NEGOTIATING LIFE CHOICES:
LIVING WITH MOTOR NEURONE DISEASE

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ABSTRACT

Motor neurone disease (MND) is an uncommon neurodegenerative disease that is terminal and has an insidious onset. With no known cause or cure, the disease triggers progressive death of motor neurones that causes increasing difficulties with mobility, communication, breathing and nutrition. Most research focuses on the disease process, but little is known of the illness experience from the perspective of those diagnosed with the disease. The aim of this study was to explore what it is like to live with MND and how people with the disease negotiate with others to exercise choice over the way they live.

A grounded theory methodology was used to explore the life world of people diagnosed and living with MND. Data were collected via in-depth interviews, their stories and photographs, poems and books participants identified as important and fieldnotes. The textual data were analysed using constant comparative analysis. The majority of participants experienced difficulty with verbal communication. Some invited a third person to interpret their speech and others used assistive technologies such as Lightwriters and computers.

Analysis revealed three constructs that, together, told the story of the MND illness experience. First, was the “diagnosis story” that described the devastating process of repeated tests had on the participants, shattering their trust in the competence of the health care system. The second construct revealed the process of living with MND as cyclical and repetitive requiring constant decision-making to adapt to the ongoing changes connected with the disease. The core theme and basic social process of “maintaining personal integrity” evolved as the third construct. This process underpinned and explained participants’ decision-making. Finally a substantive theory was conceptualised as the illness experience: “maintaining personal integrity in the face of ongoing change and adaptation”. This theory illustrates that the basic social process of maintaining personal integrity is central to decision and choice making while living with MND.

The findings have implications for people with MND, their carers, health professionals and service providers. Recommendations include improved counselling services for people at the time of diagnosis; the introduction of nurse specialists to support health professionals, people diagnosed with the disease and their families; open, accessible, realistic health and funding policies.
DEDICATION

This thesis is dedicated to the people who are diagnosed and living with MND. This document acknowledges the collaborative work of people with MND, their enthusiastic and sometimes heroic contribution to this study. Without their considerable time and patience this project would not have been possible. Some participants were unable to see the study completed but their words eloquently contributed to the group perception of the illness experience of living with the disease.

In memory of Ken Brentwood who passed away before the study was complete. He was always enthusiastic and encouraging of the project and a valued member of the advisory board.

I also dedicate this doctorate to my father-in-law, Tom (dec), who provided me with much encouragement and guidance to continue my post-graduate studies. He has been with me in spirit as my father, Derek (dec) has been and my uncle, Tony (dec).
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Ken Brentwood (dec), person living with MND
Dr Jan Browne, PhD, Deakin University
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CHAPTER ONE

THE RESEARCH PROBLEM

1.1 Introduction

Motor neurone disease (MND) is a debilitating, terminal disease with an insidious onset. Other names used, particularly in the North American context, are amyotrophic lateral sclerosis (ALS) and Lou Gehrig’s disease. This uncommon disease causes degeneration of the motor neurones in the nervous system affecting the muscles of the body. Symptom progression includes loss of movement and strength in all limbs with accompanying spasticity, rigidity or flaccidness. As neck and facial nerves deteriorate, swallowing, voice production and speech formation abilities are lost (Leigh, Williams, & Abrahams, 2001). Symptoms such as choking when eating and breathing difficulties are also commonly experienced (Leigh et al., 2003; Leigh, Williams, & Abrahams, 2001). Previously it was thought that in the main, cognitive functioning remained intact but recent studies reveal that a greater percentage of people than previously reported, do have varying cognitive changes particularly in the frontotemporal lobe of the brain (Barson, Kinsella, Ong, & Mathers, 2000; Grossman & Bradley, 2003).

Deterioration can extend to “locked in” syndrome when there is no muscle movement and the person is unable to move or communicate in any way regardless of cognitive ability (Jenkinson, Fitzpatrick, Brennan, Bromberg, & Swash, 2000; Teijlingen, Friend, & Kamal, 2001).

There is no cure for MND and no remission phases. However, recently some drugs have been identified as having the potential to slow motor neurone loss and extend life minimally (Gelinas, Miller, & Abood, 2002; Rosenfeld, King, & Smith, 2002; Wasner, Klier, & Borasio, 2000). Nevertheless, in Australia, as it is globally, life expectancy after diagnosis
remains at one to five years with an average of 27 months (Lang, 1996).
Australian statistics indicate that 530 deaths were attributed to an underlying
cause of MND in 2003 and that the prevalence rate is 1 in 15,000 populations.
In Victoria, a state of Australia, the major community service organisation,
the Motor Neurone Association of Victoria provided services to 374 people
diagnosed with the disease in 2000 (MNDAV, 2001).

1.2 Background

Research about MND has mainly implemented a medical focus on
finding an answer to the cause or causes of the disease (Ben-Shlomo,
Whitehead, & Smith, 1996; Shaw, 1999; Walling, 1999) with the aim of finding
a cure or cures (Agar & Durham, 2003; Figlewicz & Orrell, 2003) and
ultimately to understand the disease. Psychological studies have used
quantifiable information from multiple scales (Goldstein et al., 1998),
psychological instruments (Hogg, Goldstein, & Leigh, 1994; Simmons,
Bremer, Robbins, Walsh, & Fischer, 2000) and questionnaires (Jenkinson,
Fitzpatrick, Brennan, Bromberg, & Swash, 1999) to understand various
aspects of the disease such as attitudes toward assisted suicide; psychological
impact of MND on people; relationships between quality of life, physical
function and spirituality; and temporal reactions to being given the diagnosis
of MND. Other research has sought to improve life by evaluating assistive
technologies and techniques (Bello-Haas, Kloos, & Mitsumoto, 1998; Gryfe,
Kurtz, Gutmann, & Laiken, 1996).

Qualitative studies have used rating scales (Young, Marshall, &
Anderson, 1994; Young & McNicoll, 1998), semi-structured interview
schedules and researcher derived checklists with small samples of
participants with MND, to examine such aspects as positive life experiences
(Young & McNicoll, 1998) and decision making processes involved in the
reasoning to use ventilation to aid respiration and oxygen exchange (Young
et al., 1994). Other researchers have conducted interviews with small
numbers of participants to investigate information seeking behaviours
(O’Brien, 2002) and user involvement in palliative care (Small & Rhodes, 2000). Robinson and Hunter (1998) wrote about the accumulated scientific knowledge including the disease pathogenesis and symptomology, and illness experiences of people with MND in the United Kingdom, to enlighten health professionals and people with the disease about MND and the illness experience. However this knowledge was gained through studies in Europe and North America and lacks information from an Australian perspective.

Research in Australia has focused on scientific endeavours (Azari et al., 2003; Pamphlett, Todd, Vink, McQuilty, & Cheema, 2003), clinical symptom management and aspects of understanding care from community nurses’ perspectives (Baker, 1997, 2000) and ethical issues with home ventilation programs (Baker, 2001). A paucity of knowledge about the illness experience of those living with MND in Australia exists.

Little is known about the experience of living with MND, or how people living with the disease realise their emotional and social needs as few studies have explored these issues from the perspective of the person with MND (Sachs and Associates, 1995). A factor that may contribute to this lack of knowledge is that the majority of people diagnosed with MND experience difficulties with verbal communication because of dysarthria and dysphonia which effects articulation and volume of voice respectively (Yorkston, 1996). Communication is compromised because of this lost muscle control and often assistive technology is used as a substitute for speech. Despite these technological advances the ability to communicate both verbally and with assistive technology such as electronic Lightwriters and computers declines as the disease progresses and muscle function is lost. Billinghurst (2001) highlighted the challenges associated in communicating with people with MND and it seems likely that the challenges associated with the loss of physical ability to communicate have contributed to the loss of the “voice” of those experiencing the illness.
Negotiating for choices is a complex process even for individuals who have the relevant information about the choices to be made and have adept communication abilities. Conversely, limited communication abilities and lack of relevant knowledge, impedes negotiation processes for choices. For individuals diagnosed with MND, communication and negotiation capacity decreases as the disease progresses. Health professionals and complex care structures sometimes, inadvertently, obstruct access to information about the disease and care options. Therefore making informed choices can be problematic for people diagnosed with MND.

While the medical progression of the disease is widely investigated, research about the illness, that is, the experiences of those living with MND is limited. People diagnosed with MND and their carers travel uncertain pathways with the knowledge of this life-limiting illness. It is therefore vital to explore their experiences of living day-to-day with this disease and to gain insight into the choices before them as the disease progresses and the importance in maintaining control over their lives.

### 1.3 Aims of the Study

Therefore the overall aim of this study was to explore the experiences of people diagnosed and living with MND in Australia. The specific questions to be answered were:

- What is the experience of people living with MND?
- How do people with MND negotiate with others to live their life as they wish?
- How do people with MND voice their psychosocial needs to those who work with and care for them?
1.4 Underpinning philosophy

To capture fully the complexity of this phenomenon, the philosophy and methodology selected to interrogate the data needed to do more than describe and analyse the participants’ experiences. Instead it needed to explore what Schwartz and Jacobs (1979) described as the “life-world” of people, that is, their “motives, meanings, emotions, and other subjective aspects” (p. 5) of their lives. Therefore a grounded theory methodology was chosen for the conduct of this study because it was deemed the most appropriate to explore the illness experiences of people diagnosed and living with the disease, that is, their life-worlds.

Grounded theory methodology is a systematic procedure for analysing data to develop theory about life-worlds, that is, social realities. The underpinning philosophy used in grounded theory is symbolic interactionism, which provides a philosophical stance for viewing and understanding how individuals act and interact in a social system. It provides a perspective to explore explanations of human action and life-worlds. In this study understanding the illness experience and the interactions that people diagnosed with MND have with others, and the meanings they make of such interactions, are investigated.

1.5 Researcher Position

A researcher using grounded theory concepts requires theoretical sensitivity to build an awareness to conceptualise and formulate theory emerging from the data (Glaser & Strauss, 1967). Theoretical sensitivity is defined as developing a keen insight and heightened awareness of the emergent theory that is open to revelations from the data (Annells, 2003). Facilitation of theoretical sensitivity is strengthened by the personal and professional experiences of researchers and the knowledge they derive from published literature. At the same time it is important for researchers to remain objective (Strauss & Corbin, 1998). In qualitative research, objectivity
refers to researchers’ being open, having a willingness to listen and to “give voice” to respondents (Bresler, 1995; Cheek, 1996).

I am a registered nurse and have worked in several practice areas including extended care, rehabilitation and paediatric facilities; however, the focus of my practice before this assimilation into the mainstream was in an infectious disease facility. This area of nursing practice allowed me to care for people with various diseases, some of whom were marginalised in society, such as, people diagnosed with Hanson’s disease, Hepatitis B requiring dialysis, HIV/AIDS and disabilities due to poliomyelitis, muscular dystrophy and MND. Many of these patients confided that they had, at different times in their lives, felt rejected by society because of their disease and associated afflictions. Caring for these groups of people opened my mind to those whose voices are often silenced either by society because they were from minority groups such as women, migrants or disabled, or by the progression of their disease, such as loss of voice control in MND. Thus I felt it important in this study to ensure that the voices of people with MND be heard even if they had difficulty communicating or were socially isolated.

1.6 Glossary of Terms Used in This Thesis

Various terms in this thesis have multiple meanings attached to them. The purpose of the following section is to define these terms making clear their meaning in the context of this study thus eliminating the potential for ambiguity and confusion.

Use of ALS/MND Terminology

In this project, the terms motor neurone disease (MND) and amyotrophic lateral sclerosis/motor neurone disease (ALS/MND) are used interchangeably. In Victoria, Australia, the disease is known and recognised by participants as MND and not ALS/MND yet internationally the latter is used in the literature.
In this study participants identified their marriage partners as “my husband” and “my wife”, but it is acknowledged that the more modern term of “partner” identifies couples who live together or who are married. The non-gendered terminology of “spouse” and “spousal relationships” is adopted in reporting the data. No same sex couples volunteered to participate in this study.

The diagnostic label motor neurone disease (MND) indicates a pathological disease state. MND, is however, referred to in the literature variously as a disease, an illness and at times classified as a chronic illness depending on the context.

**Disease**

The definition of a disease is based on the medical model of looking at the processes that bring about the altered physiology of a person. It is an objective assessment involving a professional diagnosis with a “set of signs and symptoms and medically diagnosed pathological abnormalities” in the person (Baum, 1998, p. 4). Yet for people diagnosed with MND, diagnosis is based on many diagnostic evaluations being “normal” while their physical body deteriorates.

**Illness experience**

Illness is explained as the experience of the disease and primarily the subjective perspective of the person as well as how his/her family perceive, live with and respond to the disease (Lubkin & Larsen, 2002). Within the literature about the experience of MND, living with MND generally denotes the experience of anyone touched by the illness, meaning the person, family, friends, employers, health care professionals and care providers. In this thesis, the experience of living with MND relates to the person with the disease. This study focuses on the person with the disease and not the perceptions of others who interact with them.
Chronic illness

Whether MND is a chronic illness depends on whose definition is applied and whose needs are to be met. Corbin (2001) defines “any physical or mental condition that requires long term (over 6 [sic] months) monitoring and/or management” (p. 1). However, some people diagnosed with MND die before the six month time period. In Australia, the Medicare Rights Group defines a chronic illness as “a disease that lasts for a long period of time or is marked by frequent recurrences, such as diabetes or asthma” (p. 1). This definition is required to gain access to medical care services. MND is a disease that, for some people, lasts from one to five years but treatment is aimed at symptomatic care and not treatment of recurrences of the disease. Chronic diseases such as asthma and diabetes are life long whereas MND is life ending. Albeit for the purposes of this study, the findings are compared with those resulting from research about chronic illnesses and the associated illness experiences.

Psychosocial needs

An aim of this study is to explore how people with MND voice their psychosocial needs. For this focus, psychosocial needs denote the perceptions participants have of themselves, their self-esteem, and self-image with a focus on their interpersonal relationships.

1.7 Overview of Thesis

Sometimes in this thesis, the first person singular pronoun is used to reflect myself as the researcher. My reasons for this decision are to enhance readability and to take ownership of my part in the research, not to overshadow participant involvement, but to ensure that my involvement is clear. This is congruent with grounded theory as the researcher is, in essence, a contributor to the exploration of the phenomenon being studied through the interview processes.
This thesis has eight chapters. The purposes of the first chapter is to provide a brief overview of the background to the study, highlight the gaps in the research literature, provided the rationale and justification for undertaking the research and describe the aims of the study.

The literature to inform this study is explored in the second chapter. Reviews include literature about MND, which highlight the major current research focus on scientific endeavours to find disease causes and cures. Further, there is a lack of research about the experience of living with the disease from the person’s perspective, that is, the illness experience. The other topics for review focus on psychosocial issues, quality of life and negotiation because these were identified as important in the literature about illness experiences. During data analysis, additional pertinent literature is reviewed and included in the findings chapters and discussed in chapter 7.

In the third chapter, the research processes used in the study are detailed. The choice of a grounded theory methodology is explained and defended, including a discussion about symbolic interactionism, the philosophy that underpins grounded theory. Characteristics of this approach are outlined according to how they are used in this study. These include the sampling and recruitment issues, participant demographics, data collection methods, analysis procedures and data management techniques. Ethical implications are discussed in relation to the conduct of the study and for interviewing people who are vulnerable.

The purpose of chapters 4, 5 and 6 are to describe the findings. One of the major foci of this study was to explore participants’ experiences following diagnosis of MND. Notably, despite being asked to tell their stories, most automatically began with the events that led up to actual diagnosis. In the fourth chapter, the model depicting “The Diagnosis Story” is introduced and explained. Of significance is the diagnostic roundabout and the consequences of the process that later impacted on people as they lived with the illness.
The intent of the fifth chapter is to describe and explain the decision-making model that represents the processes the men and women in the study went through as they experienced the illness. The process is cyclic and repetitive in nature. The ongoing changes and necessary adaptations characterised negotiating processes, as they lived with MND. The conceptual model is illustrated and the seven steps are explained.

The purpose of the sixth chapter is to describe and explain the basic social process that underpinned the decision-making process, that of maintaining personal integrity. The dimensions of personal integrity for the men and women with MND are identified as feelings, control and image. The processes for maintaining personal integrity are protecting, regaining and sustaining. These understandings and processes are depicted in a conceptual model and the strategies used in the processes are identified.

In the seventh chapter, the study findings are discussed with respect to the contemporary literature about decision-making models, chronic illness and other neurodegenerative conditions. Several concerns pertinent to the illness experience are identified and discussed. This chapter identifies the contribution of the findings to current knowledge.

The purpose of the eighth chapter is to introduce the developed substantive theory. The three conceptual models are brought together to illustrate and identify what it is like to live with ALS/MND: that of maintaining personal integrity in the face of ongoing change and adaptation. The substantive theory is compared with two formal theories about chronic illness experiences. The findings are positioned within the contemporary literature and the contribution the current study makes to existing knowledge is identified. Study limitations, researcher influence, recommendations from the findings and suggestions for further research are acknowledged and made known. The chapter concludes with a summary of the study.
CHAPTER TWO
LITERATURE REVIEW

2.1 Introduction

The abundance of research devoted to the pursuit of a cause and cure for MND suggests that MND remains a baffling disease. Research continues to seek answers to why motor neurones degenerate and which treatment modalities may halt or slow the process. For example, “animal models” and in particular “mouse models” have been genetically modified (Figlewicz, 2001; Glass et al., 2003; Hafezparast et al., 2003; Silani et al., 2002) to test the degeneration process and to trial various treatments. These types of studies imply that the main focus of research into MND has been aimed scientifically at a cellular level and remains at the pre-clinical stage.

The purpose of the discussion of the three sections in this chapter is to support the premise that, while there has been a great deal of research into MND, the voices of those living with the illness remains largely unheard. The first section presents a selection of research that has focused on causes, cures and treatments. It is important to acknowledge this contribution to the study of MND as such research shows the great gains that have been made in understanding the disease, albeit with no definitive resolutions. It is within this context that people with MND attempt to negotiate life choices concerning their future health care and day-to-day survival.

An overview of the effect of MND on physical and psychological health is presented in section two. The review of this literature makes clear that there are profound changes associated with the sequelae of MND; however these studies are predominantly descriptive and derived from the use of scales, tools and questionnaires. While these findings have provided valuable information to assist health professionals in guiding specialised care, it is
argued that they leave unexplored the experience of living with MND day-to-day.

Without treatments or periods of remission people with MND live with an illness that causes the voluntary muscles in the body to progressively deteriorate. Some are confronted with making significant decisions about how they want to live with the disease. These decisions may have to be faced even before the necessity arises because the ability to verbally communicate can quickly decline. Negotiation of choices has been recognised as a key concern for people with communication difficulties (Cirlot-New, 2003; Hemsley et al., 2001) yet there is a paucity of research in this area.

In section three, the literature related to the illness experience of MND is explored. Psychosocial issues encompassing quality of life, choice and negotiation are examined. While the studies in this area can be classified as belonging to the qualitative paradigm, researchers have also relied upon structured interviews, scales and measurements. For the most part, only small numbers of participants are involved in the studies. Evidence is presented to suggest that the research, to date, does not explore fully the experience of living day-to-day with MND from the perspective of those with the illness.

Following the initial review of literature that assisted with the conceptualisation of the study and consistent with the tenets of a grounded theory approach, a subsequent review of literature was guided by concepts that emerged from the data analysis of participant interviews. The purpose of this strategy was to expand and enrich the understanding of the data analysed. Literature reviewed at this time was integrated into the findings chapters and discussed in chapter 7.

2.2 Section One: Typical Direction of Current MND Research

As noted the majority of literature related to MND is concerned with the cause and cure of the disease. While a broad literature search of the databases was undertaken, the majority of articles identified were found in
the medical database, MEDLINE. This suggests an intense medical scientific research focus in the pursuit of causes and subsequent cures for MND. The purpose of this section is to identify and discuss research literature under the headings of causes, cures and treatments. The major points of discussion include proposed causal theories, research foci into cause and cure, and clinical trials for treatments. This body of literature is reviewed to provide an overview of where the research has thus far been focused and to highlight how this focus has left unexplored the illness experience of people with the disease. This review also contextualises the study to understand the disease, therefore, some of the studies are presented in tables, and only the exemplars are discussed.

### 2.2.1 Search for causes

It has been proposed that there is no one cause of MND but that there are many possible factors or possibilities and combinations of factors involved (Grossman & Bradley, 2003; Strong et al., 1999). Published research reports of investigations into the causes of MND are extensive and encompass many theories yet, it seems, the answers still elude researchers. Some possible theories have included: viral infections; autoimmune diseases and neurotoxins; genetic and familial associations; excessive glutamate and oxidative processes that injure the motor neurones; environmental toxins, which independently or in combination have caused MND. There are some environmental aspects that are known to influence the disease but, in general, why motor neurones die and people develop MND remains a mystery (Davies, 1991). A sample of the literature outlining possible causal theories is presented in Table 2.1 (see page 15).

Globally, there are various forms of MND that are linked to the environment. In Africa, Konzo is a disease which has the same clinical manifestations as MND. It is associated with dietary cyanide exposure from consumption of insufficiently processed bitter cassava, a root crop which is the main staple food in this tropical area. Konzo epidemics have coincided
with food shortages (WHO, 1996) and it is hypothesised that it occurs because, at these times, the cassava is eaten in combination with a low protein diet and low intake of sulphur amino acid substances that are needed to break down cyanide in the human body.

In the western Pacific islands of Guam and Rota, outbreaks of a type of motor neurone disease were associated with the use of the flour made from cycad seeds which were used to bake a type of bread. According to Spencer et al. (1986; 1987) and Stone (1993), reduced usage of this flour decreased the incidence of the Guam disease. An ethno medical review of historical documents by Prasad and Kurland (1997) supported the theory of a neurotoxin causing the disease in Guam but revealed that it was not necessarily from the cycad seed. These important studies give insight into the complexity of the aetiology of MND, the role of neurotoxins and their effects on motor neurones, which has lead to further scientific research into the cause of MND.

Similarly other environmental factors, such as low frequency electromagnetic fields and exposure to metals and solvents, are thought to be implicated in MND. Consequently, the World Health Organisation (WHO, 1997) identified the need to focus research into the possible cause of diseases, such as MND, in relation to human exposure to low frequency electromagnetic fields. In other research, Gait et al. (2003) reviewed death certificates and historical occupation records of employees of a major engineering company in the United Kingdom (UK), to ascertain if exposure to metals and solvents in the work environment were implicated as a risk for developing MND. Two hundred and six employee controls were selected to compare with 22 cases of MND and a history of exposure risk. The researchers concluded that it was unlikely that exposure to metals and solvents was involved in the aetiology of MND.
<table>
<thead>
<tr>
<th>Author/Years</th>
<th>Purpose</th>
<th>Causative Theory</th>
<th>Design &amp; Methods Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Ben-Shlomo, Whitehead &amp; Smith (1996)</td>
<td>Review of research about common genetic factors in 3 neurodegenerative diseases – Parkinson’s, Alzheimer’s and motor neurone disease.</td>
<td>Genetic influences</td>
<td>Discussion of analysed epidemiological data and other completed studies</td>
</tr>
<tr>
<td>2 Cheng (2000)</td>
<td>To test the hypothesis that ALS is caused by an infectious agent</td>
<td>Viral infection</td>
<td>Scientific investigation of 17 spinal cord samples of ALS patients</td>
</tr>
<tr>
<td>3 Woodall, Riding, Graham &amp; Clements (1994)</td>
<td>Scientific investigation into enteroviruses as a causative factor in the pathogenesis of MND</td>
<td>Slow viral infection of non-polio type</td>
<td>Scientific analysis of spinal cords taken at necropsy from subjects with MND, investigating the presence of enteroviruses</td>
</tr>
<tr>
<td>4 Prasad &amp; Kurland (1997)</td>
<td>Ethno medical study of historical origins of ALS and Parkinsonism-dementia in Guam investigating other possible causes of ALS on Guam</td>
<td>Environmental toxins (deficiency of calcium &amp; exposure to toxins of cycad plant) &amp; genetic susceptibility</td>
<td>Ethno medical study: Reviewed historical &amp; recent medical histories, archaeological data, oral and written interviews dating back to 1898. Development of risk factor questionnaire for information about the various hypotheses from people on Guam</td>
</tr>
<tr>
<td>5 Spencer et al. (Lewis, 1987; 1987)</td>
<td>To test the hypothesis that cycad neurotoxin is a cause of MND</td>
<td>Environmental toxin (cycad hypothesis)</td>
<td>Scientific experiment injecting monkeys with amino acid BMAA which cycad plant is a natural source</td>
</tr>
<tr>
<td>6 Barinaga &amp; Vogel (1996)</td>
<td>To investigate gene abnormalities that cause increased levels of glutamate at neuro-junction - glutamate hypothesis</td>
<td>Increased neurotransmitter, glutamate, toxic to cells resulting in the death of neurones that control muscles</td>
<td>Scientific investigation of low levels of proteins in brain and spinal cord tissue obtained at autopsy from MND patients</td>
</tr>
<tr>
<td>7 Shaw &amp; Ince (1997)</td>
<td>To investigate “glutamate hypothesis” as a pathophysiologic cause of motor neurone injury</td>
<td>Excessive glutamate is toxic to motor neurones</td>
<td>Scientific investigation</td>
</tr>
</tbody>
</table>
As illustrated by the selected studies in Table 2.1 (see page 15), a main focus for scientific research has been to investigate various theories about motor neurone death. This has included seeking to discount some theories and promote others. Accordingly, such theories have provided a particular foundation for scientific research concerned with curing MND.

2.2.2 Search for cures

As yet there is no cure for MND and as a result many research projects continue to focus on this area of endeavour. Many theories are proposed about how motor neurones are injured and die. Researchers are stimulated to investigate cell death, how it can be halted and, more recently, how motor neurones can be regenerated, that is, the pathogenesis of MND.

Studies about cause and cure remain predominately pre-clinical. “Animal models” are used principally as a means of investigating the disease. Mice have been genetically modified to produce “mouse models” of MND and subsequent research has focused on motor neurone development, and causes of deterioration and death (Glass et al., 2003; Goto, Gralla, Valentine, & Cabelli, 1998; Hafezparast et al., 2003; Lyons et al., 1996; Shaw et al., 1997). The “mouse models” are also the basis for investigating possible cures. This has included “stem cell” research which has some proven success of regenerating motor neurones in “mutant” mice (ALS/MND Alliance, 2000; Figlewicz, 2001; Silani et al., 2002).

An example of the usefulness of animal models has been the injecting of the drug leukemic inhibitory factor into mouse models. This research has demonstrated that the drug can delay different effects of MND such as disease onset, but no significant rescue of motor neurones was evident (Azari et al., 2003). Lowry et al. (2001) treated rats with daily systemic intraperitoneal injections of antisense p75 (NTR), demonstrating that antisense strategies can reduce the loss of motor neurones and prevent motor neurone degeneration. With the relative success of the drug riluzole as an anti-glutamate agent in the treatment of MND, Pamphlett, Todd, Vink,
McQuilty and Cheema (1999) used a mouse model with MND to test magnesium (Mg) as an effective glutamate blocker. This research was based on the notion that magnesium ions inhibit the opening of some glutamate receptors thus limiting the amount of glutamate and preserving motor neurones. Results showed that a trial of oral Mg supplementation in humans was not warranted as there was no real effect. While these experiments do promote hope for the future for people with MND and their families, there is also the potential to “dash” this hope with poorly designed trials and premature results (Silani & Leigh, 2003, p. 9). Silani and Leigh acknowledge the importance of hope for a cure but caution building up false hope with results that are not rigorously proven.

2.2.3 Developing treatments

Research outcomes from the studies that have investigated cause and cure have logically directed the research into appropriate treatments. A summary of potential treatments and the theories that underpin their application is discussed. Although human clinical trials are important in seeking cures and relief from symptoms, investigators tend to overlook the physical, psychological and social impact on the people in the studies.

Clinical trials have been conducted to ascertain the efficacy of a variety of treatments for MND, which have the potential to modify the symptoms of the disease. These have included the drug riluzole; complementary medicines such as creatinine; antioxidants and marijuana; as well as treatments that combine mainstream medicine with complementary and alternative approaches (Armon, 1999; Clark & Kendall, 1996; Groeneveld et al., 2002; Shefner et al., 2003; Walling, 1999; Wokke, 1996).

One causation theory proposes that excessive glutamate, a neurotransmitter, in the nervous system causes the motor neurones to die. Ongoing human trails are in progress for riluzole, which is purported to decrease the release of glutamate thus reducing the excitation at the neurone synapse and, therefore, limiting neurone damage (Clark & Kendall, 1996).
Clark and Kendall reviewed two placebo-controlled clinical trials of riluzole in the management of MND. The reviewers concluded that riluzole was the first treatment to extend survival time in people with MND, albeit modestly. However, they questioned the benefits of the treatment because the side effects included loss of strength, weakness, nausea and vomiting. This review by Clark and Kendall, is among the few studies that have attempted to go beyond the results of scientific research and endeavoured to include the human aspect of treatments for MND.

Wokke (1996) reviewed the same clinical trials as those above but, unlike Clark and Kendall (1996), he concluded that riluzole has the potential to become a standard therapy for MND. He articulated three hypotheses to explain motor neurone death: first, an unconventional autoimmune disease causes motor neurone death; second, excessive free radicals damage motor neurones; third, excessive activation of glutamate in the brain and spinal cord is implicated in the disease. He places most hope in this third hypothesis asserting, that “the glutamate hypothesis offers opportunities for pharmacotherapy and new drugs” (p. 796) such as riluzole.

Although riluzole is the only drug considered to have some effect in slowing the progression of MND, this treatment is contentious because of cost, efficacy, modest increase in survival rate and issues about quality of life (Armon, 1999; Clark & Kendall, 1996; Walling, 1999). Because the drug is expensive it is not available to all people. Miller, Mitchell and Moore (2001) argued that it is not justifiable to withhold riluzole from any patients diagnosed with MND because the slowing effect on the progression of the disease is evident for up to 18 months. However, in a recent systematic review of the relevant research, their findings reduced this period to approximately two months (Miller, Mitchell, Lyon, & Moore, 2003). It seems time estimates of riluzole extending survival are not yet clear, which contributes to confusion and uncertainty for the people diagnosed with MND and their physicians.
MND has been considered a “useful paradigm” (Young, Tedman, & Williams, 1995, p. 53) to study other chronic or neurodegenerative diseases such as Parkinson’s disease (PD) and multiple sclerosis (MS) from the perspective of disease pathology, treatments and psychological aspects. Because there is no cure for MND or any remission time, it has been hypothesised that interventions can be introduced and tested on people with this neurodegenerative disease as there are no treatments with which the interventions can interfere. The ethics of such an approach remain unquestioned, however the introduction of the drug riluzole, which for a time was thought to significantly slow the disease, may alter this situation. As recently found (Miller et al., 2003) though, this drug has not lived up to its early promise.

Not all countries permit the use of riluzole but it has been available in the UK and the United States of America (USA) for many years. In Australia of late, authorising bodies have permitted the introduction and use of riluzole for people with MND (Kiernan, 2003; MIMS Australia Pty Ltd, 2004). At present there are no published studies of the Australian experience of using riluzole.

Other treatment approaches for MND are viewed as complementary or experimental. Newsweek (1999) reported one approach that involved the use of creatine, an amino acid, as a possible weapon against MND because amino acids have been shown to increase muscle mass in athletes. However, recent human trials of creatine by Groeneveld et al. (2002) found no evidence for beneficial effects on survival or disease progression. Rosenfeld, King and Smith (2002) examined the usefulness of anabolic steroids but results from this study also failed to demonstrate improvements in muscle strength. Despite these apparent failures, human trials and analysis of creatine and anabolic steroids are continuing (Shefner et al., 2003).

A number of complementary and alternative medicines have also been trialled. Gelanis, Miller and Abood (2002) explored the usefulness of Marinol,
marijuana, as a neuroprotective agent and established that some symptom relief was achieved. Wasner, Klier and Borasio (2000; 2001) conducted a survey of 171 MND patients to determine the types of complementary and alternative medicines (CAM) they accessed in the hope of alleviating disease symptoms and halting the disease. The respondents identified acupuncture (47%), homeopathic medicine (40%), naturopathy (24%) and other different therapies (20%) such as detoxification and herbal treatments, as their preferred choices. It was apparent from the responses that the lower the participants’ expectations of CAMs, the greater the subjectively perceived effect. Physicians were said to be involved in both the treatment and prescription of CAMs often in addition to conventional treatments. Seventy-three different methods or substances were used with some participants having tried up to 11 different treatments. This study by Wasner, Klier and Borasio, highlighted that in the face of an unknown cause and cure, people with MND actively seek ways of promoting a sense of control and enhancing their sense of hope for the future.

Whilst efforts continue to work towards treatments to potentially cure MND and moderate its effects, a recent survey identified symptomatic treatments prescribed in 39 ALS clinical centres in North America (Forshew & Bromberg, 2003). Discernable patterns with considerable differences in dosages of various medications prescribed to patients were noted. Forshaw and Bromberg (2003) highlighted the lack of clinically controlled trials with ALS subjects for several symptomatic treatments including: muscle cramping, excessive saliva production also known as sialorrhoea, dry mouth, thick phlegm, depression, anxiety, urinary urgency, disturbed sleep, fasciculations and constipation. At best the treatments prescribed at these centres were trial and error and based on individual clinical assessments, past experiences and subjective reports. Of note was the identification of symptoms not usually attributed to ALS such as urinary urgency and laryngospasm reported by 19% of patients.
2.2.4 Summary of current MND research directions

To date, most of the research about MND, reports on progress into the search for possible causes and cures, and the development of potential treatments at the cellular level in animal models. Riluzole is the only drug, to date, which has the effect of slowing the progression of the disease, albeit only briefly. Complementary and alternative medicines are used by people diagnosed with the disease in the hope that they can ameliorate the disease. Scientists have taken note of what patients have said and are undertaking trials with these medicines. In this section an overview of current knowledge related to causes, cures and treatments of MND has been reviewed to provide the context that faces people diagnosed with MND. In the next section, the research literature about the impact of MND on the person who has been diagnosed with the disease and about the illness experience is explored.
2.3  Section Two: Physical and Psychological Impact of MND

The term MND refers to various neurodegenerative disorders that are characterised by the gradual erosion of people’s physical abilities according to the selective loss of upper and lower motor neurones. The neurones innervate the voluntary muscles in the limbs and bulbar area (Donaghy, 1999). They affect different areas in the body with various symptoms as listed in Table 2.2 (see page 23). Differences may focus on spinal or bulbar influences or a mixture of both. Eventually most people with the disease experience major bulbar problems (Leigh et al., 2001) associated with deterioration in speech and swallowing.

A disease that has such profound effects on physical abilities will almost certainly affect and change other aspects of life. These changes may include alterations in psychological wellbeing, socialisation opportunities and interpersonal relationships with family and friends. The illness may also present environmental restrictions that impact upon independent living. The capacity to realise decisions becomes more time consuming as abilities decrease and reliance on the advocacy of others increases. The purpose of this section is to highlight the studies that look at the impact of MND on the individual, that is, both the physical and psychological effects of the disease on the body. It is argued that these aspects of living with MND have been assessed and statistically measured to underpin research into what happens to people with the disease, without taking into consideration the realities of living with the various physical and psychological changes associated with the disease – the subjective illness experience.
Table 2.2 Association of Spinal and Bulbar Motor Neurone Nerves that MND Effects

<table>
<thead>
<tr>
<th>MND type</th>
<th>Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spinal form</td>
<td>Muscle atrophy</td>
</tr>
<tr>
<td></td>
<td>Fasciculations</td>
</tr>
<tr>
<td></td>
<td>Progressive weakness in limbs</td>
</tr>
<tr>
<td></td>
<td>Muscle cramping</td>
</tr>
<tr>
<td></td>
<td>Spasticity in upper an lower limb movements</td>
</tr>
<tr>
<td></td>
<td>Reflexes were hyperactive</td>
</tr>
<tr>
<td>Bulbar form</td>
<td>Swallowing problems with excessive salivation (sialorrhea) resulting in drooling</td>
</tr>
<tr>
<td></td>
<td>Fasciculations of the tongue</td>
</tr>
<tr>
<td></td>
<td>Dysarthria (articulation)</td>
</tr>
<tr>
<td></td>
<td>Dysphonia (volume)</td>
</tr>
<tr>
<td></td>
<td>Emotional lability</td>
</tr>
<tr>
<td></td>
<td>Respiratory muscle failure</td>
</tr>
<tr>
<td></td>
<td>Cachexia (excessive weight loss)</td>
</tr>
</tbody>
</table>

(Donaghy, 1999; Leigh et al., 2001; Walling, 1999; Yorkston, 1996)

2.3.1 Physical effects of MND

Physical abilities deteriorate as motor neurones die. The deterioration that occurs from MND has been charted and measured in an attempt to predict progression pathways (Armon & Moses, 1998). Studies have investigated the physical effects that impact on the person. The aspects discussed are respiration, nutrition, communication and cognition in relation to living with MND.

Respiration

MND has a significant impact on the maintenance of respiration and oxygen exchange as the nerves that enervate the respiratory muscles deteriorate. People with MND usually die because of respiratory failure unless they choose to maintain life with mechanical ventilation (Moss et al., 1996). The costs of providing invasive ventilation are high because of the expensive technology, equipment and the ongoing provision of support
services such as nursing care. Most people with MND live at home. Providing this expert care in the home is also costly because constant care is required and human resources are scarce. Sometimes family and friends are trained to give care but if a crisis arises, professional support is required. Accordingly, this intervention usually necessitates in-patient care in a hospital with appropriate acute medical facilities, which again adds to the economic burden, either personally or on the health care system (Talbot & Verrinder, 2005).

An ancillary aspect to compromised respiration is sleep quality. Nocturnal hypoventilation occurs as respiration fails during sleep and carbon dioxide increases in the brain and sleep patterns are disrupted. A consequence is that the person’s quality of life is affected because of lethargy, headache, reduced appetite and feeling ill (Leigh et al., 2001) and their active participation in life becomes problematic. Often people with MND undergo sleep studies in a hospital environment to assess oxygen and carbon dioxide levels overnight, which can indicate the appropriateness of interventions for promoting effective sleep and oxygen exchange. Leigh, Williams and Abrahams (2001) assert that this is just one of many decisions that people with MND are required to make as a way of resolving nocturnal hypoventilation with non-invasive positive pressure ventilation (NIPPV).

As previously noted, measures to maintain life include either, invasive or non-invasive mechanical ventilation (NIV). Such interventions need to be introduced prior to experiencing breathing difficulties (Albert, Murphy, Del Bene, & Rowland, 2000; Borasio, Sloan, & Pongratz, 1998) because studies are inconclusive as to whether NIV has any potential benefits for individuals who decide on ventilation assistance after their respiratory muscles are already compromised and breathing is difficult (Homma et al., 1999). Some doctors believe invasive ventilation leads to a poor quality of life (McDonald, Hillel, & Wiedenfeld, 1996). In contrast, some patients diagnosed with MND believe their quality of life (QoL) improves using such interventions, particularly with modifications that promote independence such as
controlling communication technology with muscle stimulated devices, that is, a myoelectrically controlled switch (Gryfe et al., 1996). McDonald, Hillel and Wiedenfeld (1996) compared the psychological status of 18 ventilatory-supported patients with ALS with 126 non-ventilatory-supported patients using the ALS Severity Scale (ALSSS) with 10 standardised tests to measure psychological status. This study established that the people who chose ventilatory support had a perceived high QoL and psychological wellbeing despite severe incapacity and that they had a more internal health locus of control and could direct their care impacting positively on their QoL. Findings suggested that the patients who chose ventilation-support felt “that life with ALS/MND is of a high enough quality that they want to continue living” (McDonald et al., 1996, p. 39). McDonald, Hillel and Wiedenfeld also suggested that a sense of high QoL should be taken into consideration rather than the costs of providing the technology.

Similarly, Young, Marshall and Anderson (1994) interviewed 13 people with MND who either had mechanical ventilation or were considering this intervention. The aim of the study was to explore the issues of mechanical ventilation from the perspective of the person with the disease. Findings included that the principal factor for deciding to have mechanical ventilation was related to quality of life. This decision altered with time and was not related to the level of disability. Other factors such as financial concerns, emotional suffering, thoughts about the dying process and death, were not considered when making their decisions about mechanical ventilation.

An important ethical issue associated with the use of mechanical ventilation is deciding when and under what conditions to turn off the machine. In the study by Moss et al. (1996), quality of life issues and future plans were discussed with patients who were ventilated. Outcomes highlighted the necessity of open communication with physicians before the decision to have ventilation is made. This included discussions about family burden and future decisions about when to remove the mechanical
ventilation. Another facet of the effect of MND is changed nutrition status and weight.

**Nutrition**

As bulbar muscles weaken, people with MND experience swallowing difficulties and their bodies’ nutrition requirements are compromised. Sometimes, as a confounding symptom of MND, people experience great weight loss. An option for regaining nutrition levels and hopefully for gaining weight is the insertion of Percutaneous Enteral Gastrostomy (PEG) to provide liquid enteral feeds high in calories and vitamins (Leigh et al., 2003). In other literature, the nutrient qualities that people with neurological conditions require in enteral feeding regimes are explored (Corden, 1996). Health professionals promote PEG insertion for supplementary feeding and hydration, as a symptomatic support, before swallowing ability deteriorates. This invasive intervention is for maintenance of life (Smith & Andrews, 2000). As Smith and Andrews (2000) asserted, paradoxically, this intervention is not effective for people who are not going to die but is effective in terminal illnesses. In other more recent literature, variations of supplementary feeding with PEG, radiologically inserted gastrostomy (RIG) and nasogastric tube for hydration and nutrition have been assessed (Thornton, Fotheringham, & Alexander, 2002). While maintenance for living requires the exchange of oxygen for carbon dioxide, water and nutrients to enable cells to function in the body, communication is also an important aspect of living.

**Communication**

With the deterioration of the bulbar muscles and later, as the disease progresses, natural speech and verbal communication becomes problematic (Leigh et al., 2001; Shaw, 1999; Walling, 1999). The ability to physically form words is compromised. Dysarthria is a chronic motor speech disorder that has no cure, thus “treatments” are suggested to overcome some of the confronting aspects of speech and communication. “Treatment” entails
health professionals assisting persons with the problem and their families choosing appropriate alternative ways to communicate (Yorkston, 1996, p. S43). Cirlot-New (2003) explained that the means of augmentative and alternative communication (AAC) includes high-technology devices such as computers and electronic Lightwriters, and simply using pencil and paper. Doyle and Phillips (2001) asserted that acceptance and use of AAC is influenced by: the person’s tolerance of and experience with technology before the diagnosis of MND; being able to cognitively adapt to the technology before it is required and how communication partners accept the technology. Hatakeyama, Okamoto, Kamata and Kasuga (2000) contend that assistive technology promotes independence and freedom in people with MND, increasing their self-esteem and feelings of self-worth. Additional challenges occur with the deterioration of other physical abilities such as movement in hands and limbs, which require the use of alternative methods to access the technology. For example, one client in Japan was fitted with a new input device which used eyebrow movement to operate assistive technology (Hatakeyama et al., 2000) when his capacity to use other means was lost.

**Cognition**

While altered verbal communication is viewed as an effect of the disease, this can also be affected by other neuronal degeneration associated with cognition. Recent studies into MND reveal that a greater percentage of people than previously thought do have cognitive changes especially in the frontotemporal lobe of the brain (Bak & Hodges, 1999, 2001; Barson et al., 2000; Murphy et al., 2002; Neary et al., 2000). A controversy exists as to whether it is really deterioration in executive functioning that affects judgment and memory, or that the cognitive functions themselves are affected in the main by the disease (Bak & Hodges, 2001; Barson et al., 2000; Goldstein & Leigh, 1999; Murphy et al., 2002; Neary et al., 2000; Worthington, 1996).
A literature review of research into cognition and ALS revealed that MND is no longer considered a disease of the motor neurones alone but is now viewed as a multisystem disease (Grossman & Bradley, 2003). This means both motor and non-motor systems are affected and that cognitive impairment is recognised as a non-motor feature of ALS (Strong et al., 1999). Further studies have clarified the extent of cognitive impairment and the actual alterations that occur as a consequence of disease progression (Abrahams, Goldstein, & Leigh, 2003; Gibbons, Snowden, & Neary, 2003; Olney et al., 2003). Abrahams et al. (2003) conducted a prospective study of 20 non-demented ALS patients and 18 control subjects. Both groups were interviewed twice with a six month interval. Cognitive areas tested were executive functions, memory, language, visuospatial functions and behavioural areas were assessed with questionnaires on emotional lability, anxiety and depression. The authors found little evidence of cognitive deterioration but identified that patients with ALS had increased levels of anxiety and depression after six months. They concluded that more longitudinal studies were required to understand the cognitive changes, if any, associated with the disease.

The investigations into the relationship of MND and cognition do not resolve the controversy but they do indicate that the previous notion that cognition remains intact is questionable. Accordingly, identifying people with MND as having some cognitive dysfunction can impinge on their sense of wellbeing and quality of life.

2.3.2 Psychological effects

It seems that being diagnosed with a terminal illness such as MND has a psychological impact on the person with the disease. Many studies have been undertaken to measure different aspects of the impact, such as, perceptions of health (Young et al., 1995), psychological distress (Goldstein et al., 1998) and psychological factors that promote survival (McDonald, Wiedenfeld, Hillel, Carpenter, & Walter, 1994). The various facets of research
related to the psychological components of living with MND and the disability paradox are discussed in this section.

