be hospitalised (or transferred to a 'subacute' unit if available) for parental antimicrobial and fluid administration' (Ouslander et al., 1991). For suspected urinary tract infection this author suggests catheterisation for women who are functionally and cognitively impaired in order to obtain a clean specimen for culturing, before treating with antibiotics. In the nursing literature pneumonia is listed as a complication of bed-rest and other conditions. These kinds of expert opinions emphasise that good care means curing pneumonia or UTIs as they are routine complications that can be solved with simple standard procedures.

There is a paucity of research and debate about the use of antibiotic therapy for residents with late-stage dementia, one reason being the ethical difficulties of measuring outcomes. Fabiszewski et al. (1990) acknowledge the statistical weaknesses of their study about the effect of antibiotic treatment of residents with Alzheimer's disease because of the ethical implications of recruiting large enough numbers to get statistically significant results. However, their results showed that:

*Patients who developed fevers had more advanced disease than those who did not. Patients who received diagnostic work up of all fevers and treatment with antibiotics (Antibiotic Group) were compared with patients who received comfort measures only (Palliative Group). The incidence of fever was similar in the Antibiotic and Palliative groups. Survival analysis revealed that, for the more severely affected patients, there was no difference in survival between the groups. Among less severely affected patients, survival was higher for the Antibiotic than the Palliative group. These results suggest that treatment of fever with antibiotics does not alter the outcome of fever in patients with advanced Alzheimer's disease.* (Fabiszewski et al., 1990)

The authors conclude that the only answers this survey gives in relation to treatment is that decisions about antibiotic treatment need to be taken in context and on an
individual basis and the most useful indicator of treatment would be the pre-morbid wishes of the patient.

But is that a fair enough argument? If antibiotic treatment makes no difference to the outcome for the resident why is public money spent on these drugs? Is it a public moral responsibility in the same way that getting residents out of bed has become? Are both those practices based on sanctity of life rather than residents' comfort or residents' rights? What really is the prevailing ideology? It is interesting to note the recent heated debate about this occurring on NURSNET, a channel where nurses around the world can communicate with each other through the electronic mail network. In this debate nurses are questioning the morality of the indiscriminate use of antibiotics, as some see it, in cases of terminal illness. The debate has been sparked by the publication of a book called *The Coming Plague: Newly Emerging Diseases in a World Out of Balance* (Garrett, 1994). Garrett calls on history, citing case studies, to warn of the 'threatening and dangerous future' (Mann in Garrett, 1994, preface) of life-threatening epidemics that await us all if we do not control the proliferation of resistant microbes. Garrett says:

*Only by appreciating the fine nuances in their ecologies can human beings understand how their actions, on the macro level, affect their micro competitors and predators.* (Garrett, 1994, p. 619)

Michielsen *et al.* (1993) discuss the risks relating to resistant strains, mainly of gram-negative rods in a geriatric population. They discuss the matter in terms of the danger of subsequent infection for the residents, but there is a greater question here. At some stage thought will have to be given to limiting the use of antibiotics in the kind of population described in this study because they are not as benign as vitamin pills and the chances of rendering antibiotics useless for the whole of society may well be increased by the routine use of them for residents with dementia. If there is little evidence to say that they are effective the routine administering of them is even more questionable.

On the other hand, it is of paramount importance that the matter of a resident's comfort must still be considered. Fabiszewski *et al.* indicate that much more research needs to be undertaken before we know if the use of antibiotics makes people more comfortable. This study has also shown that a major factor to be considered is the symbolic nature of care; the need for the staff, resident and relatives to feel that appropriate and considered treatment is being given. However, it is possible that the other methods such as the use of sponging, anti-pyretics, massage, analgesics and low-flow oxygen may be of more comfort in promoting recovery from a fever or to
provide a peaceful death. This would entail making 'nursing care only' a positive choice with some status and direction rather than relying on the dubious nature of the taken-for-granted comforting effect of the doctor ordering antibiotics.

This move will be complicated if nursing-home staff see the attitude of doctors as one of indifference. This was sometimes the case at Bayside and Beachdale. In relating an attempt to get one doctor to discuss a resident's care one nurse reports that:

*It has actually taken 2 years to get him to talk to us, to be persuaded that we must sit down and have a discussion.*

Others talk in more general terms. They say:

*Doctors are blase about nursing homes, they complain about being underpaid.*

*We see poor little Lillian wasting away worrying and anxious and what do they do - what do they know - they only come once a month - he's done sweet hugger-all for her.*

These comments are representative of the general thrust of nurses' attitudes towards GPs found in this study. Some nurses got on very well with a particular doctor and that relationship improved communication and decision making, but such cases were the exception rather than the rule. A study by Morgan and Zhao (1993) shows that carers of cognitively impaired people also have a negative image of doctors although the point is also made that the contextual nature of the relationship between doctor and caregiver has a large bearing on the outcome. This effect of the complications of the context on the kind of death residents with late-stage dementia receive runs as a theme throughout this study as does the lack of consensus about roles in late-stage care. Lischesko and Davis (1991) describe this source of tension in a way which fits with the findings of this study:

*The absence of a meaningful role for suffering in our modern health care, our technological self-understanding, the disease versus illness foci of the professions, and the cure versus care dichotomy are all themes in the literature that demonstrate important similarities and differences between nurses and physician's practices. The themes both reflect and are reflected in the larger cultural tensions between two ethical perspectives, the absolutist and the contextualist...[but] no one policy can address the lived experience of illness for the patient and their family.* (Lischesko & Davis, 1991, p.279)
The moral dilemmas, debates and lack of knowledge about the lived experience of dying from dementia make the on-going analysis in this study and the sort of recommendations derived from it a matter of sensitivity for policy makers and staff in nursing homes and policy makers. The mobilisation of residents is a case in point.