Researchers have used both disease specific and modified scales and instruments to understand the psychological effects of MND on the person. These studies are summarised in Table 2.3 (see page 30). While findings from these studies have added to the body of knowledge about the psychological effects experienced by people with MND, the use of scales and questionnaires leaves the subjective experience of people with the disease unexplored. In the main these studies were conducted in order to gather scientific criteria for human treatment trials and disease effects (Jenkinson et al., 2000; Jenkinson, Fitzpatrick, Brennan, & Swash, 1999; Jenkinson et al., 1998).
### Table 2.3 Overview of Typical Psychological Studies

<table>
<thead>
<tr>
<th>Author/ Years</th>
<th>Study</th>
<th>Purpose</th>
<th>Sample and Instruments</th>
<th>Findings</th>
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<tbody>
<tr>
<td><strong>Study 1</strong></td>
<td>Gelinas, O’Connor &amp; Miller (1998)</td>
<td>Quality of life (QoL) for ventilator-dependent ALS patients and their caregivers</td>
<td>To quantify QoL using standardised scales. To assist patients in making more informed ventilator decisions.</td>
<td>7 ventilator-dependent ALS patients 15 caregivers ALS Quality of Life Index (ALSQL1) SF-12 Health Status Survey (SF-12) ALS Patient Caregiver Form (ALSPCF) QoL difficult to assess as QoL measures for healthy people do not apply because of maximum scores in disability items. Patients who were very limited by MND did not have a low QoL. No patient regretted the choice to be ventilated as they felt contented &amp; satisfied most of the time. Happiness came from being able to go out, participate in social activities and having the ability to communicate. In contrast, carers felt the burden of care and were discontented with their lives. This improved if they had outside interests, had a good support system and the longer the care extended past 2 years.</td>
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<td><strong>Study 2</strong></td>
<td>Goldstein et al. (1998)</td>
<td>Psychological impact of MND on patients and carers</td>
<td>To further investigate presence of psychological distress in people with MND, relating to severity of functional impairment as well as carers’ subjective burden of care.</td>
<td>19 patients and their carers ALS Severity Scale (ALSSS) Sickness Impact Scale (SIP) Ways of Coping Checklist (WOCC) Hospital Anxiety and Depression Scale (HAD) Acceptance of illness (AOI) Self Esteem Scale (SES) Multi-dimensional Health Locus of Control (MHLOC) Intimacy Scale Strain Scale Cognitive Failures Questionnaire (CFQ) Dysexecutive Questionnaire (DEX) Patient: physical disability and illness that impact on areas of everyday functioning were associated with the degree of anxiety, depression and self-esteem. Temporal aspects of symptom onset and diagnosis influenced self-esteem levels and instigated certain internalised coping strategies, such as problem-solving, reorientation and distancing, with a shorter duration of symptoms. Carers anxiety increases the shorter the duration of symptoms and is positively correlated with marriage duration possibly related to uncertainty over future disease progression and a future without their partners. Problem-solving and reorientation coping strategies used when ambulation and alertness decreased</td>
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<td>Author/ Years</td>
<td>Study</td>
<td>Purpose</td>
<td>Sample and Instruments</td>
<td>Findings</td>
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<td><strong>Study 3</strong></td>
<td>Hogg et al (1994)</td>
<td>Psychological impact of MND</td>
<td>To investigate further the psychological impact of MND in relation to physical functioning, aspects of social functioning as well as mental functioning</td>
<td>52 patients with MND&lt;br&gt;Barthel Index (BI)&lt;br&gt;Sickness Impact Profile (SIP)&lt;br&gt;Hospital Anxiety and Depression Scale (HAD)&lt;br&gt;Ways of Coping Checklist (WCC)&lt;br&gt;Acceptance of Illness (AOI)&lt;br&gt;Positive Attributions Questionnaire (PAQ)&lt;br&gt;Health Locus of Control (HLOC)</td>
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<td><strong>Study 4</strong></td>
<td>McDonald, Hillel &amp; Wiedenfeld (1996)</td>
<td>Evaluation of the psychological status of ventilatory-supported patients with MND</td>
<td>To compare socioeconomic, physical and psychological status of ventilatory-supported and non-ventilatory supported patients with MND</td>
<td>18 ventilatory-supported patients with MND; 126 non-ventilatory supported patients with MND.&lt;br&gt;ALS Severity Scale&lt;br&gt;A comprehensive data form about themselves and their lives.&lt;br&gt;Beck Hopelessness Scale&lt;br&gt;Beck Depression Inventory&lt;br&gt;Anger Expression Scale&lt;br&gt;Perceived Stress Scale&lt;br&gt;Purpose-in-Life Test&lt;br&gt;Health Locus of Control Scale&lt;br&gt;Life Rating Scale&lt;br&gt;UCLA Loneliness Scale&lt;br&gt;Social Support Questionnaire, Short Form (SSQ6) – Satisfaction&lt;br&gt;Revised Ways of Coping Checklist Psychological Status</td>
</tr>
<tr>
<td>Author/Years</td>
<td>Study</td>
<td>Purpose</td>
<td>Sample and Instruments</td>
<td>Findings</td>
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<td>Study 5</td>
<td>Rigby et al (1999)</td>
<td>Quality of life assessment in MND: development of a Social Withdrawal Scale</td>
<td>Derivation of a scale of social withdrawal based on issues of importance as reported by patients themselves</td>
<td>Patients described withdrawing from social activities as their physical symptoms increased. This was attributed to a loss of confidence in public. Major issue for patients was the experienced social changes.</td>
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<td></td>
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<td>Seven MND patients Open-ended patient interviews; semi-structured; content analysis. 24-items formed the basis of Social Withdrawal Scale</td>
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<td></td>
<td>To pilot Social Withdrawal Scale (SWS) Four MND patients Initial SWS</td>
<td>Content analysis of previous study concerning social wellbeing. 24 items into four groups to form basis of SWS. Piloted with four patients with MND. Altered format of questionnaire in response to differing physical abilities. Estimated levels of validity, reliability &amp; consistency established when one item was removed. Social relationships with family and close friends appeared unaffected by physical condition but affected by patients’ emotional response to MND symptoms. Level of anxiety increased as time since MND diagnosis increased and determined by the age of the person.</td>
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<td></td>
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<td></td>
<td>23 MND patients 21 patients with arthritis Social Withdrawal Scale (SWS) Hospital Anxiety and Depression Scale (HAD) Scale of Disability in MND Demographic questions Self-rated Physical Disability Scale Same scales given to arthritis patients, swapping arthritis for MND in the scales. Scale of Disability in MND not given to arthritis patients</td>
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<tr>
<td>Author/ Years</td>
<td>Study</td>
<td>Purpose</td>
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<td><strong>Study 6</strong>  Young, Tedman, &amp; Williams (1995)</td>
<td>Disease progression and perceptions of health in patients with MND</td>
<td>Compare progression of patients with MND and those with late Parkinson's Disease (PD).</td>
<td>14 MND patients 22 PD patients  Barthel Index – Disability and Impairments  SF36 – Patient’s Perception of Health</td>
<td>Speed of decline in self-care and mobility was more rapid than previously identified therefore the need for more frequent out-patient assessments was confirmed. SF36 test is insensitive in assessing psychological distress and wellbeing in people with MND.</td>
</tr>
</tbody>
</table>
Overall psychological studies investigated the illness experience of MND through the use of many scales and instruments. Quality of life (QoL) issues pertaining to self-esteem, self-worth and happiness, were included in findings that explored ways for health professionals to guide care to improve life for people with MND. QoL aspects that are important for people with the disease appear to be concerned with how they feel about the quality of interactions with others rather than the effects of the physical symptoms associated with disease; the latter just reminds them of the negative aspects of MND, the losses and the prognosis. What is evident is that, although people with the disease progress to increased disability, their perception of their QoL remains high. This exemplifies the disability paradox, that is, the greater a physical disability does not necessarily mean a perceived lower quality of life (Albrecht & Devlieger, 1999). Albrecht and Devlieger contended that the overall concept for QoL for people with disabilities involved the development of “a balance between body, mind, and spirit … with an harmonious set of relationships within the person’s social context and social environment” (p. 977).

In summary, the impact of MND was discussed from the viewpoints of the physical and psychological effects of the disease on the person. The research to date has for the most part attempted to measure or quantify subjective aspects of the illness experience. Statistical analyses with quantitative scores provide a detached objective view of the illness experience. Few studies have allowed individuals living with MND to provide an account of their experience of the disease in their own words. The aim of this current study was to address this gap in the literature by attempting to understand how people with MND voice their psychosocial needs to those who work with and care for them. In the following section the literature concerning the illness experience is explored and centres on psychosocial issues by first attempting to explain what is meant by this broad term.
2.4 Section Three: The Illness Experience.

In this section literature about the illness experience of MND is explored. The purpose is to highlight the lack of research into personal experiences of the disease. Points discussed include psychosocial issues such as quality of life, choice and negotiation, accounts of personal experiences in various media as well as clinical research into aspects of the illness experience. It is argued that while these studies offer important insights, few have explored the issues from the perspective of the person experiencing MND. It is also argued that despite recent developments in quality of life questionnaires specific for MND patients, the majority of studies to date do not address what it is like to be diagnosed and live with MND from the perspective of the person with the disease.

2.4.1 Psychosocial issues

There has been little investigation of the psychosocial issues pertinent to people with MND. However, some research has been conducted into these aspects for people with chronic illnesses and cancer. No clear definition or explanation of what is meant by psychosocial issues is apparent, although different perspectives have been taken to explain them. Table 2.4 (see page 36) highlights the different concepts presented in the literature about different health groups. Jacopini (2000) drew on his personal experiences as a psychologist and psychotherapist caring for people with neurodegenerative disorders to describe psychosocial issues, asserting that they encompassed the overall concept of quality of life (QoL). His ideas focused on care when cure was no longer possible, to preserve as long as possible “patients’ emotional health and wellbeing, independence, dignity, and family relationships” (p. 265). He identified individual psychosocial concepts including self-esteem, sense of hope and willingness to live life to the fullest potential.
Table 2.4 Definitions of Psychosocial Issues and Quality of Life Concepts

<table>
<thead>
<tr>
<th>Authors/Year &amp; Group Studied</th>
<th>Psychosocial Issues</th>
<th>Quality of Life Concepts</th>
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<tbody>
<tr>
<td>1 Jacopini (2000) Parkinson’s disease and Huntington’s disease</td>
<td>Self-esteem sense of hope and willingness to live life to the fullest potential</td>
<td>Embodies psychosocial issues including emotional health and wellbeing, independence, dignity and family relationships</td>
</tr>
<tr>
<td>2 Livneh (2001) Chronic illness &amp; disability</td>
<td>Personal and social identity, cognition, emotion and morality</td>
<td>Psychosocial issues are pertinent to QoL</td>
</tr>
<tr>
<td>3 Loftis &amp; Glover (1993) Aged care</td>
<td>Cognition/perception, self-image, role relationships focusing on interpersonal relationships</td>
<td></td>
</tr>
<tr>
<td>4 McGrath (1999; 2000) Leukaemia patients</td>
<td>Dealing with challenges with prolonged treatment; relocation for specialist treatment, altered body image, sexual identity, family relationships and financial difficulties</td>
<td>Interpersonal relationships, a sense of autonomy, attitude to life, life satisfaction, self-esteem and sexual identity</td>
</tr>
<tr>
<td>5 Nelson, Trial, Van, Appel &amp; Lai (2003) MND</td>
<td>Internal personality traits, relationships with families and friends; religiousness and spirituality; stresses related to mood changes, relationship difficulties and illness characteristics; and changes in lifestyle, leisure and finances.</td>
<td>Negative QoL compared with positive QoL groups; spirituality, lifestyle; people with a positive QoL used optimism and humor, felt in control, were persistent and stubborn.</td>
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</table>

Loftis and Glover (1993) defined psychosocial issues as pertaining to cognition/perception, self-image and role relationships with a focus on interpersonal relationships in gerontological nursing. The cancer patients in McGrath’s (1999) study revealed that quality of life issues such as interpersonal relationships, a sense of autonomy, attitude to life, life satisfaction, self esteem and sexual identity were important in their treatment phase, ergo these were defined as psychosocial issues. McGrath’s (1999; 2000) research into psychosocial issues for patients diagnosed with leukeamia and their families, found that there were other psychosocial issues for them including dealing with the challenges associated with prolonged treatment, the need to relocate for specialist treatment, altered body image and sexual identity, family relationships and financial difficulties. In contrast, Livneh
(2001) identified psychosocial issues for people with chronic illnesses and disabilities, as related to personal and social identity, and that quality of life was related to cognition, emotion and morality, dependent on an individual’s developmental phase in life.

Very little is known about the psychosocial issues of people living with MND in Victoria Australia, how their needs are met or what emotional and social supports they desire (Sachs and Associates, 1995). Studies that have explored the psychosocial issues of people with chronic illnesses and cancer have identified quality of life as typifying the notion of psychosocial issues. Quality of life is explored under the terms of subjective wellbeing, choice and the ability to negotiate.

2.4.2 Quality of life

There is an esoteric quality to an individual’s quality of life (QoL) that is immeasurable and thus can only be understood from the person’s perspective in their words. This claim was made by Coward (1990) in her research into understanding the experience of breast cancer, and by Baker and Pearson (1991) when exploring the experiences of patients in an aged care unit. Building on such work, the various aspects that define quality of life in general, are examined in an attempt to establish an understanding of QoL for a person diagnosed with MND.

Cohen, Mount and MacDonald (1996) documented that there is no clear definition of quality of life, as each individual has his/her own perception of what it constitutes, because the concept relates to subjective wellbeing. These authors identified that existing quality of life scales and questionnaires, measure factors such as physical functioning and the effects of interventions, but these are not subjective measures. They asserted that measures of quality of life need to be improved to include domains that are pertinent to subjective wellbeing. One domain that people with a terminal illness identified as important for them was “existential concerns”. These were defined as “concerns regarding death, … freedom, … isolation … and the
question of meaning” (Cohen, Mount, & MacDonald, 1996, p. 735). Higginson (2000) contended that some individuals who have advanced illnesses, such as MND, identified communication, information and the delivery of service as having a significant impact on their perceptions of quality of life. Quality of life appears to be multi-faceted and experienced individually by each person with a disease and thus it requires contextualisation to ascertain the unique understanding of QoL for each person.

In general, QoL studies have used scales developed to measure depression (Burckhardt, Clark, & Bennett, 2001), self-esteem (Chung & Chung, 1994; Rosenberg, Schooler, & Schoenbach, 1989), life satisfaction (Barnett & Gareis, 2000), coping with illness (Baider, Perry, Holland, & Sison, 1995; Holland et al., 1999), satisfaction with illness and quality of life questionnaires, to ascertain an individual’s attitude or quality of life (Cohen et al., 1999; Dugan et al., 1998; Hogg et al., 1994). These approaches are problematic because, although scales are used in an attempt to quantify and measure QoL, such a construct is subjective and unique for each individual, in different ways, as previously suggested by Cohen et al. (1996) and cannot be objectively quantified.

In the main quality of life questionnaires concentrate on aspects of physical functioning leaving out existential issues as previously identified as concerns about death, freedom, isolation and meaning (Cohen, Mount, & MacDonald, 1996), although according to Cohen, Mount, Strobel, and Bui (1995) and Cohen, Mount, Tomas and Mount (1996), later studies have tried to incorporate existential issues. Nevertheless, many tools have been developed in an attempt to ascertain a person’s QoL whether he/she is diagnosed with a disease or not (Cummins, 2000). Some studies have investigated quality of life issues related to a diagnosis of cancer (Cohen et al., 1995; Cohen, Mount, Tomas et al., 1996; Pratheepawanit, Salek, & Finlay, 1999), human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) (Kemppainen, 2001) and multiple sclerosis (MS)
Cohen et al., 1999; Dugan et al., 1998; Lankhorst et al., 1996; Pfennings, Cohen et al., 1999; Pfennings, Van der Ploeg et al., 1999). These studies about QoL issues have been reviewed to understand people living with MND. It is only in recent times that studies regarding quality of life have been undertaken specifically with people diagnosed with MND as the target group albeit, again with questionnaires and scales (Goldstein et al., 1998; Jenkinson et al., 2000; Jenkinson et al., 1998; Rigby et al., 1999).

A Social Withdrawal Scale (SWS) for MND patients was developed by Rigby et al. (1999), to ascertain quality of life for the person with the disease. Their associated research revealed that social withdrawal increased as physical symptoms worsened. The withdrawal was found to be related to the individual’s emotional response to the condition and not as a result of families and friends’ withdrawing. As previously identified, the SWS was developed from the analysis of interview data of seven MND patients, then tested with 23 patients at various stages of the disease. How representative it is of people living with MND is questionable, given the small sample.

In the study by Simmons, Bremer, Robbins, Walsh and Fischer (2000), 96 people with MND were prospectively studied to assess their quality of life using several instruments and scales. Existential factors and psychological domains were included with measures of spirituality and religiousness in the assessments. Interestingly, the “disability paradox” was evident because the findings revealed that patient assessment of QoL was not dependent on physical strength and functioning but rather on psychological, existential and support factors. In a more recent study by Nelson, Trail, Van, Appel and Lai (2003), a 25-item QoL questionnaire was designed to assess temporal QoL changes. One hundred patients with MND completed the questionnaire, three times at 3-month intervals. Only patients with unimpaired cognitive function, as assessed by neuropsychological testing, were included in the study. Physical strength, disease progression and severity were also measured. The study compared differences between people with positive QoL (PQoL) perceptions (n=66) and those with negative QoL (NQoL)
perceptions \((n=34)\). Assessment domains were related to lifestyle changes, sources of support and psychosocial dimensions. In the main both groups had similar assessment scores. A significant difference was reported in the psychosocial dimension of “diseased related stress”. Patients with a NQoL expressed more stress-related concerns compared to 28% of PQoL, which meant the more positive a person’s perception of quality of life, the less they were concerned with stress related to MND. Recurrent psychosocial themes from the findings were identified as internal personality traits; relationships with families and friends; religiousness and spirituality; stresses related to mood changes; relationship difficulties and illness characteristics; and changes in lifestyle, leisure and finances. This study endeavoured to move away from primarily measuring physical strength and functioning as a reflection of QoL for individuals diagnosed with MND. Their findings also reflect “the disability paradox” but the study lacks subjective reporting of QoL from the person’s perspective.

Control over life choices is “a taken for granted”, if sometimes problematic, aspect of most people’s lives. However this concept has been identified as a QoL issue for those with terminal illness. Livneh (2001), McGrath (1999) and Hayward (2000) claimed that having control over how one lives one’s life is vital to wellbeing. These researchers have agreed that having control implies being able to make choices through decision-making.

### 2.4.3 Choice

The literature concerning decision-making about quality of life choices is generalised and concerned with other diseases such as cancer and multiple sclerosis (Abbott, Johnson, & Lewis, 2001; Mastaglia & Kristjanson, 2001). Although some literature has recently been produced specifically about MND (Small & Rhodes, 2000), little is known about the decision making and choice making of people living with this disease. There is a concern, however, about how much genuine patient involvement actually takes place (Poulton, 1999) and it is questionable as to how many consumers really want
to be active participants in decisions about their care (Abbott et al., 2001; Biley, 1992; Nordgren & Fridlund, 2001; Small & Rhodes, 2000).

At some time during the progression of the disease, people with MND are required to make choices about whether to maintain life with the use of technology. The people with the disease are encouraged to make these important decisions as this promotes their self-esteem and self-worth in having control in their lives (Pace & Glass, 2000; Rosenfeld, Wenger, & Kagawa-Singer, 2000; Silvera, DiPiero, Gerrity, & Feudtner, 2000). The decisions pertain to: invasive and non-invasive ventilation (NIV) before experiencing breathlessness (Albert et al., 2000; Baker, 2001; Borasio et al., 1998); the insertion of Percutaneous Enteral Gastrostomy (PEG) for supplementary feeding and hydration before swallowing ability deteriorates; the use of newly-available treatments to slow the disease progression such as riluzole (Clark & Kendall, 1996) or antioxidant treatment (Orrell, Lane, & Ross, 2001). Essentially, these decisions are about living with MND.

To choose means to “select [one or more things] ... according to one’s own preference or judgement” (Allen, 1994, p. 245). Choosing is to decide for oneself what one wants. Individuals who are ill can choose or not choose life sustaining technology (Baker, 2001; Kutner, Steiner, Corbett, Jahnigen, & Barton, 1999; Smith & Andrews, 2000; Young et al., 1994). If informed decisions are to be made with health professionals, in consultation with the individual and the family concerned, there is a need for all concerned to understand the benefits, complications and restrictions associated with the different technologies and how these will impact on the person’s life (Smith & Andrews, 2000). Informed decision-making includes health professionals acknowledging the diversity of cultural beliefs about the care of the dying when discussing options of care (Campbell, Moore, & Small, 2000). There is a strong relationship between ethnicity and attitudes toward the use of life sustaining support for individuals diagnosed with a terminal illness, yet, at times, it seems that personal wishes can contradict the relationship (Blackhall, Frank, Murphy, Palmer, & Azen, 1999). Indeed being able to
choose implies an ability to negotiate with others for what one wants or desires.

2.4.4 Negotiation

The ability to negotiate effectively is integral to the attainment of desired quality in life choices. There is an art to negotiation (Rehberg & Sullivan, 1997). Strauss identified negotiation as having many names with different synonyms: “bargaining, wheeling and dealing, compromising, making deals, reaching agreements after disagreement, making arrangements, getting tacit understandings, mediating, power brokering, trading off, exchanging, and engaging in collusion” (Strauss, 1978, p. 1). Environmental and societal influences can affect the meaning of negotiation, as well as the outcomes.

Negotiation is a process of conferring with someone “to reach agreement on terms or arrangements affecting both parties” in an interaction (Allen, 1994, p. 865). To negotiate implies the ability to communicate and that the individuals in the negotiation have a shared understanding of the communication (Spegel, Rogers, & Buckley, 1998). Communication is reliant on a shared language and psycholinguistic schemata. A tongue, that is a pertinent language which provides words and grammatical rules that individuals use to visualise reality and communicate, and that individuals use personal reference systems, understandings and perceptions to “analyze reality, interpret events, and perform acts” (Cossette, 1998, p. 1356). Thus, if there is not a shared understanding of language with which to communicate on an equal footing, effective negotiation can be problematic.

Within health care systems, self-determination has been used to express an individual’s right to negotiate choice of care (Nordgren & Fridlund, 2001). Choice promotes self-esteem and encourages autonomy in decision-making (Madder, 1997). However, there is potential for coercive treatment in patient-doctor relationships when doctors make medical decisions for their patients based on their personal medical judgements, without taking into account the
whole person and his/her desires. Such decision-making removes the choice, autonomy and self-efficacy of the patient (Madder, 1997). In the instance of MND, often negotiation is not considered an option for the patient. Similarly Baker’s (2001) study concerning ethical issues related to home-based ventilation for people with MND, asserted that essential information for informed choice about ventilation was withheld by some doctors because they believed quality of life was poor for a ventilated patient. In this study, doctors became gatekeepers controlling access to the information, thus the knowledge to allow informed negotiation about ventilation was not presented to patients, impeding their life extending opportunities.

To summarise, information is essential for negotiating for anything in life. Barriers to information to make informed choices can be set in place by gatekeepers. Motor neurone disease is a progressive debilitating disease of the nervous system that affects the muscles of the body. The ability to communicate decreases as does the ability to eat, drink and breathe. Many decisions are required to ensure individuals diagnosed with MND are able to live the way they wish to, but little is known of the experience of having the diagnosis, being informed and how they negotiate with others to live with the disease.

2.4.5 Experiencing MND

Literature that reveals the illness experience of people with MND is sparse. Most articles and books about the experience are autobiographical or biographical, documenting personal reflections of being diagnosed and living with MND (Carus, 1980; Kiernan, 2003) as well as personal spiritual understanding of the journey with the disease (MacKenzie, 2002). Albom (2001) documented interviews with a person with MND who was in the last months of his life and recording the person’s thoughts and insights about life and death. Newspaper articles also have brought attention to the legal battles of lawful euthanasia for people with MND, initiated by people with the
disease and their families in an effort to obtain choices about death (McHugh, 1999; Underwood, 1993)

Although individual illness experiences and small group accounts about aspects of the illness are evocative in their telling, such accounts lack the “bigger picture” view of the illness. Table 2.5 (see page 45) summarises most of the available literature that promotes understanding of the illness of MND without the use of scales and tools to measure the experience.

Robinson and Hunter (1998) collated the accumulated scientific and anecdotal knowledge about MND in the United Kingdom (UK) over the seven previous years. The work included the disease pathogenesis and symptomology, as well as the researchers’ journaling of their interactions with over 300 people diagnosed with MND. The authors produced a document that gave a comprehensive discussion for health professionals and people diagnosed with MND, about the disease and the realities of experiencing the illness.

Small and Rhodes (2000) undertook a series of phenomenological studies to discuss user involvement in palliative care. They interviewed six people with MND and their carers as one element of their study. Although this study gave an excellent group description of a small sample of people with MND in the UK, there remains a paucity of information about the experience of living with MND from the perspective of the person with the disease.
<table>
<thead>
<tr>
<th>Authors/Years</th>
<th>Purpose</th>
<th>Study Design and Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Bolmsjö (2001)</td>
<td>How people with ALS communicate existential issues – meaning and guilt, relations, diagnosis and information, dying with dignity and respect for person</td>
<td>Hermeneutic study, semi-structured interviews with eight people diagnosed with MND, &gt; 6 months post diagnosis, all had communication difficulties, not audio-recorded, fieldnotes of comments and reactions during interview used. Interview around seven issues</td>
</tr>
<tr>
<td>2 Carus (1980)</td>
<td>To tell his story and create public awareness of MND</td>
<td>Autobiographical personal paper</td>
</tr>
<tr>
<td>3 MacKenzie (2002)</td>
<td>To tell his story of living with MND – a journey of emotional and spiritual waking through terminal illness</td>
<td>Autobiographical account of prediagnosis, his diagnostic roundabout, “his watershed day”, adjusting to the diagnosis and living with the disease</td>
</tr>
<tr>
<td>4 O’Brien (2002)</td>
<td>Understand information seeking amongst people with MND</td>
<td>Interpretive phenomenological approach; in-depth, semi-structured interviews with seven participants – 3 men and 4 women, 3 bulbar onset, 4 spinal onset</td>
</tr>
<tr>
<td>5 Robinson &amp; Hunter (1998)</td>
<td>Book about MND for anyone interested in the disease, people with the disease, carers, families and friends as well as people in the health profession and care providers</td>
<td>Composite of qualitative methodology and quantitative research</td>
</tr>
<tr>
<td>6 Small &amp; Rhodes (2000)</td>
<td>To explore user involvement with people with one of three medical diagnoses; MS, MND and CF</td>
<td>Phenomenological study; interviews with 6 people with MND and their carers; meetings and discussions with a range of professional service providers</td>
</tr>
<tr>
<td>7 Young &amp; McNicoll (1998)</td>
<td>Describe the nature of positive life experiences of people coping exceptionally well while living with advanced MND and the resulting significant physical disability</td>
<td>Grounded theory, interviewing 13 people diagnosed with MND; selected because of exceptionally positive adaptation to the disease 7 men, 6 women, all living at home; some had third person present who was familiar with their speech or alternate modes of communication Used demographic information, ALS severity scale, semi-structured interview schedule, checklist of possible positive life components</td>
</tr>
</tbody>
</table>
Studies about the illness experience in Australia are limited. Baker (1997; 2000) has discussed the role of the neurological community nurse in caring for people with neurological conditions, including a case study of a person with MND. The same author explored the ethical issues pertaining to decisions about maintaining invasive and non-invasive ventilation for people with MND who live at home (Baker, 2001). She highlighted the need for nurses to be fully aware of the ethics of ventilation for people with the disease. These are important discussions for clinicians but the story of the person has not been articulated from his/her perspective.

This current study seeks to fill this gap by undertaking a study that interviews people with the disease who live in Australia, to understand what it is like to live with MND in their words, and the processes they go through living with the disease.

2.5 Significance - Methodological Critique

Within the literature about motor neurone disease, there is a dearth of information about the subjective views of people living with the disease. A qualitative study about MND (Young et al., 1994) has explored participant understanding about decision making in the use of mechanical ventilation, using scales and semi-structured interviews. Another study has explored positive life experiences of people living with MND, using the ALS Severity Scale (ALSSS) and semi-structured interviews (Young & McNicoll, 1998). This latter research interviewed only those patients who displayed a positive attitude to living with the disease. Participants used cognitive reappraisal, reframing and intellectual stimulation as coping mechanisms to enable them to experience enjoyment in the face of adversity. It was found that these participants had developed wisdom about their circumstances and emphasised that interpersonal relationships were of vital importance to their outlook on life (Young & McNicoll, 1998).

Angina (Miklaucich, 1998), advanced breast cancer (Coward, 1990), Huntington’s disease (Dawson, Kristjanson, Toye, & Flett, 2004), patients’
experiences in hospital (Baker & Pearson, 1991) and self-determination of care (Nordgren & Fridlund, 2001) have been explored from the perspective of the individual but generally there is a lack of research about the experience of MND. Autobiographical and biographical information has provided some insight into what it is like to have and live with the disease (Albom, 2001). Other experiences of individuals with similar symptomatic aspects have elicited some insight into being aphasic (Wulf, 1973) and being “locked in” (Bauby, 1998). As discussed, very little has been documented and researched, from a qualitative or subjective view, about the experience of living with MND from the perspective of the individual with the disease.

Interviews with individuals with MND have recorded their experiences and their quests in choosing when and how to die. Some appealed to the legal system for the right to choose the time and means of death, that is, suicide by their own hand or physician assisted suicide (McHugh, 1999; Underwood, 1993). Others talked about the dying process and their choice to die at home (Albom, 2001; McHugh, 1999).

Billinghurst (2000; 2001) interviewed people living with MND in Scotland to gain an in-depth understanding of their experiences, problems and issues from their perspective. Although the number of people interviewed was not reported, the author focussed on the emotional impacts on the person being interviewed, the researcher undertaking the interviews and the communication challenges, but provided little insight into the MND experience. In contrast, in the Small and Rhodes (2000) study, the researchers used the phenomenology paradigm to underpin analysis of interview data in order to describe the lived experience of people living with MND in the United Kingdom. This study produced a comprehensive description of the experience of MND from an inclusive perspective and not just from the people with the disease.

The literature about the Australian experience of living with MND is limited (Baker, 1997, 2000, 2001; Harris, 1997; Lang, 1996; MND Association
of Victoria, 1999). None of the available literature sources interviewed people diagnosed with MND. Thus, within the current literature, an interpretive study that interviews people diagnosed and living with MND, including those with communication difficulties, is unique in the Australian context.

2.6 In Summary

In this chapter, a review of literature has been presented to inform this grounded theory study. Literature included current MND focused research, the impact of MND and the illness experience featuring psychosocial issues, quality of life, choice and negotiation. It is suggested here that the experience of being diagnosed and living with MND day-to-day is largely unexplored from the perspective of those with the disease. In support of this argument, the review of literature identified several knowledge gaps:

- Few studies have allowed individuals diagnosed and living with MND to provide an account of their experience of living with the disease in their own words.

- Qualitative research about people living with MND tends to include other people’s experiences of caring for the person with the disease, use statistical information and exclude those who have communication difficulties.

- Little is known about the pertinent psychosocial issues for people living with MND and how they negotiate for choices in their life.

- A lack of studies exist that focus on the subjective illness experience of people living with MND in Victoria, Australia.

- Little is known about the coping strategies people with MND use as they live with the illness day-to-day especially from those who have a negative perception about life with MND.

Therefore, the importance of this study is that exploring and understanding what it is like to live with MND and how people with the disease negotiate for their life choices, will fill gaps in the literature and
contribute to an Australian perspective for people who are diagnosed and living with MND. In essence, the explication of the group voice about living with MND in Australia is unique and contributes to the global story about illness experiences.

In chapter 3, the methodology chosen to undertake this research, grounded theory, and the underpinning philosophy of symbolic interactionism are discussed. The processes for conducting the research are outlined and rationales provided.
CHAPTER THREE

RESEARCH PROCESS

3.1 Introduction

As argued in chapter 2 the exploration and understanding of what it is like to live with MND is not well researched from the perspective of the person with the disease. Little is known about how people living with MND negotiate with others for the care they desire. Their “life world” in living with MND is explored in this study. Schwartz and Jacobs (1979) defined life world as “motives, meanings, emotions, and other subjective aspects of the lives of individuals and groups” (p. 5), which included daily actions and behaviour of individuals in their everyday lives, the structure of those actions and the influences that impact on the actions. However, it was essential to ascertain the individual’s subjective point of view to understand these interactions. Drawing on conceptions from the qualitative paradigm, researchers seek to “gain insights and understandings into aspects of the human experience” (Jackson, Daly, & Chang, 2003, p.141), which is, therefore, the best suited paradigm to assist in the exploration of people’s life experiences.

Symbolic interactionism gives emphasis to the social process of “ongoing human group life” (Lal, 1995, p. 422) and is the philosophy that underpins the tenets of grounded theory. Grounded theory research generates theory from data about social processes (Glaser & Strauss, 1967), which encompasses the actions and interactions of people in their social, psycho-social and spiritual aspects of life (Annells, 2003). Grounded theory methodology is a systematic procedure for analysing data to develop substantive theory about life-worlds, that is, social realities of the human experience – of ongoing human group life.
In this chapter, the manner in which symbolic interactionism and the grounded theory framework informs the study is outlined. Sampling techniques, recruitment processes, data collection methods, interviewing challenges and analysis procedures incorporating NVivo computer software to manage data, are all explained. The processes and strategies used to ensure the conduct of rigorous qualitative research are discussed. The group of people interviewed can be described as a vulnerable population because MND is a terminal illness with no definitive longevity. The subsequent losses experienced because of the disease progression also impact on the person’s vulnerability and the possibility for exploitation. The ethical safeguards that were implemented to protect this population of participants are summarised and the researcher’s role in the research process is discussed.

3.2 Symbolic Interactionism

Symbolic interactionism provides a philosophical stance to view and understand how individuals act and interact in a social system; it permits the study of process, action and meaning in the interactions (Charmaz, 2000). In this section, the work of key sociologists who conceptualised symbolic interactionism is discussed.

3.2.1 Mead, Blumer and others

The writings of Mead underpinned the development of symbolic interactionism in recent sociology. A contemporary variation of symbolic interactionism was known as the Situational or Chicago School (Longmore, 1998). The Chicago School of sociological studies looked at how social interaction occurred in social situations in the real world. The focus was on “how individuals define situations and … construct the realities in which they live” (Longmore, 1998, p. 46). The Chicago School aimed to examine how individuals interacted with other individuals and groups in their social environment, and to understand what the interactions meant to them in their lives, from their perspective.
Mead reflected on the inner person, where people discuss issues with themselves, practise outcomes of questions and answers, and critique their own actions in their minds, as well as develop their individual self consciousness, that is, “I”, “me” and “self” concepts. Through this process, individuals develop the meanings of actions according to how they interpret other people’s reactions to that action. Joas (1985) explained that it is the interpretations or meanings that are then attributed to the actions that become relevant.

The Chicago School contended that the “self” emerged and was maintained in face-to-face interaction between individuals. Studies based on the earlier Chicago School of social research investigated “social wholes”, such as “communities, collective activities, and occupations - centered on the group nature of the interaction” (Clarke, 1997, p. 68). The later focus was not only on the process of social interaction in naturally occurring situations and how individuals defined interactions, but also, most importantly, on how they constructed the realities in which they lived (Longmore, 1998).

Mead’s portrayal of the symbolism of language emanated from Wilhelm Wundt’s (1832-1920) studies of gestures and linguistics (Joas, 1985). His studies explained that gestures are communications between individuals which have meaning for both parties and are interpreted by both with the same meaning. Accordingly, communication requires language which is comprised of both gestures and linguistics that both parties understand. Challenges exist when an aspect is lost, such as no linguistics or gestures or like understanding.

Previously Mead was revered as the founder of symbolic interactionism, but in later years this distinction was given to Blumer (Plummer, 1991, pp. x-xx). His premises of the nature of symbolic interactionism were promoted as the tenets of the philosophy. According to Blumer (1969):
Plummer (1991) further expanded on the meanings and explanations of symbolic interactionism, conceptualising it as having three interwoven themes of human communication and meaning with process and interaction. Berg (1995) explained the uniting theme of symbolic interactionism as focusing on “the subjective understandings, as well as perceptions of and about people, symbols, and objects” (p. 7). Accordingly symbolic interactionism is concerned with exploring the subjective understandings of human interaction and communication. The purpose is to look for the symbolic meanings and understandings in the interactions and explore how the understandings and meanings have been derived for individuals in the interaction.

Grounded theory research uses the philosophical position of symbolic interactionism to interrogate data, and to explore and describe peoples’ life experiences such as living with MND. The main focus of this study is to understand the processes, actions and meanings attached to living with MND from the perspective of the people with the disease. The role of the researcher is not to impose previous theory on to the data but to generate new substantive theory. In the following section, grounded theory is discussed along with the methods, which guided the research process and the reasons for modifying aspects of this study in respect for the capabilities of participants.

3.3 Grounded Theory

Grounded theory is a systematic method of data collection and analysis in which theory is discovered as it conceptually emerges from the data
This method is used in social research to understand the meanings attached to the interaction of individuals in the real world (Glaser & Strauss, 1967). Glaser and Strauss used the precepts of symbolic interactionism in developing a methodology they called grounded theory, when researching the social realities of dying (Glaser & Strauss, 1967, 1968). The evolving methodology provided a different way of generating new theories about social realities (Strauss & Corbin, 1998) to gain understanding about the basic social processes in sociology (Glaser & Strauss, 1967). In contrast, Strauss and Corbin (1998) proposed a more succinct, grounded theory purpose, that of enhancing the understanding and meanings of actions within social research. Grounded theory does not use discovered theories to predict outcomes as in scientific/hypothetico-deductive research, but generates theory both deductively and inductively, to explain human actions and interactions in particular situations.

Strauss and Corbin (1998) advised that, when building theory, it is important to use a variety of methods to source, collect and identify data to “build dense, well developed, integrated, and comprehensive theory” (p. 33). The theory comes from, and is grounded in, the data being analysed. The information drawn from the analysis, the conceptualising and linking toward an emerging theory, guides or directs the gathering of additional data to build the evolving theory. In addition, Strauss and Corbin (1998) contend that the design of the study “must be allowed to emerge during the research process” (p. 33). Thus, the process of undertaking a study based on grounded theory principles can alter according to the analysis of the data and participants involvement. The theory to be constructed from the current study is substantive because it is related to one particular area of investigation (Strauss & Corbin, 1998), that is, the experiences of people with MND.

The overall aim of grounded theory is to generate a theoretical explanation of the interactions of individuals within the societal framework; and their interactions with themselves, each other and with groups of people.
within their natural social setting. This project is about the social realities of living with the diagnosis of MND and the increasing physical and psychological losses associated with this terminal disease. The natural social setting for people with MND is their world as they perceive it, which includes personal, social and service provider contacts. The aim of this study is to gain insight into the ways (actions) that this particular group of individuals negotiate (process) their choices about how they wish to live their lives, as well as to identify the different influences that impact on their decision-making as they live with the illness. Essentially the study is about understanding the psychological and social needs of people living with MND, how they negotiate with others to fulfil their needs and the meaning the disease has for them and in their lives.

A grounded theory approach in research uses particular strategies to guide the analytical process for generating theory (Charmaz, 2000). Charmaz identified strategies to include concurrent data collection and analysis, constant comparison methods and writing of memos about the conceptual analysis. The research process, guided by a grounded theory approach used to undertake this study, is acknowledged and discussed.

3.4 Research Process

In this section, details are provided of researcher preparation, sampling technique, recruitment strategies and responses, participants and the inclusion criteria used. Data collection and its associated challenges, data analysis and procedures to ensure rigour in grounded theory research are described. Ethical implications and the procedures followed are explained.

3.4.1 Researcher preparation

According to Minichiello, Aroni, Timewell and Alexander (1995), it is important that the researcher is prepared before data collection begins. In order to prepare for the project and develop theoretical sensitivity for undertaking a grounded theory study, it is necessary to achieve
environmental familiarisation, acknowledge biases and ensure that necessary equipment is available.

**Personal preparation**

Recognition of biases can enhance the researcher’s awareness of possibly prejudiced views that could influence data interpretation, perceptions about the “subtle nuances and meanings in the data” and recognition of concept connections (Strauss & Corbin, 1998, p. 43). The following outcomes emerged from a reflexive process undertaken in order to identify those revelations that have influenced the conduct of the study, and the development of inclusive strategies to ensure a representative range of participants.

The strategies used to prepare for the study included exploring the environment in which people with MND lived. To this end I accompanied community nursing staff of a neurological in-patient facility, on their rounds one day a week for one month. The purpose of this fieldwork was to sensitise myself to issues associated with living with MND and to see how in-home nursing services functioned for this group of people.

Discussions were also held with speech therapists about the various techniques and equipment used by people who have difficulty with communication arising from physical impairment. This fieldwork prepared me for possible variations in participants’ communication modes. Further familiarisation was obtained by physically handling and using some of the communication aids at an equipment centre, resourced by people with MND. Networking links were established with staff at the hospital as well as with staff and volunteers at the MND voluntary association. These links allowed me to witness the professional expertise and caring concern displayed by these carers towards the people diagnosed and living with MND.

To further increase understanding and sensitivity about the topic, a broad literature review was conducted (chapter 2). The review included
topics such as motor neurone disease, decision-making, end-of-life issues and negotiation.

Equipment preparation

Audio-recording equipment (SONY BM-23 Portable Dictator) with a small inconspicuous microphone (OLYMPUS Pearlcorder Electret Condenser Microphone Model ME10) was used to record interviews. Later an amplifier was included and attached to an electronic Lightwriter speaker to enhance the recorded sound quality. As advised by Wengraf (2001), prior to each interview the audio recording equipment was checked and rechecked to ensure that it functioned correctly. The need for sensitive equipment to record conversations with participants was particularly important because of variations in natural speech production and synthesised voices created by augmentative communication technologies. Despite this careful preparation, on one occasion the recording button was not fully engaged, resulting in the loss of valuable recorded data. However, notes were made of recollected details from the interview. This negative experience provided a lesson in vigilance to ensure the mistake was not repeated.

3.4.2 Sampling

Theoretical sampling is the method of choice for gathering data in grounded theory methodology. The researcher concurrently collects, codes and analyses data as the project proceeds (Strauss & Corbin, 1998). After initial selection of participants, further participants are selected on the basis of relevant emerging issues, categories and themes in the analysis (Strauss & Corbin, 1998). The purpose is to extend, modify, develop and verify emerging theory to the extent of saturation, when no new categories or themes emerge from the data and the categories and concepts are rich in data evidence (Minichiello et al., 1995; Strauss & Corbin, 1998).
3.4.3 Recruitment

Prior to recruitment, an article was featured in a local urban newspaper to raise awareness about the study and associated research grant (Appendix A). Its purpose was to generate inquiries from potential participants.

The recruitment method was purposeful, described by Holloway (1996) as an approach that specifically targets potential participants in a particular group of people. In this study, only people living with MND in Victoria were targeted to seek their expressions of interest to participate. Different strategies were used according to each place of engagement, which included fortuitous meetings, advertising in an MND newsletter, direct mail-out to rural members of an MND voluntary organisation, researcher attendance at support group meetings and referrals by the community nursing service. Each is discussed in turn and the success of these strategies is detailed in Table 3.1.

Table 3.1 Number of Participants Sourced by Different Recruitment Strategies

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Participant Contacts</th>
<th>Interviewed</th>
<th>Not interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fortuitous</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Newsletter</td>
<td>6</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td>Mail-out</td>
<td>16</td>
<td>13</td>
<td>3</td>
</tr>
<tr>
<td>Key Personnel</td>
<td>2</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Support Group</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>32</strong></td>
<td><strong>25</strong></td>
<td><strong>7</strong></td>
</tr>
</tbody>
</table>

Fortuitous recruitment

The preparatory fieldwork strategy of accompanying health professionals into patients’ homes to better appreciate the circumstances under which they lived and to develop sensitivity, resulted in later contact with potential participants. This outcome was called fortuitous because recruitment was not a goal of the fieldwork and the patients’ offers to participate happened by chance. On these visits the patient was asked if I
could attend and I was introduced as a “research nurse”. I did not undertake, assist with or observe any nursing care, yet it transpired that either the patient would ask about the research being undertaken or the community nurse would, in conversation, bring up the subject of the research project. At the patient’s request, the research was briefly outlined and questions answered. Occasionally a patient expressed a desire to participate in the study. In these cases and with the patient’s permission, contact details were taken and at a later date these people were contacted and further information provided in the form of a Participant Information Sheet (Appendix B) and a formal invitation to participate in the research. At no time was there any coercion. I neither asked patients if they would like to participate in the research, nor had any influence over their care; I was independent of the services provided to them. Formal invitations to participate in the study only occurred after contact was made by the patient or advocate and after they had read the Participant Information Sheet and had their questions answered.

One participant was recruited when I accompanied a health worker from the voluntary association to a patient’s home. The same process of introduction was followed but on this occasion the patient’s wife, as his advocate, telephoned to say her husband would be interested in being a part of the research.

Advertising in newsletters and follow-up mail-out

The MND voluntary association agreed to advertise the study and an initial advertisement requesting expressions of interest was placed in their newsletter. This newsletter (Appendix C) was mailed to all members on their database consisting of approximately 99% of all individuals diagnosed with MND in Victoria. People interested in participating, or advocates acting on their behalf, provided their contact details by mail, telephone or electronic mail. The potential participants or their advocates were contacted by telephone to introduce the study and request permission to mail out a
Participant Information Sheet (Appendix B) and consent form (Appendix D). Follow-up contact addressed any questions about the study and established a time and place to meet for the interview. The place negotiated was mutually agreed by the participant, advocate and researcher. This strategy was adopted in the initial 8-month recruitment phase, which included running a second advertisement in the newsletter.

The second strategy was to mail out individual expressions of interest advertisements (Appendix C) to all MND voluntary association members living in rural Victoria. This group was targeted again because it was under-represented in the initial pool of volunteer participants. This action was undertaken by the association on the researcher’s behalf so that confidentiality and anonymity for all members of the database was maintained. Those members who wished to participate in the study initiated contact. The timing of this mail-out depended on the number of responses to the initial advertisement. Each of six rural health regions was targeted, one per month, sequentially over six months. This allowed interview times to be consolidated within each region and so cluster travel to rural areas of Victoria. Contacts were made as stated earlier. The success of this recruitment strategy was mostly due to the diligent and enthusiastic support of the MND voluntary association.

**Key personnel referral**

An aspect that evolved from the data analysis was that participants interviewed told of hospitalisation experiences that caused them much anguish and discomfort, resulting in personal feelings of despair and low self-esteem. Thus, in accordance with theoretical sampling in grounded theory, participants who had positive hospitalisation experiences were specifically targeted for interview. Therefore, key personnel in the neurological services of a publicly funded hospital were approached and asked to assist with recruitment of people diagnosed and living with MND, whom they cared for in their service. This strategy also accessed those not on
the database of the MND voluntary association. Subsequently, two advocates of people with MND made contact and the established recruitment procedures were followed.

**Support group recruitment**

At the invitation of a participant and the MND voluntary association, a short seminar outlining the research was given to support groups in one urban and one rural area. The presentation highlighted the opportunity for people living with MND to participate in research. Invitations were distributed at the group meetings. One urban participant was recruited in this manner. In the rural group, two members requested a meeting together to participate in the research. Because ethics approval did not include group interviews, they were assigned the role of “key informants”. Their interactions with the researcher provided the opportunity to present preliminary findings and receive feedback to enhance rigour. Such feedback was subsequently included in the analysis and the findings.

### 3.4.4 Recruitment response

Recent literature reviews have revealed recruitment barriers (Ross et al., 1999) and suggested protocols to improve recruitment rates in randomised clinical controls (Donovan, Brindle, & Mills, 2002; Morrison-Beedy et al., 2001; Paskett et al., 2002). Little is known about the barriers to recruitment in qualitative research. Those encountered in the current study included slow uptake of invitations to participate and limited resources to tap rural participants. Another barrier was the population of people with MND which was 293 (a 5-year mean) in 2002/2003 (MNDAV State Council, 2003), was distributed throughout Victoria; the small number meant there were fewer people available to contribute given that it was expected that many people would not reply to participation requests.

Although recruitment barriers were experienced, abundantly rich data for this qualitative study were obtained. Initially the aim was to interview 30 participants. However 24 participants and 1 co-participant, the husband of a
woman diagnosed with MND, were interviewed because, at this time, the key themes and concepts were becoming repetitive with each interview and no obvious new data were being divulged. Whilst individual stories were unique, when talking about one particular theme, like living with MND, awareness developed of having heard similar stories in previous interviews, thus data collection ceased.

An open invitation via the newsletter to participate in research had unexpected response challenges for potential participants, because many were unable to reply independently. Individuals whose physical abilities were declining and whose abilities to communicate were deteriorating, experienced difficulties in making written and verbal responses, thus potential participants relied on carers to respond on their behalf.

The most successful recruitment strategy was the follow-up research invitation mailed to rural members of the MND voluntary association in Victoria. This outcome may be attributed to the personal invitation and to the lack of other opportunities for people with MND in the rural area to participate in research.

Participants

Participants in this study were a homogeneous sample of individuals who shared the common experience of being diagnosed and living with MND. Homogeneity has been identified as vital for in-depth study about people’s circumstances (Holloway & Wheeler, 1996; Llewellyn, Sullivan, & Minichiello, 1999). The participants all lived in Victoria, with the exception of two who lived in rural New South Wales but accessed convenient services in Victoria because of their proximity to the border. The census in 2001 estimated that there were over 18 million people in Australia. Victoria and New South Wales, states of Australia, had respective populations of approximately 4.5 million and 6 million (Australian Bureau of Statistics, 2002). As already noted, the number of people diagnosed with MND in Victoria in 2002/2003 was 293 (MNDAV State Council, 2003), a small fraction
of the total population of Victoria. Of course, other people may have yet been undiagnosed with the disease, making incidence levels difficult to determine.

Of the 32 potential participants contacted for this study, 19 were male and 13 female. Two females died before interview, two females declined, and there were three key informants, of whom two were male. Table 3.2 shows the composition of the final 25 participants who were interviewed. There were 17 (68%) males and 8 (32%) females. The gender distribution of the sample reflects that of the Victorian MND profile - 61% males and 39% females in 2002/2003 (MNDAV State Council, 2003). Twenty-two (88%) participants lived at home and three resided in nursing homes. This distribution also reflected current MND profile statistics of 87% living at home (MNDAV State Council, 2003). Eleven (44%) participants were from the urban area and 14 (56%) from rural Victoria, in contrast to the locality profile of people with MND in Victoria of 69% urban and 31% rural.

<table>
<thead>
<tr>
<th>Table 3.2 Gender and Location of Participants at Time of Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Females</td>
</tr>
<tr>
<td>Total Participants</td>
</tr>
<tr>
<td>Urban residents</td>
</tr>
<tr>
<td>Rural residents</td>
</tr>
<tr>
<td>Living at home</td>
</tr>
<tr>
<td>Resided in nursing homes</td>
</tr>
</tbody>
</table>

**Inclusion criteria**

Individuals diagnosed with MND sometimes lose their ability to communicate verbally and physically. As the disease progresses motor neurones die and muscles deteriorate, so that even using augmentative technology can be difficult. The criterion for inclusion in the study was that the person be willing and able to communicate in some form his/her story
because it was important to capture the “voices” of those living with MND. It was recognised that communication can take a great deal of work, effort and time by the person being interviewed, so their willingness and ability to do so was an important consideration.

Three people became key informants. All were diagnosed with MND and their conversations during the support group meetings, as discussed previously and at advisory board meetings were noted on paper. All had given verbal permission to have their ideas documented as fieldnotes and to be included in the data by way of enhancing other participants’ stories.

One co-participant agreed to be interviewed about his wife’s journey with MND. Unfortunately, at the time of the interview, his wife was unable to communicate in any way even with an alphabet board. She resided in a nursing home. Although her participation did not strictly adhere to the inclusion criteria, her husband was able to provide key components of her story as a co-participant. The interview elicited his interpretation and understanding of her experiences with MND from the perspective of a husband who had been in a close marriage relationship of 50 years. This interview occurred late in the study but it is noteworthy that the story he told resonated with previous participants’ stories. Information gleaned from this interview provided further evidence about the experience in nursing homes and about the impact of decision-making for residential care.

Undertaking the research process posed challenges and presented practical and ethical concerns. These included: the differing abilities and willingness of individuals to communicate; the availability of technology as an adjunct to meet communication needs; an individual’s disease progression and the researcher’s ability to clearly understand and record altered speech patterns when technology was not used; recruitment numbers; the emotional impact of the study on participants and the researcher; the death of participants before their scheduled interview time.
and before the study was completed. Each challenge was addressed as it occurred.

### 3.4.5 Data

In this project, the principal source of analytical data was transcripts of in-depth interviews. In keeping with grounded theory principles of obtaining data from diverse sources to build a dense theory (Strauss & Corbin, 1998), transcribed interview data were combined with the researcher’s fieldnotes; participant stories and personal reflections; poems, prose, songs, motivational and autobiographical books identified by participants as having meaning in their lives; exercise and documented formalised attendant care regimes, that participants followed, as well as newspaper articles about participants which they provided. These sources provided a rich data base for analysis.

The next section outlines the techniques and strategies used to interview participants and identify the sources of data collected as well as their meanings for the participants.

**Interview techniques**

In qualitative research, the interview technique must be appropriate for the chosen research method (Minichiello et al., 1995). Further, the researcher/interviewer is required to be the collection instrument for qualitative research (Sorrel & Redmond, 1995) as it is through her interactions with participants that the data essential for the study, are gleaned.

In this study, in-depth interviews were used. This technique of interviewing encourages participants to explore their experiences in depth and with reflection. In this process, the researcher is able to gain access to participants’ words about their social realities that are based on their experiences (Minichiello et al., 1995). Wengraf (2001) explained that the concept and definition of “depth” in interviews is to achieve a realisation of how little was known about the phenomenon under investigation. That is,
depth of explanation and understanding is gained when the interviewer realises how much about the experience being explored is unknown. It also means that the interviewer extracts from the conversation, everything the interviewee knows and understands about a subject.

During the interview, the researcher needs to be empathetic, and listen analytically to elicit an informative dialogue for analysis (Minichiello, Madison, Hays, Courtney, & St John, 1999). In the current study, each interview commenced with a single request: “Tell me what has been happening to you since you were diagnosed with MND”. For some participants, who had been diagnosed with MND for a long time, the request was altered to suit their individual circumstances, such as, “Tell me what it is like to live with MND”.

The interview format was unstructured, requiring the interviewer to improvise, be flexible and open to change according to the flow of the conversation (Minichiello et al., 1999). Accordingly interviewing followed a recursive model as recommended by Minichiello, Aroni, Timewell and Alexander (1995). The dialogue was iterative and had the form of a reciprocal conversation with continual clarification of issues previously introduced by the participant. Subsequent interviews included a list of issues, identified previously with other participants, to build on concepts derived from the ongoing analysis, thus following a grounded theory method for theoretical sensitivity. The issues were introduced at the end of the interview by the researcher if they had not previously been introduced by the participant.

In this study, ensuring that a recursive model was followed during interviews was, at times, challenging for both the participant and researcher. Most participants experienced communication limitations because of the effects of MND. The following section discusses the different challenges and the strategies used to ensure that participation of participants was achieved.
Communication challenges

Communication becomes a challenge for individuals with MND because of declining muscle strength related to the disease process. It was necessary to use a range of strategies to augment understanding of altered speech patterns and to improve conversational flow using electronic devices for communicating. Care was also needed to ensure recordings were clear and that participants who experienced emotional lability felt safe and able to contribute.

Understanding altered speech patterns

For some participants, their verbal language skills changed as the disease progressed due to the deterioration of facial muscle. These changes ranged from slight indistinct pronunciations to unintelligible sounds. Thus audio-recording participants’ stories that could be transcribed was a challenge.

Before the interview began, it was necessary to spend time becoming accustomed to the participant’s speech patterns in order to recognise personal nuances. During the interview, the conversation content was paraphrased, often, until it was clear that the meaning was confirmed. This collaboration took time, patience and perseverance but was intensely rewarding for both parties.

The assistance of a third person, who was familiar with the participant’s modes of communication, was often able to reduce the frustration of the participant and enhance the conversation. Other researchers use the word “proxy” (Koch, Marks, & Tooke, 2001; Philpin, Jordan, & Warring, 2005) to identify the involvement of another person who assists the interviewer to understand what is spoken and in effect at times, co-constructs the interviewee’s story by elaborating on what was said. Koch, Marks and Tooke (2001) used proxies when interviewing clients with intellectual disabilities to understand and explore their care needs. Philpin, Jordan and Warring (2005) incorporated proxies when interviewing people with communication
difficulties about living with a percutaneous endoscopic gastrostomy. In the current study, mostly the proxy was the participant’s spouse. Others included were another family member and live-in carers. The presence of another person is usually thought to act as a deterrent to openness. In this project, on the contrary, some participants revealed, in the presence of the proxy, information not previously disclosed. These disclosures often stimulated further in-depth discussion between them, a fact they revealed in later interviews. At times it was difficult to understand what seemed to be unintelligible speech, so the proxy’s assistance with interpretation was invaluable. Sometimes the inclusion of a proxy was not always possible, so the participant and researcher worked together to ensure a clear understanding of what was said.

Another strategy used to gain understanding, with or without a proxy present, was to continue the conversation even though words spoken previously were not recognisable. Sometimes the words were able to be understood retrospectively when the audiotape was reviewed and unclear passages were contextualised within the topic being discussed at the time. Billinghurst (2001) called this process attuning to a person’s particular speech patterns and vocalisations, to make audible understanding easier.

Some earlier interviews were two to three hours in length. In such circumstances, the interview was stopped at intervals for participants to have a break. At times, participants wanted to continue although they were tired so another meeting was negotiated to resume the interview on another day at their convenience.

Conversational flow using electronic devices

Communication aids used by participants in this study included Lightwriters, electronic machines that “speak”, the words are typed by the person. Some computer programs use a visual keyboard on the screen for accessing letters and common words, instead of hand keyboards. Voice synthesisers incorporated in the computers speak the sentences typed by the
person. The challenge in the current study was to ensure a suitable flow for the interview process because communication technologies tend to reduce the spontaneity of conversation. Because of differences in the ability of some participants to use their hands, varying lengths of time were required to construct sentences on the Lightwriter or computer. Keying in the sentence to be spoken by the technology to read was, at times, a slow process. It was essential that participants using electronic devices as communication aids really wanted to participate in the research as the process was tiring for them and any accompanying third person. As Diane’s husband explained:

[Others are] … happy with waiting for a little while, and once they … anticipate Diane’s answer then they move on and Diane still hasn’t finished her sentence.

The strategies developed in this current study to enhance the conservational flow were based on a format suggested by Wengraf (2001). Silence was maintained while participants constructed their sentences. Occasionally this was difficult because, as described above, I had an urge to finish sentences or pre-empt what I was being told. At times, the accompanying third person wanted to interrupt and complete the story. However, in most cases, the participant was not interrupted except for the researcher’s encouraging nods or sounds to continue. Wengraf asserts that interviewees indicate when they have finished their story with words such as “that’s all I can think of” or something similar. Such was the case in this study as participants indicated they had finished telling their story by turning off the Lightwriter or removing their hand from the keyboard and making eye contact with the researcher to continue. By closely observing non-verbal cues, I ensured the interview process was responsive to the needs and abilities of each participant.

Another strategy used to enhance conversational flow and spontaneity was to refrain from repeating what was said by the electronic devices. As an exception, only single words were repeated occasionally to enhance the audio-recording quality for transcription purposes.
Clear audio-recordings to facilitate transcription

Highly sensitive equipment (as described previously) was required to record indistinct words and synthesised electronic voices but even sophisticated devices have limitations. However, the equipment used in this project also recorded ancillary sounds such as cars passing in the street when recording in a participant’s home, and intercom announcements when in a nursing home. Attempts were made to ensure a quiet environment but this was not always possible.

The reproduction quality of the first interview using a Lightwriter was poor. The Lightwriter speaker was located under the machine, which itself was in a leather container and positioned on the participant’s lap, further muffling the sound quality. An external microphone was introduced to enhance the sound quality for a more accurate transcription. All sentences spoken by the machine were written down because using the Lightwriter or computer was a slow process for most participants. Subsequent transcribing was much improved by this strategy.

Interviewing a participant, whose verbal communication ability is replaced by technology, also required the interpretation of non-verbal expressions. These were clarified during the interview, and recorded on the audiotape as “Yes? Yes” or “No? No”, to signify head movement. The intent of the prompts was to ensure the participant had been heard correctly and had not been misinterpreted. However on listening to the recording later out of context, the use of language seemed paternalistic which highlighted the need for careful contextualisation of the interviews using the fieldnotes as prompts.

Participants with declining abilities for speech had altered word pronunciation. This combined with a very soft voice, a dry mouth or excessive saliva which related to the disease process, made clear recordings problematic. Strategies used during interviews included drink breaks to improve speech clarity and restating of participants’ words clearly to ensure
accuracy in verbatim transcription. Wengraf (2001) also suggested additional note taking by the researcher when possible as long as this endeavour did not interfere with active attentiveness to the participant. It took practice to note down cues for what each participant had said, however, such note-taking enhanced the transcription process.

Getting the right story

A less acknowledged aspect of MND is the symptom of emotional lability, also known as pathological emotionalism (Newell & Wilson, 1994), emotional incontinence (Iannaccone & Ferini-Strambi, 1996), affective lability (Moore, Smith, Gresham, Bromberg, & Kasarkis, 1997) or pathological laughing and crying (McCullagh, Moore, Gawel, & Feinstein, 1999). Emotional expressions can be exaggerated with excessive laughter or crying. The expression of feelings can also be contrary to the emotion being experienced by the person. That is, the person can cry when happy or laugh when sad. This disjunction between emotions felt and expressed can be distressing both for the person with the condition and those with whom they interact. A consequence of interviewing a person who experiences emotional lability is that the interviewer’s understanding of the story being told can be confused. When this occurred during the interviews in this study, it was necessary to seek a clear understanding of what was being said by participants. One strategy was to explain that clarification of feelings would be sought during the interview to ensure meanings were clear and not confused by the issue of lability.

Occasionally, clarification of confused or extreme emotional expressions needed to be sought during the interview. The participants themselves were sometimes confused and embarrassed by their lack of emotional control. It became apparent that several participants were unaware that their responses were related to the disease process. This knowledge created visible relief for participants who then refrained from trying to contain their expressions. The strategies used to assist participants at these times included taking time out
from the interview to gain composure and asking if they would like to change the topic of conversation. One participant suggested this strategy himself as a means of aiding symptom control and promoting clear understanding of the story being told.

Summary of interview techniques

Interviewing individuals with declining abilities to communicate required a range of specific strategies to ensure their valued participation and clear audio-recording. In keeping with the aims of the project to enable any person with MND to participate in the research, strategies were developed based on other authors’ ideas (Minichiello et al., 1995; Minichiello et al., 1999; Sorrel & Redmond, 1995; Wengraf, 2001), participant instructions, knowledge of therapeutic communication techniques and respect for each participant’s ability to communicate. These strategies enhanced communication and increased the opportunities for individuals with MND to participate in this qualitative research as both participants and collaborators. A poster presentation about these communication challenges and the strategies used to overcome them was developed for the 13th International Symposium on ALS/MND in Melbourne 2002 (Appendix H).

Transcription of audiotapes

Initially the audiotapes were transcribed personally to gain an understanding of the complexities of deciphering altered speech patterns and synthesised voices. Notes written as cues during the interviews enhanced the transcription clarity. The interviews once again came to life during this process and this triggered other pertinent information such as non-verbal expressions to be included in the transcription, thus enriching the interview data. After the first ten interviews, subsequent audiotapes were professionally transcribed. The transcriptions were then reviewed with the recordings adding the nuances of the interview such as non-verbal expressions and environmental disruptions.
Participant reflections

According to Marino, Minichiello and Browne (1999), personal reflections about life can provide rich information about experiences enhancing the quality of data for analysis. In this study, some participants enhanced their contribution with personal written reflections about living with MND. Over several days before the interview, they documented issues and concerns about care, access to services and what it was like for them living with MND. This was a way of introducing their experience of the disease and it enhanced their stories.

Some participants preferred electronic mail as a method to answer questions after the interview because they were able to spend time in constructing their thoughts without the pressure of being in an interview situation. This was especially relevant for individuals whose physical abilities were declining and it indicated their enthusiasm to contribute to the project. Electronic mail correspondence was analysed in the context of the interview data.

Other sources of data

During the interview process, participants illuminated their experiences with references to prose, songs and texts in books. These enabled some participants to express what they felt without using spoken or written words. For example one participant shared a piece of prose called “The Attic, living with MND” (Huberty, 2000). The prose was written by a person with MND and described metaphorical packing away of losses in boxes, in the attic. This piece of writing resonated with the participant and enabled her to express her pain, as illustrated in an edited extract from the transcript of her interview using a computer to communicate and her husband to translate her vocalisations.


Researcher: This is called ‘The Attic’ and you relate to it very much do you?
Diane: *Mmm … you should find that very interesting … it tells you all the things you gradually lose control over … learn to put away.*

Diane referred to the prose as a way of explaining how she judged her life. As she later noted in electronic mail:

> the reason for my determination is simply I want to live until I know it’s too hard and I’ve put away the last box, I will keep on “Living with MND”.

Songs were also important. Participant Colin referred to a Frank Sinatra song as a way of expressing how he felt about his losses caused by MND.

> you know the song “Every time you say goodbye, I die a little”… It’s famous … Well I said good bye to something of me regularly.

This participant also used euphemisms written by another person with MND as a guide for living with the disease (Albom, 2001). The relating of these different ways of telling experiences about living with MND also highlighted the idea that people, whose communication abilities are reduced, seek other ways to express their feelings including the use of metaphors, prose and analogies to communicate emotions and provocative thoughts. This strategy is discussed further in chapters five and six of the thesis.

Different sources of information about participants’ lives were requested to enhance understanding of the scope of resources used by each participant. They could relate to their care in the form of service provider plans or a photograph depicting what was important to them. One participant listed all the services that he accessed so he could live at home. Another participant supplied a photograph of a memory quilt his daughter had made for him and his wife. Members of the family had each constructed a panel in the quilt, which reminded them of their parents. This illuminated the importance of family and the supportive role they played in their lives which epitomised the participant and his wife’s belief in family.
Language impairment related to frontotemporal dementia.

In the main, individuals were interviewed in their homes. Only twice was the person alone. Two were in nursing homes accompanied by a family member while the interview took place. Participant 23 was interviewed in a neurological care unit with his wife in attendance. When arranging the meeting with the unit manager, I was informed that this participant had dementia. I was also informed that the person and the family denied such dementia.

As the interview had been scheduled with the agreement of all parties, it proceeded. I listened and observed the participant’s interactions with me and with his wife and I subsequently reflected on the interview process. The participant appeared slow in processing the information and slow in giving responses. His speech was heavily slurred. He told me that his brain was going round in circles fast and he could not get out what he wanted to say. This problem was exacerbated by the difficulty of making his oral musculature respond to form words. His wife confirmed what he was saying but at times she would say - “remember we talked about that”. He needed to process what was being requested again with the prompt. It was unclear if this was an example of dementia or language impairment.

Neary, Snowden and Mann (2000) investigated the differences and associations between frontotemporal dementia (FTD) and FTD/MND, then FTD/MND and classical MND/ALS (cMND/ALS). An identifiable feature of FTD/MND is often the subtype of purposeless, overactive disinhibition and distractibility. Another study by Barson, Kinsella, Ong and Mathers (2000) highlighted that some patients with cMND/ALS do have cognitive impairment and the traditional idea, that people with cMND/ALS are spared cognitive dysfunction, needed to be reviewed. Thus a controversy exists concerning the extent of individual cognitive ability impairments and whether there is deterioration or unchanged cognitive functions in MND (Bak & Hodges, 2001; Barson et al., 2000; Goldstein & Leigh, 1999; Murphy et
al., 2002; Neary et al., 2000; Worthington, 1996). This information suggests that the reliability of experiences reported by some participants in the current study could be called into question. According to Minicheillo, Aroni, Timewell and Alexander (1995), the concept of rationality is introduced in which all people are understood as rational and that people are mostly consistent with their existing culture. Thus participants in the study were taken at face value in trust and truthfulness. The stories participants told were about their experiences as they perceived them and, as such, were deemed truthful and trustworthy data.

**Researcher fieldnotes**

Prior to commencing interviews, a template or proforma was created for fieldnotes based on the style of Browne and Sullivan (1999) (Appendix G). The fieldnote proforma provided both cues for the researcher to reflect on the interviews and a format to document other contact interactions that occurred during the research process. The fieldnotes were incorporated into the data analysis.

The aim was to complete fieldnotes 24 to 48 hours after interviews to capture initial thoughts and reactions about the interview while they were still fresh. This was not always possible because of travelling in rural areas. Sometimes fieldnotes and post-interview de-briefing were audio-recorded. The de-briefing allowed the researcher to “free-associate” (Wengraf, 2001, p. 142) about the interview experience. Wengraf (2001) encourages this practice to stimulate cues during subsequent analysis of the interview data. Both forms of data were transcribed and included for analysis at a later date.

After analysis of each participant’s interview, the fieldnote proforma was revisited and extended with thoughts and contemplations about the interaction with the participant. This strategy allowed a more critical review of what had occurred. Data for a participant could include two transcribed interviews and several electronic communications, with references to prose
and books that he/she considered important. The inclusion of fieldnotes enhanced and brought together all the data for analysis as a whole.

Personal journaling helped to clarify my feelings and provided a method of exegesis of my reactions during the interview and subsequent analyses processes. The writings became my reflections and I was able to use them as ancillary documentation with the fieldnotes.

**Data summary**

In keeping with the requirement of grounded theory research methods, data from many sources were collected. Transcribed interviews, researcher fieldnotes, participant reflections and stories together with other sources provided a rich database for analysis in this project. The next section describes the data analysis procedures.

### 3.4.6 Analysis procedures

Glaser and Strauss (1967) explained that comparative analysis is a general method of analysis used in many fields of study including sociology and anthropology. Other purposes are to: check accuracy of evidence or facts; establish generalisability of facts; specify the dimensions of a concept for analysis of a one-case study and to verify theory. To be more specific, in grounded theory comparative analysis is “a strategic method for generating theory” (Glaser & Strauss, 1967, p. 21).

As previously stated, the population of individuals diagnosed and living with MND and accessing services in Victoria is small. It was, therefore, difficult to seek out participants according to specific criteria. Instead emerging issues, categories and analysis themes fortuitously discovered during interviews, and recognised as being analytically important by the researcher, were added to the sample framework for exploration in successive interviews.

This section explains the core basic principle for grounded theory research, constant comparative analysis; how the computer software, NVivo
(Richards, 1999), was used to manage project data and the steps used to analyse the data.

**Comparative method of analysis**

According to Strauss and Corbin (1990; 1998), when a grounded theory study is undertaken, data are coded and categorised to develop concepts and constructs. Major themes are identified and linked with ideas from the data, to find a “story line” for the study. Constant comparative analysis identifies the process of continually comparing each piece of data or coded data with every other coded section throughout the study for similarities and differences, both as data are collected and during analysis. In addition, Holloway (1996) included themes and categories identified in literature as comparison data. For example, in this study the literature about chronic illness and coping strategies provided comparative data for a more dense analysis of data.

**Analysis process**

This study used: an analysis process based on the procedures of Browne and Sullivan (1999); the insights about qualitative analysis by Wengraf (2001); coding methods of Bazeley and Richards (2000) and conceptual modelling described by Soulliére Britt and Maines (2001) as a method to illustrate and present analysis compatible with grounded theory tenets. The analysis steps of Browne and Sullivan are based on the theoretical precepts of Anselm Strauss (Strauss & Corbin, 1990, 1998). The steps reflect an analytical and methodologically sound approach (Browne & Sullivan, 1999) for analysing qualitative data for emerging theory based on grounded theory principles. They promoted analysis by interrogating word by word.

Wengraf (2001) explained the “how to” of the thinking part of analysing data, the importance of first listening to the audiotape and of recording the researcher’s stimulated memories and ideas as an ongoing process. In contrast to Browne and Sullivan’s approach, data are analysed as a whole in the context of each participant. Questions are asked of whole sections of data,
for example “What is happening here?” or “How does this affect the participant?” and “What does this mean to the participant?” In this study, questioning blocks of data became the preferred and main method applied to interrogate the data because word by word analysis was inappropriate for participants’ data which combined metaphors and broken speech patterns.

Bazeley and Richards (2000) explained that the use of the computer software NVivo for coding text, providing insight into coding methods and recording ideas as memos, assists to build up the descriptions and analysis of the developing substantive theory. In addition, Soulliére et al. (2001) proposed that conceptual modelling facilitates the understanding of conceptually dense theories developed using a grounded theory approach.

**QSR NUD*IST Vivo (NVivo)**

The data from this study were stored and managed using the computer software NVivo (Richards, 1999). This computer program assisted with analysis by facilitating the management and exploration of unstructured data for qualitative research. During analysis, the software enabled the integration and linking of data, to both codes and the researcher’s ideas, and analysis reflections through file management tools. Further, as described by Richards (1999), the software assisted with the management and synthesis of ideas while linking, coding, shaping and modelling data. The data in this project are text from different sources. NVivo enabled the tracking of data and analysis documentation under the direction of the researcher.

**Steps of analysis**

The following section outlines the steps used to analyse the data for the project. Each step is labelled and described.

**Researcher transcription and listening**

The first ten audiotapes were transcribed. Thoughts and ideas about the interviews were recorded as written notes or memos in the transcript or as separate documents (Wengraf, 2001).
Listening

Each subsequent transcript was verified for accuracy by sustained listening and reflection on the interview. Again, as suggested by Wengraf (2001), any ideas and thoughts brought to mind by this process, were noted in the transcript or memos of ideas were made in discussion documents.

Open coding

As the transcripts were read, questions were asked of each word, each line and each paragraph as applicable. Following this, questions were asked of the text as a whole, in the context of the participants and their circumstances. Often whole sections of data were interrogated because of the particular circumstances of the interview process, a strategy suggested by Wengraf (2001). The interrogation used the “eight wise investigators” of research - who, what, when, where, how, why, what if, and so what - to question the data as suggested by Browne and Sullivan (1999, p. 591). This type of interrogation stimulated cues for naming codes and documenting memos of meaning. For example, data from the participant Kevin’s transcript were coded under “denial” because he revealed that not acknowledging MND was his way of dealing with the disease.

I don’t want to worry about it [MND] … I try to put it aside … [laugh]

The following extract about “denial” was recorded as a memo about Kevin’s data which was contextualised to his circumstances.

Kevin is coded here because he tries to ignore the disease and just lives his life as he wants. He is “out there” with his behaviour - it could be described as risk taking. It is another form of denial. Kevin identifies the disease as “it” which can also be denial - ignoring the disease by not giving it a name.

Categorising

The codes were grouped into categories after 10 interviews had been coded. A category reflected a grouping of like codes that had an overarching label. Each category was labelled, had a defined meaning and criteria that defined that category (Browne & Sullivan, 1999). From the above example,
“denial” was grouped into a category labelled “coping strategies” with other codes that identified other coping strategies used by participants, such as, “ask for help” and “having quiet”. When the codes were being grouped together, questions were asked about the data already coded, in search of similarities and differences. Data and codes can be moved between the categories and descriptions modified by using the tools in NVivo. For example, the codes of “denial” and “pretending it’s not there” were seen as similar so they were merged together into the code “denial”.

When data were allocated to a category, descriptions were written about the relevance to the category. This was important for the next step of identifying the different aspects of the categories in developing provisional concepts.

*Developing concepts with sub-categories*

The coding at each category was reviewed and further interrogated according to the description developed by the researcher in the category. The different aspects of the coding were then coded-on to develop concepts. Coding-on, as explained by Bazeley and Richards (2000), means data allocated to one category can be coded again or coded-on from that category, to another category, as a concept. Full descriptions were recorded to explain the concepts developed. For example, data allocated to the codes “denial” and “pretending it’s not there” were coded-on to a category about “ways of living” and “MND as ‘it’” respectively where participants labelled MND ‘it’, not acknowledging the disease by name. Thus the same data were allocated to two categories, denial as a way of living and “pretending it’s not there” in “MND as it”.

*Progressive coding*

After the first 10 interviews and analysis of accompanying documents such as fieldnotes and stories, subsequent interviews and data collected were incorporated into the analysis. As initial categories were developed, “broad-brush” coding of linking larger extracts of the new data into the broader
categories as suggested by Bazeley and Richards (2000, pp. 54-55), was used instead of the previous interrogation methods. Some categories were renamed, merged and moved around as the integration of new data continued. As previously explained, through the use of the tools in NVivo, data can be allocated to several categories and not assigned to one particular category. This function allows the researcher to view data already allocated under various categories and to “code-on” to refine concepts. Any new or different information was also coded, categorised and later reviewed to be integrated into the project as a whole.

From broad-brush coding, the data allocated to the categories were interrogated according to the category. Concepts were developed that again reorganised the categories. Concepts are overarching ideas that incorporate and link the categories that have relevance to a particular idea. Continuing the previous examples, “ways of living” was integrated under the concept of “personalising disease progression”. The description appeared as follows.

*This concept was created to encompass the different aspects of living with MND from the perspective of the person.*

*Encompassing the personalising of the disease is the processing of life changes and how the person with the disease coped with the changes that happened while he/she lived with the disease - day to day living, planning for the future, that is, dealing with the changes that happen with the disease progression and how each person adapts to the changes in his/her life.*

**Comparing concepts in different interviews**

The computer program NVivo has the ability to apply attributes to documents and codes, or nodes as NVivo identifies them (Bazeley & Richards, 2000). Attributes can represent participant demographic data. This enables the researcher to compare interviews of participants according to criteria such as gender, place of residence and disease trajectory. As the project progressed and more interviews were completed, ongoing analysis proceeded. New relevant demographic attributes were added to the
documents, and earlier documents were accessed to allocate the newer attributes according to the progressive analysis. Tools in NVivo can be used to look for patterns, similarities and differences in the data that were allocated to codes, categories and concepts.

**Developing an explanation**

After looking for similarities and differences, and connections between categories and concepts, provisional propositions were made that sought to make sense of the data and understand participant behaviours. At this stage, pencil and paper conceptual maps were drawn connecting ideas. The intimate knowledge of the transcripts enabled me to embellish most of the concepts and categories with the experiences of the participants. This provided provisional evidence of meanings, conditions, interactions with others, behaviour strategies used and consequences of the behaviours, as well as the structural influences that impacted on the participant behaviours (Browne & Sullivan, 1999). The raw data were continually accessed to confirm the evidence thus grounding the explanation in the data.

As previously highlighted, a removed stance was adopted in order to look at the big picture - to see what was really happening. This enabled a general perspective to be developed into a model about decision making while living with MND. Soulliére, Britt and Maines (2001) explained that the use of conceptual modelling enhances grounded theory as both methodologies facilitate the discovery and development of dense theories. Conceptual modelling illustrates the complexities within dense theories to clarify their understandings. As the analysis proceeded, another model about the process of being diagnosed was revealed. The concepts ascribed in both models corresponded with the categories identified during data analysis.

Using the provisional models, the raw data were again assessed for the fit of the models with the data. This provided the opportunity to identify inconsistencies and other aspects not realised thus improving and clarifying the models.
**Identifying the core theme**

Browne and Sullivan (1999) contend that a core theme can be found throughout the different participants’ stories and that it is depicted in a myriad of ways. After explanations were developed of what it is like to live with MND and how people negotiated with others to live their lives as they wish, these explanations were interrogated. Questions were asked about what was happening, why it was happening and what it meant, in order to construct a core theme from the explanations, concepts and categories, which made sense of the links between them. According to grounded theory tenets, the core theme underpins the understanding of the behaviours of the participants. Once identified the raw data were again interrogated to find evidence of the core theme throughout the experiences as told by participants. The core theme became the basic social process that underpinned the decisions and behaviours of participants as they lived with MND.

**Verifying conclusions**

To verify that the provisional models reflected in the data, a colleague charted the raw data of ten participants against the models. They were verified as accurate with some modifications. These modifications were discussed and either integrated into the model or explained within the context of participants’ experiences and the data.

Conclusions were verified when the provisional models were presented to the advisory board and posters, based on the “living with MND” models, were presented at international conferences on ALS/MND (Appendices I, J and K). The advisory board acknowledged the process as informative and representative of what they believed happens, and the posters were well received by people with the disease, carers and health professionals.

**Developing a substantive theory**

As previously identified, the purpose of using a grounded theory methodology in qualitative research is to develop a theoretical explanation of
the phenomenon being investigated, in other words to generate theory (Glaser & Strauss, 1967). The current study pertains to a group of people with the common feature of being diagnosed with MND and, therefore, the theory developed can only be substantive. Although not the initial intent, a substantive theory that explained the personal perspective of living with MND became apparent. The two models and the basic social process were brought together. Similarities and differences were identified and a conceptual model developed that became the substantive theory.

**Summary of analysis procedure**

The data analysis was a fluid and interactive process, sometimes consisting of pencil and paper conceptual maps of evolving analyses and sometimes of revisiting interrogation of raw data for confirmation of ideas documented by the researcher utilising the computer program NVivo and its tools. As suggested by Glaser and Strauss (1967) and Browne and Sullivan (1999), raw data and coding were continually compared for similarities, differences and connections to ensure the theory developed was dense with data and meanings.

This section detailed and explained the procedures used to analyse the data. Grounded theory methods were explained and it was shown how these were integrated into the analysis. The use of the computer software NVivo to manage data and the researcher’s analysis ideas in the form of memos was also outlined. The software tools were explained in conjunction with the steps of analysis, detailing how the researcher returned to pencil and paper to conceptualise the analysis and develop models depicting the social reality of living with MND. In the next section, achieving rigour in this qualitative research project is discussed.

### 3.4.7 Rigour

Although dated, one definition of rigour given as “strict enforcement of rules”, (Allen, 1994, p. 1077) still applies to interpretation of quantitative data where experiments require “strict adherence to conventional benchmarks of
internal and external validity, reliability and objectivity” (Lincoln & Guba, 2000, p. 166). In contrast, rigour in qualitative research does not have benchmarks and is not objective, thus the concepts that embrace rigour in such research are different. Discussion abounds about what is applicable and not applicable to qualitative studies (Silverman, 2001) and how reliability and validity can be transferred or transformed for application to qualitative research methodology to ensure that, or ascertain if a study is “good” (Lincoln & Guba, 2000).

Sandelowski (1986) used the concepts of fittingness and trustworthiness to ensure rigour in qualitative research, explaining that rigour was not about adherence to rules and procedures but “fidelity to the spirit of qualitative work” (Sandelowski, 1993, p.2) with the focus being trustworthiness for a truthful research project. Emben and Sandelowski (1998; 1999) concluded that no one set of criteria for establishing quality in qualitative research can be expected to fit every research study because of the diversity of approaches and traditions within the qualitative paradigm. More recent texts discussed rigour as methods to ensure credibility of qualitative research (Silverman, 2001), evaluation criteria for good research (Strauss & Corbin, 1998), verifying conclusions to ensure good grounded theory (Browne & Sullivan, 1999) and conceptions of goodness (Emden & Sandelowski, 1998, 1999; Miles & Huberman, 1994). Burns and Groves (2001, p. 64) explained rigour as being:

associated with openness, scrupulous adherence to a philosophical perspective, thoroughness in collecting data, and consideration of all the data in the subjective theory development phase. Evaluation … is based, in part, on the logic of the emerging theory and the clarity with which it sheds light on the studied phenomenon.

Thus there are many conceptions and ideas of what and how rigour in qualitative research is achieved.

In this study, strategies to ensure rigour were guided by the procedures identified by Browne and Sullivan (1999) as they corresponded with the
procedural steps of the analysis used in this study. Strategies included participant feedback and auditability of findings which have been previously used in similar research (Emden & Sandelowski, 1999; Sandelowski, 1993; Silverman, 2001).

Two methods of participant feedback were achieved. One method was to return raw transcripts to participants to ensure they were a true representation of their interviews. Some meticulously edited the transcripts deleting, modifying and explaining what they meant to say. These edited transcripts became the raw data. Others did not alter the transcripts. Not all participants wanted to review what they had said and some were too ill to ask. A second method was to send draft copies of the analysis to participants. This was not always possible because some participants died before the study was completed, some were not interested and others were too unwell. Feedback on the analysis was sought from other people diagnosed and living with MND who were not in the study but who became key informants as previously explained. Their comments were included in the final document. Credibility for the analysis was established by their contributions.

Maintaining an audit trail ensures auditability of decision-making and thus establishes trustworthiness in the study (Rodgers & Cowles, 1993). An auditor can follow the decisions and thought processes of the researcher to confirm or verify the analysis of the data. Confirmability of the study gives assurance that the data, interpretations and resulting outcomes are from the data and not from the researcher’s imaginative mind (Piercey & Woolley, 1999). In contrast Cutcliffe and McKenna (1999; 2004) proposed that audit trails only confirm the methods used and that confirmability needs to be the application of the product and its usefulness. Alternatively, Browne and Sullivan (1999) suggested that “good research provides thorough explanations, and accounts for alternatives” (p. 608). In this study, many excerpts of relevant participant data are used to support the concepts developed, thus ensuring that the analysis was grounded in the data. In addition, auditability and confirmability was achieved when a colleague
charted the models according to a selection of the raw data, as discussed previously. This identified coherence with the models and some new insights of contextual influences.

Rigour in this study was developed through the processes of key informant feedback, extensive participant data extracts and use of the models by a colleague as a form of audit trail. Hall and Callery (2001) noted that further enhancement includes the acknowledgements of reflexivity and relationality when interviewing participants, which reflect participant-researcher interactions and influences in constructing data. In the context of the current project, this involved the social construction of knowledge about the phenomenon under investigation.

Hall and Callery (2001) explained that reflexivity refers to the influence of participant-researcher interactions on the construction of the data. They argue that incorporating discussion about the interactions and co-construction of data within the procedures section of research reports provides evidence of rigour. Examples of researcher-participant interaction effects are woven through descriptions about interviewing participants with communication challenges. The efforts undertaken in this study, sought to ensure inclusion translated into open conversations where emotions were expressed without embarrassment. One participant forgot her husband was present because, on one occasion, we were so engrossed in reciprocal endeavours to understand what she wanted to say, that she revealed her end-of-life choices of which he had hitherto been unaware. Most interviews were in participants’ homes where they felt comfortable. In the following discussion, researcher influence in the context of relationality in this current study is presented.

**Researcher influence**

In the process of interviewing participants and using methods to attain theoretical sensitivity, I sought to ensure that questions were based on previous interview data. At times these questions stimulated discussion
between participants and their carers about sensitive issues such as choices about place of death. At the second interview, participants and their carers appeared proud and excited that they had actually discussed the new issues and had made some life decisions. In this way, it became apparent that, though such an impact was unplanned, the research process influenced decision making and future plans. This was accepted as the reality of the interview process.

The process of drawing out, from interview to interview, similarities and differences across participants’ experiences gave some the impression that information was being provided to them. Several times the participants thanked me for providing them with information though this was not the intended purpose of this procedure. It seems that many participants believed that they had not been given any information about how to live with MND by their neurologists and service providers and so they believed any new information, whether it was from someone else’s experience or not, was useful to them.

3.4.8 Ethical implications of the project

The cohort of people who volunteered to participate in this study was considered vulnerable both, because they were diagnosed with a terminal illness and had disabilities associated with disease progression. The processes instigated to protect this group of people were of particular importance. In this section, the processes for ethical clearance, which included consideration of participants’ anonymity and confidentiality, storage of data, management of risk and sensitivity to participants’ quality of life, are discussed.

General implications

Ethical clearance for this study was sought and gained from respective governing bodies – Deakin University and Calvary Health Care Bethlehem Inc. (Appendices E and F). The researcher was well prepared to undertake
this study because of prior clinical and academic experiences. Avenues to discuss any ethical problems that emerged during the project included the research supervisors and staff with the study’s industry partners. Ethical issues addressed included anonymity and confidentiality, sensitivity of the interview material, consent issues, and potential risks for participants and the researcher.

**Anonymity and confidentiality**

The anonymity and confidentiality of the participants was assured through several strategies. These included using anonymous “expression of interest” forms and interviewing participants in their own home or in a private space. Each participant was allocated a pseudonym and code, and all data including fieldnotes and electronic communications were identified by their pseudonyms. These were subsequently used in reporting the analysis in this thesis and elsewhere at conferences. Identifying information was stored separately from documentation and audiotapes and access was restricted to the researcher, supervisors and the professional transcribers of audiotapes and documents. These data were stored in locked cupboards in Deakin University to be destroyed five years after completion of study and files on computer systems were password protected.

**Consent**

Participant Information Sheets (Appendix B) and Statement of Consent forms (Appendix D) were the two documents used in gaining informed consent to participate in this project. Consent was audiotaped. This approach was used with all participants, irrespective of their ability to sign a consent form manually. Further, the interviewer signed the verbal consent form noting the number of the audiotape on which consent was given. Participants were assured they could withdraw from the project at any time without prejudice to their care.
Sensitive issues

Sensitive issues in this study related to topics such as end-of-life issues, institutional care, diagnosis issues and the loss of independence. Discussion about sensitive issues was necessary to obtain a rich database for analysis. In a study by Kellehear (1989), findings revealed that participants readily appreciated an opportunity to engage in open dialogue about their experiences about dying, yet, in this current study, participants were generally unwilling to talk about end-of-life issues.

As the project progressed, participants invited a third person, usually their spouse or family member, not only to act as an interpreter during the interview when altered speech patterns were difficult for the researcher to understand, but also for the participant’s comfort (Young & McNicoll, 1998). Ethical approval was gained for such presence during data collection.

Counselling services were available and offered to participants if they became distressed during the interview or required post interview debriefing. An independent counsellor provided by the study or pastoral care workers associated with a hospital with neurological in-patient services provided the services. Participants recruited through the MND voluntary association were offered access to counselling services of the same organisation or an identified independent counsellor. Although, at times, participants displayed distress all offers of counselling services were declined. The researcher contacted participants two to three days after the interview to inquire about their welfare.

With reference to possible coercion, potential participants were never placed under any obligation to participate in this study and at no time were their care compromised because of their decisions. This was assured because the researcher was independent and not directly involved in patient care. One prospective participant was introduced to the study through a snowball recruiting technique and requested information about the study. There was
no reply to a subsequent electronic communications therefore the person was not pursued further and the invitation to participate was assumed to be declined.

General implications concerning ethical issues surrounding confidentiality and anonymity have been addressed in this section. The strategy for obtaining informed consent and issues concerned with participation in the study was also explained. Adaptation to communication abilities of the participants have been identified and ethical concerns addressed.

3.5 In Summary

A grounded theory methodology, which allows insightful development of theory based on participant information about their real worlds, was explained and shown to be useful for the current study. The aim is to explore the social reality of the individual diagnosed and living with MND and how they negotiate with others and service providers for the care they desire.

In this chapter, the research process used in the study was outlined and discussed. The groundwork undertaken by the researcher before commencement of the study included personal and equipment preparation. Participant sampling and recruitment methods were identified as well as data collection and analysis methods to ensure the research was rigorous. Ethical implications of the project and the effective management of these were discussed.

In the next three chapters, the study findings are reported. There are three constructs that together explain the phenomenon of illness experience of MND and the life-world of people living with the disease. In chapter 4, the first construct is a model representing the diagnosis process. This is “The Diagnosis Story”. The second construct is a decision making model that reflects the processes that participants went through as they lived with MND. This model is named “ongoing change and adaptation”. It is identified
and discussed in chapter 5, with the passive and active strategies used by participants to adapt to the ongoing changes in their lives. A premise of grounded theory studies is to identify a core theme that underpins the study findings and a basic social process that explains the phenomenon being explored. This third construct is introduced and explained in chapter 6.
CHAPTER FOUR

WHAT HAPPENED BEFORE: THE DIAGNOSIS STORY

4.1 Introduction

In chapter three, it was argued that a grounded theory approach was the appropriate method for exploring how people diagnosed with MND negotiated their lives. The intent of the study was to understand the phenomenon of “living with MND” by exploring participants’ experiences following diagnosis of the disease. Notably, despite this focus, most participants automatically began with the events that led up to the actual diagnosis. It was necessary for them to relate their experiences of uncertainty and frustration at this time. Some gave long accounts of the processes they went through to finally get an answer for the perplexing behaviour of their bodies. The reflections that were shared covered such aspects as recognising the first symptom, seeking help, being on a diagnostic roundabout, confirming diagnosis, re-evaluating life and the future, and finally living with MND. These themes formed the six phases of “The diagnosis story” which are explained in this chapter, the first of three findings chapters. Various antecedents contextualised each experience of the process of the “story”. Even though going through the diagnosis “story” was a once off process, the consequences of the process influenced future negotiations for choices about living with the disease. The consequences are introduced using participants’ words to illustrate how each antecedent influenced the experience of being diagnosed with MND.