Mobilisation of residents and body maintenance

What is the purpose of getting residents who suffer from late-stage dementia out of bed, showering them and dressing them in day clothes? Is it directed at comfort and relief of suffering? This question pierces the heart of reforms in the gerontic area over the last five decades, reforms that have made this practice the bedrock of nursing home care. But the question cannot be avoided. We will not be able say that residents with dementia are receiving palliative care, while we continue these life-supporting measures. As has been previously stated these activities prevent residents getting pneumonia and they also help to reduce contractures, prevent pressure sores, and provide a sense of caring for both staff and relatives. It is accepted orthodoxy in the SRV movement that this contributes to the feeling that the person is still valued and provides them with dignity. But it may contribute significantly to their distress. Is the continuation of invasive procedures such as these really showing we are valuing the person as they are - or as we would want them to be? Could we say that death is preponderant over life in these patients? Current treatment patterns do not reflect consideration of this kind.

All the death trajectories I have reported show evidence that each resident was suffering what, in other cases, would be seen as signs and symptoms of terminal disease. These signs and symptoms were variable from resident to resident and the time span from their development until death also varied. However, at some stage each exhibited signs such as 'poor appetite, weight loss, recumbency, lassitude, failure of physiological systems and progression of the disease' (Ashby & Stoffell, 1991) all of which are accepted as indicators of a systemic body failure. The following table indicates types of symptoms experienced by people dying of cancer and the percentage of times they were relieved by any treatment offered. This survey was undertaken with patents who could be said to have been receiving optimum palliative care options.
The prevalence and severity of symptoms experienced by 100 cancer patients and the extent to which treatment helped - as reported by relatives (South Australian Parliament, 1992)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Experienced? % of all cases</th>
<th>Severe? % of those experienced</th>
<th>Treatment helped? % of severe cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weakness</td>
<td>87</td>
<td>75</td>
<td>3</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>83</td>
<td>69</td>
<td>11</td>
</tr>
<tr>
<td>Weight loss</td>
<td>80</td>
<td>71</td>
<td>0</td>
</tr>
<tr>
<td>Pain</td>
<td>73</td>
<td>77</td>
<td>75</td>
</tr>
<tr>
<td>Constipation</td>
<td>58</td>
<td>78</td>
<td>42</td>
</tr>
<tr>
<td>Difficulty breathing</td>
<td>53</td>
<td>60</td>
<td>63</td>
</tr>
<tr>
<td>Trouble sleeping</td>
<td>48</td>
<td>21</td>
<td>62</td>
</tr>
<tr>
<td>Nausea/vomiting</td>
<td>42</td>
<td>50</td>
<td>43</td>
</tr>
<tr>
<td>Cough</td>
<td>42</td>
<td>33</td>
<td>14</td>
</tr>
<tr>
<td>Confusion</td>
<td>42</td>
<td>38</td>
<td>0</td>
</tr>
<tr>
<td>Fluid retention</td>
<td>40</td>
<td>63</td>
<td>40</td>
</tr>
<tr>
<td>Other</td>
<td>26</td>
<td>77</td>
<td>25</td>
</tr>
</tbody>
</table>

(Hunt, 1995)

Palliative Care Specialists indicate the approach of death by this grouping of diagnostic criteria but aged care staff describe these conditions in a different language. They report their acknowledgment of the approach of systemic failure by describing the person in behavioural terms such as 'she's getting so frail' 'she's lost everything since that fall - we do everything for her now', or 'he eats like a sparrow'.

The discomfort they seem to express may arise from the attachments they have built up with the resident and/or their family or may simply mean they do not have a language and value base to describe this progress any differently. Also, the feeling of death as a failure rather than part of care underlies much of the nursing-home culture.

A major feature of systemic failure described in the residents in this study that does not appear in the table above is body breakdown as seen, for example, in the appearance of decubitus ulcers. This is not considered a medical matter; there is an unspoken presumption that skin integrity can be maintained by good nursing care. Body breakdown must be an inevitable result of prolonged weakness, weight loss and
loss of appetite, all of which are reported above as symptoms experienced in a high proportion of cases of people dying and have been shown to be symptoms experienced by residents in this study. Any discussion of dementia palliative care must be cognisant of the fact that all the symptoms in the above table may be present for people with dementia. Difficulty in breathing and nausea and vomiting were not observed in this study whereas body breakdown and confusion were. Comparison with the table also indicates that any program of dementia palliative care will need to consider other factors than palliative care as it is now perceived. A person receiving 'dementia palliative care' following thoughts presented in this analysis may well be far more immobile for longer periods, lying in bed, perhaps almost semi-conscious, but if this person is being eased towards a peaceful death and they are not suffering, not screaming, not calling 'help me, help me', then, I maintain, this is a more humane process than the process described in some of the case studies presented.

In Beachdale and Bayside discussion about different ways to handle body maintenance did arise amongst nursing staff but those discussions took place within the old paradigms. The issue of skin breakdown is the most common and persistent problem of all in the care of people with late-stage dementia. It is connected to incontinence, falls and the morale of the workers. Breakdown of skin on a body exemplifies failure for nurses. The photographs throughout the study have demonstrated the kind of skin breakdown that can occur as a person becomes immobile and old. Field notes and participant observation show that none of these residents was neglected in any way.

When Mrs Miles's skin began to break down the care workers felt as if they should be able to stop it. The RN, Sheila, had sympathy with the care-worker, Madge, who kept assuring her that they were doing 'strict pressure area care'. Sheila understood Madge's point of view and says it was because they felt the breakdown shows:

"it's poor nursing care, because her hips are broken now, her back's broken and her foot's broken, but I explained to Madge [that the breakdown was unavoidable] and she's had twelve years nursing experience but she said 'It still doesn't make you feel any better knowing that it's breaking down and there's nothing you can do to stop it'."

In trying to get to grips with this kind of dilemma within the body maintenance argument, one welcome advance is Volicier et al.'s (1993) work which attempts to predict survival times for people with advanced Alzheimer's disease (Volicier et al., 1993). The motivation for these authors was to find evidence to fit the criteria needed to be eligible for mainstream palliative care services and US medical insurance
rebates. Nevertheless, these kinds of formulae may well be useful in Australia, but until they have been tested and established, or others developed, we need a more flexible approach.

An approach which, for example, trials marijuana, the new atypical neuroleptics, Clozapine and Risperidone or Prozac, the new anti-depressant, or any other drugs to relieve distress could be appropriate as part of new thinking regarding medication for assisting with the late-stages of dementia. The fact that few of these drugs have been tried in nursing homes may demonstrate the lack of creative thinking about relief of suffering that has been available for this group of residents. These drugs have been trialed in mainstream mental health or palliative care services.

Further work such as the research by Kurric and Cameron (1995) which investigated the use of morphine for residents in a nursing home, some of whom had dementia, would be useful. Any review of interventions which produce comfort, for example leaving people in bed, not turning them, different pressure area care, wound care and so on will all need carefully crafted protocols but these possible paths deserve to be investigated.

Protocols which indicate when a resident with late-stage dementia has entered the terminal phase of the disease will also need to be established. One indicator of an advance towards death for a resident with late-stage dementia is when their mobility becomes compromised and they are unable to walk around unaided without falling.

**Falls**

Dijk et al. recorded an average of 4.1 falls per year for residents in an 261 bed psychogeriatric aged care facility (Dijk et al., 1993). The quantitative data I have collected has no meaning at all unless it is linked with the qualitative results of this study but, averaging out the falls recorded for the 14 residents in the study, the average of falls per resident is 23.3. This data can only give an indication that people in the late-stages of dementia fall, on average, more often than the total resident population of another aged care facility. Preventing and responding to the effects of falling is a significant and difficult part of care. For the purposes of this study, an increasing number of falls by a resident could be a useful marker for the beginning of the terminal phase of the resident's illness.

As has been discussed the damage that may occur to a resident during a fall is one of the most emotionally stressful parts of a nursing day. But there is also the difficulty of how to treat the results of the falls, or the inevitable skin breakdown that occurs
over time. Photograph 16 show the use of steri-strips and tulle gras which, when removed, run the risk of taking more skin with them.

Dealing with skin breakdown to the point where it is like tissue paper has little work or research on which to draw. Mobilisation has a double-edged effect. In moving anyone there is a risk of knocking the skin, but the movement will increase circulation and therefore increase nutrition to the area. This dilemma was apparent to staff but was overridden by the policy of creating the dignity of leading an apparently normal life for people by getting them up and dressed.

As shown by the remarks of various relatives, this is a choice that they prefer. We cannot know about the residents themselves. For the relatives and staff, getting the residents up and dressed stops them feeling that people are turning into 'vegetables'. It often also prevents relatives being aware of the sores on the resident's body. Nurses have to deal silently with the dilemmas. The acceptance of the futility of body maintenance does not negate treating any person with dignity up to death. A person can receive low dose morphine when up and dressed as easily as being in bed. The sitting out of bed may be futile in one sense but it may be helpful for those working and watching. This needs to be balanced, on the other hand, with how much suffering it is causing the resident. A further complicating factor in maintaining a person's dignity is the management of continence.

Continence

Although the management of incontinence was a continual factor, to a greater or lesser degree, in all the cases in the study it was a routine task that nurses were knowledgable about and managed well. Lawler (1991) describes how one of her nurse respondents felt it was much easier to communicate with those people who have a down-to-earth attitude about life because in talking about excreta they used commonly accepted words such as 'shit' and 'fart'. The staff at both nursing homes were able to deal with care involving human excreta in the same direct way. At both Bayside and Beachdale the level of discussion about continence ranged from the vulgar to the technical. It was a constant in conversation, it did become an issue between night staff and day staff and it featured among the issues in dealing with death, as has been recorded in the case studies. However, when it was accepted that people were dying, the task of changing a bed and cleaning up a resident so that they were comfortable seemed to give the staff a sense of a job well done and a feeling of satisfaction that they had done the very best they could for that person. A well-worked-out regime for management of incontinence can play an important part in making visible the invisibility of nursing work, of giving physical expression to the
WOULD THIS BE PAINFUL?
DOES THIS BODY BREAKDOWN WARRANT THE USE OF MORPHINE?
regime of 'nursing care only', of giving the staff a sense that the body of the person they have cared for is clean and fresh.

A move in this direction was instigated at Bayside by Jan and Charmaine who have invented a way of combining aspects of complementary therapies and medical care by making a special cream for putting on the residents after they had been incontinent or when their skin was being treated to prevent decubitus ulcers. Jan and Charmaine combined their knowledge of the therapeutic effects of smell, after attending an aromatherapy course, with common-sense ideas about comfort and cleanliness. They produced a special home-made cream which was having great success. From this they were able to gain satisfaction that they were doing something really pleasant for the residents.

The issues of faecal impaction and bowel habits has also been discussed in the case studies. The issue of constipation, which can be a complication from the administration of morphine, will need to be explored further in the management of dementia palliative care. Morphine slows bowel movement and therefore may increase the likelihood of impaction. If no other method than manual removal of impacted faeces is available when choices such as increased fluids, bran, Metamucil and aperients have all failed then a co-ordinated approach that takes account of intake into the alimentary system as well as outputs could be the most sensible. As was shown with Mr Jared, the staff saw his constipation as the main aspect of his care as he progressed towards death. If he was constipated he was uncomfortable. This illustrates the complexity of the care that is needed for dementia palliation. Reducing his intake of food would have relieved this problem too, and avoided the need for manual removal of faeces, but that was never discussed or considered by staff.

The limiting of food and fluids is the biggest moral dilemma this study had to deal with and it is closely connected with by far the most difficult issue of all. In discussing body maintenance and limits to care the issues surrounding the supply of food and fluids are the most sensitive and involve habits and attitudes that staff in nursing homes could not let go of without a good reason. For some residents in the study the gradual withdrawal of food and fluids happened naturally, either because the resident would not, or could not, eat any more. For a case like Mr Jared the withdrawal would mean a positive decision with a team approach. For many, withdrawing food and fluids in this situation would be seen to be stepping over the boundaries of palliative care into the realms of euthanasia. For Mrs Jared, the wife of the resident, this would not have been the case. These questions need further
clarification and debate. The following section attempts to be a small part of that larger issue.