4.2 The Diagnosis Story

The diagnosis story began when participants became aware that something was wrong with their physical selves, usually something minor but persistent. At this stage most participants actively sought answers to
their niggling problems, undergoing many diagnostic tests and visiting different specialists. The tests usually indicated that nothing was wrong but, as noticed by Gary, most felt that “there was something”. At no time did the medical practitioners consulted suggest to any of the participants that there was a possibility of MND. Therefore, finally being told the diagnosis and prognosis was devastating news. The diagnosis story is depicted in Figure 4.1 (see page 96).

Essentially the story that revealed itself was the process that participants went through from the time they had trivial symptoms to the time of diagnosis and the subsequent assimilation of the disease into their daily lives. During this period they went from recognising physical problems to seeking medical help from their local doctor, followed by a cycle of: diagnostic events, invasive and non-invasive treatments and finally a more than probable diagnosis of MND. This cycle varied from 2 months to 10 years for participants although the average diagnosis period reported in the literature is 18 months (Leigh et al., 2003). Further Chancellor (1996), a specialist in neurodegenerative diseases, highlighted that it is not easy to diagnose MND, a process that can take months or years, as reflected in the experiences of most participants.

Following an almost certain confirmation of diagnosis, participants began reflecting on, seeking clues and developing theories as to, why they had this disease. It was a time of coming to terms with the significance of having motor neurone disease. Sometimes participants requested a second opinion because they did not fully believe what they were told by their local doctor or the diagnosing physician and they hoped the diagnosis was wrong. Coping with the disease diagnosis stimulated both active and passive coping mechanisms in attuning to an altered future. These mechanisms were interconnected and cyclic, moving to a period where participants reluctantly or philosophically integrated MND into their lives. In the following sections, each phase of the story is explained and illustrated with excerpts of participant transcripts.
"The Diagnosis Story"

**Antecedents**
- Health beliefs
- Other illnesses
- Locus of control
- Gender
- Relationship
- Age
- Urban/rural settings

**Influences**
- Time before diagnosis
- Phase of illness course at referral
- Reactions and meanings attached to misdiagnoses
- Quality of interactions with health professionals
- Supports
- Partner/spouse
- Family
- Friends
- Employer

**Phase I**
Recognising a problem

**Phase II**
Seeking medical help

**Phase III**
Being on the diagnostic roundabout

**Phase IV**
Confirming MND

**Phase V**
Re-evaluating life and the future

**Phase VI**
Living with MND

**Self-awareness**

**Other medical concern**

**Other noticed**

**Meaning of referral**

**Time:**
- Unknown
- 2 months to 10 years

**Coping**
- Attitudes, goals, strategies
- Active (seeking information, fighting)
- Passive (taking life as it comes)

**Supports**
- Partner/spouse
- Family
- Friends
- Employer

**Meaning of referral**

**New meaning of referral**

**Figure 4.1. Model of the Diagnosis Story.**

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4.3 Phase I: Recognising a Problem

The recognition of a problem began the sequence of events that was the diagnosis story. This phase began at the first acknowledgement of the existence of niggling physical changes that did not resolve. Often these changes were ignored by participants because either they saw them as inconsequential or it was not usual for them to seek health services for minor ailments. Three typical prompts caused participants to seek help; self-awareness of symptoms, other people noticing the symptoms and mentioning physical changes when consulting the doctor for another medical problem.

Self-awareness

When persistent physical changes impacted on participants’ day-to-day routines, they sought a medical consultation with their local general practitioner (GP). Participants reported varying symptoms.

Euan:  I was falling over my feet.

Kevin:  I had trouble with my toe – my big toe – was turning under… and I started to walk as if I was drunk.

Lionel:  My left index finger was the first sign.

Patricia:  I used to play golf. I used to wonder why I couldn’t hit as far … I used to come home and say, “Oh, I haven’t got enough strength to hit the golf ball” … my legs would feel pretty tired. I went on for a while like that and then … I found that it was difficult for me to do buttons up, peg out the washing … I put up with that for a few weeks and then I went to my doctor.

In the main, this self-awareness prompted participants to seek medical help from the doctor because the problems interfered with their day-to-day living. However, this step was often delayed as initially most denied the problems and associated them with the aging process, which was consistent with what was to be expected as one got older.
Others noticed

For some participants, the subtle changes were first thought to be significant when other people observed and commented upon them. These comments from friends and family members stimulated self-awareness of hitherto ignored physical changes and, as a result, participants were prompted to seek help. As Colin recalled:

*He first noticed his left nostril was blocked after exercise then the muscles on left side of his face became affected…. Friends became aware and alarmed about his increasing debility and conveyed alarm to his wife when he couldn’t read the lesson at church very well – he was slurring. A friend strongly recommended he see a neurologist.* [fieldnotes]

Often participants were aware of inconveniences but ignored them until someone else noticed or commented. For example, Denis’s wife commented:

*[I noticed] his walking, his speech, his lack of dexterity with his hands.*

Other medical concerns

Some participants visited their GP for other concerns. Mark sought help from his doctor initially because of another condition, his cold hands. He reported that he was unaware of his deteriorating physical condition:

*Well, it happened in 1988 with my cold hands. I went to the doctors and they could see that I was wasting on my top half of my body.*

Similarly, Vince visited his doctor for something else:

*I was at the local GP here in town for something totally different and I just mentioned it [a slight problem].*

Sometimes there was no prompt to seek medical assistance with niggling problems. It was only when participants visited their GP for other concerns, that the health professional would associate the physical changes with symptoms of possible neurological problems.

Recognising that there was a problem was the first conceptual phase of the diagnosis story. Recognising and noticing a physical change that
interfered with their day-to-day living was the prompt for participants to seek medical advice. The next phase in the diagnosis story was the process of seeking medical help.

4.4 Phase II: Seeking Medical Help

The time taken from first symptom to seeking medical help was not clear because niggling problems were often ignored for some time. Some reflected that they had experienced symptoms a long time prior to actual diagnosis. As an example Wendy noted:

I reckon I had it a good 12 months before. I had the flopping left foot …. I had that for a good while. I’d go to the doctor, he’d … try my reflexes … they would be all right.

Once participants became aware of physical problems, they realised that other minor complaints had been evident for some time but had not been noticed. Overall there was a sense that the symptoms “creep-up” which echoes the insidious nature of the symptomatology (Bury, 1982), a common feature of chronic illnesses.

Of those participants who did seek medical help at the onset of symptoms, several were critical of their experience, believing that medical practitioners did not listen to them and merely sent them for diagnostic tests with no results. For example Gary protested:

they weren’t listening … the doctors should listen ….

Wendy visited her doctor several times before he “listened” to her because she demonstrated to him that she could not get up off the floor. Prior to this he appeared to pass the symptoms off as “normal” and attributable to the aging process:

I split some water on the floor … I got down to wipe it up, couldn’t get up. I had to crawl to a chair to get up, so back I go to the doctor. “No the reflexes are all right”, so being me … I got down on the floor and showed him how I couldn’t get up. He nearly had a fit …. He said, “lift up your
Gary and Wendy persevered to have their voices heard despite believing their doctors did not “listen” to them. The quality of these interactions, however, influenced their future decision-making concerning their treatment. Following the “seeking medical help” phase, the “diagnostic roundabout” began.

4.5 Phase III: Being on the Diagnostic Roundabout

Investigating why a person had continuous and compounding physical problems became a roundabout of diagnostic events. This involved specialist referrals, tests, diagnoses or tentative diagnoses, invasive and non-invasive treatments followed by another referral, and more tests because problems did not resolve. Denis’s wife recounted her husband’s misdiagnosis, treatment and disease progression:

*We went to a neurologist who sent us on to a neurosurgeon [who]*

*discovered … a compression of the spinal cord, so he performed an* 

*operation … he said [that the operation] would arrest the problem…. It did* 

*… but it was not to be the cause of what we were worried about. That was* 

*over 9 years ago*

To a large extent, physical problems increased in severity and number, which created urgency for getting a diagnosis and treatment. Participants reported many misdiagnoses in this cycle, culminating in diagnosis uncertainty and anxiety. Finally, there was a diagnosis of “probable MND” based on tests that were normal. Jack wrote of his experiences over 17 months. His story exemplified the drawn out course of events experienced by many participants:

*In April 2000 I got a cold and afterwards I had a croaky voice …. In* 

*November it hadn’t got better. In fact, it had got worse so I went to my* 

*GP… [he] sent me to an ear, nose and throat specialist …. The specialist* 

*put a[n] optical fibre in my nose and down my throat, and told me I hadn’t*
got cancer, nodules or polyps, and it would get better by itself. It didn’t. So in January 2001, I went back to my GP… he sent me to a voice pathologist … who gave me exercises to do … and that didn’t work either. So I went back to my GP, and this time he sent me to another ear, nose and throat specialist. The new specialist … said I did have nodules and they could be removed surgically. But first he sent me to hospital.

A specialist put a camera down my throat and told me to “hum” … that showed I didn’t have nodules, but the flaps in my voice box weren’t closing properly.

I was sent back to my specialist who wandered around his surgery, obviously flummoxed, and eventually said, “Perhaps it’s neurological.” He sent me to see Prof at the hospital.

[He] put me through a series of tests which took several months: an MRI scan, blood tests, swallowing, breathing and strength; and then in late August 2001 he told me I had the bulbar version of motor neurone disease.

Finding out what was wrong was a step-by-step process of treating one diagnosis then another. The process of elimination was frustrating and in the main, time consuming. The time interval from seeking help from the GP to a probable diagnosis was variable with no particular pattern in the sequence of diagnostic events.

It was common for participants to seek a second opinion “just in case it isn’t MND”. Various treatments were tried such as gammaglobulin infusions and chemotherapy, “just in case” they made a difference but there was no change, the muscles kept deteriorating and the diagnosis was 99% confirmed. It is important to note that even with advanced technological equipment and tests, confirmation of MND diagnosis is only possible from an autopsy (Swash, 1998). Participants were made aware of this fact and accepted the 99% probability as confirmed. Brendan’s wife recalled:

[The doctors] admitted [Brendan] and they did the nerve conduction test … the spinal tap…. They did lots of tests. They just kept watching him, monitoring him and then they came to the conclusion in September…. So it
was a couple of weeks after that they sat down and said, “Look it’s MND. We’re 99% sure.”

This cycle of tests, possible diagnoses, treatments and tests again varied among participants, from 2 months to 10 years which were the limits experienced in this study. Andrew’s experience provided a typical example of the difficulties associated with diagnosis process:

It would be 5 or 6 years ago. First of all I got numbness in the hands, pins and needles, and I was sent to a neurologist. They thought it might have been the carpal tunnel, which it wasn’t…. That went for 4 years … then all of a sudden I started feeling different things altogether; it wasn’t just the needles, I was having trouble with mobility in my arms and hands. But the neurologist wasn’t sure … Then all of a sudden something I told him… he said, “We’ll have to have a further look at you” and he did a whole lot of tests. I had to go down to Melbourne hospitals and ended up with a scan to make sure there wasn’t something wrong with my spine or brain rather than the neurone business. That was about 11 months ago. He sent me to another specialist for confirmation, and that’s when they decided.

Sometimes, when the first referral was to a neurologist who had knowledge of MND and could recognise its symptoms, the diagnosing phase became a process of confirming the disease. Vince recalled:

I was told … “It looks like you’ve got motor neurone disease.”… The next six months … [I] was looking to see if it was treatable and trying some treatment … [but] everything looked rather bleak because the treatment that costs thousands of dollars had no effect. Finally they said, “Well, if it’s your sensation of feeling, if that’s got some problem it might still be treatable.” So I had a sural nerve removed and it was said that “everything was all right in that department.” So that was kind of bad news because that summed it up as untreatable.

Participants spoke of the strength and fortitude required to undertake the tests, because at times these were invasive and painful. Heather and Ian recalled the unexpected pain they endured with the nerve conduction tests, whereas Vince rationalised the pain in understanding the test’s purpose:
Heather: So you just front up to the hospital to have your nerve conduction test and you don’t know what’s going to happen to you and you just put up with it until the end. And I kept thinking, “well it’s not as bad as having a baby.”

Ian: I didn’t know what it was…. I lied down on the bed…. [the operator] said, “we will put these little probes in – you will feel a tingling sensation.” … It gives you a jolt … I was in a cold sweat. It was bad. Oh, it was terrible. … Then they use … like acupuncture needles … sending an electric current through…. And this [pain] is ten times worse than [a splinter under your finger nail].

Vince: Yes it is painful. … some sort of electric shock treatment. But I’d imagine if it was in other parts of your body it would be even worse…. I didn’t mind at the time because it was for a good reason and it’s not like torture … because it was the test, it didn’t worry me too much, but it wasn’t very pleasant.

For some, the experience of being on a diagnostic roundabout generated negative feelings that affected the way they accessed health assistance in the future. The consequences of the many tests, misdiagnoses and various other treatments resulted in some refusing to trust medical practitioners and as a result they did not use health care services even when they were required. While the roundabout of referrals resulted in frustration for the participants, there was some degree of relief with the final acknowledgment that “something was the matter” as declared by Ben.

The diagnostic roundabout ceased when participants were given a provisional diagnosis of MND. What followed was a period in which participants looked for other answers and ended with a probable confirmation of the disease.

4.6 Phase IV: Confirming MND Diagnosis

The confirmation of MND was an emotional time for participants and their families. Some had not suspected that such a diagnosis or prognosis was possible. Others had some inkling but remained hopeful that they were wrong. The concepts that evolved from the data with regard to confirmation
of diagnosis related to the manner in which the diagnosis was given, the initial reaction and secondary response to the news, and the quality of the information given at diagnosis.

### 4.6.1 Delivery of the diagnosis

Besides the shock of the diagnosis and prognosis of MND, the manner in which this news was communicated impacted on participants’ recollection of this phase of the diagnosis story. This impact was evidenced in the passionate and emotional way most participants retold their stories.

In general, it was a neurologist who informed participants about the diagnosis and prognosis of MND. Some reported this process as blunt, uncompassionate and needing to be improved.

Heather: *the second opinion guy … was actually the one that gave me the worst prognosis…. He was so depressing, so negative, and so awful.*

Patricia: *[The neurologist] was very, very frank with us. He … told me that I had MND and he said that “it’s worse than cancer because there’s no treatment for it.” … When we drove back home, I was so upset and so was my husband....*

Vince: *I thought perhaps [how I was told the diagnosis] was a little blunt and brutal … I realise that’s probably what they are advised to tell the truth straight off and not hedge around it, but I could have done with a bit of hedging around. Just to be told that you’ve got something that is life threatening is very hard to hear from anyone. … I’d almost say the doctor or neurologist or whatever should be told to just make three or four appointments over a month and just ease into it…. I know that’s not really the right way but gee it would have been a lot better. It took me ages to get over the bad news…*

In contrast, the experience of other participants was that the neurologist was compassionate and concerned. Although the disease was devastating for these participants, they believed their doctor was empathetic and thoughtful.
Una: [My neurologist] said, “it’s real nasty, it’s not very pleasant”. I said to him …, “Well it can’t be easy for you to have to tell people something like that,” and he just looked at me over his glasses and he said, “Yes but it’s not easy living with it either.” He’s a very, very nice doctor, very compassionate. I will go to him for as long as I’m able to travel and see him.

Colin: I think that he empathised. He knew how I felt. He knew I needed time to absorb his news.

Wendy: I had the bit of muscle taken. Then he had to go back and he said that I had Motor Neurone Disease. I said, “Well what’s that,… and what can you do for it?” “Well we can do nothing for it.” I said, “Well that’s clever … you can put a man on the moon but you can do nothing for a disease.” … So that’s all there was really.… He had books and things here and I said, “No…. I want to think about it for a bit.” Anyway I was back the next week.

According to whether their experience had been positive or negative, participants tended either to distance themselves from these health professionals, or trust them even though they had been shocked at the time, and this impacted on their subsequent relationships with the medical profession.

4.6.2 Initial reactions

Some of the emotion that surrounded the diagnosis of MND was generated from the “shock” at the prognosis because the possibility of MND had previously never been discussed. As a result participants reported a variety of emotions. As Jack recalled:

I was shocked…. I had never heard of motor neurone disease…. [The neurologist] told me about it and told me it would kill me eventually.

Colin recalled that he had read a book by Stephen Hawking who was diagnosed with MND, several years before and had thought the disease was interesting. However the disease came as a

kick in the stomach … I was too numb to relate to [the doctor].
Colin also revealed a greater emotional response came just after the diagnosis when he grasped what having MND actually meant. Up until this time he had been supporting his wife and family to come to terms with the disease and prognosis, and had not given himself time to acknowledge the reality of the significance of the disease. He provided the following analogy to explain his feelings:

*Just after the diagnosis was made, I was overwhelmed by a sense of the inevitability of the disease. I saw my mind, as if a rat in a tumble wheel, running, running, running, the wheel ever spinning, my mind unable to escape the prison of my body.*

Diane initially received a diagnosis of multiple sclerosis (MS) but was then told she had MND as well. She found that this was “more devastating than the initial diagnosis”. Her vocalisations were interpreted by her husband:

*We* did some research … on the computer…. *The MS wasn’t going to kill Diane, it was something you could live with to old age but then with [the] diagnosis [being] MND … the prognosis was not exactly long term … and that’s the thing that’s hard to accept, isn’t it?

Euan’s wife explained that even though they knew Euan may have MND and had a philosophy of getting on with living, both were still stunned when given the diagnosis. As Euan exclaimed:

*I had real shock…. But then I thought … there was no point of being angry or any other negative emotions and it’s not the final thing [in life].*

Neville’s wife reported that for her husband, his initial reactions were like a “roller coaster”:

*I think that … reaction … was more at the beginning when he had to come to terms with what had happened, and then it was a roller coaster, it was appalling.*

Some participants thought they were in a bad dream and would wake up okay. Patricia was one person who had such a response:
I was diagnosed in early March … that was a terrible, terrible blow to me…. It was funny, I just felt as if I was having a nightmare…. I was hoping it was a bad dream and I would wake up and think, “Oh, thank goodness that was only a dream.”… I still haven’t really accepted that I have got [MND].

Kevin was sad for what he would not see in the future:

In a way [I was sad], yes …. I wanted to see my grandkids grow up

In contrast, Andrew was not surprised because of his age:

Well it didn’t surprise me. I’m not as worried about it. I’m 84. I’ve had 59 years of good marriage. … The wife is still talking to me after all this time and we’re great mates still. So I’ve had a good life. If I’d been 50 I’d be horribly upset.

Initial reactions to the diagnosis of MND were varied. Emotional sensations that participants experienced included “shock”, “devastation”, feeling “numb” and being on “a roller coaster”. Later responses were moderated as participants drew on their usual ways of responding to problems experienced in life.

4.6.3 Secondary responses

Some participants viewed the prognosis and advice as a challenge to change the course of the illness. Heather decided not to accept her prognosis of eight months:

We were told there is nothing you can do except three things. I should take a nice holiday, I should spend quality time with my family, and I should see a psychologist to cope with the aspect of dying. They were the three options I was given and we immediately said, “There must be more you can do.”

Commonly, the first diagnosis was not accepted; for example, Ian kept looking for alternative diagnoses, visiting three specialists:

The first specialist said it was the same thing [MND]. The third one didn’t make a difference because we knew [that] … two people couldn’t have made wrong [diagnosis] and looking at the Internet and all the things that … the
Vince also searched for other reasons for his condition, trying alternative treatments that excluded other diagnoses:

“Well there was an IV of some sort of haemoglobin which was I think $3000 for one go at it and I had three of those. When I was asked, “well how do you feel now?” as if to say, “everything must be all right”. I said, “Exactly the same!” So that was obviously the end of that because that didn’t do anything. Then I guess I did get a second and then a third opinion from a neurologist, but the first one I went to in [my local area] was exactly correct. It wasn’t that we didn’t believe them I just didn’t want to accept the fact.

In contrast for some, being told the diagnosis was a relief that finally there was a name for what was wrong. Having a label opened up services that hitherto had been denied. For example, as Ben explained after 3 years of being on the diagnostic roundabout:

“It was inevitable. I knew … by that stage I had something – that was not physical and neurologic[sic] … whatever I had it just couldn’t be diagnosed but … I had seen neurologists and they couldn’t diagnose me but they said that I had progressive spasticity, so they didn’t tell [me] anything I didn’t know. What I thought, it just put a name on something that I knew I had and opened up the services for me from the Motor Neurone Society and [hospital].

4.6.4 Information given at time of diagnosis

It is clear from the discussion thus far in Phase IV that the diagnosis of MND had a profound effect on participants. One factor that appeared to compound this effect was that participants were given little information about the disease or what course of action to take. Patricia protested:

“So, anyhow, there’s nothing. The doctors don’t advise you to do anything. They didn’t even tell me about the association.
Commonly participants complained about the lack of guidance in how to live with MND or what to do next. The guidance offered was related to advice concerning activities to prepare for the end of their life.

Vince: [the diagnosis time] would have been the opportunity [for] the neurologist [to] say, “You’ve got this, now here’s an association that will now help you.” That would have been better than … “go and do something that you’ve always wanted to do” – that was his suggestion.

Carole’s husband: We were sitting in the neurologist’s office … [H]e said, “You know what’s wrong with you?” and we said, “No.” … He said, “You’ve got MND. Do you know what that is? No. Well if you want to do anything in the next 12 months, do it now … then it’s going to be too late. You’re going to go probably in a wheelchair and then you won’t be able to get around and then you’re going to die. You’ve got two years. Good-bye…. there’s nothing I can do for you.”

The participants reacted in various ways to the diagnosis and the lack of information but most searched for ways of living with the disease and maintained a hope for a future life. They were, as noted above, unhappy with the pessimistic attitude of the health professionals they dealt with and so decided to “do their own thing”. This meant different things to different people. For example Rose tried alternative therapies such as the healing rituals in Brazil, while Neville and Lionel explored naturopathic and homeopathic remedies. Overall participants gained the impression that some neurologists were reluctant to inform them about MND, neglecting to direct them to sources of information about the disease and illness.

In summary, being diagnosed with MND was a traumatic, life-changing event for participants, their families and significant others. The delivery of the diagnosis, the various effects and reactions to the news of the disease, and a lack of information became the context in which participants began to come to terms with the diagnosis of MND and what it meant for the future. Confirming the diagnosis phase was a sequence of events to ensure the correct diagnosis had been given. In general, the participants’ perception
of the process of being told the diagnosis coloured their future interactions with health professionals. Those participants with a more negative perception did not readily consult with other health professionals, did not seek available medical assistance when required or investigate alternative advice, whereas those whose experience was more positive accessed resources readily.

Often the diagnostic roundabout was extended over many years and the eventual “bad news” was almost welcomed as it provided an answer for the vague symptoms. Others perceived the long diagnostic processes as a reflection on the competence of health professionals who “would not listen”. The next phase of “the diagnosis story” relates to the re-evaluation of life and life plans.

4.7 Phase V: Re-evaluating Life and the Future

After the initial shock of a diagnosis of MND, participants moved into a phase that involved evaluating and reflecting upon their past in a search for why they had this disease. This phase, which was sometimes revisited, required participants to reframe life goals to somehow come to terms with having a debilitating, terminal illness and living with it as opposed to dying from it. Some drew on past coping mechanisms to guide their initial living with the disease, some developed new strategies and others simply chose to deny the diagnosis.

4.7.1 Reframing the future

Participants absorbed the realisation of the consequences of MND in different ways, reframing their perspectives on life and the future. Some accepted their altered future and got on with life while others thought of their families, their unachievable plans and the effect of a death sentence on their current lifestyle. Euan’s wife recalled:

_We just … sat in the car stunned for a while, didn’t we? … Then we just thought, “well let’s get on with life” and so we headed off._
Colin thought of his family and their plans that had gone awry. He wrote:

\[\text{My brain was whirling round thinking of [my wife] and kids as well as lots of things we hoped to do.}\]

Heather reflected on her changed future expectations of life and refocussed her energies on living differently:

\[\text{Suddenly your whole world has been turned upside down. I always thought that I would live a long life, all my relatives, my oldies lived to … their 80s and 90s. And suddenly driving home that day was like this weird … outlook on your life and the world and everything. It was really different…. It had a profound change. I became more focussed on taking vitamins … and checking out my body and … doing all those other things [health promoting activities].}\]

Una altered her travel plans so that she stayed in Australia rather than travel overseas. Rose reconsidered her treatments and included alternative therapies. In addition, she maintained a therapeutic massage business at home to ensure she had money to live well with the illness. Edward asked his lady-friend to move in to his home as his carer and they both holidayed in a warmer climate in Australia each winter until the time he was unable to travel. Wendy, who was in her 70s, did not reframe her life. She considered that getting MND was part of God’s plan for her so just lived her life day-to-day as before, making the adjustments her physical decline warranted.

For some participants, reframing the future was a necessary process to acknowledge before they could move on with living; for others, MND was just another aspect of life that needed to be incorporated into living. Accordingly, this phase of re-evaluating the future was experienced on a continuum. At one end MND was incorporated as a part of life, at the other end MND meant a complete alteration to life plans.

4.7.2 Looking for answers – theorising

Some of the reasons put forward as causes of the disease included too much stress, not “enough holidays”, too much work, an imbalanced body
chemistry, a genetic or familial link, environmental toxins, post-disease
effects, payback for doing something wrong in life and a missing hormone.

Counsellors and doctors involved in Colin’s care suggested that his
symptoms were related to the stress of his retrenchment. Similarly Ben
hypothesised:

I didn’t take enough holidays. I’m convinced the stress ... is somehow to do
with my condition. Too much work and not enough play ... stress and
tension … must have something to do with the onset of this condition.

From a different perspective, Heather used the metaphor of “a jigsaw
puzzle” as a way to conceptualise her understanding of what was wrong
with her body chemistry and as a way to change her prognosis:

I think MND might be a situation where there are aspects that all join
together – it’s like a jigsaw puzzle. And it’s [the] pieces of the puzzle and
some of my pieces were getting imbalanced. Whether it was my immune
system or my ‘whatever inside me’ and the tests prove that ... there’s
obviously other factors … environmental, it might be genetic or whatever. I
believe then, over a period of time, bang! – my picture – all the pieces came
together and my picture was MND.

Thomas suggested that exposure to environmental toxins such as lead,
mercury and radiation may have been to blame. He reviewed his life history
looking for answers, documenting his suspicions, searching for clues and
writing down ideas for others to follow. He wrote:

In … region[X], at the time of my diagnosis, there were five cases of MND,
suggesting a cluster group. (Could there have been something in the
swimming pool, where I took my weekly swim?) … Familial connections –
My Father had a mild case of Polio, when an infant. … [my] Father’s
daughter, my Stepsister, contracted severe Multiple Sclerosis in her 20s. …
Suspicions – Hair and Blood analysis indicates high levels of Mercury and
Lead. Suspect: … many amalgams removed without precautions. …
Hepatitis B Inoculations 6 months before MND symptoms, produced
severe muscle cramping …. Giardia infection (not confirmed) probably
about 12 years ago, which was most debilitating … I experienced lethargy
for many years…. I wonder if some agent (environmental chemical?) may trigger the retention of too much of particularly minerals, such body chemistry imbalance culminating in damage to the anterior horn cells. …
One month prior to MND symptoms, I received many Mosquito bites whilst fishing on the Murray River… suspected by my GP to be Ross River Fever, however this was not confirmed as symptoms apart from Lethargy did not continue. I lived in Scotland when the Radioactive Cloud came over Britain from the Chernobyl Disaster. Contracted Herpes in late 1970s, but I have not had a sign of the infection in the last 4 years.

Vince reflected that he felt guilty for having MND. He wondered whether the disease occurred as retribution for some past disrespectful action to another person.

The trouble is … when you look for a reason, why has this happened to me and I think, “Gees did I ever ‘chuck off’ [sneer] about someone in a wheelchair and now I’ve got to be in one?” “Did I think someone didn’t speak very clearly and now my speech is changing?” – that sort of thing. You have to have an answer but there isn’t one, I know. You think it must be my fault, that’s silly isn’t it to think that? But out of all those millions of people, why me? Because it’s quite a rare disease, not that many people have it really. I just can’t figure out why I was chosen. I just can’t. I try to think of something that I’ve done wrong I suppose. But there is nothing.

Another theory postulated involved a perceived link between the way children developed and the way the disease caused deterioration of their bodies. Colin and Lionel identified a point in their disease progression where they and their grandchildren were at the same stage, albeit developing in opposite directions. Lionel hypothesised:

I try and analyse why they are going one way and we are going the other… and it makes you think. “OK, now if I’m going back to being a kid, then maybe there’s something in the chemistry of the body”…. that they’ve got and we’ve somehow lost…. So my theory is [that] … as you develop, the body produces hormones to make you progress… maybe we’re missing that hormone – it’s been withdrawn … that’s my theory.
The theories varied from scientific possibilities to personal ideas that seemed plausible to the participant. Accordingly, some participants were distressed and confused about why they had developed the disease while others blamed their previous lifestyles.

4.7.3 Coping with the diagnosis

During the re-evaluation phase, participants used different coping mechanisms that helped them come to some understanding about the disease. Coping was influenced by attitudes about life, goals for living and strategies that preserved the person’s sense of self. Sometimes participants actively engaged in activities to help themselves such as researching the disease via the Internet, reading books and accessing MND associations. In contrast, others took on a passive role having the attitude to “take life as it comes”, leaving active approaches to others but vicariously garnering the benefit. Hence coping mechanisms could be delineated as active and passive. At times, participants moved between the two, depending on the situation.

Attitude to life

Attitude to life was an important personal feature in coping with the diagnosis. Often participants were able to identify their usual way of coping with problems and used these skills in this life changing event. Mark’s attitude included a sense of humour and an attitude of being positive about life.

* I think people like me for my sense of humour … the way I look at things …
* I’m very grateful that I am like that because that’s how we cope.

Heather’s attitude was to always weigh up the possibilities before deciding and taking action, whereas Vince and Neville chose to rise above it:

Heather:  It’s my nature to “weigh things up”…. I think that ability came very much to the fore already on day one…. at least I’ve had 49 wonderful years.

Vince:    Well I suppose being a very fit and healthy person and someone who relies on their strength, and to have it pointed out that you’re weak and there’s something gone wrong with your strength, I guess that flattened me. Yeah,
that particular side of it. And I just rose above it with the attitude that I’d either stop it getting worse or you know – not that they were wrong, but that it just wouldn’t happen to me and I got by on that.

Neville: I don’t worry now; get on with what I’ve got to do.

**Seeking knowledge**

One important active coping mechanism was to gather as much information as possible about the disease and possible ways of delaying the course of the illness in order to gain some sense of control. Researching information promoted participants’ self-esteem and gave them hope for the future because it provided a sense of fighting the disease progression and not giving in.

Heather was initially stunned by her prognosis that suggested she had only eight months of life remaining; however, she and her husband were motivated to look for other answers. As a consequence of this activity, she felt she had some control and never succumbed to a sense of hopelessness.

*Via the Internet … we immediately asked the question: “well what was happening, elsewhere in the world?” And we found out that there were things happening in the rest of the world and people were in research groups. What we decided we would do was based on what 325 odd people were doing in Germany…. We immediately thought, “Well that’s hope. Let’s do … what they’re doing.” It was better than simply just going on holiday…. We searched and searched for information and it became like a job. We had files of information … so it wasn’t a feeling of hopelessness. It was taking control … in an intelligent way.*

Similarly, Patricia felt she needed to find out more about what to do but her need for information was not satisfied:

*I came home and I thought, “Well, I’ve just got to find out more about [MND] and do my own thing.”… My daughter … in Melbourne … found out about [MND and] the association [on the Internet]…. I found them very helpful to start with … because they sent me a lot of literature … little*
booklets and things … but it doesn’t really tell you what you can do. Just … more or less ‘do your own thing’.

Seeking information about MND was a common coping mechanism. Visiting the library and using the Internet were the main sources of knowledge about the disease and about possible treatments. Participants found little to help them in living with the disease. As a consequence, living with MND became “doing your own thing” and deciding on ways of living with the illness such as on a “day-to-day” basis.

Accepting the inevitable

In contrast to those who actually attempted to find a way of living with MND, some participants accepted the disease passively. This involved tolerating the outcomes of the disease and taking the consequences as they came. Passivity included not fighting MND but making the decision to live with it and adjust to the changes, to let the disease run its course. Wendy recalled:

Our daughter got on the … Internet…. She came out with all this heap of stuff…. It was there for a week and I looked at it. Then I said, “Now I’ve made up my mind, you can hide that … I don’t want to hear anything about it. I’ll go day-to-day, I’ll live today, I’ll live tomorrow and whatever comes I’ll take.” And that’s how I’ve been.

A common belief for participants who looked at living with the disease “as it came” was that one “is born to die”. Three of the participants discussed their attitude to this terminal illness as an acceptance of death.

Brendan and his wife I’m not afraid to die … he’s always had that motto … You get born to die.
One day at a time and be happy.

Gary: No one wants to die … but we are born to die…. I have faced death before.

Wendy: I think I might have had two howls over [having MND]…. I’ve great faith in God and my prayers…. I’ll leave it up to God – he can do the worrying.
These participants accepted their diagnosis as part of living. This meant they did not look for other diagnoses or treatments, leaving nature and God to decide the time to die.

Re-evaluating life was a phase in which participants came to terms with the diagnosis of MND and what this meant for them in the future. They theorised and looked for answers as to why they had a disease without a cause and cure. Perhaps the most important aspect of this phase was the realisation that what they were actually looking for was how to live with the disease and obtain information about the illness experience. Participants employed coping mechanisms that had previously helped them deal with catastrophic or life changing situations. Strategic actions included galvanising their attitude to life, seeking knowledge and accepting the inevitable. These actions paved the way to build self-esteem in the face of a lost future. In Selder’s (1989) transition theory, this type of life re-evaluation after a major life transition such as being diagnosed with a terminal illness like MND, was termed “reframing future”. This revealed the processes participants experienced as they endeavoured to adjust to life with an illness or disability, as a phase of restructuring and finding meaning in a new life pathway. In the current study, after initially coming to terms with MND, living with it encompassed their lives.

4.8 Phase VI: Living with MND

The outcome of the re-evaluation phase was living with MND. This occurred after being diagnosed, overcoming initial reactions and questioning life. Participants encapsulated their feelings about MND in the following words:

Euan: [It’s] like being given a handicap that never goes away …. It was given to you … but it won’t beat me yet.

Andrew: [It’s] a bad bugger.

Wendy: Well I think it stinks.
Lionel:  [It’s a] pain in the arse.

Vince:  It absolutely destroys your life and your family. That’s it. It does.

Some eventually accepted the disease and lived with it, meeting challenges day by day. For others, the search for answers continued while learning to live with the consequences of the disease. Some maintained hope that the diagnosis was wrong while others hoped the disease would slow so they could complete life tasks or witness key milestones of their grandchildren. In contrast, Patricia continued to deny the disease and “fight it” even when the disease consequences seemed to be evident.

As far as accepting that it’s going to kill me…. I’m still fighting it. I’m still trying to fight it and live … as long as I can with quality.

Once the participants had reached the stage of discussing living with the disease, the “what happened before” story came to an end as depicted in Figure 4.1 (see page 96). Although the beginning of the experience of living with MND is the focus of this research, living with MND could not be explored until “The diagnosis story” was told because it was integral to the process. To complete the story, the following section discusses the influences that impacted on the processes of seeking assistance, being diagnosed and coming to terms with MND.

4.9  Antecedents to the “The Diagnosis Story”

While the phases of the diagnostic story were followed by all participants, there were differences in their experiences that seemed to be influenced by their previously defined individual understandings, identified as antecedents. Participants had a variety of life experiences and held beliefs about health and illness. Some had experienced other diseases and some perceived themselves as “healthy”. There were also demographic differences such as age and gender, residential location and marital status. All these antecedents impacted on the way they responded to early symptoms, sought help from medical practitioners and went about re-evaluating their lives.
Health beliefs

The process of seeking medical assistance was dependent upon each person’s individual attitude to illness and experience of other illnesses. Some individuals were reluctant to seek medical assistance because of their beliefs about health. If a person had always been healthy, going to a doctor was not customary behaviour and some believed illness was resolved by just letting it run its course. This group of people often delayed seeking medical advice until the physical changes affected their day-to-day functioning. This action possibly hindered early diagnosis and compromised access to potential treatments to slow progression.

However for some participants diagnosis was relatively quick. This occurred in part because the medical practitioner had knowledge about neurodegenerative disorders and recognised the symptoms. As well, the doctor seemed to be more willing to take notice of what was said if the person sought medical advice only as a last resort. As a result, diagnostic testing and referral was often instigated immediately. Vince viewed being sick as a weakness and believed one should just work through illnesses and not seek medical advice:

*It was really only a matter of a couple of months that I felt a slight problem…. So we had a closer look and he [the doctor] had experience with motor neurone disease and … sent me to the neurologist, like the next day.*

The second outcome, a delay in seeking help, meant the physical symptoms were more pronounced. Thus the illness was already well advanced before medical assistance was sought. As an example, by the time Colin sought medical assistance, he appeared to others to be drunk. He slurred his words, had difficulty with swallowing and writing indicating that he already had significant upper motor neurone involvement. He recalled:

*[I] was slurring. Doctor and psychologist thought it was stress…. Several people were certain I had a stroke. [They] talked to [my wife]…. But probably most significantly … a friend, [a] cardiologist, in [the] congregation … said I should ask for referral to [a] neurologist.*
While having an early diagnosis may be seen as advantageous for specialists, this sometimes impeded timely service provision. For example, Mark was diagnosed early in the disease progression and registered for assistance for future needs; however, when the time came to access these services, the administrators had taken his name off the list.

All those years ago [we applied for funding]. This is a long time ago. Then when nothing happened over a few years … they thought I’d died so they kicked me off the list. So we had to reapply.

Reapplying meant that Mark was put at the bottom of the waiting list again. He believed that this event was why he and his wife could not “even get to first base” with the authorities to receive appropriate funding for his needs.

Other illnesses

Another possible explanation for late diagnosis concerned existing health conditions that can mask other illness symptoms. For some participants, the time period for doctors eventually to recognise neurological problems was longer than if there had been no existing illnesses.

In cases where an individual had other illnesses that required regular medical check-ups, such as cardiac conditions, chronic depression, or check-ups consistent with normal ageing concerns, then seeking medical assistance was part of the usual way of life. Brendan’s experience provided an example of existing illnesses confusing timely diagnosis, as his wife recalled:

We noticed slurry speech was the first symptom. We presumed there was stuff prior but we didn’t think anything [of it]. You get aches, pains and stuff like that, but it was the slurry speech. Brendan has high blood pressure anyway, so we thought, “Oh dear.” I said, “I think you might have had a little stroke” because all the symptoms were there, because the blood pressure was really high, he wasn’t feeling very well at the time, yeah and then things just started.

Sometimes the family did not recognise the significance of the deterioration because of the existing conditions. At times medical
practitioners did not immediately act on the information provided by their patients because the symptoms were seen as just a part of the person’s usual presentation. It was not until the physical changes were problematic that the doctor or specialist initiated further investigations. This process occurred over several consultations, as in Una’s case:

*I was on medication for the depression. Often the medication would have the side effect that it lowered my blood pressure, if I got up too quickly but I’d stagger and I’d get a warning and I’d be able to grab against the wall or grab against somebody…. But with the falls with motor neurone, they just came out of the blue, I was on the floor before I realised it…. Since the falls I decided I should use a stick, but because of the back problem I had, I’d had some nerve endings burned in my lower back last year and the back surgeon thought the back muscles just may have been weak, so he sent me to a physio. I really didn’t get any benefit, [I] couldn’t understand; I just felt worse. He was trying to get me to do exercises that I couldn’t do. After a while he said he would review it and he checked everything I’d done. I felt quite ill after I came out from the physio, and my walking was deteriorating although I wasn’t using a stick at that time but I was finding it harder to walk further and further. I went back to the back surgeon and when he saw how I was walking he said, “Oh we can’t have this. We’ll have to investigate it.”… But in the meantime the psychiatrist who I was seeing had seen me like that when I was in hospital and made an appointment for me to see a neurologist because he felt there was something not quite right.

Sometimes other illnesses confused the symptomatology of MND because some symptoms and presentations appeared similar to other diseases and conditions. Diane’s symptoms were confused with multiple sclerosis; Andrew’s with carpel tunnel; Gary with gall bladder problems and Denis with a spinal condition, some resulting in surgical interventions that were not subsequently required.

Locus of control

Locus of control is defined as the underlying psychological predisposition of people to act for themselves, be responsible or blame others
for events in their life. With external locus of control, individuals look to others to be in control and make decisions for them passing responsibility to other people. Individuals with an internal locus of control look inward to find reasons for problems, take responsibility and effect control over their decisions (Allen, 1998; Krause & Stanwyck, 1998; Strauser, Ketz, & Keim, 2002). The decision to seek health assistance was related to where the participants’ locus of control was situated. While this phenomenon was not actually measured in this study, participants reported health behaviours that seemed attributable to either an internal or external locus of control.

Wendy did not fuss over her doctor not listening to her but persisted until he did take notice. She then acquiesced in the decisions he made. She appeared to have an external locus of control, relying on others to make her decisions. Despite the fact that her daughter researched the disease for her, she did not read the information until her husband had interpreted it. In contrast, participants such as Vince, Colin, Neville, Jack, Diane, Heather and Una sought to find solutions to the issues they faced by problem-solving each new stage. This group appeared to adopt a strong internal locus of control in that they did not look to blame others for their circumstances but looked for ways to achieve objectives.

**Gender issues and marital status**

Analysis revealed some gender differences in the way health care was sought and the way disease and illness was accommodated. Men such as Vince were reluctant to seek medical advice because they associated illness with weakness. In contrast, females such as Wendy and Una appeared comfortable in seeking health advice and did not express any concern about visiting their doctors.

In this study, as previously stated, the women appeared to be at ease with seeking health advice if they were unwell or if they experienced any physical changes. In contrast, it was usually the wives of male participants who encouraged them to go to the doctor, even arranging appointment times.
and researching possible diagnoses. Men mainly tended to put off going to the doctor because the inconvenient physical problems were minor and they believed these would resolve themselves.

Age

A further factor that influenced the timing of medical assistance was the participants’ age. The older people in the sample were more likely to have co-morbidities. The participants’ ages tended to influence their attitude to MND and dying. Andrew, who at age 84 years, had many other illnesses including emphysema, a cardiac condition, arthritis and glaucoma, reported:

_Something will take me out before then at 84, that’s what I say to the doctor. I’m on heart pills, I’ve had two heart attacks – only light; man could have a stroke. Hopefully anything at all that takes you out quick._

Zara, aged 86 years, believed her family history of longevity meant that she would not die too soon even from MND. For this group, acceptance of death was seen as part of the process of living. This perspective is relevant for understanding perceptions about living with MND because the greater percentage of people diagnosed with the disease is in the older age group: the average age of onset is between 50 to 70 years (MNDAV State Council, 2003).

In comparison, Brendan, who was in his forties had difficulty in finding a GP to care for him. Brendan’s wife explained:

_A lot of doctors just don’t know how to handle this disease. I’ll be honest with you, I think this is about the fourth one we’ve been to. It was getting quite alarming, the fact that no one would take him on, because they’d be honest they’d say, “I just don’t know enough about it and I really don’t want to be committed to something like this.”... One said, “I’m too old to do this.” Another one said [he] would take him on but Brendan and him and me didn’t click. He didn’t take the time to listen to Brendan and Brendan’s speech was better [then]. He was talking over him like, “Yeah, yeah, yeah. I know what to do.”_
Brendan was demoralised with this rejection. He said, “That’s the worst thing” – being rejected because he had a terminal illness that doctors appeared to not want to confront themselves because caring for him appeared to be too hard for them.

**Residential location**

Participants in this study resided in both urban and rural areas and their ability to access medical resources appeared to be influenced by their location. In the rural area, there were few medical practitioners, either GPs or specialists. Regional hospital clinics with visiting medical practitioners and specialist consultants provided periodic specialist care. Often participants were referred to specialist consultants in Melbourne. However, in the urban area, medical assistance was readily available but, paradoxically, not easily accessible because of long delays between making and attending appointments.

In both rural and urban areas, transportation was a concern in accessing medical assistance. In the urban area, the reliability of taxi services, being available and being on time was problematic. The concern in the rural area was the distance required to attend clinics in regional centres and in Melbourne. Participants reported low government reimbursements for transport costs incurred in travelling from rural to urban areas to attend appointments. Therefore, irrespective of location, access to, and availability of, existing resources affected how a participant sought medical assistance.

In summary, the processes that made up the diagnosis story were influenced by the participants’ different life experiences and their beliefs about life. Various consequences evolved as participants moved through the diagnosis processes, ultimately colouring the choices they made in the future, as they lived with MND.
4.10 Consequences of “The Diagnosis Story” Process

When participants had completed the phases of being diagnosed and commenced living with the knowledge of having MND, their experiences of the process of diagnosis influenced their living with the disease in different ways. Three broad consequences of the diagnostic processes were identified: experiential influences; shifting from diagnosis uncertainty to living with uncertainty; and a new meaning of referral.

4.10.1 Experiential influences

Beliefs and attitudes that changed with the experience of MND are described as experiential influences. In particular, the experience of being on the diagnostic roundabout appeared to alter participants’ former beliefs about and meanings of illness experiences. For example, the reactions and meanings attached to misdiagnoses impacted on how some participants sought subsequent assistance. Ian would not undertake further nerve conduction tests again because it meant more pain and “torture” for him. He believed he did not have to deal with such “torture” just after receiving the devastating diagnosis of MND. In contrast, Heather later underwent a second round of painful testing because it meant that she could maintain what she viewed as a productive and positive relationship with her specialist. In dealing with the discomfort, Heather made a downward social comparison of her personal experience of child birth pain to the pain of the testing. Yerby (2000) contends that pain is a multidimensional experience; that in general, women develop coping mechanisms from previous pain experiences associated with childbirth, which can be called upon later in life to cope other types of pain. Heather, who had given birth to two children, was able to draw on her past experiences to endure the pain with the nerve conduction tests, whereas Ian’s previous experience of pain was limited to acupuncture. He experienced the pain as torture. Indeed, MacKenzie (2002) who wrote about his experiences in living with MND also described the test as “a mild form of torture”. His way of coping was to draw on his cultural beliefs as a “typical Aussie bloke” and “suffered in silence” (p. 7).
Participants’ trust in the diagnostic results and the capabilities of the health professionals appeared to be compromised in some circumstances because of their experiences with health professionals during the diagnostic process. Some participants such as Patricia, Vince, Kevin, Gary and Carole’s husband spoke of the bluntness and uncompassionate way that practitioners communicated the diagnosis and their lack of encouragement for follow-up appointments. As a consequence, some participants had not seen the diagnosing neurologist for many years and were distrusting of health professionals in general. In contrast, others revered the specialists who cared for them, like Euan, Una and Brendan, because of the helpful attitude they encountered. They would travel great distances to ensure they kept contact with specialists, including neurologists.

Most participants said they received no information about MND from their specialist neurologist. The perception of not having knowledge hindered participants’ later decision-making and information-seeking behaviours because they lacked the appropriate knowledge to make informed choices about what to expect with the disease progression and how to access support services. As a consequence, participants often “did their own thing”; they were uncertain about what they were doing and looked for reassurance from other health professionals.

4.10.2 From diagnosis uncertainty to living with uncertainty

Another consequence of the diagnosis story was shifting from a sense of uncertainty about diagnosis to a sense of uncertainty in living with the disease. The overarching sense experienced by participants while they moved through the phases of detecting symptoms, seeking help from health professionals and looking for a diagnosis, was diagnosis uncertainty. The views of several participants illustrate this point.

Colin:  *With the first neuro saying, “It’s probably MND”, we wanted to make sure something else wasn’t the cause or just to confirm … if it was. At least if you know what IT is, you can acclimatise yourself to it. If you don’t know, the*
uncertainty is corrosive.

Euan: I was not happy that they weren’t putting a name to it and I thought, “Why don’t they know what it is?” We could start working on a remedy for it.

Some participants and their families had researched possible diagnoses and continued their day-to-day lives in the knowledge of possibilities. The uncertainty increased stress and anxiety levels. As a consequence for this group of people, the newly acquired knowledge did nothing to lessen the impact of the diagnosis.

Euan’s wife: When we went we were sort of prepared in a way, weren’t we Euan … we had a little bit of preparation. But then, it was still a shock to actually find out.

Patricia: So I had that many [tests] and it went on … for three and a half months before I was really diagnosed with MND. But all the time I knew about it and I thought, “Oh, this is terrible. Have I got it or haven’t I got it?”

After the diagnosis was given, uncertainty moved from “what was wrong” to “how to live with the disease”. Some participants did not accept the disease wholly. For example, Patricia had been diagnosed six months prior to the interview:

No I don’t want to accept it…. No, I don’t. But maybe, is it easy when you do accept it? … I mean … how do you accept something? You’ve got a fatal disease that’s not treatable. How do you accept it?

Participants asked many questions about living with the disease; were they “doing the right things”, how long they had to live and how the family would cope financially. All these concerns were embodied in the notion of living with uncertainty. This type of uncertainty intensified as participants lost confidence in specialists following referral for a diagnosis for their symptoms.

4.10.3 New meaning of referral

An altered meaning of referral to specialists was another consequence of the process of being diagnosed with MND. Participants believed that being referred to a specialist implied that specialists were knowledgeable
and that there was a known cause and treatment available for the problems being experienced. The expectation was that the treatment would cure or ameliorate the disease symptoms. What is more, they believed that if a specialist did not know what the problem was, then he/she would be able to redirect them to someone who would know and that information about the problems or disease would be available.

However, with the diagnosis and prognosis of MND – having no known cause, and no cure or treatment to ameliorate the disease – participant expectations were not realised and the inferred meaning of referral was changed. This altered understanding meant participants would question the reliability and necessity for being referred to other specialists when the need arose.

4.11 In Summary

The analysis of participant data revealed three constructs to living with motor neurone disease. First, participants mostly told their story about trying to get a diagnosis of what was wrong. The “story” phases ranged from when they had niggling persistent problems to seeking help from health professionals, getting a diagnosis, having confirmation of MND, re-evaluating life and the future to embark on living with the disease. This second construct included development of personal coping mechanisms and attitudes about life that seemed to hold them in good stead for living with MND. Consequences of the process that influenced the next aspect of living with the disease were participants’ experiences of interacting with health professionals and service providers. In the main these were negative and coloured future interactions. In the next chapter, the second construct of living with the disease is reflected in a model of decision-making processes that participants moved through, in the face of “ongoing change and adaptation”.
5.1 Introduction

In the previous chapter, being diagnosed with MND was identified as a life altering phase that precedes participants’ time of living with the disease. This became “The Diagnosis Story” (Figure 4.1; see page 96). What followed was a pattern of decision-making associated with the ongoing change and adaptation that was characteristic of living with MND, which evolved from participants’ stories. Ongoing change represented the compounding losses associated with the progression of the disease. These included loss of physical capabilities, family roles, societal roles and future expectations. The need to adapt was revealed by many participants, as stated by Vince:

> It’s almost like the progression is slowing down but I don’t think it really is. It’s just the way it seems. And I’ve just been able to adapt to some degree to keep things going.

In this chapter, the decision-making processes are presented as a model for living with MND. The model reflects how participants made choices about the continuing changes and associated adaptation mechanisms. It is briefly explained and each of its seven steps are discussed in turn. While people living with MND typically utilised the same decision-making process, three different disease progression patterns were evident.

5.2 Overview of “Living with MND”

After initial adjustments to the diagnosis had occurred, the “Living with MND” phase began, as Euan and his wife explained:

> We’re living with [MND] at the moment, aren’t we really? (Euan: yeah we are) … [like] cancer [it] sort of eats away at you, but we sort of go along.
Participants described the disease progression as “ongoing change and adaptation” and as “a journey of learning to cope”. They explained the process of adjusting to change from both physical and psychological perspectives.

Thomas:  *Because of the high degree of change in my condition I’ve had to adapt continuously all the time.*

Diane:  *With MND you just seem to be making changes as needed but … ongoing … [Diane] seems to be making changes day-by-day … subtle changes I suppose in a lot of respects … but … when you look back they’re big changes that have been made.*

In contrast Heather depicted her living with MND as a journey and a challenge:

> It’s been an incredible learning experience … learning to cope – and it’s been very much a journey, from that early time of my diagnosis and my prognosis.

Living with MND was a daily struggle to overcome the restrictions the disease imposed. It was “hard work” and required much “concentration” and participant self-talk to live and achieve while knowing death was an assured reality in the near future.

The model shown in Figure 5.1 (see page 133) depicts the decision-making processes involved in living with MND, particularly as they related to the ongoing changes participants experienced. These processes began when participants became aware of a change in their lives that affected them personally. An initial emotional reaction was experienced that undermined or sustained their self-esteem depending on the nature of the change. Next, participants went through a process of making meaning of the change and how it affected them, their families and their friends.

Participants either passively ignored or denied the change in order to “live with it” or actively altered their life to accommodate it. Sometimes combinations of passive and active strategies were chosen. Participants used
their own criteria to gauge success and effectiveness of actions that assisted them to cope with the change. The outcome of this assessment was emulated in participants’ sense of wellbeing which was reflected in perceived stress levels. Some participants, who assessed the chosen method as increasing stress levels, then tried another until they felt they were successful in adjusting to the change and, as a consequence, reduced their degree of stress. When another change occurred and was acknowledged, participants would start the decision-making process again in relation to that particular change.

The timing of successive changes varied as indicated in Table 5.1. (see page 168). Changes could be quick and unrelenting; sometimes ongoing changes occurred preceding a period of no change, like a “plateau”, followed by more changes and plateaux in due course; sometimes changes occurred gradually over time. While participants reprocessed the same decision-making steps with each change, a sense of “living with uncertainty” was always present as their physical, and sometimes cognitive, functioning declined.

The steps in the decision-making model were identified as “perceiving change”, “reacting to change”, “appraising change”, “adapting to change”, “adjusting to change”, “sensing wellbeing” and “facing another change”. Each step is defined and illustrated with participant data.

5.3 Step 1: Perceiving Change

Perceiving change entailed participants’ recognising an alteration within themselves like an altered finger movement, or externally, like a change in administrative policies that impacted on their welfare and consequently on their environment. Changes were psychological, emotional and environmental, but in the main, physical change was detected first. Not all changes were associated with loss of physical capability; occasionally the change was positive and promoted a sense of improved wellbeing. These positive changes were mostly associated with outside influences like new funding structures that improved service provision, or the improvement in
equipment such as an upgrade to a motorised wheelchair. Other changes experienced by participants were categorised as unpredictable events such as poor service provision, recognition of increased safety issues and new policy interpretations that impacted on their clinical care. Whatever the perceived change, the decision-making process for living with and accommodating it, took the same path. In this section each change characteristic is explored in turn.

Physical changes were generally perceived first before diagnosis and they triggered the “diagnostic roundabout”. During that uncertain time the participants scrutinised their physical symptoms, looking for clues for possible diagnoses. After diagnosis, vigilance regarding physical abilities increased, however, the focus was on the changes and patterns associated with deteriorating muscles and disease progression.

Euan: I noticed a gradual winding down of my capacity in speaking, walking, lifting.

Diane’s email: I am noticing increased weakness especially in my arms; also it has become harder to lift my head.

Gary: I have a problem with ‘C’...and ‘R’ [when pronouncing words].

Vince: Up until recently I would have said, “Look it seems to be just arms and legs,” although no-one notice. My speech is not quite as good as it was.

Neville realised people could not understand him. He then noticed he was having trouble with the letter “S” when speaking. Jack, who exhibited bulbar involvement, noted his deterioration in graphic terms:

Since the diagnosis I have been going downhill fast. My breathing and swallowing have got worse, and I’ve lost a third of my weight. Last June I looked like a slightly plump but active 67 year old; today I look like a soldier from Changi and I can do nothing.

Noticing and realising physical change was a consequence of constant vigilance for signs of physical deterioration.
"Ongoing change and adaptation" decision-making model

**Contextual influences**
- Urban/rural settings
- Living circumstances
- Gender
- Wealth
- Culture
- Illness beliefs
- Life stage
- Coping style
- Previous experiences
- MND experiential knowledge
- People and groups who support the person with MND

**Interactions**
- Self-talk
- Intimate carer
- Family and friends
- External supports

**Basic social process**
- Maintaining personal integrity underpins choices and negotiation interactions

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**Step 1**
Perceiving internal/external changes

- Undermined self-esteem
- Sustained self-esteem

**Step 2**
Reacting to change

**Step 3**
Appraising change and creating meaning

- MND in control: lowered self esteem, negative self-perceptions
- "I have control": increased self esteem, positive self-perceptions

**Step 4**
Adapting to change: selecting strategies

- Passive strategies
  - No alterations to support structures
- Active strategies
  - Support structures altered

**Step 5**
Adjusting to change

**Step 6**
Sensing wellbeing

- Negative wellbeing - increased stress
- Positive wellbeing - decreased stress levels

**Step 7**
Facing another change

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**DECLINE IN FUNCTIONING**: LIVING WITH UNCERTAINTY

**DECLINE IN FUNCTIONING**: LIVING WITH UNCERTAINTY

Figure 5.1 Model of “Ongoing Change and Adaptation”
5.3.1 Physical changes

Another example of physical change was the recognition of jumping muscles or fasciculations, a known symptom of the disease.

Patricia:  I’m feeling twitchy and a bit weak.

Heather:  My nerves jump like mad … I feel jumpy.

An aspect of ongoing change was weakening leg muscles. This had consequences that were far more complex than they appeared on the surface. When change was profound enough to require the use of a wheelchair, other losses became apparent. Participants became aware that they no longer were in charge of their own mobility and this impacted negatively on their level of independence.

Ben:  I have become a sort of passive participant … being … pushed in to see a movie in a wheelchair … a different perspective on life.

Colin wrote:  As my hands have weakened that old walker started to run away from me, not a comfortable prospect. My wife came back to me in the local shopping centre to find a crowd of sympathetic shoppers picking me up from the polished floor. Since then I’ve been wheelchair bound when out. Captive to directional whims of my pusher.

Heather:  I’d go[shopping] with [my husband] and then he’d be pushing me in my wheelchair, and I was more attached to someone.

Neville:  I suppose someone will push me [in the wheelchair] someone being (indicated his wife).

The consequences of physical change and losses included reduced recreational and social interactions. These usual activities were curtailed when the participant could no longer mobilise independently or be understood clearly. For Ben, his physical changes meant there were more things he could not do, in particular, change limited his recreational activities:

I would say that reading was a big … activity…. But I can’t read anymore … for ages [be]cause I can’t pick books up. I can’t turn the pages – heavy
books I just can't pick up…. I couldn't get out as I was increasingly
paralysed and I found my ability to mix with people was deteriorating. I
could not make conversation – [I was] just becoming more self-conscious
– more isolated socially.

In contrast, physical changes provided challenges for Euan:

I have become more left handed now … I have a problem cutting with the
right hand… [so I am still able to cut up my food].

Ben and Euan coped differently with the ongoing physical changes
associated with MND. These responses were not unusual as most
participants vacillated between these attitude extremes at some time in their
illness.

Colin was able to ponder the irony of the changes he was experiencing
by comparing them to the efficiency of others around him.

My second granddaughter was born eighteen months ago. At the time I
was walking normally, I did have a slight glitch in my left foot but it was
only noticeable when dancing…. As she has grown I’ve had to relinquish
holding her, at least when I’m not securely seated, I’ve admired how she has
tackled the business of learning to walk. As she has acquired her legs, I
have lost mine. For a brief time we were equals, both walking somewhat
unsteadily but unaided between furniture. Now she walks as I once did.
While … I walk holding onto a frame or from one piece of secure furniture
to another and she’s become aware that she can push me around, when she
pushes my frame now, I go where she wants… As my eyes have been
opened to it, my mind has come to appreciate the magnificence of a body
being stable, gracefully so, in complex motion. Watching those about me in
their everyday tasks, moving with unconscious, fluid, graceful ease, I
marvel anew at the wonderful body we have and grieve anew for what I’ve
lost. Now my granddaughter is in the process of learning to talk.

Lionel also spoke of the wonder of human development and deterioration in
a similar comparison between himself and his granddaughter. Both
participants viewed their physical changes in terms of outward comparisons.
The participants were vigilant in their search for signs of physical change. Heather was adept at reading her body, noticing associations between her emotional state and her physical health.

*I can feel the difference of what happens to my body when I go through anxiety, stress, despair, depression, all of that. It’s like an on/off switch.*

The impact of physical changes extended to other aspects of participants’ lives such as independence, choice, socialisation and recreational opportunities. In addition, physical changes were recognised fairly easily as participants constantly read their bodies, however, psychological changes were not as easily discernable.

### 5.3.2 Psychological changes

In order to cope with the diagnosis of MND, some participants changed their previous ways of approaching life, resulting in a greater appreciation of living in the present. Physical changes sometimes necessitated life adjustments that affected positive and negative outcomes. For example, Euan said:

*When I … [realise I’m frustrated because I cannot do something] … then I’ll find something I can achieve and enjoy that and change direction*

Participants, such as Euan, reassessed their lives, modified their hobbies to meet their changing abilities and moved on. In this way they were able to maintain psychological wellbeing.

Similarly, physical deterioration meant Heather needed to acquire an electric scooter. While the deterioration itself was difficult to accept, the outcome of the scooter provided unexpected independence which led to positive psychological change. Fieldnotes illustrate the point:

*Heather … spoke about her trip to [a large shopping complex] where she rode on her scooter to shop. She said she amazed herself (again) by being on the scooter for 8 hours – she said she thought this was wonderful. She said she did not become over excited as a rebound and that she was able to sleep soundly that night. She appeared exhilarated with the freedom that the*
machine gave her…. She was so “high” with freedom that when she got home, although it was dark, she put on the headlights and went scooting down the road.

Heather’s story exemplified how psychological acceptance of change can lead to independence and freedom.

However, some participants found it difficult to adapt to living with MND. They felt diminished by the loss of dignity associated with others attending to their personal care needs.

Gary:  
I suffer … I feel hurt … humiliated … because [I] can’t dress [myself], do dressing, drying after the shower. [I] can’t explain things, not doing very simple every day things … and that [I] felt humiliated … and hurt.

Vince:  
It might be more of a guy thing to [ask] someone to help them because of their physical inadequacy. It is pretty hard…. I even find that with my wife that it’s hard to ask her to do things, have things done that you really just assume that that would be your own private … just something you’d do yourself. There’s no thought of not being able to [attend to personal hygiene]. I wouldn’t have minded if I was in my 90s or something I’d understand it but in my 50s.

Brendan’s wife:  
There’s a bit of an embarrassment thing with him [about personal hygiene care] too but he’s getting over [his sister–in–law attending to his needs] slowly. But with his paid carer, he feels so relaxed.

Others learnt “to let go” of negative psychological thoughts and feelings to counteract distressful impacts of the illness.

Mark:  
I think it’s me being more embarrassed being in the chair at times than my daughter. I think that’s a thing you got to grasp to learn … you find out that you’ve got to be in a chair or you are a bit different than other people … you’ve got to have a certain outlook in life … I just [say to myself], “oh well, this is the way it is and I’m coping the best way I can.”

 Una:  
I’m trying very hard to … not feel guilty about not being able to do things. That was something I was finding hard to cope with… I said to my husband …. “I think I’m learning to cope with the idea that if I can’t do it, I can’t do it. I’ll just stop feeling guilty about it.”
A major issue for participants appeared to be concerned with personal intimate care related to washing and drying of their bodies and going to the toilet independently. Guilt and embarrassment also eroded healthy psychological perspectives on life. “Letting go” seemed to be a method to counteract these feelings thereby cognitively compensating for and coping with the progression of the disease which maintained psychological health.

5.3.3 Emotional changes

While alterations in emotions were strongly linked to psychological changes, there was the added element of emotional lability that is an outcome of MND (Goldstein & Leigh, 1999; Newell & Wilson, 1994). This uncontrollable symptom was experienced by some participants as bewildering for them, as Colin explained:

While I read that MND accentuates the tendency to tears and laughter, no one has spoken about the emotions behind them. Since the early stages of my impairment I have experienced much more significant emotional surges. Before MND was considered, I noted them with puzzlement and concern in my work diary…. The same stresses do not exist now, but others do. I find it unsatisfactory to assume the psychological stress in me is of the same order to account for the emotional surges experienced before and after diagnosis. Stresses of the same or more severe order had existed before but had not induced emotional change, and I don’t feel as quantitatively stressed now. Alternatively, if MND induces emotional change then these might have been experienced before diagnosis, a more reasonable explanation. Knowing that emotional responses are exaggerated helps me to work through them. However it would be helpful to talk with another at times.

Experiencing emotional lability often reduced socialisation opportunities because participants were embarrassed about displaying uncontrollable laughter or crying in public situations. Brendan chose to stop working because of his inability to control his extended laughing. Similarly Ben had uncontrollable emotional responses:
Laughing when I am feeling helpless. I cannot explain myself. All my sense of the ridiculous overwhelms me. I just break up laughing – not good....

(laughing)

The condition often embarrassed participants especially when people around them did not understand. Diane’s husband tried to protect her from negative reminders about MND by shielding her from inconsiderate people whom he believed, caused her excessive crying. He believed these experiences upset her “for the rest of the day”.

Several participants were relieved to find that the emotional extremes they experienced were part of the disease. Many had not recognised this and felt diminished by it. Most participants attempted to moderate emotional expressions, nevertheless, one area that was not easily controlled was the range of environmental changes they had to confront.

5.3.4  Environmental changes

All participants needed to instigate home modifications to accommodate the increasing effects of MND, such as changing a bed height, ramps outside for wheelchairs and bathroom modifications. Some moved their residence to be nearer their families and their care services, some moved to accommodation with additional nursing care and some into nursing homes in recognition of future care needs.

Ian:  
I was sleeping on a normal bed and needed to raise the bed up. I knew what to do, but I couldn’t do it.

Una:  
The gentleman we bought the house from, [his wife] was in a wheelchair and that’s why we’ve got sliding doors.... It’s all flat out there and there’s a ramp at the back.... There’s a nice veranda.... We’ll have the bathroom changed.

Brendan’s wife:  
We decided to move [near] my mum, sister, and brother.... I knew my sister would be a great support and my mum. I knew she … [could] help [with] the kids.... I knew there wasn’t going to be a great lot of help with Brendan and me [where we lived] ... financially we wouldn’t afford to by a house down.
here [in Melbourne]. We knew we could buy a house up there [rural area] and financially [there] would be no stress.

Vince: We’ve modified things in the home … to make it possible for me to actually get from one room to another, and a stepless shower, things like that.

Some participants discovered that disability services were inadequate when going out or when on holiday. This resulted in changed plans, embarrassment and anger.

Heather: There have been a couple of issues that can be upsetting – like when you strike a disabled toilet that’s not right…. [the restaurant owner] was using it as a storage room …. She got really annoyed because she had to remove her boxes.

Mark: [The community has]… a performing art centre…. The main issue is the accessibility … [for] most people in wheelchairs …. There is no spot for me except near the orchestra pit which is just flat and then the seats go up … the toilets are disabled … [they’re] very good…. But I just sit in front of the first row so anyone in the first row would be blocked by me…. There is no provision for me as a person … it … makes you stick out.

Diane’s husband: People … contacted us to [ask] if we would be interested in going there on a 10–day holiday. “Oh great, sure” … take your dog and [the accommodation is] suitable for people with a wheelchair and this type of thing. The guy that ran the place – his interpretation of wheelchair suitability was that you … can enter the front door in a wheelchair. That was it. You couldn’t get into the bathroom. You couldn’t use the toilet. You couldn’t use the shower …: [it] had a step … and it was … a narrow bathroom. We had to go and use the … community centre where they had … a stepless shower with grab rails and whatever … we used that … otherwise we would have to … just go home.

Ben lived alone and relied on many service providers for care and maintaining his independence. His speech was slurred and he exhibited behaviours associated with emotional lability. He organised holiday accommodation, specifically designed for people with disabilities, to be near his relatives at Christmas, via the Internet and telephone. He recalled the facility was “great except [it was] remote”. Shops and recreation areas were
not accessible for a person alone in a wheelchair. As well, Ben’s relatives had to travel over an hour to visit him and the hoist he hired over the phone was inappropriate:

that hoist [had] ... a sort of winding handle on top. It’s a bastard! The guys [paid carers] could not use it…. It was just so hard for the guys to use it. Plus it was on a tricycle frame they couldn’t move it around. They just hated it.

Change or lack of change in the environment often restricted participants’ lives. Unless the restrictions were overcome, negative consequences of lowered self-esteem, feeling humiliated and loss of dignity ensued.

5.3.5 Unpredictable events

Despite the careful planning that is evident in the previous accounts, participants still experienced a range of unpredictable events. Small events were managed without incident but sometimes they escalated into something bigger. Unexpected events elicited outcomes that were, at times, detrimental to participants’ wellbeing and self-esteem.

Services

Navigating through the different support services was more difficult and time consuming than participants and their families expected. For example, Jack discovered that his nutritional support fluids were delivered to the wrong suburb and were of the incorrect concentration. Euan and his wife discovered that access to a wheelchair while on holidays interstate was not as easy as in their home state of Victoria. GPs and specialists were often not supportive or helpful. Frequently health professionals negated participants’ concerns, having little regard for them as a person, as Patricia explained:

I said [to my GP], “I keep worrying about having MND and what it’s doing to my [husband and] my daughter. It does worry me.” And he said, “Oh don’t worry about them … they’re all right.” I said, “Well what can I
do?” And he said, “Just dress nicely and put a smile on your face.” So …
it’s not much to go on is it, really?

Participants discovered that not all aspects of their living with MND were as they preferred and expected. Most participants wanted guidance and assistance from supportive groups they trusted but sometimes this did not happen. The support did not live up to expectations. These realisations often evolved into a “wake-up call” about whom to trust.

Wake-up calls

“Wake-up calls” were timely reminders about personal vulnerability, disease progression and safety issues, which initially triggered despair and fear. These calls stimulated participants and their carers to problem-solve activities to prevent repeat experiences and act proactively for the future. Usual living arrangements were easily disturbed by unexpected events such as illness or absence of usual carers. Neville’s care was jeopardised when his wife became sick.

[being ill] was something that just showed us how vulnerable we were really. It did make us address that problem, or the possibility that we had to have a backup.

Similarly, Carole needed to be admitted to a nursing home when her husband became increasingly unwell.

Some participants talked about experiencing crises, increased stress levels and carer tiredness. Each crisis awakened a realisation in them of their disease progression. Thomas wrote:

With some reluctance we [my wife and I] had to admit we were in crisis.
Negotiations and arrangements, which may have been difficult before, now seemed insurmountable.

These instances also served as reminders for families not to become too complacent about safety issues especially when carers were tired and participants’ needs were increasing. Heather explained one of her crisis situations:
It all really came to a crescendo a few weeks ago – we had an accident in the van with [my husband] … well both of us, because I didn’t watch either – not tying the wheelchair down properly in the van…. The wheelchair flipped back…. Although it was fifty per cent my fault … he felt very responsible. [He] was really physically tired and mentally tired with everything…. He felt just terrible because when it first happened he thought my neck was broken and I think it gave him a tremendously traumatic time…. Then the next day he was still very tired and a bit depressed, which is not normally what he’s like…. We went shopping at the supermarket…. I didn’t want everything put away straight away. He wanted to just shove it all in the cupboards and they were messy…. Our little argument turned into this big argument, and he was saying, “Why don’t you just go away and leave me and stop putting your nose in it?” … that’s what I didn’t like, because I also want to be part of the household…. The argument went from a stupid little discussion about supermarket shopping being put away to other much harder, harsher statements that we would never normally say.

Incidents such as these highlighted the tenuous positions of carers and participants alike. Safety issues were often the trigger for re-examination of carer relationships, environmental facilities and the necessity to be alert and problem-solve. For example: Una, Andrew and Wendy fell down with no one to assist them to get up; Kevin accidentally ignited the sheepskin he was sitting on when smoking a cigarette and no one was present to help extinguish the flames resulting in him being burned; Thomas, Denis, Euan, Zara and Colin were unable to reach call bells for help when left alone in a residential room or a toilet; slow repair services of an electronic hand control impacted on a Thomas’ ability to get out of bed until the control was repaired.

As the disease progressed, participants were reminded about their deterioration and vulnerability when “wake-up calls” occurred. Sometimes new government policies served to counteract potential safety and equity issues.
New policy interpretations

Changes that were necessary because of new health care policies and varying interpretations by governing bodies impacted on participant care and services. For example the implementation of the “no lift policy” for carers in a nursing home impacted negatively on some. Staff interpretations meant they would not transfer patients from the wheelchair to a car seat. Zara’s daughter recalled an incident:

[Zara] doesn’t walk … [the nursing home] introduced a “no lifting policy” here…. We did maintain it, probably six months. We didn’t go out…. as far as transferring to the car from here [the nursing home], it didn’t happen. That was very difficult because it isolated Mum.

Changes in funding policies and guidelines either improved care or made it more difficult for participants to access money for care services. Kevin discovered his funding for general respite close to his home was “cut” so he was required to access specialist respite services across the other side of Melbourne and away from his residence. For Kevin, the distancing was a good outcome in providing a break from his family, but transportation was an issue for his family because they could not easily visit him. Mark’s wife told their story of trying to access preferred government funding through the Independent Home Assistance Scheme (IHAS) but not quite satisfying the criteria for inclusion:

*We did have palliative care as a support group to help us…. The reason why we couldn’t get IHAS, they said, “You’ve got palliative care and we thought Mark was going to pass away soon so you won’t need our services.” I said, “Well we’ll get rid of palliative care then.” They said, “Yes, you get rid of palliative care then we can help you.” So we got rid of palliative care. Two years later they still haven’t helped us. So we said, “Well we’ll apply again to palliative care, [while] on the waiting list” … and they said, “No you can’t even be involved with palliative care while you are on the waiting list.”… I don’t want Mark to go to hospital to die. I want him just to die at home…. His level of care is going to increase from week to week and I would like to know that I’ve got that support team there*
behind me so when it comes to the stage when Mark needs monitoring … for 24 hours a day or whatever, I can call in and have people come. Dealing with the social department side of having a disease is really hard work, it makes you feel very unwanted.

Mark and his wife also felt that they were “a real burden to [government agency]” because they were frequently reminded by this funding body how much it was costing to keep Mark living in his own home. This government agency was funded to connect people in the rural areas with care services according to needs. Mark and his wife understood that “apparently, now, this is the policy so that you know how much you are costing the government”.

Another policy that had change implications for participants was the amendments to the confidentiality laws (Federal Privacy Act 1988, 2004). This impacted on them because they had to repeat their details to many service providers instead of one that could inform the rest. Neville called it “a waste of time” and “a useless type of law”.

The process of perceiving change is a characteristic of the human experience of chronic illness. Morse and Johnson (1991) alternatively labelled this as “reading the body” as exemplified by Heather when she talked about noticing the associations between her emotional state and her physical health.

I can feel the difference of what happens to my body when I go through anxiety, stress, despair, depression, all of that. It’s like an on/off switch.

Charmaz (1995) labelled the same characteristic as “experiencing an altered body”. She suggested that people tended to notice physical changes in relation to “diminished bodily functions” (p. 659). Moreover, Hawthorne (2001) claimed that women are more attuned to their bodies than men, ensuring a more reflective attitude to approaching recovery. The difference with MND is that there is no recovery but the women in this current study
noticed subtle changes in response to the adaptations they made to counteract symptoms as they moved through the decision-making process.

In summary, the nature of perceived changes varied from disease consequences to unpredictable events. Initial emotional responses to the changes were experienced. Some impacted negatively on participants and others did not. Others were incorporated into individual lives or ignored by participants, as reflected in the next stage.

5.4  Step 2: Reacting to Change

Participants’ initial reaction to the ensuing change tended to be intrinsic. Their emotional responses were influenced by the nature of the change, its impact on them, and previous experiences of other changes in life and with MND. Reactions included tears and despondency which effectively undermined participants’ self-esteem, or feelings of being “OK” with the change which sustained self-esteem. As well, there was oscillation between positive and negative reactions as shown in Figure 5.1 (see page 133). Each is discussed in turn.

5.4.1  Undermining self-esteem

Responses that expressed distress and frustration effectively lowered participants’ sense of wellbeing, self-esteem and affected their perception of who they were in life. Typical examples were “just cry, scream and yell”, “self-pity”, “feel really sad”, or being despondent because participants “can’t do” something else like eat with a dominant hand, walk anymore, pronounce words or do things they “used to” such as writing letters. Jack’s cognitive deterioration resulted in frustration, distress and anger because he could no longer link words to thoughts. The impact of feeling “frustrated”, “humiliated”, “weakened” and disappointed by the health funding system yet again, lowered self-esteem:

Neville:  I get frustrated because I always did the dishwasher. Now I can’t lift the bloody plates (emphasised with hitting his arms) up to put them away. You
know, I made all these things, can’t take the things out – I can’t even do that now – the washing, the lawn.

Mark’s wife: The changes are always as a result of funding…. I don’t think the rules are set as rules, when you apply you might have to meet this, this and this criteria but then if funding is tight the boss will say “No, we can’t have this, this and this – therefore you can’t apply.” There’s no book of rules. We have done everything that we’ve been told to do. Mark has a life threatening illness, we’ve been on the waiting list for nearly nine years. He’s been assessed twice now for IHAS [generic funding title], and we’ve done everything that they’ve required us to do but we just don’t seem to be hitting home base.

Patricia: You walk away and you feel as if they’ve left you for dead and that they don’t care what happens to you, it’s an awful feeling and I get really frustrated…. My GP, he just doesn’t care.

Participants’ expressed their fears of possible indignities later as the illness progressed. These reactions impacted negatively on their self-esteem and self-identity. They feared being “a human vegetable” and having “all … thoughts trapped in [their] head”. When other people needed to attend to participants’ personal hygiene needs, they felt indignant until they were able to “let go” of previously held beliefs about independent self-care. Neville felt “ashamed” when he saw his daughter undertake jobs he previously carried out. Participants discussed becoming “self-conscious” about their slurred speech in public, which they viewed as detrimental to their self-image. Vince explained the indignity associated with MND for him as a person:

It’s a funny thing, but if I’m just sitting there on a chair, I feel ok. But if I went uptown on one of those little scooters or something, I just wouldn’t feel right….. I guess I was just always a proud person that stood tall and was way above anybody who couldn’t run fast and all that sort of thing.

Participants’ responses to some changes were often detrimental to their self-esteem, self-worth and sense of identity. For example, Zara’s response to her reduced socialisation opportunities because of the “no-lift policy” was that her stress levels increased and her sense of self-worth as a person
decreased. Other participant reactions included feeling humiliated, indignity, shame and fear as well as being uncertain and self-conscious about life. Often participants were able consciously to alter their responses to a change so as to sustain their self-esteem.

5.4.2 Sustaining self-esteem

Some participants’ instinctive reaction was to view the new change as enhancing their wellbeing, a “surprise” or a “challenge”. They focused on the positive outcomes derived from certain changes that helped deal with the obstacles presented by MND. Responses effectively sustained and promoted their self-esteem and made them feel good about themselves. Several participants said they were “surprised” about a change. Euan, whose finger dexterity was declining, usually experienced a lot of cramping. He painted a model ship with a toothpick and reflected:

_I didn’t have any cramping. I was surprised that I didn’t._

This experience sustained his self-esteem and encouraged him to continue with his pursuits. In contrast, some participants experienced surprise in relation to a lack of something important such as key information from the neurologist. They found this lack of information-giving curious, especially when such knowledge was freely available on the Internet. However, they experienced increased self-esteem from accessing information independent of health providers.

Sometimes participants’ response to the new change was to view it as a “challenge” instead of as a “loss”. Heather’s challenges with MND endowed her with the inner strength to undertake public speaking, something that she had never been confident enough to do before. Her reaction and response to a dedicated toilet for people with wheelchairs being used as a storage room in a restaurant, was to campaign to ensure facilities for people with a disability were maintained.

_I was involved in quite a few issues with international hotels where they don’t have the right facilities [for people with a disability]. Initially I_
thought, “I haven’t got time to be bothered with all that”. But then I thought, “No that’s not right. I’ve got to do it for other people”. Then you battle on [with] lots of phone calls and you try to follow it up…. I once got upset a little bit. I didn’t display [it] but I felt it inside.

Heather viewed the issue of accessibility as both a challenge and a community service. Vince endeavoured to find other ways of undertaking activities successfully as this was how he usually approached problem activities:

[adapting] is almost a challenge. If you can’t use the hand you usually do, and if things aren’t working, there is always another way of doing something, even though it is a very diminished method. I can still get food to my mouth most days.

Thomas reclined in a motorised wheelchair, used a microphone to amplify his altered words and although all his limbs were immobile, he could move one finger. He wrote:

I am still enjoying life, doing different things, sharing good times with my Loves and Friends, at a slower pace, meeting a new set of challenges. Amongst my latest objectives is to break a land speed record for electric wheelchairs.

Euan, Heather, Vince and Thomas turned the losses associated with the disease progression into challenges by setting new goals and self-promoting an optimistic perspective on life. These actions advanced their self-esteem and self-worth because they maintained a sense of achievement.

Another reaction expressed by some participants was to blame someone else for the things going wrong. The blame was often extended to esoteric and spiritual forces and not to particular people. Frequently God was rebuked for the increasing adverse events. For example, as Diane’s husband said:

Listen God there’s six billion people in the world, get off our case for one day. Just go and concentrate on somebody else … we’ve got enough to worry about … share a bit around.
Initial reactions to adverse events were to get on with what was happening. When they grew to be overwhelming, the reaction was to call out to invisible forces. This in effect gave participants and their carers, time to breathe and recoup before returning to address the problems at hand, thus lifting self-esteem to more optimistic levels.

In summary, spontaneous negative reactions to changes effectively undermined participants’ self-esteem. Conversely, participants who naturally reacted to the changes with “positivity” [sic] and enhancement, as a surprise or a challenge sustained their self-esteem. Often these initial reactions were later tempered after participants appraised what the changes really meant for them and how they would affect their lives.

5.5 Step 3: Appraising Change and Creating Meaning

Whatever the initial response to the change, the next step for participants was about making meaning of both what had happened and the effect the change would have on their everyday lives. They reflected on the changes and appraised the situation. During this step they modified their already altered illness beliefs and beliefs about life, which had been a consequence of the “The Diagnosis Story”. Sometimes the perceived meanings were negative, in that yet another ability had deteriorated and life was restricted further with the consequence of reducing self-esteem. The understanding was that MND had control over life choices. In contrast, appraising the change was sometimes internalised and accepted positively by participants, with the attitude that ways could be found to incorporate the change into their lives. This promoted a sense of being in control, increasing their self-esteem. Participants sometimes oscillated between “MND in control” and themselves in control. The two opposing subcategorises of “appraising the change” are explained.

5.5.1 MND in control

Being in control of life events, in some respect, was important for all participants. The perception of not having control elicited pessimistic
assessments about life. Participants began to feel “hopeless” and worthless. A common aspect of hopelessness was linked to poor knowledge and poor information about MND. Worthlessness appeared to be linked to guilt about not contributing to family life and the increased burden placed on others. When certain changes occurred after periods of minimal change, events overtook participants’ sense of control. As Vince said, “the change is too fast” although he rationalised:

> You always come to terms with things in time but if it’s only a matter of months that you go from walking to wheelchair, it’s just a little hard to go out in public.

Often participants felt lost, with no control over the events in their lives when decisions were made for them. Wendy had weakened lower limbs and was having some problems with her swallowing but she was still able to eat. One doctor said she did not need a Percutaneous Endoscopic Gastrostomy (PEG) but another said she did. The latter doctor arranged her admission to hospital and subsequent operation.

> Well [the doctor] discussed it with me and he said he’d “put it in, in November.” So [my husband and I] go to see the doctor that was putting it in and he couldn’t see any reason to wait. He said, I “could go down quickly.” … I am on the thickened fluids and I’m up to the stage where my food is just put through a blender. I do choke sometimes…. So I saw him last Wednesday and this Wednesday I got it done…. I think I could have waited because I’m not eating through the PEG at the moment.

Wendy felt she had no choice in the decision to have the tube inserted. Her appraisal of the situation was that she really did not need it so soon. This viewed contrasted with that of the second doctor. Her lack of knowledge and understanding about PEG tubes subsequently evoked a sense of not being control. The decisions made by health professionals took away her right to choose and the anticipated disease outcomes bore heavily on the decision making. This was a significant alteration in Wendy’s life; it lowered her self-esteem because of her poor knowledge and limited choices. Similarly Neville
only realised how much medical appointments controlled his and his wife’s lives when they went on a holiday:

We had two weeks of seeing who we wanted to see…. [I] didn’t know we could get away from it [MND] but we did. That was good.

Participants talked about the build-up of small adverse events. Sometimes they and their carers felt like they had no control over the happenings. As Diane’s husband explained:

Different days … like [at the] start of the day … something goes wrong … just something small but it’s significant because … it can throw your whole morning out just a small thing happening – a shower or toilet – doesn’t it [Diane]?

Sometimes events had a negative impact on participants’ day-to-day living, giving the impression of MND being in control.

Several participants talked about “if only” a particular ability was regained, their life would improve and they would cope. Gary was emaciated, was able to walk, had minimal speech and communicated by writing on notepaper. Previously he was very talkative, so losing his voice affected him greatly.

Gary’s wife: I think [Gary] could cope with everything else if only he got his voice. 
(Speaking to Gary) I said, “you could cope with other things (Gary: mmm in agreement) if only you could talk properly, wouldn’t you.” (Gary: mmm in agreement)

Patricia: If I could only get some strength back in my hands, it’d be great because I can’t hold my knife and fork properly.

Regrets about lost abilities tended to promote participants’ pessimistic perceptions about life. This limited participants’ abilities to deal with some MND outcomes, therefore, fostering the perception of MND being in control. In contrast some participants distanced themselves from pessimistic views to aspects that were more optimistic, reflecting that they felt they had some control of their lives.
5.5.2 “I have control”

When participants appraised a change and its effect on their lives, being able to say that they still had control over the disease was not always possible or evident. What was evident was that participants initially felt lost, they then instigated tactics or actions that gave them a sense of control over their situation again. Participants were subsequently able to make choices and have them enacted. The consequence was that participants nurtured optimistic views about their lives and living.

Heather and her husband felt lost with no guidance and no hope of controlling the disease. The change they perceived was one of finding hope through researching how other people in the world fought MND. Heather took control of her disease by designing care routines based on the knowledge she and her husband obtained through the Internet.

[My] circulation improves through my water exercise group, my food, my way of thinking, and [reducing] the chemicals that we release, whether we’re stressed or whether we’re calm…. What I’m doing makes me feel energetic and healthy and with hope and like I’m in control and MND’s not in control of me.

Heather experienced a slowing down of the disease progression in response to her specific regimes, thus promoting a sense of control over MND, increasing her level of self-esteem and self-worth, and creating an optimistic outlook on life and living.

Appraising change involved participants’ using self-talk to negotiate the meaning of how the change would affect them. Whether participants perceived MND was in control or that they were in control, they selected adaptation strategies in response to the change that occurred.

5.6 Step 4: Adapting to Change: Finding Ways and Means

Participants made decisions about ways and means to cope with the changes they were experiencing. These tended to be passive when no alterations or modifications were instigated or active when adaptations were
made. Some responses oscillated between the two and sometimes groups of adaptations were involved. Sometimes the responses were visible to others, such as a new piece of equipment. At other times the adaptation strategy was internalised and not seen by others, such as participants consciously altering their thought patterns about events and changes.

5.6.1 Passive adaptation strategies

Participants who took the passive path had decided that the change did not really affect them and had no meaning in their life at that time. These participants did not alter any aspect of their lives to encompass the change because they felt it was unremarkable. Sometimes the appraisal of the change was that it was just too hard to cope with and so participants ignored it. Passive adaptation mechanisms, in most cases, were a form of denial. Different approaches were apparent. Strategies included ignoring the change, dreaming the improbable, affirming “I’m doing all right”, living “day-by-day”, “giving in” to MND and persisting.

Even though being in denial appeared to be a passive coping mechanism in response to what was happening with changes associated with MND, often the methods enacted to maintain denial were active and sometimes had a positive effect in the person’s life. Mark dreamed and looked on the bright side, enjoying each day for what it was:

Mark’s wife: [We] live in denial, that’s the best thing [with MND]. It’s frustrating because Mark lived in denial for about the first five years and that bugged me so much because I felt it was only me grieving. Mark had it, but I was grieving. … I realised later, that was Mark’s coping mechanism … even our daughter … lives in denial. We always say we’re going to buy motorbikes, we’re going to do this, we talk as if Mark is not sick.

Mark: We have a dream. What’s wrong with having a dream? How many people who are healthy don’t have dreams? Most people have dreams of going on a cruise or an airplane flight or jumping out of an airplane, with a parachute of
course…. Whether or not we ever do it, is beside the point. I deal with them when I’m by myself.

Vince thought about other things and looked out to sea:

*I think I’m still getting by on – not by denial but pretending it’s [MND] not there …[by] always having something other than [my]self to think about…. I can look out there [across the bay] and think of anything that I like.*

Colin persisted in struggling to walk:

*Recently I’ve been struggling with the aid of a new walking frame to maintain my walking in the face of a feeling that I wasn’t as able as I was before.*

Other participants concentrated on the day and tried not to project possibilities into the future.

Vince: *Sure I do think about [MND] getting worse … but that is, again, a side that I tend not to dwell on … because I see it does no good at all to do that.*

Andrew: *I can see what’s coming…. when [I] can’t do anything. Even now I have a little trouble swallowing. Of course if it gets bad enough, they put a hole in your stomach and pump it through a pipe. Even getting up to the toilet, even wiping your backside is difficult. Things like that, well that’s going to get worse. When you sit down and think about it, it’s not very nice…. I only think about it when I’ve got to.*

Diane: *I live one day at a time.*

Participants’ used their inner strength and mental vigour to ensure the attitude of denial. As Mark said, it was “hard work” to live with MND.

The selection of the identified passive strategies was actually a positive and active way of living as these approaches reflected participants’ ability to focus on what was important in life and in coping with the disease outcomes. The next section explains the various active strategies enacted by the study participants.
5.6.2 Active adaptation strategies

When participants decided the experienced change was significant in their lives, some made active adaptation strategies to cope with its effects by altering their support structures to encompass it. In the main, strategies such as thinking creatively and problem-solving were chosen when participants viewed the changes as challenges, as in the case of Una:

> There was one night … [my husband] went to bed before me and I was sitting knitting. I wanted to finish what I was doing and I said, “I’ll come later”. Well, I couldn’t get out of this chair, and I’m calling him. He’s deaf in one ear and he was lying on his good ear so he didn’t hear me. So an hour and a half [later] … he woke up and realised I still wasn’t in bed. He came through half asleep and I was sitting in the chair after I’d been trying to call him. So we decided if that happened again, he’d leave the mobile here and the phone is next to the bed and I could ring…. We had that worked out.