The supply of food and fluids

To nourish is basic to nursing and caring. Assisting someone to eat is so basic as almost to make it a core representation of the act of healing. But we need to ask ourselves whether this mythic power obscures from us some of the effects of rendering that assistance to a person with late-stage dementia. Could not the act of spooning food into the mouth of a demented individual, of instructing him or her how to open the mouth and how to swallow, be likened to the work performed by life-sustaining machines in Intensive Care Units (ICUs)? What exactly is the difference between the ICU machines and the carers of late-stage dementia sufferers who go through the daily rituals of body maintenance? It is all too possible in the light of this study to conclude that, when the comparison is made, the main difference is that the nursing home staff and their charges are both wounded by the continuation of the sustenance rituals in ways which neither group can adequately express.

In recent years there has slowly grown up an acceptance that there are occasions when it is appropriate and acceptable to withdraw that mechanical support for lives which themselves are no longer anything but mechanical. But to gain acceptance for the notion that this situation is a parallel to that which often arises in the care of the seriously demented is a very difficult task, especially when it touches on the emotionally-charged issue of nourishment.

Polarised positions are usually taken, with one group understanding the respirator metaphor, and wanting to tackle the difficult questions this raises, the other wanting no part of the debate, charging that any change to the present paradigm of care would turn nursing home staff into 'death squads'. Once again, the question is one of balance. Where is the fine line between, on the one hand, withdrawing food and water consistent with providing optimum comfort and, on the other hand, being neglectful so that the person is suffering from hunger and thirst?

It is accepted that eating has a symbolic and important place in our lives and, perhaps we should add, our deaths. McCue takes the view that 'very elderly patients eventually undergo a process of functional decline, progressive apathy and loss of willingness to eat and drink that culminates in death' (McCue, 1995, p 1039). Carson (1989, p 84) supports this with a story about an 85-year-old man who had chosen to stop eating and who:
told the physicians who tried to talk him out of his action to mind their own business.

But this is a course which is not open to people with late-stage dementia and it is difficult and perhaps impossible in the present circumstances for nursing home staff, relatives or medical staff to make that decision on their behalf.

Carson (1989) goes on to say that:

... symbolic meanings are not sufficient for determining the rightness of actions, but they are as powerfully present at our dying as they are in our lives generally ... new (old) forms of care can be fashioned that are both effective and an antidote to the personal suffering and calamity that might well ensue were the lives of the dying to become cheap and expendable. (Carson, 1989, p.88)

Many people with late-stage dementia begin to reject food. Research looking at these difficulties describes the behaviour of residents as ranging from refusing to open the mouth, spitting, allowing food to drop out of the mouth and not swallowing (Watson, 1994). These same behaviours were observed repeatedly during this study. Watson outlines ways that requirements and desires for food and water could begin to be measured (Watson, 1994). If it was decided that the time had come to stop offering food to a resident who consistently rejected it, palliative care consultants could assist with questions about electrolyte imbalance and dehydration in the pursuit of comfort.

Other researchers describe observations of staff assisting people with dementia with meals and conclude that how much nourishment the person gets depends on the moral stance taken by those who are offering food and fluid to the resident (Akerlund & Norberg, 1985). The act of nourishment becomes confused with issues of care, keeping people alive and the need for staff to feel connected, not alienated from their work. The views of staff expressed in this study show that the prospect of a resident being alone when they die is the most distressing aspect for nursing home staff. Putting this finding together with the views of Akerlund and Norberg (1985) it can been seen that being able to spend time at least trying to assist someone to eat is a way of contact and showing some care and devotion, especially for those staff who have known these residents, and often their family, for years. In any public policy formation about palliative care this need would have to be considered for the sake of the resident, staff and kin. To replace the need, for both staff and residents, to give and receive nurturing, alternative techniques such as massage and aromatherapy would start to come into their own.
something demonstrated their caring. At times staff were observed patiently offering him minute amounts of food while keeping up a constant stream of words telling him that they loved him and they just wanted him to eat a 'little bit for me'. This kind of persuasion was often the case as the residents drew close to death. On the other hand, when it was clear that Amy was dying and she could not or would not swallow, the staff felt quite content to revert to sips of water and mouth toilets only. Once Amy had stopped wandering the staff seemed to accept that she was ready for death. The fact that Amy was a diabetic probably allowed her the peaceful and speedy death she experienced.

However, the withdrawal of food and water in the case of people with dementia is, perhaps, the most difficult moral issue that philosophers, nurses, doctors, family and ethicists face in this area of care and one which has had little research.

Akerlund's research, carried out in Sweden in 1985, showed that 'when patients with incurable dementia diseases no longer take food or fluid voluntarily, the care workers experience stress and anxiety' (Akerlund & Norberg, 1985). The study went on to demonstrate that fear, as well as stress and anxiety, arose out of the ethical dilemmas inherent in the task of eating and drinking, when the patient was no longer able to make themselves understood and the carer is required to interpret their behaviour. Those staff who put a strong value on the ethic of keeping the patient alive and felt sure that compression of the lips and the pushing away of food was a consequence of the patient's brain dysfunction and not indicative of a wish to die could cope reasonably easily with the task of offering nourishment, were patient and coaxing with the food and did not suffer anxiety. They acted from a deontological ethical principle; they were sure that persuading patients to eat had an internal quality of being right, while letting them starve was wrong. The staff who subscribed to the value of 'keeping the patient alive' but also to the value on non-violence, and who saw the act of continuing to put food into a patient's mouth when they were pushing the food away as a violent act, did suffer anxiety and stress during the task and were the majority. A third group consisted of staff who were very experienced. They gave priority to the value of not causing suffering as well as realising the importance of the task of keeping the patient alive. This group seemed to be able to balance the amount of food given within these two values and had less anxiety about 'feeding' or the chance of a patient choking. However the ethical positions of staff in this group were not clear or conscious.

The group that was most anxious and found their work unpleasurable were those who expressed the feeling that it was immoral to 'cause suffering'. They tried to avoid
having to put food into patients' mouths, or stopped it as soon as possible. The researchers drew the conclusion that this group were not acting from a position of moral reasoning but acting in a defensive way to avoid closeness to the patient. The fieldwork associated with the present study would suggest that these findings of Akerlund and Norberg (1985) may be only part of a much more complicated story.

One question that needs to be asked in looking at these conclusions is what effect would these differing feelings from staff be having on the resident? They may be on a see-saw of being sick with overeating or miserable with hunger. Yet each staff member could be filling their role in a way their conscience dictates is truly right, and had mobilised psychological defences to protect themselves from the anxiety they felt.