Other methods included participants’ accessing and using assistive technologies to overcome some of the physical deteriorations as the disease progressed in areas such as communication, mobilisation, respiration and nutrition:

Thomas wrote: *My voice has now been reduced by 90%; I require a voice amplifier to communicate. Even using this device some people find it impossible to understand me. I have to exercise much patience to ensure I am understood particularly to have my crucial needs met.*

Colin wrote: *‘Chatterbox’ [my Lightwriter] and the blessing of mobility has enabled me continue to exist…. Chatterbox enabled me to stay in touch. I suspect if instead I’d lost mobility [first] that I may have given up, daunted and isolated by reliance on others and the implications of life in a wheel chair.*

Mark: *[My daughter] just sees me as a person, as a dad, and she’s not embarrassed with me being in the chair. I think it’s me being more embarrassed being in the chair at times than [her].*

Thomas wrote: *In hindsight considering my earlier quality of life, I would put off until absolutely necessary the assessment and use of a ventilator.*
Jack: I was told it was the loss of weight that was causing the ill feelings, and I should have a PEG fitted (a tube directly into my stomach). I agreed.... The PEG is to stop and reverse my weight loss, and that hasn’t worked so far. I’ve lost 3 kilos since I went into hospital.

Participants applied self-help strategies to accommodate the changes not only physically but also cognitively. For example, Lionel wrote in felt-tipped pen, sayings on his kitchen walls to remind him to be positive about life with MND:

*Don’t tick like a clock sway with the breeze*
*Don’t live existing, live doing*
*There are no limits, live outside the boundaries*
*All is well in my world!!*
*The miracle is within. I am working on a miracle, change the blueprint.*

Humour was used by some participants as a way to counteract inner negative feelings and demoralising aspects of life. Laughter, teasing and black humour were facets of humour that were evident. Laughter played an important role in long term marriages for Euan, Neville and Andrew. Andrew said:

*The wife and I, we still have plenty of laughs. We still have plenty of fun at home here. There’s no way I’m going to let it get any other way, as far as I can. I think that’s one of the things that’s kept us together. We can have an argument and either one of us will end up saying something funny and we’ll laugh and that’s it.*

Patricia, Neville, Andrew and Brendan all asserted that laughter was very important in coping with the effects of MND. Diane and Lionel often sent “sick” jokes via the Internet to their friends and acquaintances. Seeing the funny side of MND was very difficult because of the disease outcomes but participants still endeavoured to cope with life through laughter.

Teasing was another form of humour participants and their families used to make light of serious situations. On one trip to her favourite shopping centre, Heather’s husband had forgotten the slide transfer board
for her to manoeuvre from the car to her wheelchair. She really wanted to shop so she transferred herself quickly with minimal aid from her husband and carer. As a result of this show of independence and agility, her family threatened her teasingly:

“We’ve got to not let you go shopping for three months, and get to … somewhere really good. Then we’re going to say, ‘We’ve forgotten your wheelchair’. And I say, ‘Well blow this business of not walking, I’ve got to get in there’, and I’ll just walk in”…. So that’s a new aspect of healing.

Participants used black humour as a way of boosting their self-esteem and their sense of control in a situation. This form of humour had the power to distress others but empower participants. In particular, nurses were often the brunt of the antagonistic banters. Yuri had deteriorated slowly, was bedridden and had been ventilated via a tracheostomy for the past three years. He talked about being “difficult” with the nurses:

Nine times out of ten it’s only “stirring”…. I don’t win with them anyway … they’re good like that [with having a joke]. They stir me and I stir them back…. It helps that they don’t mind.

Mark also used black humour to “stir” the nurses and his friends. The reason given was “to keep them on their toes”.

Social comparison was occasionally used as a coping mechanism for self-enhancement. Downward comparisons enhanced self-esteem thus bolstering wellbeing because the outcome generated a “positive affect reflective of positive self-evaluation” (Sirgy, 2002, p.139). Participants often used such comparisons to put their life in context with others who were worse off than themselves. Euan said having MND was “better than cancer”. Heather often reminded herself:

I think I’m also very blessed that I can still speak because a lot of my MND friends cannot.

Participants also used comparisons with themselves. Colin was thankful for being able to use his Lightwriter, which he named “Chatterbox”, and a
motorised wheelchair. He compared his present disease stage with what was in store for the future and viewed the present as better:

I'm very appreciative of the loving care I receive I suppose I'm becoming gently initiated into the realm of institutional care, where the staff are slaves to a routine driven by the clock to process tasks in economic order. I dread the prospect. It puts my current niggles into sobering perspective.

This way of thinking promoted Colin’s perception of himself as being better off now than he would be in the future.

In contrast, participants in the current study rarely used upward comparisons as a way of improving their goals for living, because the comparisons would be with others with MND whose disease was more advanced. Some participants did not want to meet others with MND because “seeing where they were going” was too hard to consider, while other participants wanted to meet others with MND for hints about how to live with the disease.

Some participants sought quiet and calm environments. This strategy assisted them to lower their stress levels. Kevin’s family moved homes to an area where the neighbours were quieter. Kevin’s wife and daughter explained:

It's better [here]. The neighbours are better, it’s quieter, it’s like heaven livin’ here (laugh)]… It’s a lot easier for my dad with his stress and that … [he] relaxes a lot easier.

Patricia and Heather believed that some physical changes could be ameliorated by being calm. Their discovery revealed that increased stress levels seemed to be related to their twitching or that the twitching was an indicator of increased stress levels.

Patricia: I find that, if I’m feeling twitchy and a bit weak, if I sat in a chair and try and relax and do some deep breathing, after about five minutes I sort of settle down again – the twitching stops.
For me if I can control ... stress, on a hourly basis – try to be really calm and positive then I know that the fasciculations are very minimal – otherwise I feel the jumps, and .... I feel much stronger. My hands don’t go weak and there’s an incredible correlation there – [by] just keeping calm.

Seeking calmness in the day was incorporated into their day-to-day living.

To summarise, all strategies chosen in Step 4 empowered participants to shape a supportive arrangement that enabled them to live with MND. The structures in the arrangement were either not altered in any way and remained static, or they were altered to accommodate the change. Strategies could be visible such as a mobile phone, or invisible like thinking laterally and creatively. Participants assessed the effectiveness of chosen strategies in response to the experienced change.

5.7 Step 5: Adjusting to Change: Level of adaptation

Outcomes of the chosen strategies were either ineffective or effective according to criteria participants developed from their own personal understandings. Adjusting and using the chosen tactics involved participants in either making no modifications to any structures that supported them in living with MND, or actively making alterations to accommodate the changes into their lives. As Euan expressed:

I never self assess on a continuum. I wake up and get out of bed and go on with the day. I know that in the last six months my speaking has gone down about maybe 50% ... so I don’t struggle with it, I only adjust.

Sometimes the basis for participants’ choosing a strategy was to maintain their sense of dignity. For example, Diane, Kevin and Gary refused hospitalisation when medically necessary, that is, they did not modify their health care environment. Thomas wrote about his negative experiences in hospital when being fitted with a non-invasive ventilator. On returning home, he found the equipment still was not functioning correctly although professional carers attended him there. He said:
Currently I feel I have to compromise and accept this situation. The alternative is being another visit to the hospital. As it takes me weeks to overcome the physical and emotional effects of being an inpatient and the 2-hour one-way trip to Melbourne, this is not a very attractive option.

A strategy of not making any modifications to accommodate a change was assessed as effective by participants; however, this decision sometimes had an adverse impact on their wellbeing.

As previously discussed in Step 3, being in control of life events was of paramount importance for participants because this feeling appeared to promote self-esteem, self-worth and personal integrity. In association with the effectiveness of chosen strategies, the assessment outcome again impacted on the awareness of whether the disease was in control of life decisions or participants had a sense of being in control of what was happening to them. This latter belief was tempered by participants’ abilities to accept the change, adapt to it and move on with their living.

5.7.1 Assessing adaptations as ineffective

An adaptation strategy was assessed as ineffective when the outcome of its implementation did not meet with participants’ expectations or evaluation criteria. Sometimes the ineffective assessment stemmed from the participants’ impressions that the disease and outside influences were still in control of their lives. They felt they could not do anything, that there were no choices available to ameliorate the change. Quintessentially, “MND was in control”, self-esteem deteriorated, stress levels increased and participants’ sense of wellbeing and quality of life declined.

For example, Gary did not want anyone else in his home caring for him except his wife, even though his care needs were increasing in response to his deterioration. He felt humiliated with having to be assisted with his personal care. His strategy to maintain dignity was to reject help from anyone but his wife. His support structures in the home remained unaltered, that is, no outside care services were contacted for assistance. This was
effective for him in protecting his personal integrity by controlling his home environment care structures, but as a consequence his wife had no assistance and her health was compromised. A crisis in his health was subsequently poorly managed as he had no health carers to assess his needs and no crisis management plans prepared. Despite his feeling that this isolation strategy was effective for his integrity, he also viewed the situation as ineffective because the progression of the disease had not altered. MND was in control. His sense of self and integrity were compromised and eroded.

Similarly, other participants also expressed their concerns about others’ attending to their intimate personal needs. Vince did not mind his wife and adult sons attending to his needs; Brendan’s wife and sister-in-law attended to him; Edward who initially lived alone, asked his lady friend to move into his home so he had someone he knew attending to his personal needs. Negative consequences for the preferred carers included increased stress levels, and lowered sense of wellbeing, which impacted upon their ability to support the participants.

5.7.2 Assessing adaptations as effective

Assessing chosen strategies as effective meant that participants believed the strategy was successful if they regained a sense of control in their lives. Having control enabled participants to experience a sense of achievement and reduce their stress levels. Heather, as well as Patricia, “did her own thing”. Heather developed an analogy of “a jigsaw puzzle” to conceptualise her body with MND. She designed a diet and an exercise regime to make her body into “hazy” picture of MND. She believed that it was successful for her. She said:

I think … it’s all like a big jigsaw puzzle…. Let’s say at some stage [my body] was balanced and healthy…. Do all the tests we possibly can to see what is not in balance, what’s not healthy inside me. And they said, “You are nearly diabetic. Your selenium and magnesium levels are off the bottom of the chart. You’re this, that and the other”. So under the care of an integrated medical doctor … we’ve [tried] to make my body, particularly
my immune system, operate really well…. I think MND might be a situation where there’s aspects that all join together – it’s like a jigsaw puzzle … and some of my pieces were getting imbalanced … the tests prove that…. Over a period of time, bang … all the pieces came together and my picture was MND. For somebody else it might be cancer or … rheumatoid arthritis. Then, if you can say, ok, take away some of those pieces of that puzzle, of that picture, of my MND picture and maybe – you might not cure yourself but you might make the course of that disease different. So [my] immune system is really up and running and it’s ticking away really well. [My] circulation improves through my water exercise group, my food, my way of thinking….. So I believe that I’ve changed my picture. I’ve still got an MND picture but it’s not a vivid one. It’s a bit of a hazy one now…. Maybe I’ve sort of imagined what’s happening … maybe that’s just totally wrong, but it works for me. What I’m doing makes me feel energetic and healthy and with hope and like, I’m in control and MND’s not in control of me.

Patricia recognised an association between fasciculations and relaxation, without guidance. She realised that by consciously relaxing her body the muscle jumping stopped. She developed her own exercise program to maintain her muscles, using a small weight. She felt proud of developing creative self-help strategies which gave her a sense of being in control, if not of the disease, then in endeavouring to do something to prevent further physical deterioration.

Not being able to gain control, as exemplified by Gary’s story, conveyed a sense of fighting a losing battle with MND which increased stress levels. In contrast, taking control of changes in a positive manner, in the way that Heather and Patricia had, enhanced their self-esteem and self-worth. This assisted them in regaining and sustaining their personal integrity.

The next step of the decision-making entailed the evaluation of participants’ individual perceptions of themselves in regards to adjusting to change. They personally assessed their level of adaptation and judged the
meanings they attached to the adjustments to the change. This directly influenced participants’ stress levels and their sense of wellbeing.

5.8 Step 6: Sensing Wellbeing

Adaptation strategies and their effectiveness were directly linked to stress levels and the current wellbeing of participants. In general, increased stress levels resulted from the use of adaptation strategies that were assessed as ineffective and thus negatively impacted on wellbeing. Conversely, when adaptation strategies were deemed effective, stress levels decreased and wellbeing was enhanced. However, there were possibilities that an ineffective assessment could promote a sense of wellbeing, and equally, a sense of being in control could increase stress levels and decrease a sense of wellbeing.

5.8.1 High stress levels – negative wellbeing

When a chosen strategy was assessed as ineffective because of a perception that the disease was taking over and participants believed they had no control over events, feelings of hopelessness and powerlessness were experienced, resulting in increased stress levels. Despair was evident in their voices and actions.

For example, as Jack lost his ability to speak he began to use a Lightwriter to maintain communication with other people. While this was an effective strategy for communication, some negative aspects impinged on his self-esteem. His wife explained:

_He hates the accent…. We tried to ask if they had an Aussie or an English sound. [The service provider] said, “They only manufacture them in an American accent.” They’re pronouncing differently to us. People find it difficult to understand._

Jack assessed the use of the Lightwriter as ineffective, even though it did assist with communication. It was ineffective because the voice on the machine did not reflect him as a person. He felt demeaned by this and this lowered his feelings of wellbeing.
5.8.2 Low stress levels – positive wellbeing

If the chosen strategy was assessed as effective, usually participants felt good about themselves for achieving something in their lives. Successful negotiations for equipment to enable social opportunities, such as modified cars and use of a hospital bus for outings, promoted a sense of achievement.

Vince: So with a bit of equipment I’m still managing.

Mark: Over a period of time my foot would droop forward and all this pain would come up on the top of your foot, up the top of your leg, up along your shin … I couldn’t pull [my toe] up and that was quite unpleasant. … I’d have to yell out … [to] roll me over or do something to change positions. So I got 2 splints … I’m on my back, and my feet up, 90 degrees, but they are comfortable. With this mattress I’m on my back again, I get my hands in a comfortable spot. I might be like that 10 or 12 hours but I’m refreshed when I get out of bed. And it hasn’t been like that for 4 or 5 years … but with this mattress that I’ve got now and the splints, together are fantastic.

The successful negotiation activities for personalised leg splints and a new mattress gave Mark a sense of achievement. They were deemed effective, allowing him to sleep comfortably overnight and not disturb his wife for turning. This lessened his stress levels and increased his sense of wellbeing. Heather’s and Rose’s support structures were modified to include motorised self-directed mobilising machines – a scooter and wheelchair respectively.

Heather: For quite a while I really didn’t want to go away and now suddenly I want to get going and go on holidays… That’s I think a real interesting switch because it’s really good and I want to go off on my buggy now by myself down to the shops.

Rose: Last November [I got the wheelchair]…. I didn’t use it for … two months. I thought, “I won’t use it.” … It got to the stage I [had to] use it and be more mobile … and now I’m hooked on it.

The scooter promoted Heather’s independence and returned some freedom to her. Her stress levels decreased and her wellbeing increased. Rose had a similar response to her electric wheelchair, increasing her self-esteem and
independence. Participants talked about many successful alterations they had instigated that overall promoted their sense of wellbeing. Many were proud of their achievements in counteracting the changes that MND threw at them.

Alternatively, when some participants assessed the chosen strategy as ineffective, they would try again. The decision-making process would be repeated until they were successful in achieving an effective outcome. As a consequence, they gained a sense of control for themselves, decreased their stress levels and increased their sense of wellbeing. Not all participants tried again because they did not have the resources to do so or another change had already occurred. Time was a critical factor in the decision to try another strategy for the same change because changes were ongoing and unpredictable.

5.9 Step 7: Facing Another Change

Adaptation strategies, once decided upon, continued to be used until a further change occurred that impeded or negated those actions. Decision-making processes were activated, and then participants began moving through the same steps again. Neville’s words exemplify the consciousness and expectations of unrelenting change that participants dealt with anew each day.

*The thing to do now is face out the problems when they occur. [Some] days I’m a bit wobbly… the wheelchair will be the next thing, but we’re not thinking about that now. We just face them as they present themselves, because that’s the only way we can cope with the large things.*

While going through this recurring decision-making process, there remained for participants the constant experience of living with uncertainty about the future and which part of the body would fail next. This uncertainty was heightened by the inevitability of the progression of the disease and continued decline in body functioning, and promoted an overall view of themselves as on a “downward” trajectory.
The decision-making steps were clearly apparent in the participants’ descriptions of their losses; however, these steps could perhaps apply to any person who undergoes significant life changes. What is different for people with MND is that their lives are generally ruled by continuous body reading and searching for solutions to problems, while in their physical functioning, they experience unrelenting deterioration. Reality told them that there would be no remission but they still hoped. As Vince reflected:

I still have a little bit of hope that they will actually tomorrow say, “Well look these stem cells or something, that’s it, they’ll fix you up in a flash.”

It’s nice to know they’re trying and you do pin a little hope onto that.

5.10 Decision-making Patterns

As participants told their stories about how they lived with MND, three patterns of decision-making processes were evident. Participants described these as “fast track”, “step-wise” and “gradual decline” as shown in Table 5.1 (see page 168).

5.10.1 “Fast track”

Participants on the “fast track” pattern moved through the process quickly with no time for adaptation strategies to have an effective outcome. The time between diagnosis and death was a maximum of 14 months.

Jack: Since the diagnosis I have been going downhill fast.

Gary and his wife: I was normal … when I went in [for an operation]…. When [I] came out I was not…. I would say that [the operation]… bought [MND] on more rapidly.

Jack and Gary both demonstrated signs of distress about their demise and increasing disabilities. Gary’s inability to communicate clearly caused feelings of grief and anger illustrated through non-verbal facial expressions with crying and fist pounding.
Table 5.1 Characteristics of Three Decision-making Patterns

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>“Fast track”</th>
<th>“Step-wise”</th>
<th>“Gradual decline”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time from diagnosis to death</td>
<td>• up to 14 months.</td>
<td>• 2-5 years</td>
<td>• 6 years up to 10 plus years.</td>
</tr>
<tr>
<td>Illness trajectory</td>
<td>• “going down hill fast”.</td>
<td>• steps</td>
<td>• “gradual progression or regression”.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• a ladder</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• “plateaus” then falling off</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• “spiral downward”</td>
<td></td>
</tr>
<tr>
<td>Ability to adapt</td>
<td>• limited adaptation opportunity</td>
<td>• Time to make adjustments to accommodate change</td>
<td>• extended time to adapt</td>
</tr>
<tr>
<td></td>
<td>• time is critical</td>
<td></td>
<td>• making plans for long term future</td>
</tr>
<tr>
<td>Impact</td>
<td>• feel like MND overtaking</td>
<td>• “I’m in control” sometimes</td>
<td>• informed longevity 2-5 years but still alive</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• feel cheated because future plans were put on hold.</td>
</tr>
</tbody>
</table>

Neville and his wife were both distressed during the two interviews with me. At times they were able to keep their emotions hidden but in the subsequent second interview this was difficult. Neville had lost significant weight and speech, was more frail and he was tired. He expressed his anger at the accumulated losses and the consequences of those losses.

_I’ve done these things for everybody (voice breaking with tears) … Pa will fix it._

Neville had always fixed everything for the family and one of his greatest regrets was not creating a bedroom suite for one of his grandchildren. Although he had completed some end-of-living tasks, he felt distressed about what he could not do.
5.10.2 “Step-wise”

Those who fitted into the “step-wise” pattern talked about “plateauing” or a time of constancy when there were no changes due to the disease and everything seemed to be settled and balanced. Vince explained:

I think what I’ve decided is [it is like] a plateau of seemingly like nothing is changing and then it’s a little bit of a sudden loss of being able to step or use a hand or something like that. And sometimes it can be a month or more and I think, “Well no change. This is great”, but it’s almost like it just falls off a plateau and then I get use to that after a while, and I think, “Gee it’s not that bad”. And you just go down another step each time and it could be months between. The only way I can say, that it was pointed out, that you can get by with only 15% of the neurons, you can lose 85% and not even notice it. And I just feel that’s what’s probably happening. They’re running out and then suddenly it gets out to that 15% and I notice it. That’s all I can put it down to, but it’s not really gradual weakness, there’s a definite plateau and then suddenly….

Others used different metaphors to describe when the plateau stage came to an end.

Mark: I have experienced that the changes were like a ladder. Something changes and then we do things to fix them up, like alternative ways of doing things, and we’d really get it down pat and it would be working great for a month or 2 or 6 or 12 months, and then it would change and then we would have to think about it how to fix the change.

Colin: I seem to deteriorate on a slow downwards spiral but occasionally slip from one level to the one below or even several below. Such a step is usually accompanied by a cluster of falls as I struggle to achieve an accommodation with my new status.

Wendy: Oh well. Just another step down the road.

5.10.3 “Gradual decline”

The final pathway was represented by a “gradual decline” and was defined by longevity of more than 5 years. As Ben described:
I have been in decline steadily for about ... 6 or 7 years – gradual progression or regression. I just get used to a stage of disability and something else happens and you notice you can’t lift your leg out forward or can’t do this or do that, and it just happens gradual.

Euan had lived with the disease for more than 10 years and had minimal deterioration of physical functions. For example, he was still able to manage using only a walking frame in the home. He had only recently lost some use in his right hand and had some speech difficulties. Mark lived with the disease for more than 12 years. He required full assistance as he was unable to use his arms and there was minimal strength in his legs but his speech was easily understood. Kevin lived with his extended family and had not seen his neurologist for 12 years. He was able to use an electric scooter to get around and although his speech was hard to understand, it had remained unchanged for a period of time.

In contrast, Carole’s husband noted that she had been diagnosed with MND for 10 years but had been a resident in a nursing home for the last five of those years. While her initial decline had been rapid resulting in her requiring full nursing care, over the past 5 years she had slowly deteriorated. At the time of the study her husband described her as having “locked in syndrome” as she spoke only with her eyes.

The impression given by some participants was that the disease was taking a long time and the waiting was at times burdensome. This appeared to be related to the uncertainty of living with the disease while the deterioration of functions continued. Some felt cheated because they had changed their life plans because of the prognosis but in reality some of their plans could have been fulfilled such as travelling overseas.

The pattern called “gradual decline” defined a slow progression of the disease over time with some participants experiencing significant physical changes while others were minimal in comparison. Some patterns appeared to be a mixture of fast track, stepwise and gradual decline phases.
5.10.4 Summary of patterns

Living with the changes and adaptation was a downhill journey of failing abilities – of falling down “another rung in the ladder” or “falling off a plateau”. The journey was also described as “another step closer to the end”. While there was no dominant pattern, all participants seemed to have a sense of the inevitability of the course of the disease and the downhill path to the end of life. What was important to them was how they traversed that path. As Mark said:

“Oh well we're all going to die, one way or ... other. Let’s do the best we can in the time we have.” We have got this time so let's make it the best we can – happiness in being together. It builds memories so when the day comes that I do breathe my last – people will be sad for a period of time because I have gone but they'll ... think ... of all the good times ... “Oh well. He did the best he can and he was here for a reason and he enlighten our world”, just by knowing me.

5.11 In Summary

Living with MND is represented by a decision-making model developed from participant data. Participants continued to move through the decision-making cycle each time they perceived a change. Contextual influences impacted on participant decision-making and choices. The core theme for living with MND, which was interwoven through all participants’ stories, was “maintaining personal integrity”. This became the basic social process that underpinned all decision-making and choices. These are discussed in the following chapter.
CHAPTER SIX
MAINTAINING PERSONAL INTEGRITY

6.1 Introduction

In the previous findings chapters, the two models developed to represent how most participants lived through the process of being diagnosed and then living with motor neurone disease were discussed. The first model depicted the diagnosis story as a process that each person experienced before being able to move on to deal with actually living with the disease. The second model revealed the decision-making processes that were integral to the experience of change. Changes were not just physical but a myriad of occurrences that appeared to impact on participants in various ways and were perceived as ongoing. Some of these changes were subtle and apparent only to the person.

Negotiation was a fundamental activity in participants’ lives. Many decisions were internally negotiated by participants and these included the decision to inform, or not to inform others, of the subtle changes that were occurring. Negotiations also occurred with intimate carers, family, friends and health providers when decisions were to be made about care and life choices. As the disease progressed and participants’ abilities to enact their choices were reduced, intimate carers took on the role of enablers or advocates assisting the participants to achieve their life and care choices.

In this chapter, the core theme of “maintaining personal integrity” is explained. Integral to this theme was the process of negotiation. Negotiation is explored through looking at internal and external processes. The dimensions of personal integrity and the processes of maintenance are described, drawing on participants’ experiences, as they traversed the diagnosis story and living with ongoing change and adaptation. The
conditions that impacted on participants’ ability to maintain their personal integrity and the strategies used to buffer negative effects are explained. The concepts of protecting, regaining and sustaining a sense of self in the face of ongoing change and subsequent adaptation, are brought together as the basic social process that underpins decision making while living with MND, that of “maintaining personal integrity”. Three key threats that placed participants’ personal integrity at risk were identified from the data. Impaired communication, experiencing but hiding “bad days”, and negative interactions with health professionals and service providers, were found to put at risk participants’ ability to maintain their personal integrity. It highlighted their vulnerability as they dealt with the ongoing changes and adaptations that explained the phenomenon of living with MND. This is the third construct of living with MND.

6.2 Core theme of “Maintaining Personal Integrity”

The key to understanding the struggles, choices and ways participants lived with MND was explained through the core theme of “maintaining personal integrity”. This theme connected the different facets of the decision-making processes and negotiations for choices that underpinned living with the disease and illness. The manner and effort of maintaining personal integrity differed slightly for each individual but for all participants, maintaining personal integrity was influenced by their feelings, level of control and the image they portrayed, both privately and publicly, about themselves. These dimensions of feelings, control and image were interdependent, influencing each other to form personal integrity. The maintenance processes of protecting, regaining and sustaining, actively encompassed personal integrity to ensure it remained intact and within participants’ capabilities, as shown in Figure 6.1 (see page 174). Although this conceptualisation depicts an idealised perspective of what participants typically experienced, outside influences such as contextual conditions and threats had integral roles that either enhanced or impaired the maintenance
of personal integrity. The maintenance tools that participants used to buffer the negative effects of change were the strategies they chose.

"Maintaining Personal Integrity" Conceptual Model

Fundamental to the core theme was the process of negotiation, which was necessary to enable the maintenance processes that encompassed personal integrity. Self-talk and inner debating constituted participants’ internal negotiation processes, whereas external negotiations included those people other than participants.

6.2.1. Negotiation processes

Participants in this study revealed three approaches associated with negotiation. First, participants instinctively contained their discussions, considerations and negotiations within themselves, using self-talk to debate what to do and to make choices that gave them the best outcomes in their compromised situations. Second, participants discussed and negotiated choices with intimate carers, families and friends based on their initial internal discourses. Third, they discussed options with people outside their
close circle of carers, including paid health care workers, care agencies and volunteers.

**Negotiating internally**

Participants used inner negotiation or inner debate to calm themselves by rationalising events and circumstances to prevent emotional outbursts and increased stress levels. Some participants felt there was a link between such stress and feelings of strength as physical capabilities deteriorated. Increased stress levels manifested “like a big wave … of weakness”. Although Heather endeavoured to ensure enough preparation time before an activity, she used self-talk to calm herself if she found she was running late.

*Today … I left myself lots of time … I was fine. I was quite strong…. Then we were running a little bit late … but … then I told myself, “well it doesn’t matter if I’m five minutes … that’s ok”*

Heather explained her inner debate about emotional times that were detrimental to her wellbeing:

*On one hand it’s important to allow yourself to feel those emotions and to express why you feel angry or why you think, “This is pretty rotten thing to have to go through.” Other times though it’s good if you think, “Well hang on a minute, I’m not going to allow myself to go down that track, because it’s just too exhausting and I’d rather have a better day than going to all this screaming and crying and sobbing business.”*

Kevin internally negotiated his suicidal thoughts coming to the conclusion “that’s a coward way out”. Participants often had conversations within themselves about important issues like deciding to inform or not inform others about increasing weaknesses or rationalising events so they did not seem to be detrimental to self. Inward discussion or self talk became more prominent as participants’ ability to communicate verbally became more compromised. Much inner debating ensued before using time and energy to operate augmentative and alternative communication (AAC) technology to communicate with others.
Negotiating with intimate carers

As the disease progressed, it seemed that negotiation and discussion of choices in life narrowed from a broad range of people to include only participants and their intimate carers - usually their spouse if they were married, or specific people whom they trusted, if single. Often discussion about choices was prefaced by “we decided” or “we chose”. Negotiation for choices were generally enacted or enabled by these intimate carers as they advocated on behalf of participants for their chosen life options. For example, Diane’s end-of-life choice was not to die at home. Although her husband wanted her to remain at home, he ensured she spent her final days as she chose – in a hospice. Because Thomas chose to stay at home, his wife negotiated with support services to ensure this was possible when he decided to discontinue non-invasive mechanical ventilation.

Negotiating with others

Negotiating with family was important for some to make memories for the future when they were no longer able to interact with others, and their families. For example, Una negotiated with her son for quality time with her granddaughter:

*Having our granddaughter here at the moment is lovely. I’m really enjoying that. I think our son realises that I need to spend as much time as I can now because we may no longer be able do that. I spoke to him yesterday … and I said, “Look let’s be open about it, there’s going to come a time when I’m not going to be able to do these things and let me enjoy it while I can.” Normally [my granddaughter] would just stay overnight but … she wants to stay … some of the holiday…. She lost a tooth while she was here so the tooth fairy come. She lost her second front tooth as well. It’s been quite exciting.*

Una decided to enjoy her life as a grandmother while she could. Other participants negotiated with their children to assist with care in preference to having outsiders come into the home. Vince preferred and asked his adult sons to help him, when his wife was unavailable. In contrast, Wendy did not
engage in negotiation with others, even though she had expectations of how others would assist her in the future:

Well we could get neighbours to help I’m sure. We could get someone. Anyway we’ve got a son who lives [nearby], so [he] can come down and give us a hand.

Although in most situations participants were satisfied that their advocate acted on their behalf, a disparity existed in some instances. For example, participants became disconcerted, felt demeaned and demoralised particularly when their needs were discussed in front of them by people other than their intimate carers, as if they were not present, thus denying their inclusion in decision-making about care. In these instances, intimate carers addressed the issue with the outside people, to ensure acknowledgement of participants’ rights as individuals.

For most participants, negotiation with health care services could be frustrating because of what appeared to be the hidden agendas of government funding bodies. Mark and his wife continually tried to negotiate for services but could never get to “first base”. Brendan and his wife seemed to have a constant battle in trying to negotiate their entitlement to paid hours of care and transport. His wife ultimately arranged transportation from a rural area to an urban hospital at less cost and more comfort for Brendan than the health service proposed. In contrast, Ben seemed to be aware of his entitlements and negotiated and assigned his paid hours of care as he wished. He did live alone so this may have been a factor for him in navigating and negotiating with people in the healthcare system without complaint.

In summary, participants’ negotiations were variously conducted internally, or externally with intimate carers and others outside the circle of carers. Significantly, participants’ beliefs regarding what was important and right for them personally and for their families, formed the nature of their negotiations about living with MND. Integral to participants’ beliefs and
values on which decisions were made was maintenance of their personal integrity. Participants revealed personal integrity typically within three broad dimensions of feelings, control and image.

### 6.2.2. Dimensions of personal integrity

The dimensions of personal integrity were identified as feelings, control and image. None was independent of the other; the three were irrevocably linked and interwoven to comprise an integrated sense of self for each person.

**Feelings**

Participants described a variety of feelings they experienced while living with MND: fear, “indignity”, “humiliated”, “independent and liberated”, “uncertainty”, confusion, “being positive”, being “self-conscious”, “healthy” and thinking it was all a “bad dream”. Although these aspects were all identified by participants, descriptions of personal integrity also included good feelings about oneself, feeling “special”, loved and cared for in an environment that was nurturing and warm, and which promoted self esteem, self-worth and respect.

In spousal relationships, the concern for the other was reciprocated with the caring partner playing the more active role of enabler in the relationship. Such intimate relationships were important for personal integrity. As Thomas acknowledged:

> Reminding myself of how very much I am loved and cared for is immensely settling for me. So is how much I love and care for [my wife] and others.

Central to the feelings associated with personal integrity was the need to be treated “normally” and be seen as the person he or she was and not as the disease or the fragile body, as two participants reflected:

Diane’s e-mail: *There are a few who continue to speak to me …, who treat me "NORMAL”*

Mark: *[My daughter] just sees me as a person, as a dad, and she’s not embarrassed with me being in the [motorised wheel] chair*
Feeling worthwhile, having purpose, and contributing to life, living and society were all various facets of personal integrity expressed by participants.

In contrast, not all feelings associated with personal integrity were positive in nature; indeed, many participants considered it important to avoid negative experiences such as feeling “humiliated, “patronised” or “embarrassed”. Gary felt demeaned and devalued by physicians. He underwent many invasive diagnostic procedures and treatments over an extended period of time but he continued to deteriorate. He perceived that the physicians did “not listen” to him and he consequently had “no faith” in the medical system. He also gained the impression that he was not important to them as a person. Patricia experienced similar feelings when her doctor did not acknowledge her concerns about the effect of the disease on her family. Thomas wrote about poor professional care and effects on his wellbeing:

> I hope someone in the profession will note that simple things (like having to wait 45 minutes for a urine bottle or an hour for someone to feed you, while your meal sits in front of you going cold, and I could go on and on) can have a gross effect on a patient, diminishing their confidence and increasing their anxiety, affronts their dignity and negatively affects their wellbeing.

What seemed to participants to be patronising behaviours on the part of health professionals had the effect of demeaning them. Brendan felt embarrassed when co-workers did not understand his episodes of emotional lability – of going “into a fit of a laugh” when people spoke with him.

Participants talked about the fear of their future with MND:

**Ben**  
My days of being an ... independent person are ... [numbered] ...it is not a very attractive thought.... You like to retain your dignity and independence as long as possible and to be a human vegetable - that's not an attractive idea.

**Diane’s e-mail:**  
It has become harder to lift my head I’m terrified I’ll become totally paralysed with all my thoughts trapped in my head.
Ben and Diane could not dispel these fears for the future, which caused them angst and had the capacity to diminish their feelings of self-worth and dignity.

How participants felt about themselves and what actions they took to feel “OK” influenced the choices they made in living with the disease while dying. Feelings appeared irrevocably linked to a sense of control in participants’ lives and a necessary facet of personal integrity.

**Control**

The control aspect of personal integrity was associated with a sense of being able to manage and influence events in life, extending from within the home or living environment to exerting an inner restraint on self. Often participants sensed within themselves, negative reactions to the consequences of MND progression emanating from feelings of having no control in life. Mark’s words illustrate his understanding of control in relation to the disease and the needs of “man”.

*Man as a whole is very inquisitive and we like to be in control of our environment, same as we like to be in control of our daily activities. I feel with this disease, the first thing you realise [is] that you haven’t got control: it’s dependence on other people - come in, getting you up, feeding you, grooming you, being nice to you.*

In this quote, it is not apparent if Mark means “man” in a generic or gender sense. However, his thoughts about the comparisons of control within the life of someone with MND are relevant. Having a sense of control promoted dignity, self-esteem and independence, which contributed to participants’ perceptions of personal integrity.

Conversely, no sense of control resulted in the erosion of personal integrity. Heather described what happened to her when she did not have command over her self:

*When I have my bad times then I become totally opposite [of being in control], I become this poor little sodden mass of hysteria.*
Such reactions compounded negative perceptions of self. MND, the disease, was seen to be controlling because it took away and limited participants’ choices. While the disease progression appeared uncontrolled as muscles deteriorated and participants lost strength and became weaker, the illness experience itself indicated that the disease was controlling the participants’ decisions in life.

Image

The third dimension of personal integrity was concerned with image. It too appeared inextricably linked to both feelings and control. The public image was one that participants endeavoured to project to people other than those who were part of their inner circle of family and friends. The private image was kept at home, out the view of the public, keeping all the detrimental effects of the disease and emotions away from critical eyes. An aspect that combined both public and private images was how the home environment was perceived by others, in connection with the way others perceived them. In essence, participants’ perceptions appeared to reflect that their home environment epitomised who they were. Image was found to operate in three main areas, public, private and home.

Public image

Although participants explained the public arena as leaving the privacy and safety of home, they included in their definition people from outside the home environment, and outsiders who came into the home, for example; paid carers, health professionals and service providers. Projecting a positive personal image in public and to friends was important for personal integrity. As Vince said:

*I could go back a few months and I was up at the pub and so forth. I don’t think my friends want to see me eating now, because it’s not really a thing to do in public.*

It seemed that Vince believed that his friends would reject him because his eating abilities did not meet the accepted social standard. Because he was
embarrassed, he limited his socialising opportunities in order not to destroy the positive image his friends had of him.

Image was about variously having a “smile”, “laughing”, being silent, not complaining and upholding community standards. Many participants believed it important to hide real feelings. Colin noted:

Outwardly I was putting on a brave face; inwardly I was aching at the prospect of ... further curtailment of my freedom.

Importantly, being well-dressed promoted the perception of being cared for and happy, which contributed to feelings of wellbeing in a positive sense. As Mark explained:

I feel if you’re a bit groomed nicely you feel better. You’ve had your hair brushed and you’ve shaved or whatever, you feel better ... [in contrast] this young man didn’t look like he’d been looked after.... And I thought “Oh, that poor man”.

To be thought of as a burden and pitied, especially in public, was a constant threat to self-esteem. As Vince reflected:

You always come to terms with things in time but if it’s only a matter of months that you go from walking to wheelchair, it’s just a little hard to go out in public.

Vince acknowledged he needed time to adjust to his altered self-image and identity because the changes associated with the disease progressed “too fast”. Participants’ disliked the feeling of being pitied. As noted earlier such a sympathetic response from people outside their close circle of family and friends seemed to the participants to render them invisible as individuals; they lost their sense of self to the disease. Participants recounted times when they found themselves responsible for counselling another about that person’s fear of death and dying from a terminal illness. As a consequence such people were avoided although in most cases they did not return of their own volition. To avoid interactions such as these, participants ensured that they presented a public face and image of wellness. Thus the dimensions of
feelings, control and image were entwined to reveal participants’ preferred public image.

Further, participants’ notions about image were prefaced by several personal impressions and beliefs. These included the public impressions they projected, how other people regarded them, and deciding what image to project to encourage a preferred response. It seemed that when the contrived images did not meet participants’ personal criteria, they tended to withdraw from public view and allow their sentiments of that particular day to evolve in the safety of their homes or residences.

Private image

Being out of the public view and at home with intimate carer/spousal relationships were defined as private by participants. Also considered private were thoughts and reflections that the participants were able to keep out of reach of others. Huberty (2000) illustrated the importance of private thoughts for people living with MND. She poetically described packing up aspects of her life into boxes as the disease process rendered them unusable but even the disease could not access the last box that contained her “private” thoughts and reflections.

Bad times were part of the private image, when the outpouring of emotions took over and were hidden from public view. Heather explained what it meant to be a “poor little sodden mass of hysteria”:

*I go with it. It makes me cross though because I end up with the biggest most swollen eyes you’ve ever seen and I say, “Blow it. I was going to do something the next day and now I can’t”.*

Heather was concerned with her public image being marred by her swollen eyes. Her public image could not be contrived, so she stayed at home until her eyes returned to normal. Participants often stayed at home and did not go out because their image did not meet their preferred public criteria. They were embarrassed and lost self-esteem because of their appearance and behaviours attributed to the disease, which ultimately influenced their
personal integrity. A further dimension which combined both public and private was the image portrayed by participants’ home environments.

*Home image*

Image did not just encompass the way participants physically presented themselves but included the environment in which they lived and how it was perceived by others. Presenting a tidy, neat, clean home was important for participants as it gave them a sense of self-esteem and dignity. For females with MND, this was especially difficult because they were reliant on others to maintain their home and this was not always done to their usual standards. The women felt they had lost ownership of their homes because their husbands and others attended to the cleaning and tidying, placing different signatures on their homes, thus they lost their image as the homemakers.

Diane: *Lose control over house - house is kept.*

Heather: *I like things to be pretty neat and tidy at home otherwise I get a bit agitated - a lot agitated because I can’t do it and then that annoys me.*

For most male participants this was not so problematic as, in line with typical gender divisions of labour, it was mostly their partners who had ensured that homes were neat and tidy. Partners still did this, in order to ensure that personal carers and people from support services had a positive image of them as a couple. For those who lived alone, local council support services maintained their homes. To an outsider some participants’ homes may have appeared messy as their many belongings were clustered around for the convenience of participants whose dexterity and mobility was diminished; having everything within easy reach was effective and efficient. One participant wrote words of encouragement and hope on his kitchen walls to remind him to not give in to the disease. Accessibility, independence and being positive overrode the need to preserve an image of being a tidy and clean housekeeper.
In summary, feelings, control and image made up the concept of personal integrity for each participant. As previously reflected these dimensions were interdependent and evidence of their presence was woven into the participants’ stories. Similarly participants illustrated the various negotiation processes they used in their day-to-day living with the disease. Una illustrated the integration of feelings, image and control as well as negotiation processes with herself and with her husband.

The other thing I’m trying very hard to do is to not feel guilty about not being able to do things. That was something I was finding hard to cope with - my husband doing things for our visitors. He’d maybe end up doing the cooking and I felt [that] people think I’m lazy. Then I think well, “I’m only punishing myself by pushing myself too hard and I’m not winning anything by doing it. I’m only making myself feel worse.” So I said to [my husband] the other day, “I think I’m learning to cope with the idea that if I can’t do it, I can’t do it. I’ll just stop feeling guilty about it.”

Una’s effort to reject the image of “lazy” by rejecting feelings of guilt, demonstrated her inner strength and control gained from self-talk negotiations. The actions she used in resolving her inner issues reflected the processes of maintenance of self integrity. It seemed that by stating aloud the decisions to let go of certain feelings about image assisted her to protect, regain and sustain her personal integrity. All participants at some stage in their living with MND encountered similar deliberations which promoted or demoted their personal integrity experiences by utilising the maintenance processes.

6.2.3. Maintenance processes

Personal integrity was not static. It altered as the myriad of changes personally affected each participant. Thus, it seemed that most participants endeavoured to maintain a level of personal integrity that was satisfactory for them. Maintenance consisted of three processes; protecting, regaining and sustaining. Each process identified groups of actions used by participants in their efforts to keep their personal integrity intact as their bodies
deteriorated. Participants chose or developed strategies to buffer negative effects of change in order to regain a sense of balance in their personal integrity. They endeavoured to sustain and protect themselves by remaining positive and not dwelling on the negative aspects of the disease, for example, comparing their illness to cancer: seeing cancer as worse than having MND. Ironically, some strategies used by participants to protect personal integrity had the potential to increase stress levels in the home environment as revealed below.

Protecting

Protecting personal integrity was a reaction to change or circumstances related to change, when participants felt devalued and demeaned as a person. A need was generated to protect personal feelings from further harm. Such instances occurred when participants experienced: sudden deterioration of a physical ability; “emotional outbursts”; disagreements with carers; “everything going wrong in the day”; feeling “humiliated” or “embarrassed” in certain situations. Various strategies were used including focusing on self, denying reality and withdrawing from the public arena and into self.

Focusing on self

While the decisions and choices made to protect personal integrity were generally successful for participants, conversely some were detrimental to their wellbeing in the long term as they placed extra stress on their carers. As an example, Gary only allowed his wife to care for him because he felt the disease had robbed him of his identity and demeaned him and he did not wish others to see this. This strategy protected his personal integrity but increased the stress on his wife as she was his only carer. Although such strategies seemed to be selfish in nature by other people, it was a way that participants used to protect their personal integrity.
Denying

Participants often denied a change that was impacting on their self-esteem and self-worth, although ultimately the change became more obvious to them and denial was no longer possible. As Colin revealed:

*Recently however my progress has been increasingly a slow shuffle. I was in a measure of denial that I had slipped.*

Similarly, when talking about how he coped with MND, Kevin said, “I don’t want to worry about it … I try to put it aside” – a version of denial. In addition, his wife and daughter said, “we try to steer away from the motor neurone and try to … treat him the way he wants to be treated, like … [normal] … it’s better that way”. Kevin had been diagnosed with MND for more than 10 years. He and his family’s efforts in living with the disease required great fortitude to ride Kevin’s waves of emotional lability, forthrightness and assertiveness as he endeavoured to live his life the way he wanted. These outward expressions of his personality traits were possibly his way of protecting his personal integrity. As a consequence, he and his family had a succession of community social workers who did “run away” after interviewing the family in their home environment.

Some participants used denial as a way to protect themselves because they did not want to know about the future with MND. Some said they did not attend support groups because they did not want to see what was “down the track” for them. Some participants, while not in direct denial of their disease progression and illness, chose to be informed by indirect means to protect themselves from detrimental emotional impacts. For example, Vince reported:

*I’m obviously interested in how everyone else is getting on but I’d rather just hear a bit of gossip on the side - that’s enough.*

Denial took many forms in protecting personal integrity.

Because MND eroded voluntary control of physical abilities, some participants coped with this loss by substituting physical control with
psychological control by detaching themselves, euphemistically, from their diseased bodies. This illness experience can be explained through the concept of duality which conceptualises opposites, as in the Chinese model of “Yin and Yang”, such as, active and passive, the moon and the sun, masculine and feminine (Poon, 2000). In this study, participants divided themselves into the healthy person and the person with MND. That is, they had a mental perception of themselves as healthy people who were capable of achieving anything, albeit within the confines of their motorised wheelchairs. They protected their integrity from the realities of the illness experience. When they became unwell, they accepted and nurtured their bodies until a balance allowed them to detach again. Detachment was similarly practised by some participants who preferred to deny the existence of the disease altogether. This strategy required psychological determination and control in order to deny obvious disabilities, such as not being able to walk, write or speak clearly. Such strategies permitted participants to protect their self-esteem by giving in to the disease when ill and regaining integrity by detaching and denying the presence of illness when feeling well.