A later study, seeking further information about the eating behaviours of people suffering from severe dementia, was undertaken in America, Asia, Australia and Europe (Norberg et al., 1994). This study found that nurses were willing to comply with decisions about offering food or not if these decisions were made by a doctor, a request from a spouse or at a staff meeting. Australian nurses, together with their Canadian and Swedish counterparts most often chose not to continue offering nourishment to a person with severe dementia, basing their reasoning on the principle of autonomy. Other differences in ethical reasoning emerged, as they have in other studies (Norberg & Hirschfield, 1987) due to culture. But differences in ethical reasoning have also been contributed to by gender (Gilligan, 1982) and by level of education (Rest & Thomas, 1985). The last study indicates that many questions about ethical reasoning for nurses in their daily work remain unanswered.

Ethical reasoning in nursing homes needs particular attention which relates to the reality of the situation. Liashchenko and Davies (1991), in explaining why nurses and physicians in long-term settings have a closer agreement about nutritional support than physicians and nurses in acute care settings, point out that 'the social meanings of illness and disease are frequently a function of the setting' (Liashchenko and Davies, 1991, p.263).

The case study stories have demonstrated how this tension between doctors and nurses existed in both nursing homes in this study. But another tension arose for the Director of Nursing in her role to make sure that residents are being cared for adequately when she perceived that residents were not receiving 'adequate nutrition'. Adequate nutrition is measured, within the present policy and philosophical paradigm, by monitoring the weight of each resident. This is confirmed by a recent article which begins 'An assessment of weight is considered to be the cornerstone of
physical and nutritional assessment for elders in nursing homes' (Wright, 1993, p. 157).

Responding to this kind of policy pressure the question of the residents losing weight was raised by the DON of Bayside in an RN meeting. The following story illustrates the kind of pressure brought to bear on the issue of residents' eating.

The DON begins the meeting by telling the staff that 'most residents are losing weight'. The RNs reply that this is not the case: rather, 'some people are putting on weight'. The DON ignored this comment and went on to explanations from the staff for what she perceives as too many residents losing weight. There is a subtle indication that this is because the staff are not bothering to spend time offering food to them.

The staff's voices are defensive as they reply. One staff member says that 'the three residents in room 1 just clamp their mouths. Most of them had fruit and custards' The discussion trails off with no resolution except the opinion is expressed that 'The dementias are at the stage where the body is suffering'. There is no response to the challenge set out by this remark.

The feeling that the staff were being watched to see if they were neglecting the residents by not being patient enough in offering food was further enhanced the following week by a note to all staff. The loss of weight of the residents was linked to staff being lazy. The note read:

All employees of the Bayside nursing home are aware that the reason they work at this facility is for the benefit of the Residents. Residents are our top priority and as such are given the benefit of first class care and consideration. No resident is exempt from this concept. The philosophy of care, as outlined by X [the name of the organisation] is the acknowledgment that each and every resident is first and foremost, and without exception entitled to sufficient care and nourishment to fulfil their needs.

Following reports from various members of staff and the loss of weight of some residents there exists a probable serious deficiency in the adequate nourishment of some residents of the Bayside therefore the following processes will immediately be implemented.

Daily lunch times for nurse assistants who work the am to 1.30 pm shift is now 11.00-11.30 am. 10 minute tea break between 9.30-10.00 am. Daily lunch times for nurse assistants who work the am-pm shift is now pm-1.30 pm 10 minute tea break between 10-10.30 am. Daily
Appendix 7: Colleen's story in her words

THOUGHTS OF MOTHER

It is now three years that my mother has lived in the nursing home. At the beginning of these three years my emotions were running riot.

I would go from guilt to relief, sadness to sorrow, anger to sheer frustration. At this time a friend suggested that I could try to put into writing how I was feeling and that it may help me adjust more easily to the situation. I didn't really feel I would be able to do that but one day in desperation I picked up pen and paper and started to write. I even surprised myself, once I started writing the thoughts came quicker than I could write them down.

My husband thought it a good idea and he encouraged me to keep going. Each night he came in from work he was interested in catching up on what I had written, one day he commented you will end up writing a book at this rate. I didn't write a book but I did contribute to one chapter in a book titled 'When I grow too old to dream'.

The writing did help me a great deal and from then on I felt I had my emotional feelings more under control.

Through the nursing home I have just come in contact with a lady who is preparing a thesis on dementia and she has suggested I start writing again and fill in on the three years that have just passed. She has also said she would be interested in reading my notes on my personal reaction to the various changes experienced during that time and this would also help her gather information for her thesis. She said it would be a help to her if she had a full history from when a person started with dementia through to the final stages and the eventual death of that person concerned. At this stage I feel I would like to do so but I no longer have the same frustrations that made me write in the first place. I will give it some more thought and perhaps I will be able to continue and contribute yet another chapter on some effects that Alzheimer's disease has on family and friends.

I have given my consent for this lady to observe mum's behaviour and she has reassured me she will not do anything at all to embarrass mum or identify her in any way. I feel quite happy with this decision as I realise someone has to give this consent so as to gain the information that may one day help someone else.
The first few months of getting mum settled in the nursing home were emotionally upsetting but once the initial problems were overcome it did get easier to cope with the situation.

When mum was admitted to the nursing home we were advised that the policy was an unlocked environment. The nursing home accepted mum knowing she was a wanderer and we accepted their policy as such. This policy proved to be a bit of a problem as mum was found on a couple of occasions wandering down the road and on another occasion she made it to the main street before it was realised she was missing.

Cutting a long story short the front gate did eventually get an extra safety catch attached. I can honestly say this did put my mind at ease and I’m sure it has made it easier for the staff as now the residents can benefit by going outside in the yard and the staff are not on constant watch to see that the residents are still in the yard.

The first twelve months that mum was in the nursing home my husband and I lived interstate from her which meant we were able to visit only at intervals of about five or six weeks, depending on when we were able to get time off work together. This proved to be very tiring and time consuming but at this time mum was able to enjoy our visits so that made it all worth while.

During this first twelve months my sister who lived in the area occasionally took mum shopping or took her home for Sunday lunch but as mum deteriorated my sister appeared to have trouble once more accepting the situation and her visits became less frequent and I feel she was just another victim unable to face the fact that mum would only get worse from here on.

We had been living in this area for about three months when there was a fire at the nursing home. I received a phone call in the early hours of the morning to ask if I could take mum for about twenty four hours until they could organise somewhere for the residents to go. The twenty four hours ended up to be five days. I have to admit they were very long days. I cared for mum during the day and my sister took her of a night which enabled me to sleep, ready to face the next day. Mum was very unsettled and wandered around the house looking very confused. The staff from the nursing home were very good and called in to the house each day to make sure everything was going OK. The management were fortunate to be able to obtain a house close by that they were able to rent. It took about two months for the nursing home to be repaired and the residents were able to get back to their familiar surroundings.
During the last three years I have found that people in general and at times me included just don't know how to cope with the changes of the person who has Alzheimers disease. The personality changes are so vast at times just so different to the personality we have all known and loved for so long. To cope some people seem to choose not to have contact with the person who has dementia and to me it seems that old saying 'out of sight out of mind' is coming over loud and clear. I'm sorry to say I do still feel very sad at times when I think of all the love and care mum gave to some family members and now these people no longer acknowledge her.

Even making allowances for their difficulty in accepting and coping with mums decline in health I still feel it would be nice for her to get a card at Christmas or on her birthday even if only to acknowledge her existence. Even a phone call to me once a year to ask about her would do wonders for my emotional feelings. I still keep in touch with mums old neighbours as they are all interested to know how she is getting on. It is just a bit sad that there again, the distance of interstate travel restricts them visiting. I must admit it is so much easier now that we are living close to mum this enables me to call in on her at any time.

The management at the nursing home has changed since mum was accepted as a resident and I am happy to say I find it easier to approach the new management. Even though I still do not fully agree with their idea of normalisation I do feel they are doing a wonderful job of looking after the residents and I can't complain about the care they all receive.

I know it would be wonderful to have my mum classed as normal for want of a better word but I realise because of her inability to do anything at all for herself in my opinion she can no longer be classed as normal.

I shudder some days when I visit the nursing home and I see one lady in particular wandering around on her own as she is so unsteady on her feet. One day I couldn't stand the stress of watching her and I left the nursing home earlier than I had intended to, only because I had visions of the lady falling down and there was nothing I could do about the situation. I did explain to the staff the next day why I had left early and they understood. To me in this case normalisation would be to restrain this lady and have her in the lounge room watching TV with the other residents. I am constantly reminded that this is not the policy of the nursing home and that the residents are free to move around as they please.

I used to enjoy seeing mum walking around the nursing home often hand in hand with one of the other ladies, they were really good company for each other. Sadly
though as mums health failed and she lost the ability to walk this pleasure was also lost. It wasn't long after mum stopped walking that her friend died. It was a very sad time at the nursing home as within a period of four months there were four deaths. It was also hard for me to visit around this time as I was so used to seeing all the familiar faces it just wasn't the same any more.

With each death came a new unfamiliar face. I am happy to say I have adjusted and once again feel comfortable with all the residents.

When I look back now it is hard to put into words all my feelings of how I felt at the different stages of mums failing health. I used to take her out to get her hair cut or take her for a walk to the street. Sometimes I would take her for a drive in the care which she used to enjoy. Here again now because of the difficulty of getting her in and out of the care I can no longer do this.

Often one of the volunteers at the nursing home would take mum out for afternoon tea and that gave pleasure to both parties.

Gradually though little by little all this has now finished. Mum is now dependant on a wheelchair for her mobility, which does put a restriction on things. I am still able to wheel her out in the sunshine weather permitting and there again once a month if it is a nice day I can still take her to a singalong. Even though mum is no longer able to sing the songs, occasionally her foot gives a bit of movement in time to the music and her lips move on certain songs so I like to feel she is still able to benefit from this outing.

My husband still visits mum but it is getting hard for him also as he doesn't like to see mum's health failing. One day recently when we were visiting, mum actually called my husband by name and I felt that was better for him than if he had won the lottery.

My daughter has had her share of personal worries and seeing her nanna just sitting in a chair unable to recognise her as her granddaughter, is very hard for her to accept.

My eldest son lives interstate and visits us on average twice a year, he is always anxious to visit mum but he always ends up getting upset when he is there but still he is able to return the next day and try again.

My younger son also lives interstate so his visits are also few he too is anxious to visit mum and he seems able to cope easier or perhaps it is just that he does not show his emotions in quite the same way.
Some days I feel a bit low and think I can't visit, thankfully these feelings don't last long as I realise there is nothing more I can do to improve mum's life for her. She has very kind and caring people tending her every need so now I try to make the most of the good days and forget about the rest. I am very good at telling other people that they should have this attitude but sometimes I have trouble to put into practice what I preach.

I am grateful that I have had my loving mum for as long as I have. I guess some people who never knew their mums would be happy to change places with me right now.

I do sit and wonder at times why so many people end up with Alzheimer's disease, to me it is such a cruel disease for both the sufferer and their families. It seems no one is safe from it as I know of some very clever people such as an industrial chemist, a doctor, an A1 mechanic and then just everyday wonderful people like my mum, and most of the ladies at the nursing home appear to me to have been very loving and caring people.

One thing I am having trouble to come to terms with is to feed mum. I have managed to give her a cup of tea on a few occasions but a main meal I have yet to tackle. I have said to the staff how I feel and they appear to understand. If the occasion arose that I had to feed her I'm sure I would manage some how but for the moment I think I would be better off if I fed one of the other residents and let someone else feed mum.

It's got to be THAT EMOTIONAL FEELING taking over but believe me at this time those feelings are very strong feelings to come to grips with.

The management seem to me to be always fighting for their staff hours, it appears to me that the better attention they give their residents the less money they receive from the government. I think this will be an on-going thing as everyone is trying to save money by cutting corners but in some cases I don't feel this is possible. It is good to have volunteers coming in but to me volunteers are a luxury for the staff to enjoy and should not be seen as necessary for the staff to be able to cope.