Withdrawal

In another strategy, participants characteristically withdrew from the public eye if they believed their personal integrity was under threat or they kept silent about being upset and did not inform others of their concerns and issues. These actions of hiding at home may have protected participants’ personal integrity, but subsequent consequences were typically more detrimental to them and their families’ integrity, advancing the feelings of hopelessness and helplessness. Participants who withdrew into themselves when feeling sad or out of control needed to find courage within themselves to regain some self-esteem and hope. As Mark explained:

"I don’t want to tell people my little irks and quirks that makes the day bad. I’d rather concentrate on making it better if it’s bad… [Other people] have … dreams and I think, “Why can’t we?” Whether or not we ever do it is beside the point. I deal with them when I’m by myself."
In most instances participants required assistance to move forward so that personal integrity could be regained. Neville spoke of “we” making choices. He and his wife worked together to overcome losses:

*The wheelchair will be the next thing, but we’re not thinking about that now. We just face [the changes] as they present themselves; because that’s the only way we can cope with the large things.*

For some participants, asking for help was very difficult and uncomfortable but once they were able to meet this challenge, self-esteem and self-worth were improved and as a consequence, a perception of being in control again ensued.

**Regaining**

The task of regaining personal integrity was not achieved by all participants because it was “too hard” and too difficult. Sometimes this effort was too much for some and they continued to withdraw into themselves. Jack said he tried using the Lightwriter but did not like the synthesised voice. He did use the computer to maintain contact with his family overseas, but even that was becoming more difficult because he was losing the ability to remember appropriate words. For some participants, MND seemed to just overtake them, leaving them little or no time to regain some personal integrity. For most, regaining personal integrity was necessary to continue fighting against the experience of losses and changes and in order to live with some quality of life as they perceived it. Regaining balance in life was about asking for help, getting a sense of control back into their lives, having access to everyday services and reframing thoughts.

*Asking for help*

Declining physical abilities were difficult for participants to come to terms with and they were kept out of sight as much as possible. However, there came a time when the ability to maintain aspects of personal integrity such as control and image, could be regained only by asking for help. Heather provides an example of such a time:
I went to a seminar … for a few days. I was wheeling along a bit more then, but it was difficult on the carpet. People would walk past and you’d think, “Gee I wish they just say, ‘Could I help push you?'” They think, “Maybe she wants to be independent” or they don’t even think about it, but you’ve got to say, “Excuse me, could you just push me” and then they say, “Oh yes,” and love to do that. So you have to be the one that initiates it often.

The participants gave up some aspects of personal integrity when they asked for help, such as a sense of independence, but regained other parts that, at the time, were more important to them. For Heather this was moving around at the seminar, albeit with assistance.

Gaining a sense of control

Gaining a sense of control motivated participants and contributed to regaining personal integrity. It appeared that having control mediated the sense of helplessness and hopelessness, which seemed linked to the incurability of MND. Many participants sought out knowledge about MND through the Internet and books as a way of empowering themselves. Participants used “chat rooms” to converse with others who had MND, all over the world. This promoted the swapping of “how to” ideas about dealing with different problems associated with the illness. For example, Mark found out about dental prosthetics that prevented ulceration due to biting the buccal lining of the mouth. Heather found out how another person used naturopathy, diet and exercise to slow the disease progression. Diane found someone with whom she could talk and who understood what it was like to live with disease because she also had MND. Having knowledge and information empowered participants and gave them a sense of control in what is an uncontrollable illness. Having knowledge also provided the foundation for requesting appropriate assistance using the correct terminology, which promoted self-esteem and personal integrity.
Having access

Accessibility was a major concern for those participants who used wheelchairs. Not being able to access shops, theatres or walkways seemed to demoralise participants, their families and friends. Mark explained:

*It’s amazing how you feel not being able to go into a shop because it’s got steps. Like newsagents, I’d like to go in there and have a browse at the books and magazines, but I can’t get in there. They’ve got a rail but they’ve got two steps.*

Brendan felt he could not go out because the pathways were not wheelchair friendly without ramps and space to pass others. Denis felt vulnerable when out in his wheelchair because he had been attacked by a dog while on a walk. As a consequence he refused to go out, which made it difficult for his wife when she wanted to go.

In contrast, participants felt good about themselves when they were able to access facilities. Mark said, “It’s a good feeling to be able to go into a shop and have a look without feeling a nuisance.” Edward felt less trapped at home with ramps fitted to his front and back door steps. Having access, and feeling good and not trapped, enabled participants to regain some personal integrity that had previously waned and eroded.

Reframing thoughts

Many participants talked about turning their thoughts away from the negatives into something positive or rationalising the “why” of their actions. This was a way of regaining the feelings of self-worth and understanding so life was not coloured with sad, angry and despondent thoughts. Vince looked out to sea and thought of his family and the view to forget about his sadness. Rose cut down her massage table so she could still attend to clients from her wheelchair. She did this to maintain a living and a sense of being useful, despite opposition from her family who said that she could not continue with her livelihood. Her family’s negative attitude motivated her to keep doing what she wanted to do in her life. Neville was distraught by the
consequences of the disease but decided to complete projects before he died. He completed a chess table for his son, photo albums for each of his children and was creating one for his wife which represented their life together. This gave him a sense of achievement because these were his goals prior to the disease, and now he had completed them albeit as end-of-life activities.

Although Yuri was not included in the decision to perform a tracheostomy because he was unconscious at the time, after a while, he came to accept the intervention by reframing his thoughts and concentrating on his relationship with his daughter. In this way, he was able to regain a sense of being worthwhile and having purpose in life.

Some participants had trouble in shifting the negative consequences of living with MND to a more positive and comforting way of viewing things. For them, therefore, regaining personal integrity was challenging. For example, Gary often dwelt on all the aspects of his life that had been taken away and that he could never attain again, such as being the man of the house, traveling with his wife to China and Bogotá and not being able to care for and protect her as he had previously. He seemed to mourn these losses repeatedly and to be unable to reframe his thoughts or to relive his memories of the good times in a positive way. Ben also typically dwelt on what he could not do and brooded over his losses. He tempered positive achievements with associated negative accounts of things going wrong:

*It was a holiday but ... this cottage's in the middle of nowhere. You can't go anywhere in your wheelchair.... It's ... in the middle of a cow paddock.... They are very remote.... I wouldn't stay there again.*

Generally, participants sought to regain some personal integrity in their lives when it declined. They were motivated to act because they wanted to feel better about themselves and to improve their lives with their families and friends. Participants variously used strategies of: asking for help, gaining a sense of control, having access, and reframing thoughts. When participants sensed a regaining of personal integrity to a suitable level, different strategies
were instigated to sustain their feelings of well-being and control. The primary nature of these strategies was one of surveillance.

**Sustaining**

Participants sustained their personal integrity by being aware of situations and circumstances that were potentially detrimental to them. They found ways to counteract the potentially negative effects in their lives by taking advantage of circumstances, by pre-empting detrimental situations and seeking “positivity”.

**Taking advantage**

Sometimes participants took advantage of what were potentially demeaning incidents, and reversed expectations so that there was a good outcome. Such actions sustained participants’ sense of self and worthiness. For example, Mark accepted that the label and visual perception of a person who was disabled like himself, elicited stigmatising reactions from others, but he changed his thinking and actions, which consequently altered expected reactions:

> People get threatened by the wheelchair at times I found, and I think “Oh that’s sad that they get that” but most people are happy to have a yak and talk about things, which I think is very good for me, good for them and if I wasn’t in the chair I don’t think it would happen. So I feel I’m using the situation to the best of my advantage, which really tickles me…. That’s what I feel.

Taking advantage reflects an alternative to reframing thoughts by viewing disabilities as a positive outcome as opposed to loss of abilities. Ian found when on holidays in Europe, he and his family were first on rides at a Euro Disney complex instead of lining up like others. He chose to see this as an advantage and he felt that his family’s holiday had been enhanced, which gave him a sense of satisfaction and helped sustain his personal integrity.
Pre-empting

Pre-empting negative consequences and being prepared to address them effectively, sustained personal integrity for some participants. Thomas did so by identifying what demeaned him and affronted his dignity, and then revealed how it was an ongoing process of working through his issues and concerns. Because he was aware of situations that negated him as a person, eroding his feelings of self-esteem, self-worth and sense of control, he could pre-empt them and continue to repel their effect. His words exemplified many participants’ stories:

*I may be over cautious [about] having my dignity affronted. Some events have certainly tested my limits. This has ranged from not being asked my preferences … [to] insisting I undertake treatments I have not required. Discussing me as if I am currently visiting another planet or suddenly become a different species, keeping me waiting endlessly in discomfort or pain because professional time has (in their arrogance) become more important than mine has. Stonewalling (“Well, I’m sorry…there’s just no funding…. You will have to be flexible here” … “We can’t find the Doctor” … “I’ve just run out of time” … and so on) which has included attempts to impose decisions on me motivated by expedience. I am still working through these issues; currently I’m not sure if it’s me or just some health professionals I’ve met on a bad hair day.*

By acknowledging situations that were detrimental to their dignity, participants were able to neutralise their feelings, work through the issues and look for answers to “why” such circumstances occurred.

Participants gained experiential understanding about what and when situations and events could affect their self-esteem, sense of control and their preferred public image. Thus, they learnt from their experiences of living with the disease and pre-empted detrimental and derogatory situations. When participants pre-empted such feelings and used different strategies to buffer the effect, they sustained their personal integrity.
Similarly pre-empting included planning for future needs; in this way participants could make choices before concrete decisions needed to be made such as moving into institutional care. Zara moved in to a newly-built nursing home before she became debilitated. She pre-empted the decision before being forced to do so by the progression of the disease and before she became what she viewed as a burden in her children’s lives. In contrast, Carole was admitted to a nursing home because her husband was too ill to care for her. Carole was not included in the decision-making about admission or choice of nursing home. Her husband recounted the experience, “that was probably the hardest thing … [Carole] just … went to pieces…. It was very traumatic.” In this case Carole’s husband’s illness was the impetus for her move to residential care. He chose the facility because it was close enough for her friends to travel to visit her. Carole had no involvement in the decision concerning the admission, the timing or the nursing home to which she was admitted. The doctors and her husband made the decisions and she was devastated.

Making the choice themselves to relocate allowed participants to pre-empt the need to do so later, taking the decision out of the hands of family members, health professionals and the disease itself. This resulted in positive experiences for participants as they felt that had control.

Seeking “positivity”

Often a method of sustaining personal integrity used by participants was to avoid negative people, and seek positive interactions with others and positive and happy events. Rose sustained her personal integrity by avoiding people who were negative and who complained about their own sicknesses. She wanted “positive things” in her life and not the negative words of others. Rose recalled:

> And then someone said, “Are you getting worse?” What a thing to say! … [I want] positive thing[s]…. Well I try to avoid those people…. Then there’s the phone calls to see if I’m still alive [laugh].
Several participants chose to laugh off derogatory events or just laugh with their intimate carers to find joy in the moment instead of sadness and anger.

Heather endeavoured to keep positive:

_I think ‘God, who cares about not walking when I have so many friends who are having difficulty just breathing?…. It helps me … to always keep the positive/negative in the right perspective. I love to be part of that group…. Recently we had a little memorial service to the ones that we’d lost. We lit candles for them and that hadn’t been done before and everyone spoke so bravely and openly and it was wonderful._

While a memorial service might be sad for some people, Heather found it a positive experience because she described others in positive and uplifting terms, and experienced a sense of happiness in the event. Lionel wrote sayings on his wall to promote a positive view of life, to sustain his inner being and thus his personal integrity. Diane wrote about how she remained positive in her life:

_I live one day at a time. There are some days, trying to stay positive can overwhelm me. This thankfully … does not happen often. Having a normal functioning brain sitting on the shoulders of a non-functioning body tends to get your mind working in overdrive. Fighting frustration and boredom is the biggest hurdle otherwise depression can easily consume you. All my life I have said, “I don’t want to merely exist on life support, being fed through a tube.” This is a real possibility with MND…. Knowing I am still able to communicate with my wonderful family is a bonus._

Most participants sought positives in their lives and in doing so sustained their personal integrity. Although some interactions with others hurt participants, they developed ways to endeavour to sustain their personal integrity by knowing who to avoid, hanging up on detrimental phone calls, seeking the positives in life and laughing.

_Laughing_

Many participants used laughter as a way of getting over tense situations. Married couples often talked about defusing such moments by
laughing together. Some had a greater propensity to do so than others depending on their previous life experiences. Laughter could also detract from obviously demeaning experiences, such as being carried up and down two staircases by four burly men while in an electric wheelchair, to attend a wedding reception, as Mark experienced. At the time he was fearful but afterwards he and his wife could laugh about the incident and sustain his integrity. He pursued discussions with the hotelier about accessibility issues for people with disabilities, which was a focus for continuing societal endeavours that he espoused. Similarly Euan and his wife, and Andrew and his wife used laughter as a coping mechanism for the hardships they faced from the consequences of MND, thus sustaining their sense of integrity.

Other ways that participants endeavoured to sustain their integrity was learning to give up detrimental feelings or perceptions of self, to stop “feeling guilt”; they chose to accept what could not be achieved and find something “achievable”. Often, if participants were unable to achieve these tasks, the opposite occurred and personal integrity waned. Overall, it appeared that the process of sustaining by participants, concerned balancing their states of personal integrity, of being able to “go with the flow” of the highs and lows of change and adaptation, as on a “see-saw”.

In summary, the three processes of protecting, regaining and sustaining were evident throughout the stories that participants told. The processes were interwoven within the dimensions of personal integrity and negotiation. At times participants sensed stability, sustaining their personal integrity when life was being lived day-by-day, with what seemed like, no alterations. This depicted a “plateau” in the illness experience. This feeling promoted confidence and self-assurance about life. A comfort zone followed in which personal integrity was constant and small illness experiences and incidents ignored. Crises, “bad days” and wake-up calls challenged this comfort zone, reminding participants and their families of their vulnerability and the need to remain vigilant in order to protect personal integrity from insidious change. Each crisis eroded personal integrity, which meant more
effort was required to regain a level that was sustainable and acceptable for each participant.

Other influences became apparent and seemed to impact on negotiation and maintenance processes as well as affect the dimensions of personal integrity. As previously revealed, living with MND was "hard work" so various contextual conditions had the potential to enhance or detract from the efforts already expended by participants.

6.2.4. Contextual conditions

A number of contextual conditions impacted on each participant’s struggle to maintain personal integrity. Demographic aspects such as age, gender, residential area and socio-economic group influenced the different ways participants endeavoured to bring about balance to their lives and thus maintain their personal integrity. Usual coping styles such as attitudes to life and locus of control, previous life experiences and experience and knowledge about MND, all influenced the process. This specifically included past experiences of the health care system by participants and their families.

Past experience of the health care system

Past life experience and knowledge had the potential to assist the maintenance of personal integrity. For example, some participants had prior knowledge about the health care system because they had worked as health professionals, had previous contacts with the system through the experiences of other illnesses or had family members who worked in the system. Having this knowledge provided an advantage when negotiating health care services. This insider knowledge effectively enhanced participants’ self-esteem and personal integrity because they were able to negotiate the system for their preferred choices. In contrast those who were dealing with the health care system for the first time often floundered and had treatment delayed, and as a result they felt demoralised and their personal integrity was diminished.
Socioeconomic aspects

The individual financial circumstances of participants had the potential to impact on their capacity to maintain their personal integrity. Although Rose explained, “Money is nothing. It lets you do what you can, to be well”, those with easy access to money were able to buy services that were not available to others on lower incomes. Being able to choose to have an expensive medication, a massage twice a week, alternative treatments or a paid carer, improved personal integrity for some participants because exerting choice was empowering. Paradoxically, this perceived advantage had limitations as it precluded these participants from accessing mainstream options. Private health insurance and private care limited the options available in the public systems. However, being in a lower socioeconomic group also limited options because of increased needs. Many options were available but had to be stretched across a number of other groups with similar needs for supportive care, such as people diagnosed with multiple sclerosis, terminal cancer, renal failure and dementia.

Knowledge of the health care system and socioeconomic status had the potential to impact on participants’ endeavours to maintain their personal integrity. To counterbalance the effects of change and impacting conditions, participants drew on strategies to maintain personal integrity to buffer feelings, take back control and protect their public image.

6.3 Maintaining Personal Integrity as a Basic Social Process

The basic social process that underpinned all the decisions and actions of participants was one of maintaining personal integrity as depicted in Figure 6.2 (see page 201). The effort to maintain personal integrity was evident in the participants’ stories and underpinned their decision making, as illustrated in both the diagnosis story and the ongoing change and adaptation model. The choices participants made about living with MND came from a desire to ensure that they maintained positive self-esteem and offset negative beliefs about themselves and their futures, as they contended
with the realisation that the diagnosis of MND meant dealing with ongoing physical and psychological changes that were characteristic of the disease. Maintaining personal integrity was not always about personal feelings and self-esteem. Some participants maintained their personal integrity by engaging in situations that actually diminished their self-esteem and feelings of safety, in order to do what was best for their families. For example, some chose to go into respite care although they intensely disliked institutional care. They made these choices because they recognised that their families needed time away from their roles as full time carers. Though not their first choice, this type of decision enhanced participants’ personal integrity as it demonstrated that they could still “look after” their families. However, as part of this endeavour, participants used self-talk to negotiate inwardly.

Throughout participants’ stories of living with MND, it was evident that having personal integrity was important for participants as they lived with the progressive decline of their bodies. Integrity was maintained by setting small achievable goals for the day and having flexible plans to allow for disturbances in their day-to-day living, such as experiencing constipation, blocked PEG tubes, non-arrival of carers, or a computer breaking down. Participants realised that time was different for them because activities took longer as physical functioning deteriorated. Acceptance of this allowed participants to feel a sense of achievement thus impacting positively on their sense of integrity as a person. If participants had difficulty in coming to terms with extended time frames, they became distressed and sad, sensed a loss of control and of the disease taking over, which led to diminished personal integrity.
In general, participants’ persistence in negotiating choices about living were focused on warding off feelings of despair and loss of control. These feelings threatened to overwhelm some participants as the sensation that the disease was “in control” overtook them. Sometimes metaphors helped participants explain what they were experiencing. Seigleman (1990) contended that the characteristics of metaphors are such that:

they combine the abstract and the concrete in a special way … to go from the known and sensed to the unknown and the symbolic … in a way that
typically arises from and produces strong feeling that leads to integrating … insight. (p. ix).

One example was Heather’s warlike metaphor of army defences, used to repel MND:

I also see it is really like an advancing army and that I’m … putting up defences. I’m making obstacles so that the army isn’t overtaking me. But every now and then, one man falls and there’s a few sneak in - so I do see it as a threat but I’m not living with a constant feeling that I’m a victim…. but certainly that I’m in control.

Metaphors allowed the generalisation of the fight against MND without reference to explicit feelings about it. Defences included personalised activities such as nutrition and exercise regimes, attuning to body nuances recognised as “reading the body” and maintaining a balanced level of emotions. With respect to maintaining personal integrity, sometimes such defences faltered as participants became over-tired or did not plan activities to conserve energy. At these times, emotional outbursts often followed the breakdown of self-imposed defence mechanisms that maintained a valued sense of self. Strategies to counteract or buffer these episodes were required to re-build self-esteem and regain personal integrity.

As identified by Heather and other participants, regaining and sustaining control was important for quality of life as they perceived it. It seemed that projecting a positive public image of managing at home was important for those participants who lived in their own residences. Sometimes escalating problems were hidden from those people who were close to or cared for them. The discovery of such predicaments by family members, friends or health professionals often triggered supportive suggestions which were then negotiated with participants and their intimate carers. This defused tense situations because the problems were shared. As an example, Heather’s niece instigated employment of a personal carer for two days a week, which gave her usual intimate carer, her husband, time for himself thus easing tension in the home. Mark and his wife struggled to
negotiate funding from government institutions until a carer suggested contacting the disability advocate who then acted on their behalf. Such actions ultimately improved quality of life, self-esteem and self-identity for participants. They allowed them to regain some control in their lives, although altered, and once again, the projected positive public image remained intact.

The reverse appeared to be true when participants were unable to regain some positive aspects or purpose for living, but instead, sustained negative thoughts, poor self-esteem and feelings of guilt. Several participants expressed feelings of guilt at the disruption to the family that their diseased and illness state caused. For these participants’ quality of life deteriorated.

After experiencing disturbing changes, participants sometimes regained their personal integrity by learning to live and cope with the various losses associated with the disease. Participants consciously altered their goals or adjusted them as their levels of ability degenerated and they used these moments for reassessing how they would continue to live their lives. Vince held that in time, there would be “a cut-off point” when he could no longer accept further deterioration of his body and life yet, he conceded, that he kept “raising the bar or lowering it” as each cut-off point was reached. It seemed that he re-evaluated his life for purpose and his ability to cope with his continuing deterioration, and found that the cut-off point had not yet been reached. Generally, participants negotiated internally about the question of whether life was still worth living. These internal debates and outcomes embodied the fight to maintain personal integrity because the decisions made, reflected the effects of coping with change.

Another aspect of maintaining personal integrity concerned the control of choices in life decisions. Diane wrote on her computer:

*I believe in having a choice. Not to have a PEG or ventilator. I have made a medical power of attorney when I made a Will before my diagnosis. Even more determined [now].*
Many participants asserted their choices with regard to having and not having life sustaining interventions, such as PEGs, to maintain nutrition, or a tracheostomy for invasive ventilation to maintain oxygenation in the body. Mostly their intimate carers were aware of the choices they had made but not all had legal powers to guarantee the discharge of such life choices. Legal documentation, such as a medical power of attorney and a trusted advocate, was a method of documenting pre-empted decisions to ensure that personal integrity was maintained even when the power of communication was lost.

Participants experienced many changes that impacted on their personal integrity, which they needed to address as they lived with MND. In addition, the data revealed three main threats to the basic social process of maintaining personal integrity, which impacted on participants’ illness experience.

6.4 Threats to Maintaining Personal Integrity

Living with MND was a constant challenge for participants particularly when conditions threatened their attempts to live well on a day-to-day basis. Impaired communication, having bad days and dealing with health professionals and service providers, had the potential to demean participants and produce feelings of hopelessness and loss of control. While these were only potential threats, the strategies chosen by participants to counteract such detrimental feelings could, at times, also enhance their self-esteem as they constantly stove to balance and maintain their personal integrity. Such were the paradoxical consequences of dealing with the threats. These are explained in relation to the potential threats.

6.4.1. Impaired communication

Impaired communication abilities appeared to threaten the participants’ innate sense of self. As Colin wrote:

*When the onset of that loss is in the ability to talk it immediately strikes at the very core of the person’s identity.*
Communication was seen as a challenge by some as they tried different technologies to communicate. Using Lightwriters both enhanced and detracted from participants’ feelings of self-worth. Some viewed the Lightwriter as benefiting their wellbeing because it enabled them to keep in contact with their families and loved ones when their natural speech faltered. This technology facilitated the maintenance of their self-esteem, feelings of self-worth, and enabled their participation in decision-making and choice-making. Often acceptance of the altered image was integrated imperceptibly with the realisation that the communication technology was integral to regaining a sense of independence and freedom because communication was again possible. Colin remarked in his writings:

> My son was to be married in UK. I was concerned that I wouldn’t be able to do a speech for the newly weds [as] I had done one for my other son ... I was introduced to the Lightwriter ... Some frantic reading, typing, gnashing of teeth when I had to edit, link memories and I was enabled to do a speech on the day. Lightwriter even remembers jokes and with … [its] multiple voices is able to give even more impact in their telling. Having it was an enormous psychological boost. Doing a course of study in counselling, I was aware that though I could attend lectures and do assignments, speechless I couldn’t participate in interactions demonstrating my competence. The Lightwriter, quickly renamed Chatterbox, resolved this obstacle.

Using other technologies, such as computers, also opened up a world that had hitherto been unknown. The World Wide Web chat rooms with PALS (People with ALS), e-mail communication, information searching on Internet sites for such issues as holiday facilities accessible for people with disabilities and on-line shopping, created opportunities to explore independence, freedom and socialisation which was excluded as the disease and illness progressed. Although verbal communication was impaired, the ability to communicate was enabled and extended by the various technologies so that feelings of self-esteem and self-worth were maintained.
In contrast, some felt demeaned by the Lightwriter because the synthesised American voice did not reflect them as Australians or the people they were, so the machine was infrequently used. Others found electronic Lightwriters too slow when constructing sentences and relating what they wanted to say. Participants explained that it took great concentration to move parts of the body, thus the produced movement was slow and deliberate. As a consequence, the perceived slowness of the technology caused frustration for participants, which impacted on how they felt about themselves. Diane wrote about using the Lightwriter:

> I used to be so out going and a chatter box, but I get so ... [tired] trying to make myself understood. If I use the Lightwriter to type out my thoughts by the time I’m ready the topic has changed. Extremely Frustrating.

The slowness in using Lightwriters caused some people consternation and as a consequence they felt rejected because they were overlooked in conversations. On the positive side, as Colin explained, the slowness of using the Lightwriter allowed him time to reconsider initial thoughts and be more constructive with words when angry.

> ‘Chatterbox’ has often been the buffer between what I normally would have said and what on second thought was seen to be unhelpful and didn’t.

Augmentative and alternative communication (AAC) technology was not always appropriate or available in all situations. For example, when in hospital some participants reported they endeavoured to communicate with nursing staff verbally but gave up because they could not be understood. As a result, participants said “nothing” because the effort to communicate eroded their self-esteem, self-worth and identity and it was tiring. The consequence of this action was that often their choices were not communicated to others.

When communication was lost, often safety issues surfaced, care was compromised and participants withdrew from social and care situations. For example, when in hospital, Denis was unable to get carers to listen to him as
his speech was slow and laboured. The rash on his body was misdiagnosed by staff although his special creams were with him. Inappropriate care resulted in a major exacerbation of eczema which caused his wife great anguish and him both physical and mental distress and suffering. In cases such as these, not only was physical health affected by diminished communication abilities, but personal integrity was threatened.

6.4.2. “Bad days”

Another threat to maintaining personal integrity was experiencing “bad days”. Bad days happened when participants experienced changes that they perceived as detrimental. Changes extended from lost movement in one finger to revised health service funding policies that impacted on paid support services. Such days were “black” and “just too hard to cope with because they [seemed] never ending sometimes”. Some said they “just felt lousy and seemed to be sick” all over their whole body. Participants often hid such days and chose to cope, in private, at home. The consequences of such choices, on the one hand, protected participants’ self-esteem and integrity because other people did not see them in distressing states and perhaps pity them. On the other hand, hiding bad days limited the support they received at critical times because health professionals were unaware of compounding problems.

Some participants recognised that bad days “don’t last” and that there are both “bad days and good days”. As Mark explained:

I think bad days you can make more of, if you work on it. The same as you have good days because you work on it. I think, as I said before, most people would be working for the good days because the good days are always better. They might take less to happen than bad days. Bad days blow up and get bigger and bigger and bigger if you don’t do it. Where you can have a happy day or a good day, they won’t get really big as in everyone happy but you’re little world will stay happy…. Like a smile. Smiling uses less muscles than a frown. That’s amazing. Yet so many people won’t smile for
whatever reason, and that’s my goal is to make people just have a smile. If it costs me being silly that’s fine.

A poster that represents this aspect of living with MND is in Appendix I. Experiencing bad days and not being able to find or have good times or days impacted on participants’ personal integrity. The threat to maintaining personal integrity derived from participants’ inability to cope with such sad, bad days because their needs tended to be unseen, sometimes, by families and health professionals.

6.4.3. Health professionals and service providers

Often participants experienced detrimental feelings when negotiating with health professionals and service providers. For example they felt: “frustrated”; demeaned, because they had to beg for funds; lost, because they perceived no guidance was given; worthless, because of the way doctors reacted to their intellect – treating them as though they were children. These responses ultimately affected participants’ personal integrity. As Colin wrote:

Highly trained, competent and caring professionals can be very irritating as they get on with what they know is right. As an ex-professional, it’s very frustrating to have one’s ability set aside by someone who only sees an invalid who can’t talk.

Mark and his wife described their frustration in trying to get the government care services they wanted. They used an analogy to explain the experience:

Mark’s wife: It’s almost like playing scrabble with an older brother and he keeps changing the rules. “Oh you’re not allowed to do that”, “Didn’t you know about this?” It’s almost … that level of frustration

Mark: I think we can’t even get to first base with them.

Mark’s wife: No we don’t even know what first base is

Patricia described her experience of meeting with her general practitioner (GP) when concerned about her family and the effects of the disease on them.
You just feel you walk away and you feel as if they’ve left you for dead and that they don’t care what happens to you, it’s an awful feeling and I get really frustrated.

Some participants recounted attempts to remain in control of their lives and choices when hospitalised. They described traumatic experiences that coloured their subsequent decisions. Diane attended the emergency department of the local hospital because of pain. Allied health professionals seemed awkward with her because she had minimal communication ability. They laughed over her and ignored her requests to stop a procedure which caused pain. Her husband reported the staff “seemed to focus on [kidney stones] as being the cause” but did not request any information about ongoing or previous “medical conditions” that may have impacted on her presenting condition. Diane wrote, “They do not understand … it was frightening … I was questioned but [my husband] had to answer.” He said Diane was glad to come home, “the worst thing the doctor could have said was that, ‘you’re going to have to stay in, tonight’ … even one night”.

Similarly Heather told about her experience in hospital, which took away her self-esteem and control impacting on her integrity:

Most of the six days I was just in bed, so I was getting weaker and weaker as the days went by, because it was sort of safer just to stay in bed [voice faltering]…. It wasn’t a very good experience.

Mark rationalised his experiences in hospital but overall he and his wife decided that respite was not worth the effort.

Mark: When my wife gives me a wash [she] washes me properly. Not just a quick one like they do in the hospital…. [It] is important to have a proper wash in your vital parts of you, where in hospital they don’t do that…. They hose you with a little hold on hose…. Where here [home] when the nurses come they give me a great shower because it’s under my shower. They do me with soap. I turn it up nice and hot because I like it hot, where the hospital is really cold. I can understand that … so for me I bear it. I know some people have to go [to hospital] and that’s fine but I wouldn’t want to go there every week, or even
once a month. It would drive me nuts because it’s a job for them whereas my
wife, she loves me and she’ll go that little extra minute there or even five
minutes making sure I’m comfortable. Even putting me in my chair, it’s just the
little things that [she] does that wouldn’t take the nurse any longer but they just
don’t learn that.

Mark’s wife: Hospitals are for sick people really, and [Mark]’s not that sick he shouldn’t be
there. We were using the hospital for respite once a fortnight weren’t we…. That
was all right but our little girl fretted, she didn’t like it and Mark hated it….
He’d come home extra grumpy and extra tired. I’d think, “Oh this is not
working. Let’s just shelve this idea.”

Mark: I didn’t think it really worked very well.

Mark’s integrity as a person was threatened when he was in respite in the
hospital. Besides coping with showers that were cold and not as thorough as
he wished, he did not complain. Subsequently when the reason for being in
respite did not occur, that is rest and relaxation time for the family, Mark’s
wife stopped accessing the respite service.

Heather reflected on her experience of respite care for three weeks. She
talked about the effect of an interaction with a nurse that made her sad and
homesick:

It was some issue with transferring…. I think she was doubting me, what
we were doing or she was getting a bit ruffled by it all … I remember
saying, “Well I’ve been doing this for three years, you know”. [sigh] I just
felt like it was all getting all too difficult…. And then you do feel a bit sad
that you’re somewhere and not home.

Sometimes participants’ attempts to maintain control had the side effect
of angering and frustrating health workers who then withdrew their services.
This, in turn, placed greater stress on their intimate carers and in their home
and care environments. Although not all participants were able to resolve
problems or experienced detrimental interactions in all situations, the
consequences for those who did, was to refuse to return to hospital or see
their specialist again. In this way they felt they were protecting themselves from further distress. As Thomas revealed in his writings:

> Currently I feel I have to compromise and accept this situation. The alternative is … another visit to the … hospital. As it takes me weeks to overcome the physical and emotional … [effects] of being an inpatient and the 2 hour one way trip to Melbourne, this is not a very attractive option.

Brendan felt demoralised when health professionals rejected him. He said, “That’s the worst thing” – being rejected because he had a terminal illness that they did not want to confront themselves because caring for him appeared too hard for them.

Contrary to the previous experiences, one participant coped well with his hospitalisation after his initial admission. He subsequently met a fellow patient with whom he could communicate and who had similar experiences of living with a neurodegenerative disease. They timed their periodic admissions so they could keep each other company. However, Saylor, Yoder and Mann (2002) contend that people are stigmatised when they are diagnosed with a disease with no clear aetiology, cause, cure or treatment, and that some health professionals will refrain from providing equitable care because of this stigma. In this current study, such stigmas had the capacity to jeopardise participants’ personal integrity. Overall participants’ interactions with health professionals and service providers threatened their abilities to maintain personal integrity as they coped with the ongoing change and adaptation that reflected the experience of living with MND.

### 6.5 In Summary

Participants’ stories told of the decisions made in response to ongoing changes caused by MND. They appeared to seek information from health professionals, care providers and volunteers on ways to live with the disease. However, the answers appeared to be concerned with the disease itself rather than the illness experience. Without guidance, participants based their decisions about living with MND on a process of maintaining their personal
integrity in the face of the ongoing changes and adaptations. Negotiation for life choices was mainly internalised by the participants then discussed with intimate carers who enabled their decisions. Maintenance included protecting, regaining and sustaining processes that underpinned personal integrity. Personal integrity for participants was the product of the interaction of feelings, control and image. The basic social process that underpinned negotiations was maintaining personal integrity while living with MND. Congruent with grounded theory principles, literature is reviewed as data is analysed. Thus, in the following chapter, the findings are discussed in the light of other research literature.
CHAPTER SEVEN

DISCUSSION OF FINDINGS

7.1 Introduction

The intention of this grounded theory study was to explore the life-world of people diagnosed and living with motor neurone disease. A major focus was to gain an understanding of what it is like to live with the disease while negotiating with others to influence future life choices. A further aim of the study was to give this group of people a voice so that others can gain an understanding of what it is like living with a disease such as this. As shown in the previous chapters, the findings reveal three constructs. The illness was experienced first through the diagnosis story, which outlined what happened before, during and directly after diagnosis. Second was the decision-making processes adopted by participants to deal with ongoing change and adaptation, and third was the basic social process of “maintaining personal integrity”, which underpinned decision-making.

In this chapter, the focal aspects of the diagnosis story and the ongoing change and adaptation model are discussed in relation to current, relevant literature. The nature of personal integrity in the lives of the people with MND is an integral feature. The processes of “maintaining personal integrity” are explored, and comparisons made between the strategies used by participants in this study and those reported for people with other illness experiences.

7.2 The Story Behind the Process of Being Diagnosed

The main issue evolving from the diagnosis story concerns the participants’ attempts to develop a therapeutic relationship between themselves, their general practitioners (GPs) and, in particular, their specialists. Research identifies that such relationships can benefit
patient/clients’ health status and wellbeing (Blattner, 1981). A therapeutic relationship implies the existence of trust, empathy, hope, active listening and rapport that promotes curing or nurturing to a level of wellness if cure is not possible (DeLaune, 1998). The health professional endorses a holistic perspective of the person, by focussing on the person and not just the disease, illness or disability (DeLaune, 1998). This fundamental understanding of the therapeutic relationship was one initially expected by the men and women in this study.

7.2.1 “In the beginning...”

Participants recounted complex stories regarding the process of being diagnosed with MND. The root of their discontent was physicians’ communications of the disease process and its terminal nature. Although the uncertainty surrounding their vague symptoms was distressing, participants believed that the diagnosing physicians failed to provide information, guidance or hope about “living” with the disease. Participants were, for the most part, not given the time and support to develop understanding about MND and the illness experience at diagnosis. As a result, they emerged after diagnosis feeling “angry”, like being “kicked in the stomach”, “shocked”, “sad”, “traumatised” and “uncertain” about their future. Subsequently when given the opportunity to discuss living with MND in this study, participants were keen to recount the actual diagnosis process. Documenting their stories, either on audiotape or in writing, appeared a necessary activity before they could proceed to discuss living with the illness. The need to recount this experience in profound detail seemed to suggest unresolved emotional distress.

Research literature indicates that motor neurone disease is difficult to diagnose because there is no definitive diagnosis. Symptoms are confused with pre-existing illnesses (Chancellor, 1996; Kalra & Arnold, 2003; Leigh et al., 2003; Leigh et al., 2001; Walling, 1999) and implicate other diseases such as carpal tunnel syndrome and multiple sclerosis (Leigh et al., 2003). Many
diagnostic tests are required to exclude other conditions such as cerebral lesions, cervical myelopathies, inclusion body myositis and myasthenia gravis (Leigh et al., 2003; Leigh et al., 2001), as the diagnosis is certain only with autopsy (Swash, 1998). The uncertainty around the long drawn out process of finding a diagnosis seemed to cause the participants more frustration and distress than actually obtaining the diagnosis. Mackenzie (2003), a neurologist diagnosed with MND, described the months of uncertainty and false hopes before diagnosis as “the worst four months” of his life (p. 2). Even with his medical knowledge and understanding of the disease, he still experienced the diagnostic process as a traumatic period.

Most participants in the study did not have any detailed medical knowledge. This put them at a disadvantage when they dealt with health professionals and tried to understand the meaning of the extended diagnostic roundabout. At the time, participants seemed to understand the need for different referrals, tests, treatments even surgical interventions to investigate the confounding symptoms. When each test returned a “normal” finding, participants allowed themselves to believe that nothing was wrong until another change occurred. It was not until much later that they realised the physicians had suspected a possible MND diagnosis all along. However, it seems that in most cases discussion about the prospect of MND never occurred, therefore, the diagnosis was even more devastating because it seemed to come out of nowhere. The long drawn out phase of not having an overall understanding of the reasons for the repeated referrals often left participants frustrated, lost and uncertain. The detrimental feelings associated with the process weighed heavily on them, eroding their feelings about themselves, their control of life events and overall personal integrity.

Similar issues about diagnosis were identified by Cox, Henderson, Anderson, Caglierini and Ski (2003) in their study of women with endometriosis. These women found it difficult to find a medical practitioner who was sympathetic to their symptoms and they described the merry-go-round of “doctor shopping” (p. 6) to arrive at medical answers and treatment
for their condition. Although participants in both the Cox et al. (2003) study and this one, experienced difficulty finding a doctor who would listen, doctor shopping was not a feature of the current study; instead, participants repeatedly returned to the same GP. Participants admitted initially to having a high degree of trust in their relationship with health professionals but after diagnosis, most felt their trust had been misplaced.

While the women in the Cox et al. (2003) study described frustration and disappointment, the distress of the participants in this study seemed to have more in common with the stress suffered by victims of posttraumatic stress disorder (PTSD). The American Psychiatric Association (APA) defines PTSD as “a syndrome” that develops after a person experiences an extreme traumatic stressor (Sadock & Sadock, 2003, p. 623). Symptoms include reliving the stressor in dreams and daily thoughts as well as avoiding any associations that may trigger re-experiencing the trauma. Initially, exposure causes acute stress disorder (ASD) and if symptoms persist after four weeks and longer, the diagnosis is PTSD (Sadock & Sadock, 2003). The Sidran Institute (2003) identifies a life-threatening illness and invasive medical procedures as examples of traumatic stressors. In this study, although the actual diagnosis was devastating in itself for participants, the diagnostic process itself seemed to be the traumatic stressor.

Timely debriefing and/or counselling can resolve the initial response of ASD, preventing the subsequent development of PTSD. Studies have also identified debriefing as an important tool in the process to resolve PTSD (Gamble, Creedy, & Moyle, 2004; Gamble, Creedy, Webster, & Moyle, 2002; Irving & Long, 2001). It may be that for participants in the current study the opportunity to retell the experience of diagnosis acted as a means of debriefing. Gamble, Creedy and Moyle (2004) explored women’s perceptions of counselling needs as an intervention to facilitate recovery after a traumatic birthing experience. These authors suggest that traumatic childbirth produces PTSD in women and that debriefing can reduce the prevalence of postnatal depression and PTSD (Gamble et al., 2002). The women identified
issues that would assist them in their recoveries, such as having the opportunity to talk about the birth, developing an understanding about the events, talking about other possible scenarios, and discussing the future (Gamble et al., 2004).

Similarly, it may be that people newly diagnosed with MND would benefit from debriefing and discussions with qualified and knowledgeable health professionals within the first weeks after diagnosis. This strategy may ameliorate some of the post diagnosis responses evident in the stories and could perhaps lessen the detrimental feelings experienced when not listened to, heard, or dealt with honestly.

Communication skills are integral to the therapeutic relationship and are necessary for successful debriefing/counselling. Harris and Templeton (2001) studied women with breast cancer and Jackson, Blaxter and Lewando-Hundt (2003) researched patients and carers living in deprived areas. The findings from both these studies suggest that the most helpful physician behaviours were listening actively, acknowledging experiential knowledge, being honest and participatory. Listening was the skill ranked as most important. In addition, patients experienced frustration, panic and worry that extended to their families if they thought the physicians did not hear what they were saying (A. Jackson et al., 2003). The participants in the current study generally did not have experiential knowledge about MND at diagnosis. They expected their physicians to be honest and listen to what they had to say.

7.2.2 “Getting the bad news”

The findings in the current study indicate that without effective communication channels, gaining information about how to live with MND and how to access materials about the disease is problematic. Other studies about people diagnosed with MND echo this concern (Robinson & Hunter, 1998; Small & Rhodes, 2000). Many health professionals reportedly experience difficulty giving “bad news” and the act of providing pertinent
information is often neglected (Maguire, 1999; Ptacek & Eberhardt, 1996). Physicians themselves highlight the need to improve their skills in relaying such news (von Gunten, Ferris, & Emanuel, 2000) and, according to Johnston, Earil, Mitchell, Morrison and Wright (1996), the specialist physicians who appear to experience the most difficulty in giving the diagnosis of MND are neurologists (Chancellor, 1996). Johnson et al. (1996) reported that people with MND desire and value straight answers to their questions and do not seek protection from the diagnosis because they feel that having a label for the condition facilitates their coping efforts. The participants in Johnson et als’ study believed that physicians were unnecessarily pessimistic about MND, a finding supported in the current study, which further illustrates the difficulties experienced by both the participants and physicians at the time of diagnosis.

Negative experiences and communication issues between patients and health professionals have been reported in other studies that have investigated the process of diagnosis. For example women with breast cancer (Harris & Templeton, 2001), individuals with skin cancers (Winterbottom & Harcourt, 2004), and with chronic illnesses (Maguire, 1999; Kralik, Brown & Koch, 2001) expressed similar frustrations. Participants in these studies describe encounters where they felt they were not heard and that their symptoms/problems were not recognised or acknowledged. These studies also highlighted that people diagnosed with an illness have a need for information about the disease and how to live with it. Also unacknowledged for most was the pervading sense of loss and feelings of being lost at the time of diagnosis. In concert with the findings from this current study Kralik et al. (2001) found that women diagnosed with chronic illnesses, attached similar meanings to the diagnosis process. The women had comparable expectations and experiences. That is they hoped for the possibility of treatment and cure; they expected to have relevant information available so they could learn about their illness and how to live with it; and they lived day-to-day with uncertainty and with a “disrupted self-identity” (p. 595). The current
findings confirm the continuing problem highlighted in these previous studies: that the process of being diagnosed with a chronic or life threatening experience does have a negative impact on people who are ill and that the consequences seem to shape and colour future interactions with health professionals.

Some neurologists find facing their patients’ emotional responses difficult, as do some oncologists when giving “bad news” (Maguire, 1999). In response, medical researchers have sought to improve the “standard of consultation” by developing key steps to guide “diagnosis telling” (Borasio et al., 1998; Willey et al., 2002), recommending that knowledgeable neurologists give the diagnosis (Leigh et al., 2003), then follow-up with consultations and provision of information about MND services. More recently, McCluskey, Casarett and Sideowf (2004) developed a survey based on the protocols used for giving bad news to cancer patients, identified as SPIKES (Baile et al., 2000). The results of the survey indicate that physicians can improve the “telling” by using the protocol. The key elements include allowing a minimum of 45 minutes to tell the patient and their families the diagnosis, and arranging another consultation in the near future to allow for discussion.

In 1998, the MND Association in Victoria produced a patient pamphlet in conjunction with The Council of the Australian Association of Neurologists. Although neurologists received the pamphlets to distribute to their patients with MND, most participants in the current study had not received this readable information. Consequently, they employed a variety of other means to seek out information. Although international research and local activities are directed towards improving the physician-patient relationship for people with MND, this study indicates that a communication gap between people diagnosed with MND and their physicians remains, warranting further research.
7.2.3 “Doing my own thing”

Because of the communication difficulties that existed between health professionals and participants, the latter group searched for information about MND from other sources in order to understand the illness experience. They often sought solace in the personal accounts of illness from others, in particular those who lived with MND. Such readings provided a focus for some to seek ways of living with the disease – choosing to do their “own thing” when no other obvious guidance was available. As an example, the writing of Australian, D. MacKenzie (2002) proved inspiring to some. He discussed his diagnosis day as his “watershed day” (p. 18) because it changed his life forever. Most of the participants related strongly to this sentiment. They connected emotionally to his accounts of drawing on religious beliefs as he became increasingly frustrated, angry and sad about his losses. Likewise, an American academic documented aphorisms to live with MND while dying (Schwartz, 1996), and some participants drew on these to guide their thoughts as they too focussed on living while dying. As the disease progressed, he described living with the disease to his former student who documented his journey (Albom, 2001). His journey inspired others to find goals in life.

The participants used the Internet extensively as a source of information about the disease. Some discovered the Motor Neurone Disease Association of Victoria through such browsing and subsequently made contact to access support services. Others found possible treatments and regimes to assist in living well and slowing the progress of the disease. Although the reliability of the information on the Internet is variable, for those people who had no guidance, it was a rich lifeline. As participants began to live with the disease, chat rooms on the Internet often became the socialisation centre for supportive conversations with other people living with MND around the world. In the absence of guidance about how to live with MND, the participants developed such strategies to gather information and plan their life with the illness. However, many carried with them a
degree of bitterness that scarred subsequent relationships with health care professionals.