I have just come home from visiting mum where I was advised that the staff are having trouble getting her to eat. I am concerned that this could be the beginning of yet another downhill time and that mum will forget that she has to chew and swallow her food.
I didn't go to see mum yesterday and I am trying to make up my mind to go and see her today near lunch time, to see for myself how she is eating.

Well I did make it to the nursing home for lunch time and I stayed and fed mum. She ate her vegetables very slowly but when it came to ice-cream that was no effort at all for her. It was emotionally hard for me but I'm glad I made the effort and was able to get through the whole meal. I feel very sad at the moment I guess it is the realisation that mum is failing further yet again.

It is about three weeks now since my visit to feed mum and I haven't been again at meal time but the staff say she is eating OK now just very slow with all meals.

Mum recently had her 85th birthday and I made up my mind not to give her a birthday cake as I felt she would not gain any benefit from it and she would only have trouble eating it. Even though I said no birthday cake I really wasn't happy with my decision. I thought about it a lot and then came up with the idea of an ice-cream cake. I felt mum could manage that and also the other residents would be able to enjoy it with her. This proved to be a good decision and everyone enjoyed the 'ice-cream cake'. I said to mum I don't know that you have ever had a birthday cake made of ice-cream before but I guess there is a first time for everything and you are never too old to enjoy ice-cream. She did manage a smile but I don't know that she really understood what I had said to her.

Things are about the same with mum some days she is quite bright and other days it is hard to get any reaction from her at all.

The singalong hour still seems to give her enjoyment which gives me pleasure also to be able to continue the outing.

It is now yet another three months that have passed and mum seems better now than what she was six months ago. She is responding more when spoken to and on odd days even answers quite quickly.

There are still some days when she speaks that sadly I am unable to understand what she is saying so I answer as best I can hoping I am on the same wave link as she is.

The library have a reading for the elderly on one day each week, weather permitting I have been taking mum along to this outing. Sometimes she appears to nod off to sleep but when I speak to her, her eyes open wide and she answers yes when I ask if she is enjoying the story. It does give her a break out in the fresh air so even if the reading is not fully understood the outing I feel is good for her.
There has just been another three deaths at the nursing home two occurring just one week apart. I still feel sad losing the faces you get used to seeing each day. I guess it is a part of life that I just have to learn to cope with.

Mum is about the same most days she is quite bright in herself and that does make it easier for me when I feel that she is content.

It is the monthly singalong today and the weather is beautiful so mum should enjoy the walk in the sunshine as well as the outing.

My sister does seem much better towards mums deterioration, she has been visiting more regular and I feel she has now accepted the situation and that does make me feel better also.

My husband still visits regularly and most times he gets a very good reception from mum.

We have just had Christmas and I was lucky to have my family all together for Christmas day. We visited mum during the afternoon and when she saw her grandchildren she had tears in her eyes, I do feel she recognised them even if only for the moment. The recognition may not have been of grand children as such but it was certainly some feeling of emotion. Mum was quiet but she did manage a smile and a few words. It was hard for the children when they said Nanna and got no response from her but when they said her Christian name she was very alert. They have now accepted this and even though it is hard for them they call her by name so as to get her attention.

Another four months have gone by and mum is about the same. She has celebrated yet another birthday and on the day the staff made sure that she enjoyed her special day which I feel they do for each resident.

I still find it hard some days when I get no response from mum. Seeing the other residents also going down hill is hard too as I have become quite fond of them all and I can't help my emotional feelings attached to them.

The staff have had a change of roster and I personally am having trouble adjusting to the change. I used to be able to visit at any time of the day and know who would be on duty but now I am totally lost in that respect. It should not be any of my concern but it is just that I feel more comfortable helping out when certain staff are on duty and now I am out of that routine. It does appear to me that the new roster has caused a bit of conflict between staff also and I am not happy with the ill feelings I see shown
towards others. I realise that throughout life there will always be situations of personality conflicts and I guess this is just one time I have to accept this situation. I don't feel the residents are aware of the changes so I guess that is my main concern and as long as the residents are cared for in the usual good manner I will learn to adjust.

The change of roster has lasted about 3 months and I have just heard that the old roster is to be brought back. It appears that the change of roster hadn't worked out as well as anticipated.

At this time again there really isn't much change in mum, except for her loss of conversation which at times I still find hard to accept. She still responds to certain names but as she appears to have lost the ability to retain what has been said to her I feel it is all only moments of recognition.

She still appears to enjoy when I take her for a walk out in the fresh air and seems very alert when we stop to admire the flowers and look at the scenery.

One morning recently when we were out walking I heard the whistle of the train and her expression told me she had heard it also. I walked to where we could see the train and she really did appear to watch it go by. I said to her it is a while since we saw a train and she answered yes. Who really knows what or if any recognition was there but I still have hope that she has those moments of pleasure.

Mum's elder sister has recently passed away and my sister and I wondered about telling mum but we have decided not to say anything. Even though we feel quite confident that she would not be able to fully understand the situation. If there was the slight chance of her understanding, we feel the news would do more harm than good, so have said nothing to her.

It is now over two years since I started to once more put my feelings down on paper. I have not heard from the lady that was doing the thesis on dementia for well over twelve months. I would have liked to have caught up with her to see her finished product and am disappointed that she did not make contact with me on completion of her studies here. I guess like most of us this day and age we are all busy and can't always catch up with everyone. There again a phone call to say what or if she had benefited by her observation of mum's deterioration would have been nice to receive.

When I look around at the changes to the nursing home, re security of residents during mum's time there and try to count the number of residents that have come and gone, it really is incredible. Each outside exit now has a security lock and if asked I
am sure the present staff would wonder how they ever managed without this security. Numbers come and gone I just don't have the heart to count them.

Today when I called to take mum for her weekly visit to the Library she was not well enough to take out, so I hope it is just an off day for her.

We have just had yet another Christmas, which was spent very quietly.

My husband and I visited mum on Christmas day and she was quite alert which did give us a lot of pleasure.

A few days before Christmas I read a card to mum that her grandson had sent to her and she appeared to follow every word with me, giving a nice grin when I mentioned her grandson's name.

I still can't help but wonder at times just how much she is able to take into her mind.

Today when I visited mum, again she is not well. I feel very sad and can't help feeling that she is slipping away, once more on a downward trend.

Good news another two weeks gone by and mum is her usual self, today when we visited she again called my husband by name and believe me that was a bonus we didn't expect. I really do feel that as mum has only known my husband as an adult it has to be easier for her to recognise him rather than people she has known all their growing years. Seems from now on I will really have to take things day by day by accepting this way of life for mum.

Up until the last few weeks the progress with aroma therapy has been very good for mums hands and fingers that have started to curl into a fist, but today she has a splint back on her hand as the hand is turning back the wrong way. Hopefully the splint will help prevent the hand twisting for a little bit longer.

Today was one of mum's good days so I took her to the opticians to see if he could give her some lighter frames for her glasses. I was surprised at how well she managed to co-operate by lifting her chin when asked and also looking at the light when the optician asked her to do so. He was able to test her eyes well enough to improve one lens and he seemed to feel there was no need to alter the second lens. With plastic frames and plastic lens instead of the glass there should be quite a change in the overall weight.

Over the past six weeks mum has had quite a few bad days again today when I intended to take her to the library she was not well enough to take out.
Mums change in health has seen a visit from the doctor and also a visit from a speech therapist. It appears mum has now lost the ability to swallow properly and this is causing her to become sick during meal time. The staff are going to try feeding her more frequently with smaller meals and also with medication to help with the digestion of her food and see if this will help the situation.

It is birthday time again, hard to realise where the last 12 months have gone to. We had afternoon with mum to celebrate the occasion and shared her ice-cream cake with several of the residents who all appeared to enjoy it. Three weeks on, the new method of feeding has helped mum considerably. There are still a few days where she still brings her food up during meal time but overall there is an improvement.

The new glasses look good on mum, she no longer has the red marks on her nose caused by the old frames and hopefully they have also improved her vision.

I have made up my mind not to continue with the visits to the library as I honestly feel mum is no longer gaining any benefit from this outing as she usually falls asleep during the reading.

I will continue to take her out for a walk weather permitting as she does stay awake during the walk and appears to enjoy looking around at the flowers and gardens.

Mum is no longer able to tolerate solid foods so her diet is liquids and very soft foods. She is given ensure which I am told has all the necessary vitamins that she needs. She was enjoying an egg flip when I called in on her this morning and the staff are very kind in trying to give her various things to encourage her to eat.

Even with all the tender loving care mum has still gone down very quickly in the last few weeks, some days even the liquids are too much for her to tolerate.

Final days. I received a phone call from the nursing home yesterday morning to say that mum was not responding to them and they felt that if we wanted to see her while she was reasonably coherent we should go in as they felt she may lapse into unconsciousness.

I have said my last goodbyes on several occasions lately and thought I would cope with this sad time when it did eventuate but I am finding it very difficult.

Just to see mum fading away not able to take fluids of any sort, it is very hard to put my feelings into words. My son is spending a few days with us as he has holidays and my husband is on days off from work so we were able to visit mum together which
did make it easier for me. Mum appears to know we were there, when we spoke she answered by blinking her eyes but she was just so very tired. Her breathing was very heavy and it seemed to take all her energy just to get her breath.

The emotions brimming up in me are very sad. I know in my own heart that this is really and truly mum's final struggle with life, for me it is just so hard to let go. I have had the unpleasant task of informing my other two children of their nanna's decline and believe me it was a very hard thing to have to do, especially knowing that at this time they are both too far away to be able to come and visit.

We visited twice yesterday and the same again today. Mum appears to be breathing easier today but she just looks so pale and worn out I feel that it would be lovely for her just to close her eyes and have eternal sleep.

Our third day still not getting any easier. When we called on mum this morning she was sleeping soundly, when she woke we were pleased with the reception we received. As each of us stood at her bedside she made eye contact and I'm sure she was trying hard to speak but sadly only very quiet sounds emerged, and again she blinked when spoken to. I once more am wondering just what her brain is capable of absorbing. I still feel there is enough power left for her to understand briefly, just that there is no ability to retain anything. I can only hope that she knows we are there for her.

The staff are really very caring people and have made a special table beside mum's bed to enable her the chance to see the flowers that her grand-children gave her and have placed her statue of Our Lady in view also. To me this is a very kind thought.

Each time we have been into mum she has had company, it is a pleasant thought to know so many people are caring and have concern for her.

This morning at 1.40am our dearly loved mum and nanna passed away. My husband and I went to the nursing home and said our last goodbyes. I have wondered how I would cope at the very end and am pleased that I was able to face up to seeing mum for the last time. She was laying in her bed and she looked so peaceful, it was really a good feeling to see her at peace. Now I hope we can get through the funeral without too much upset.

Yesterday was spent notifying relatives and friends, and finalising arrangements for mum's funeral. I spend a good percentage of the day talking on the telephone and felt quite weary by the finish of the day.
I had previously made tentative inquiries regards mum's funeral arrangements and I now know that was a very good move. It made things just that little bit easier as most of the paperwork and choice of casket etc had already been completed.

As always there are a few last minute things to attend to but I feel with the guidance of the funeral director everything will be fine.

We travelled back to mum's home town for her funeral, it was a long trip but to me it was the only thing to do. My son travelled from interstate to attend the funeral. He wanted to see his nanna to say goodbye so I took the unexpected opportunity to see mum for the very last time. She looked so peaceful I really felt I could hear her breathing. It was a lovely way to remember her at peace with the world.

The funeral service went off very well no mishaps. The sun managed to shine at the right time so that made it a little easier.

There were quite a few tears of sorrow shed for the loss of a wonderful lady but in all honesty I feel no one would wish to have mum back to continue living as she had done for the last few years of her life.

Her death has left a very big gap in my life that will be hard to fill.

I know that mum would want for each of us to just get on with our lives and not mope about feeling miserable or sad.

Her death has brought to an end yet another phase of my life, and at the same time the beginning of a new one. I also know I will have to keep myself very busy to enable me to make that fresh start.

I truly believe that my loving mother has left behind only good memories created for each member of her family and her friends who will recall those memories with love.
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