### 7.2.4 Getting “on with the rest of my life”

Although subsequent relationships with health professionals were marred for many, the relationships with their family and friends took on greater importance because the participants realised these people would be part of their life with MND. This re-evaluating life phase included reframing of life goals and nurturing personal relationships for reciprocal care and comfort to get on with living and life. Although this phase was often emotional for participants and their families, it was a necessary transition to find a “space” in which living with the illness was possible. In the literature about chronic illnesses, a phase such as “reframing future” represents the restructuring of a new reality that encompasses the reality of life with a chronic illness (Selder, 1989). In the current study, while both being diagnosed and receiving the diagnosis itself were shattering, some in the group had no method or process of regaining a “normal” life because it was irrevocably changed and it kept changing. Thus began life with MND. Lives of facing the challenges of ongoing changes and choosing adaptation strategies to meet the alterations provoked by the disease.

### 7.3 Ongoing Change and Adaptation Model

Once the diagnosis was a near certainty, living with MND became a day-to-day challenge of responding to each change caused by the progression of the disease. Findings reveal that the process of dealing with change settled into a distinct decision-making pattern, whose components are shown in the conceptual model of Figure 5.1 (see page 133). Decision-making patterns or algorithms are evident in many day-to-day problem-solving situations. Algorithms are often used as guides, for example, in cardiac and pulmonary resuscitation (CPR) with Danger, Response, Airway, Breathing and Circulation (DRABC) (St John Ambulance Australia, 2000). These key words define a specific pattern adhered to for assessment and
resuscitation of an unconscious person. This ordinary example reflects an episodic linear decision-making process with an end-point.

### 7.3.1 Decision-making pattern

The findings in the current study indicate that decision-making formed a significantly different pattern to that described above. The ongoing change and adaptation model is cyclic and continuous with a variety of outcomes depending on the different challenges faced. This decision-making model relates to a pattern for life and choice-making about living with the illness experience of MND. As the disease progresses, integral decisions are concerned with the maintenance of life using technology, such as invasive and non-invasive ventilation equipment, but the majority of decision-making is concerned with psychosocial issues. Psychosocial issues include choosing appropriate accommodation, discovering activities that were achievable, deciding to retire or deciding when to get a wheelchair.

The pattern of the decision-making process has seven steps; perceiving, reacting, appraising change, adapting, adjusting to change, sensing wellbeing and facing another change. Participants continually faced change as the disease progressed and change was ongoing. Sometimes there was time to adapt to the change and sometimes there was not because another change was occurring. Regardless of the timeframe, participants followed the same pattern for each change.

Such steps resonate with the concept of coping developed by Lazarus and Folkman (1984). They defined coping as “successful adaptation” efforts and those adaptation strategies deemed as unsuccessful as defence efforts (p.140). Their concept concerned the response patterns of people to changes that they had “appraised as taxing or exceeding” their resources (p. 141). Individuals questioned or appraised the stressful events in order to ascertain their nature and impact on wellbeing. According to Lazarus and Folkman, decision-making is divided into primary and secondary appraisal phases. The primary appraisal consists of evaluating the significance of the event and
secondary appraisal concerns the dynamics of deciding what to do about the event and choosing coping options.

A similar process occurred for participants in the current study, which involved recognising a change, appraising its impact on personal integrity and creating a meaning for change. This process approximates the primary appraisal phase of Lazarus and Folkman’s (1984) concept of coping, while the adapting and adjusting stages of the decision-making model described in the current study, correspond to Lazarus and Folkman’s secondary appraisal phase. Indeed, the ongoing change and adaptation model takes this concept further. Participants in the current study, embarked upon another appraisal phase related to deliberation about the outcome of the chosen strategy and its effect on their stress levels, overall wellbeing and personal integrity.

Although the gamut of changes perceived by participants was physical, psychological, emotional, environmental and unpredictable, such changes were not always perceived as stressful. This perception resonates with Lazarus and Folkman’s coping model, although their model focused mainly on changes that threatened a person’s integrity. In the current study, it seems that perceived changes may not only threaten an individual’s notion of self and personal integrity, but may also enhance wellbeing and reduce stress levels.

7.3.2 Illness trajectories

As noted, the decision-making pattern was cyclic and involved moving progressively and purposefully through the process and starting again when another change occurred. This pattern was reported repeatedly as the disease progressed. Although this cycle of perceiving, reacting, appraising, adapting, adjusting, sensing and facing another change, was typically followed, some participants experienced plateaux that permitted respite while others were constantly engaged in the process. Three distinct rates of change were identified - “fast track”, “step-wise” and “gradual”.
As explained in chapter 5, the people on the “fast track” experienced no adaptation periods. Change was ongoing and their condition deteriorated rapidly as a consequence. The “step-wise” trajectory involved periods of near stability reflecting plateaux of imperceptible changes. The rate of perceived changes seemed to increase and decrease over time representing peaks and troughs of disease activity. Participants on the “gradual” trajectory experienced a slow progression of changes, which seemed to have minimal impact on them at the time, but over time deterioration was clearly evident. On this trajectory, people had time to adapt to each change, although some experienced a slow and even progression with increasing impact and minimal time to adapt. For this group, living beyond their prognosis sometimes became a burden. Some perceived that waiting for changes was at least as detrimental to their personal integrity as experiencing rapid deterioration.

Other studies identified patterns of survival of MND in relation to the pace of the disease progression (Robinson & Hunter, 1998; Small & Rhodes, 2000). Some people died quickly and others experienced plateaux when no further deterioration occurred. Olney et al. (2003) proffered evidence that people with frontotemporal lobe dementia (FTLD) tend to have a shorter survival time and an increased rate of body function deterioration similar to the fast track trajectory. The findings in the current study indicate there are three separate illness trajectories when disease progression is charted from diagnosis. A confounding condition was that some participants later realised they had experienced symptoms long before seeking medical assistance, therefore, identifying their actual trajectory was problematic. Nevertheless, the three patterns can provide an explanation and clarification of the illness experiences for people diagnosed with the disease.

Research about living with a terminal illness reveals perceptions of normality as “a reference point” for people to redefine their current state of living while dying, in respect to their lives before the onset of illness (Carter, MacLeod, Brander, & McPherson, 2004, p. 614). For example, people with
acquired disabilities negotiate within themselves an acceptable redefined normality to integrate and encompass their transformed bodies and lost abilities (Krause & Stanwyck, 1998) and to identify themselves as a person with a disability (Morse & O’Brien, 1995). A reframed sense of normality encompasses physical, psychological, spiritual and environmental perspectives held by individuals pertaining to themselves. Some illness decision-making models are linear and episodic signifying a return to a normalised state, for example, people living through a hysterectomy (Chassé, 1991) or heart attack (Johnson, 1991). People experiencing these illnesses expect to return to a normalised state similar to their pre-illness level, after the events. According to King (2002) people adjusting to the diagnosis of myocardial infarction create an altered normalised state by “taking stock” (p. 434) of life, as they often needed to rethink their lifestyles in the reality of their condition. In the current study, it appeared that a degree of normality seemed to be out of reach of most participants. MND, unlike other illnesses, does not allow for periods of normalisation as change is ongoing. Once ability is lost, it is not regained. There are no remissions, although sometimes the disease process slows. Sometimes windows of normality were possible, albeit short-lived, as functioning continued to decline and evidence of the disease persisted. The decision-making process to deal with change is, at all times, continuous and focused on maintaining a sense of personal integrity while dealing with issues and concerns related to living with the disease.

7.4 Maintaining Personal Integrity

Central to both the diagnosis story and the ongoing change and adaptation model is the concept of personal integrity. In the absence of guidelines or advice on how to live with MND, participants made decisions and choices based on maintaining personal integrity. In the main, this outcome was a personal matter for participants. As the disease progressed, intimate carers, family and friends acted as advocates and enablers so participants could achieve and have their choices carried out. Maintaining personal integrity was not a self-centered action but one that generated
concrete standards that each person could use; these typically did not change unless the person chose to do so. It was “hard work” for participants to live with the disease - physically, psychologically and emotionally. Goals for living included negotiating ways to make them feel good about themselves. Self-esteem, self-worth and dignity were all valued but difficult to achieve as body functioning deteriorated. The disease took away muscle control, demeaning participants’ perception of themselves as they faltered in day-to-day living. Importantly they needed to re-establish a sense of control in their lives because it enhanced their personal integrity.

**Hard work**

Maintaining personal integrity was “hard work”, constant and life-long. Living with MND required great effort to adapt continually to the changes that are symbolic of the disease. Effort and hard work were required to live day-to-day, even just to achieve the level of concentration required to move a finger or leg. Any distraction from the task meant the neural message was lost, so that participants dropped cups or fell down.

People in the study worked hard to hide to their feelings of distress from their families because they felt it was necessary to protect them. It was an effort to maintain a positive public image by smiling and being pleasant when inside they felt terrible, sick and depressed. The effort continued with the complex negotiations needed to receive funding and to access adequate services, because the bureaucratic rules kept changing. Reframing or “letting go” of activities and goals, as well as searching for replacement activities that were achievable and satisfying, needed considerable cognitive and physical effort. These activities required participants to work hard on refocusing their lives but, at times, they became tired, despondent and withdrew from society altogether. Sometimes they were able to overcome these sensations and other times they could not. The effort and hard work required is similar to the experiences of people with eating difficulties after a stroke (Carlsson, Ehrenberg, & Ehnfors, 2004) and to those living with Parkinson’s disease.
(Marr, 1991). The Carlsson et al. (2004) study revealed the constant struggle and hard work needed for people recovering from a stroke to adjust to severe eating difficulties. Marr’s (1991) study of people diagnosed with Parkinson’s disease also identified their hard work and effort to maintain independence and to achieve a level of normality in life. Such efforts of personal endurance and fortitude promote self-esteem and personal integrity.

7.4.1 Personal integrity

The hard work by participants to engage in strategies for protecting, regaining and sustaining personal integrity in the face of the ongoing changes characterise MND, and was a feature of this study. Various research studies have identified the concept of personal integrity, using different labels but in essence all with similar meanings. Randers and Mattiasson (2000) used a concept of integrity with 10 categories, as a theoretical framework to explore the perspective of elderly patients in geriatric care. The concept included variations associate with personal property, private territory, corporal self and secret self that consisted of “a person’s ‘secret rooms’, which accommodate feelings, wishes and memories” (p. 505). In a study by Widäng and Fridlund (2003), hospitalised male patients defined integrity as self-respect, dignity and confidence. Jacelon’s (2003) study about hospitalisation experiences of elderly patients revealed the processes this group went through to manage their “personal integrity”. They defined personal integrity as health, dignity and autonomy with attributes that included self-dignity in “dignity”, feelings and wellness in “health”, and control and independence in “autonomy”. In the current study, the definition of personal integrity evolved from participants’ stories when they talked about their feelings, about having control in their lives instead of MND being control, and about the importance of maintaining a positive public image. Three dimensions of feelings, control and image that were identified are discussed in the following section.
Feelings

Participants talked about their feelings throughout their stories. The context of their feelings pertained to their integrity as a person. They talked about such sentiments as “dignity”, “self-esteem”, not “being embarrassed” and not “being pitied”. Other studies reveal that participants talk about feelings also, but not in the context of personal integrity. Swedish researchers, Olsson, Lexell and Söderberg (2004) interviewed 10 women diagnosed with secondary progressive multiple sclerosis to elucidate the meaning of fatigue. The women described feelings as physical sensations of fatigue such as, their arms being “heavy” and emotions of, “frustration, stress, sadness and anger in themselves” when they had no physical strength, because of fatigue, to undertake activities even though they had the will (p. 10). Although such sentiments can suggest personal integrity, the focus of their study was the experience of fatigue. In the Charmaz (1994) research, men expressed negative feelings about coming to terms with chronic illness; they revealed that having a sense of personal control was vital in preserving integrity in their lives.

Control

Control was an important dimension of personal integrity in the Charmaz (1994) study. Likewise, a sense of control in life over decisions and choices was important to the participants in the current study, particularly because much of their physical life was out of control. As the disease ravaged their bodies, robbing them of the ability to walk, talk, swallow and even draw breath, the men and women sought to maintain their personal integrity by controlling aspects of their life. Control as a characteristic of personal integrity, has been found in other research studies to be integral to people’s lives. For example, in the Carter, MacLeod, Brander and McPherson (2004) study with people who have a terminal illness, “taking control” was a theme for encompassing and focusing on choices for life and living, and not dying. Blomsjö’s (2001) study of eight people with MND revealed that each feared
the loss of control should they be ventilated. Above all, they feared to not being able to turn off the ventilator and not having their requests for this course of action honoured by staff. For them, having a sense of control meant maintaining their self-esteem and self-worth as autonomous individuals. Further confirmation of the importance of control comes from Bandura’s (1986) theories about human thoughts and actions. His psychological foundational theories support the suggestion that having control in one’s life is an important human need to maintain a sense of integrity in life.

**Image**

Another aspect of personal integrity is image. In the current study, projecting a positive image in public was essential for participants’ personal integrity. They expressed a need to be viewed as someone happy, coping with their illness, independent and welcoming of interactions with other people. It was important to them that other people did not pity them, as this eroded their self-esteem and self-concept. If they felt their public image was not how they would like, or if they felt unwell, they chose to stay at home and not interact with those outside the safety of their home environment. In this way, they believed they protected their image and, therefore, their personal integrity. These actions highlighted participants’ discomfort with exhibiting themselves when they looked unwell. Such behaviour was revealed in the “hidden MND” and in “bad days” that participants experienced.

Image is an important issue for most people but for those with physical disabilities that are visible because of disfigurement, awkward behaviours such as walking with a shuffle, or using assistive technology such as a Lightwriter, it can become a key issue that influences personal socialisation opportunities. Rumsey, Clarke, White, Wyn-Williams and Garlick (2004) surveyed and interviewed 458 patients with a range of disfiguring conditions to explore their psychosocial needs. Conditions included burns, tattoos and visible congenital disfigurements that required elective plastic surgery. The
findings revealed that the majority of problems were associated with social interactions, being in the public eye and being stigmatised by other people because of their ignorance, and negative comments.

Participants in the current study appeared to experience similar concerns about body image. They withdrew from public view and hid because of the visibility of their impairments and because the image they projected, was not one that they accepted. People with Parkinson’s disease (PD) have similar experiences. Caap-Ahlgren, Lannerheim and Dehlin (2002) interviewed eight women with PD to explore their experiences of living with the symptoms of their disease. Findings identified that the women feared negative evaluations and detrimental comments by people in public because these caused them to feel ashamed. These women tended to withdraw from the public eye; avoidance increased as the visible signs of the disease increased. Likewise, when the men and women in this study were uncomfortable with their projected image, they were likely to retreat, stay at home and withdraw from social activities. Similarly, if people were experiencing “bad days” with everything going wrong and they felt sad and unhappy, hiding obvious signs of distress and anxiety became a part of the hidden MND experience.

The hidden MND

There seems to be a hidden MND, one that is out of sight of the public eye and often not known or realised by health professionals. This is especially evident when “bad days” are experienced, personal integrity is low, self-image is not acceptable, feelings are negative and a perception of the disease being in control of life decisions overwhelmed participants.

The men and women in the study told of their reluctance to allow others, not in close relationships with them, to see the sad and demoralising side of the MND illness experience. They told of “bad days” and the strategy of staying at home and hiding, of not interacting with other people, as a method to protect their self-esteem, and their integrity as a person. Often
hiding such days resulted in a worsening of problems that further eroded their personal integrity and relationships with intimate carers. Participants demonstrated a reluctance to involve others outside of the home in resolving issues related to bad days. Morse (1997) revealed that people with serious illnesses and injuries tend to withdraw into themselves to deal with symptoms that were overwhelming and a threat to their integrity. Similarly, people with catastrophic illnesses and injuries used protecting strategies of hiding the extent of their disabilities and limiting the sharing of information about their illness to others – they “concealed their distress” (Dewar, 2001, p. 604). This invisibility helped maintain self-esteem and personal integrity by hiding the more demeaning aspects and consequences of the illness.

Participants in the current study endeavoured to cope with mobility and communication difficulties without support from allied health professionals. It appeared that intimate carers supported participants in their endeavours to keep the distressing aspects of the illness experience hidden at home, because admitting one needed help, was detrimental to self-esteem and self-worth influencing personal integrity. This intention to promote a positive image is echoed by Charmaz (1994) who found that preserving self included preserving a public positive identity by minimising the “visibility and intrusiveness of illness” (p. 276). The men in her study consciously endeavoured to keep hidden, from the public eye, the consequences of their chronic illness. Similarly Nijhof (1995) found that people diagnosed with PD reported feelings of “shame” which were related to the notion that they were breaking public behaviour rules by exhibiting the visible symptoms of PD. Nijhof identified that this group of people divided their life worlds into private and public domains. Much like the participants in the current study, people in Nijhof’s study endeavoured to retreat from the public domain when they realised the symptoms of PD were visible to others.

The findings from the current study suggest that withdrawing from public view was not so much associated with shame but with not having a public image congruent with the one they wished to convey. Those who had
not adapted to the visibility of their symptoms, such as exaggerated expression of feelings as a consequence of emotional lability or being pushed in a wheelchair, retreated from the public domain to protect their personal integrity. However, for others, maintaining personal integrity meant being out in public and being involved with life. The visibility of their symptoms was not a concern to this group. Being involved in life, seeking “positivity” and laughing with others were all strategies related to image and aimed at sustaining personal integrity.

7.4.2 The processes used to maintain personal integrity

It was hard work to continually maintain personal integrity on a daily basis. Making decisions about perceived changes was a constant and ongoing struggle. Maintenance consisted of three processes, protecting, regaining and sustaining. Other studies have used the terminology of “preserving” as representative of methods used by individuals to sustain their integrity when feeling vulnerable. The idea of preserving explains how people bring their sense of self back into balance while moving through critical experiences. Morse and O’Brien (1995) used “preserving self” to describe the actions taken by patients when they survived serious traumatic injuries. For Charmaz (1994), “preserving self” defined the actions men undertook as a way of reconciling their identity dilemmas they experienced as they came to terms with having chronic illnesses and disabilities. Irurita (2000) and Irurita and Williams (2001) found that patients sought to preserve their integrity in response to feelings of vulnerability during acute hospitalisations. The researchers developed a theory of “balancing and compromising” as a method of explaining the reciprocal preservation of integrity as experienced by nurses and patients. The nurse’s role involved “conserving, protecting and restoring” a patient’s integrity while in hospital (Irurita & Williams, 2001, p.286). Within this context, restoring meant nursing behaviours that gave control back to patients.
The processes of balancing and compromising (Irurita & Williams, 2001) suggest a sense of rebalancing integrity that entails the whole person, physically, psychologically and spiritually, to an optimal performance level. Another way of expressing this process and outcome is through the concept of homeostasis, or the act of bringing together aspects of personhood to regain a state of equilibrium (Ben-Sira, 1985; Blattner, 1981). Garrett (1998) regarded recovery from anorexia nervosa as reconstituting the whole being by bringing together the seven bodies of the person – a process of homeostasis to regain a sense of self and thus, a sense of personal integrity. Similarly, findings in the current study indicate that there was a need to reconstitute a sense of self and personal integrity in the face of the ongoing changes by rebalancing or regaining the positive feelings, regaining a sense of control and projecting a positive public image. Although participants drew on past experiences and constructed and developed strategies to adapt to changes and to maintain their personal integrity, most found that attaining a sense of balance or homeostasis was out of their reach because of the continually deteriorating nature of the disease process.

7.4.3 Strategies

Participants used a myriad of strategies in attempting to adapt to change and to maintain their personal integrity. In response to change, they developed, constructed and thought about adaptation strategies as a way of deciding what to do about the perceived change. These strategies were categorised as passive and active (Table 7.1). The passive strategies let events happen without taking into consideration any possible outcomes. In the main, these strategies were forms of denial, which pushed aside the realities of the disease progression in favour of keeping a positive view about life. Active strategies entailed participants’ acknowledging change and actively finding ways to incorporate the change and cope with the disease progression.
Table 7.1 Passive and Active Strategies Used by Participants to Adapt to Changes

<table>
<thead>
<tr>
<th>Adaptation</th>
<th>Strategies</th>
<th>Adaptation</th>
<th>Strategies</th>
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<tbody>
<tr>
<td>Active</td>
<td>• thinking creatively</td>
<td>Passive</td>
<td>Forms of denial –</td>
</tr>
<tr>
<td></td>
<td>• problem-solving activities</td>
<td></td>
<td>• ignoring the change</td>
</tr>
<tr>
<td></td>
<td>• viewing changes as challenges</td>
<td></td>
<td>• dreaming the improbable</td>
</tr>
<tr>
<td></td>
<td>• accessing and using assistive technologies</td>
<td></td>
<td>• affirming “I’m doing all right”</td>
</tr>
<tr>
<td></td>
<td>• seeking knowledge</td>
<td></td>
<td>• living “day-by-day”</td>
</tr>
<tr>
<td></td>
<td>• using laughter, teasing and black humour</td>
<td></td>
<td>• giving in to MND</td>
</tr>
<tr>
<td></td>
<td>• using downward social comparison</td>
<td></td>
<td>• persisting</td>
</tr>
<tr>
<td></td>
<td>• seeking calm and quiet environments</td>
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</table>

Equally, participants used various other strategies to maintain their personal integrity. These were categorised as protecting, regaining and sustaining strategies (Table 7.2). Protecting strategies aimed to shield personal feelings such as self-esteem and personal integrity from further harm. Regaining strategies aimed to enhance previously eroded personal integrity to improve quality of life while sustaining strategies balanced and kept personal integrity in an “OK” state. These particular strategies were an attempt to “go with the flow” and accept the highs and lows required of change and adaptation as on a “see-saw”.
Table 7.2 Maintenance Categories, Strategies and Purpose in Maintaining Personal Integrity

<table>
<thead>
<tr>
<th>Maintenance category</th>
<th>Strategy</th>
<th>Purpose</th>
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<tbody>
<tr>
<td>Protecting</td>
<td>• focusing on self • denying reality • withdrawing from the public arena and into self - hiding</td>
<td>• protecting personal feelings and personal integrity from more harm. • often detrimental to overall personal integrity</td>
</tr>
<tr>
<td></td>
<td>• protecting personal feelings and personal integrity from more harm.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• often detrimental to overall personal integrity</td>
<td></td>
</tr>
<tr>
<td>Regaining</td>
<td>• asking for help • getting a sense of control back into their lives • having access to everyday services • reframing thoughts</td>
<td>• regaining eroded personal integrity • improving quality of life for self and family • it is “hard work” to regain personal integrity</td>
</tr>
<tr>
<td></td>
<td>• regaining eroded personal integrity • improving quality of life for self and family • it is “hard work” to regain personal integrity</td>
<td></td>
</tr>
<tr>
<td>Sustaining</td>
<td>• taking advantage of circumstances • pre-empting detrimental situations • seeking “positivity” • laughing • giving up guilty feelings • finding something achievable</td>
<td>• balancing personal integrity; going with the flow. • counteracting potential negative affects in life. • an active, flexible attitude to life • also “hard work”</td>
</tr>
<tr>
<td></td>
<td>• balancing personal integrity; going with the flow. • counteracting potential negative affects in life. • an active, flexible attitude to life • also “hard work”</td>
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Similar concepts are identified by Dewar and Lee (2000) in exploring how people were able to bear their illnesses and injuries when their suffering was continuous. They categorised strategies into three broad areas – protecting, modifying and boosting and suggested that these strategies are used to limit the boundaries of suffering and to preserve a sense of self (Dewar, 2001, 2003; Dewar & Lee, 2000). As such, the purpose of the protecting strategies was to hide distressing aspects of illness and suffering, to protect significant others. The purpose of modifying strategies was to manage day-to-day living similar to the idea of balancing as proposed by Irurita (2001). The purpose of modifying strategies was to accommodate and adapt to change. Boosting strategies enhanced self-esteem. The authors (Dewar, 2001, 2003; Dewar & Lee, 2000) suggested that people with catastrophic illnesses and injuries limit the boundaries of suffering to
preserve a sense of self, by using these strategies. Further, they reported that the strategies represent “adaptation to ... changed and changing circumstances” (Dewar, 2001, p. 602). The strategies used to protect, modify and boost are congruent with the actions and behaviours used by participants with MND in the current study to maintain their personal integrity.

Young and McNicoll (1998) interviewed 13 people diagnosed with MND who were coping well with the disease to explore their experiences that related to a positive quality of life. The findings identified adaptation strategies such as learning to let go so as to control what could be controlled in life; humour, including black humour; living a day at a time; maintaining a positive attitude, including projecting a positive image in public; and finding intellectual challenges. In a recent study by Hughes, Sinha, Higginson, Down and Leigh (2005), 9 people diagnosed with MND, 3 carers and 15 health professionals were interviewed about the experience of living with MND. The findings revealed some similar strategies such as ignoring or denying the illness; seeking knowledge to be informed for decision-making and negotiating life choices; and concealing or hiding the more distressing aspects of the disease from family, friends and work colleagues to promote a coping image to others. The strategies used by people with MND in these two studies echo those revealed in the current study.

Tables 7.1 and 7.2 (see pages 234 and 235) demonstrate that participants used a variety of strategies to adapt to change and maintain their personal integrity. Often participants hid negative feelings from others in order to protect those people and themselves. This strategy of hiding feelings resonates with the findings in the Hughes et al. (2000) study, in which, humour was used both as a positive strategy in coping with change and as a way to demean others to enhance one’s own self-esteem and confidence. Often paid carers would be the brunt of caustic humour because it seemed to boost participants’ sense of control in situations where they had no perceived control, for example when being showered by a paid health carer and not
having control over the time taken for the shower, the temperature of the water and the showering and drying process. This explanation resonates with a concept in Randers and Mattiasson’s (2000) framework of integrity, that ridiculing or putting other people down in order to amuse others ultimately enhances self-esteem for the person doing the ridiculing.

The current findings identify the use of social comparison as a way to sustain personal integrity. Illness status was compared with others believed to be worse off. Such comparisons gave participants a positive view of life as things could be worse – they could have cancer! Overall the findings of the current study resonate with those identified by Dewar (2001; 2003), Dewar and Lee (2000), Young and McNicoll (1998), and Hughes et al (2000) when interviewing people with enduring and chronic illness and MND.

The strategies used in the current study demonstrate that some participants had an ability to keep working to achieve goals in their daily lives. Such characteristics suggest aspects of optimism and resilience. Scheier and Carver (1987) discussed the relative nature of optimism in coping with stressors in life. Some exhibited resilience when continuing to work at a problem or adapt to a change. However, once it was realised that a goal was not achievable, participants “let go” or disengaged from the problem and moved on to something more attainable. Scheier and Carver (1987; 1993) contended that this disengagement was not a failure but an optimistic endeavour to accept what was unachievable and to move on with life. Some people in the current study sought positive aspects in their lives by reframing their thoughts and actions, and seeking “positivity”. Such reasoning seems to correspond with the notion that good things will happen in life. This notion reflects an “optimistic orientation” as explained by Scheier and Carver (1987, p. 171). In discussing self-reporting of symptoms experienced, the authors suggested that optimists tend to play down symptoms and tend to “put on a happy face”, which does not reflect their actual feelings (p. 175). Vanderpol (2002) explained that resilience factors in people are characterised by the internal strengths they draw on “to overcome
severe adversity” (p. 302). In the current study, the strategies participants used to maintain personal integrity included laughter, withdrawing from stressful experiences both internally and externally to protect self, seeking out people who did not pity them, focusing on positives in life and those aspects of living that were important and dismissing those that were not necessary and stressful. These resonate with the common facets of resilience as identified by Vanderpol. Therefore, some of the strategies used such as projecting a positive image in public by smiling, dressing well and being non-complaining, and avoiding stressful experiences, suggest that participants exhibited optimistic and resilient characteristics, which facilitated their endeavours to maintain personal integrity.

7.5 In Summary

Living with MND involved making decisions and adaptations in response to ongoing change as the disease progressed and disability increased. Unique to these findings was that the outcomes of the diagnosis story were integral to the whole process of living with the disease, because they coloured future interactions with health professionals and service providers. The basic social process that underpinned decision-making was one of maintaining personal integrity. The pattern of decision-making was cyclical and repetitive and unique in that the decisions about changes were about life in general and not specific for the disease. However, life in general for the people with MND, emulated the illness experience because the disease infiltrated all aspects of their lives. The key process for the participants was to maintain their personal integrity in the face of the ongoing changes that were characteristic of the MND illness experience.

In this chapter, the findings of the study were discussed with reference to contemporary literature. A key concern for participants was the lack of therapeutic relationships with health professionals. Facets of optimism and resilience were revealed in some of the strategies used by some people to cope with the disease. Although it is relevant to identify such a positive
aspect for people with MND, it seems that they would not view having the disease as “positive” in life. Indeed, living with MND was hard work and required great effort to manage such strategies.

At the commencement of this research there was no intention or expectation of developing a substantive theory. As the findings developed, it became evident that there were integral relationships that linked the three models. Thus a substantive theory was conceptualised to bring together the whole story about living with MND. The following chapter concludes the thesis with discussion of the theoretical implications of the developed substantive theory and recommendations for practice. Future directions, limitations, researcher influence and reflections are highlighted.
CHAPTER EIGHT

THEORETICAL IMPLICATIONS AND CONCLUSIONS

8.1 Introduction

In the previous chapters, the research findings in relation to contemporary literature were discussed. The diagnosis story revealed the complex emotional journey that the process of diagnosis involves and parallels were drawn between the behaviours of the participants and those diagnosed as experiencing posttraumatic stress disorder (PTSD). The need for debriefing at diagnosis was suggested as a strategy to ameliorate the obvious distress. The decision-making model of ongoing change and adaptation uncovered a cyclical and repetitive pattern for making decisions in response to perceived change. The discussion about maintaining personal integrity focussed on similarities and differences with other related conceptions of personal integrity. The strategies developed by participants to maintain personal integrity seem to demonstrate facets of optimism and resilience in the face of both deteriorating functioning and increasing physical and psychological loss. These findings suggest that, for the men and women with MND in this study, maintaining personal integrity is epitomised by their struggle to live life and to exercise choice over the way they live it.

As discussed in chapter 3, an overall aim of a grounded theory approach is to generate a theoretical explanation, or a substantive theory, of the phenomenon under investigation. Soulliére, Britt and Maines (2001) suggest that the use of conceptual modelling enhances the explanation of a grounded theory because it facilitates understanding of dense theories that are abstract such as those developed in this study. Although generating a substantive theory is a philosophical expectation, it was not the initial intention of this study. However as the findings evolved, it became clear that
such a representation would be useful. The purpose of this chapter is to bring together the three constructs described in this study and present a theoretical representation of the experience and process of living with MND while negotiating life choices. The substantive theory is compared with two formal theories about chronic illness to ascertain its relevance within that context and to the literature about MND.

The discussion in this chapter concludes with an exploration of this study’s contribution to contemporary literature. Prominent findings are highlighted; recommendations for practice are identified and study limitations are acknowledged and suggestions are given for further research.

8.2 Overview of the Substantive Theory

The aim of this study was to gain insight into how people diagnosed and living with MND negotiate and make decisions about the choices they face on a day-to-day basis during their illness. The substantive theory that has evolved from the findings demonstrates that the process of decision-making and negotiation concerning perceived change is best understood in the context of the desire to maintain a sense of self. This occurs through the processes of protecting, regaining and sustaining personal integrity in the face of ongoing change and adaptation. Overall, this theory involves a cyclical and continuous process of maintaining personal integrity, which is central and integral to decision-making and negotiation. Maintaining personal integrity also underpins the strategies developed in response to threats and changes that occur as a consequence of MND.

As depicted in Figure 8.1 (see page 243), two approaches are pursued in the process of maintaining personal integrity. The first is followed when a perceived change impacts on personal integrity, the second when conditions pertinent to the experience of living with MND threaten the ability to maintain it. In both approaches, a response is required to adapt and incorporate the change into one’s life or to buffer the impact of threats. The
strategies chosen to maintain personal integrity are applicable to both approaches.

The first approach to maintain personal integrity is via a decision-making process that commences when a change is perceived. This process is cyclical because the need for ongoing change and adaptation is inherent when living with MND. Typically perceived changes are assessed according to how they affect personal integrity. Some changes enhance feelings about self and others, and are detrimental. Depending upon how the change is assessed, strategies are chosen to protect, regain or sustain personal integrity in a way that is congruent with personal standards.

The second approach to maintaining personal integrity is used in response to threats that are interpreted as impacting negatively on the ability to negotiate and enact strategies that maintain personal integrity. Threats also affect personal integrity itself, resulting in devalued opinions about self, loss of dignity, feelings of unworthiness and a sense of no control in life. The actions and interactions used to resolve threats involve the same strategies as those associated with maintaining personal integrity. These strategies include acceptance, denial, inertia or actions that counteract the impact of the threat.

Protecting, regaining and sustaining strategies are instigated when there is a feeling or desire to do something about perceived change and threats, in order to buffer the resulting affects on living one’s life. Correspondingly, active and passive strategies instigated to maintain a sense of personal integrity aim to achieve a level that is sustainable. The choice of strategy is drawn from personal inward discussion using self-talk and inner negotiation before concrete decisions are made and then negotiated with others.
Substantive Theory of Maintaining Personal Integrity in the Face of Ongoing Change and Adaptation

Figure 8.1. Conceptual model of the Substantive Theory of Maintaining Personal Integrity in the Face of Ongoing Change and Adaptation.
Negotiation provides the link between the components of maintaining personal integrity and is implicit. Negotiation commences with self-talk about how a change affects the self, what it means in the context of present and future life with MND and progresses to involve negotiation with others including intimate carers, family, volunteers, friends, health professionals and service providers. Depending on decisions made after the process of self-talk, the purpose of outward negotiation with others is to collaborate to ensure the chosen strategy is implemented. The outcome of deliberation and choice of strategies that buffer the change or threat, is to progress to assessing their relative effectiveness. Each adaptive strategy is assessed for effectiveness in terms of subjective well-being, and its ability to buffer the change or threat. If the chosen strategy is ineffective or a new change is perceived, the cycle of decision-making is repeated by revisiting the process of maintaining personal integrity. Concurrently, conditions that threaten the ability to maintain personal integrity are accommodated in the same process.

The process of negotiation is the same for perceived changes and threats as it is for maintaining personal integrity but the patterns and outcomes are different because of the impact of internal and external factors that have the potential to moderate the overall process. Moderators are structural influences that affect how individuals respond to and cope with the disease and illness experience of MND. They also influence personal perceptions of personal integrity and how it is assessed. The following discussion illustrates the components of the substantive theory derived from the findings of this study.

8.2.2 Threats

Several hidden and overt conditions threaten the ability to maintain personal integrity. One of the first threats appears to be the process of diagnosis. Diagnosis is a critical element of the substantive theory; although the process can be lengthy, it only occurs once. It seems that the distress of diagnosis colours subsequent decision-making and choices about how to live
with MND, and is made more complex by the processes of ongoing change and adaptation. It appears that the distrust and negative perceptions of health professionals and service providers that emerges adds to the distress. Such pessimism about the roles of health professionals tends to threaten future negotiations for choices and, as a consequence, limits the capacity to maintain personal integrity.

Impaired communication ability threatens the capacity to verbally negotiate choices. While accessing and using assistive technology seems to alleviate some communication difficulties, as the disease progresses and physical impairment increases, the use of technology is compromised. Constructing sentences using technology is hard work and takes time. In addition deteriorating neurological functions and emotional lability add to the difficulty of trying to communicate. In the process of negotiating with others, time and patience for reciprocal communication using assistive technology is vital. If these conditions do not exist then the ability to maintain personal integrity and personal integrity itself, are threatened. In these cases communication is cut short with others “jumping in” and making assumptions about what is to be said or thinking that they know what is being requested. At this time the person with MND is ignored altogether and negotiation is conducted with an intimate carer or an accompanying person. Such actions by health professionals and service providers pose threats to the ability of people with MND to negotiate and communicate for personal options and choices.

Pertinent information about the disease and how to live with it, does not seem to be readily provided by health professionals. It appears that some health professionals view a diagnosis of MND as the endpoint requiring only guidance about end-of-life issues. Spegel, Rogers and Buckley (1998) and Cossette (1998) suggest that successful negotiation is only possible when there is a shared understanding, knowledge and language, and an ability to communicate. Within the context of living with MND, the lack of knowledge about the disease and how to live with it, and the inability to be understood,
all threaten the ability to negotiate choices in life. Impaired communication ability is physical, psychological and emotional. In essence, the process of communicating with others is moderated by an ability to communicate verbally; effective use of assistive technology; the willingness of others to take time in reciprocal conversation using technology; having knowledge about the disease and how to live with the illness; as well as having the personal willingness to communicate and negotiate with health professionals and service providers.

Another threat to maintaining personal integrity is the experience of “bad days”. Often the “sad” and “bad” times are hidden from public view and, subsequently from health professionals and service providers who can offer help. Coping with bad days alone and hidden from others erodes personal integrity and makes it difficult to maintain a sense of wellbeing. The consequences of bad days includes negative feelings about self, a sense of isolation and the feeling that things are going wrong; in short, that the disease is in control. Bad days produce a great deal of negativity and threaten personal integrity and make the formulation of strategies to enhance wellbeing and personal integrity difficult. Constant change signals repetition of the cycle of ongoing change that requires another adaptation or prompt to accommodate the next change.

8.2.3 Change

Change is a constant in the lives of people with MND. Change can be physical, psychological, emotional, environmental and unexpected. Various ways of coping are used when change is assessed as detrimental to personal integrity. Often passive strategies of denial or ignoring change are used as a way to protect personal integrity. The purpose of such initial strategies seems to be an attempt to cocoon the innermost self from the shock, despair and reality of another change. Secondary responses sometimes include choosing strategies that aim to regain and sustain a level of personal integrity congruent with self.
The consequences of decision- and choice-making in response to change are subjective wellbeing and corresponding levels of stress. These consequences are repeatedly challenged when a new change is perceived and its effect reviewed against perceptions of personal integrity.

8.2.4 Personal integrity

Personal integrity appears to have three dimensions – feelings, control and image. It is individual and personal and seems to be a composite of how people with the disease view themselves, their perceptions of how others view them and how they feel about themselves. In the main, a homeostatic view of personal integrity is threatened by aspects connected and integral to living with the illness of MND, which are out of personal control and influence. The nature of personal integrity remains variable and unstable while living with and experiencing the disease. When change is not able to be adapted into life, subsequent consequences for personal integrity are low self-esteem, poor valuing of self and great anguish. Adaptability is individual and linked to a person’s ability to debate personal integrity in inner negotiation. Inner negotiation provides the personal impetus in deciding whether a strategy is required to buffer the effects of change. Strategies are constructed, developed and achieved when negotiation with others takes place.

Strategies

Maintaining personal integrity requires activities to buffer or negate threats. When integrity is threatened, strategies such as hiding are used to buffer the impact. However, this strategy has the effect of simply delaying the influence of the threat and leads to a greater distress in the future.

Various strategies are used in attempts to adapt or not adapt to change and to maintain personal integrity. As identified in Tables 7.1 and 7.2 (see pages 234 and 235 respectively), both groups of strategies are equitable; the passive strategies in response to change are equated with the strategies for protecting personal integrity. Similarly the active strategies used to adapt to
change equate with the strategies used in regaining and sustaining personal integrity. Table 8.1 illustrates the associations between both strategy groups.

**Table 8.1 Maintaining Processes, Adaptive Strategies and Outcomes**

<table>
<thead>
<tr>
<th>Maintaining processes</th>
<th>Strategy</th>
<th>Outcomes</th>
</tr>
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| Protecting (passive adaptation) | • focusing on self  
• denying reality  
• withdrawing from the public arena and into self – hiding | o protecting personal feelings and personal integrity from more harm.  
o often detrimental to overall personal integrity |
| Regaining (active adaptation) | • asking for help  
• getting a sense of control back into their lives  
• accessing everyday services  
• reframing thoughts | o regaining eroded personal integrity  
o improving quality of life for self and family  
o doing “hard work” to regain personal integrity |
| Sustaining (active adaptation) | • taking advantage of circumstances  
• pre-empting detrimental situations  
• seeking “positivity”  
• laughing  
• giving up guilty feelings  
• finding something achievable | o balancing personal integrity; going with the flow.  
o counteracting potential negative affects in life.  
o having an active, flexible attitude to life  
o doing “hard work” |

The strategies used in both processes are intricately linked to each other and to the processes of negotiation. For example, the strategies of “asking for help” or “cognitive reframing” of the perceived change from a problem to a challenge, enables the negotiation of strategies from passive to active, thus enhancing and regaining personal integrity. Also, the strategies of learning to pre-empt events, to be prepared, and humour, have the effect of sustaining integrity as change is accommodated. The reciprocal links between personal integrity and the processes of protecting, regaining and sustaining are managed through inner negotiation and negotiation with others. The strategies and the actions and interactions that evolve in response to change,
threats and negotiation processes are influenced by both internal and external moderators.

8.2.5 Moderators

Moderators are internal and external structural influences that impact on how individuals respond to the disease and illness experience. These represent the combination of: antecedents, influences and supports that are inherent in the process of being diagnosed; the contextual influences and interactions that impact on the processes of decision-making for ongoing change and adaptation; the contextual conditions and threats associated with the basic social process of maintaining personal integrity. The moderators also mould perceptions and assessments of personal integrity. Personal internal factors include gender, locus of control, coping style, previous life experiences, health and illness beliefs and experiential knowledge of MND. External factors are linked to socioeconomic status, the existence of other illnesses (co-morbidities), personal relationships, age/life stage, the presence of supportive people and groups, and residential location – rural or urban areas. Each factor has the capacity to shape and modify reactions to the disease and change, as well as compelling circumstances and situations that are out of the control of the individuals who are experiencing the disease and illness of MND.

8.3 The Substantive Theory Compared with Other Theories

Contemporary literature offers two formal theories that have some relevance to this study. These are: “The Illness-Constellation Model” (Morse & Johnson, 1991) and “The Shifting Perspectives Model of Chronic Illness” (Paterson, 2001).

Morse and Johnson (1991) constructed a formal theory “The Illness-Constellation Model” from a meta-synthesis of five grounded theory studies about the illness experiences of three groups of people with chronic illnesses and two groups of carers of people who were experiencing medical and surgical interventions. They identified four stages: I) Uncertainty, II)
Disruption, III) Striving to regain self and IV) Regaining wellness with the core variable of “minimising suffering”. In their theory, each person endeavours to regain, preserve or attain some form of personal integrity or sense of self before he or she can progress and complete the episode by: (a) regaining control after a heart attack (Johnson, 1991); (b) establishing boundaries of normality after a hysterectomy (Chassé, 1991); and (c) becoming ordinary enough to leave a psychiatric hospital and return to the community successfully (Lorencz, 1991). The three phenomena of personal illness experiences, which they explored, were episodic and so differ from the substantive theory formulated from this current study. The two phenomena of carers’ experiences differed in that one was about husbands’ experiences of their wives’ chemotherapy (Wilson, 1991) and the other concerned mothers’ experiences of their teenage daughters’ abortions (Norris, 1991). The Morse and Johnson Illness-Constellation Model comprises two sections; the “self” that represents the person’s perspective of the illness experience and the “others” that reflects the carers’ and other peoples’ perspective. In their theory, the final stage in the Illness Constellation Model focuses on regaining wellness. In contrast, the substantive theory about living with MND developed in the current study, has no such final stage; the person merely experiences subjective wellbeing before facing another change. Such a theory reflects an ongoing and cyclical process and, therefore, cannot be integrated into the formal theory of the Illness-Constellation Model.

In the second formal theory, Paterson (2001) developed “The Shifting Perspectives Model of Chronic Illness” from a meta-analysis of 292 qualitative research studies about chronic illness. In this theory, Paterson relates living with a chronic illness, to an alternating focus between aspects of wellness and illness, while living with a disease. That is, people with chronic illnesses focus on living with wellness in the foreground of life and illness in the background when the illness is controlled. Life decision-making and choices are focussed on living well. When a person becomes unwell
there is a shift to illness in the foreground as it becomes the focus of attention and wellness recedes to the background. In this context, decision-making, choices and energies are focussed on the illness. This theory conceptualises personal perceptions of living with chronic illnesses when there are periods of remission and exacerbation of symptoms.

The experience of living with MND is similar in some respects in that, for some people, there are plateaux of minimal change, where the symptoms of the disease seem not to be increasing. At these times having wellness as the focus in life may be possible if ongoing changes have been normalised into to day-to-day living. Yet, for the majority of people, such a situation is not possible as evidence of the disease and illness consequences are always present. Although Paterson’s model does reflect the ongoing nature of chronic illness with the notion that at times there are periods of wellness, in the main this is not the experience of people with MND because illness is usually in the foreground.

The substantive theory is distinguished from the two formal theories by the fact that it concerns the perspective of the person with the disease, whereas the other two include intimate carers and others. While the broader context is considered by some as important for a holistic perspective of viewing experience (Hughes et al., 2005; Small & Rhodes, 2000), this was not the aim of the current study. The major focus of the study is the diversity of participants’ stories and the array of ancillary data deemed important to them. Of significance is the fact that living with MND does not have periods of remission without change because the disease is always active even though at times only the person with the disease is aware of it. In contrast, both the formal theories incorporate the notion of health, wellness, remission phases and focus away from illness in the forefront of concern in life. The substantive theory reflects and explains the unique illness experience of living with MND as an ongoing process of body function deterioration. It is a cyclical and repetitive process that continues until death.
The next section highlights the contribution of this study to the literature about the illness experience of people diagnosed with MND.

**8.4 Contribution to Knowledge**

This study sought to explore what it is like to live with MND in Australia. A grounded theory approach was used to understand in their words, the processes people with MND go through, in living with the disease. The substantive theory formulated from the findings suggests that, for people with MND, there is a continuous process of decision-making in relation to the ongoing changes that occur because of the progression of the disease and as sequelae of the illness experience. The theory provides insight into living with a terminal illness and contributes to the literature about illness experiences.

In this qualitative study, 25 people with MND living in Victoria, Australia were interviewed. Data for the study were their words, stories, photographs and the books that were important to them. Participants with impaired verbal communication were not excluded from this study. Most had some difficulty with vocalisations and several used assistive technology during the interviews. Some participants invited a third person to act as an interpreter to make it easier for them to be understood. Thus the words and stories became the participants’ group voice about the subjective perspective of the illness experience of living with MND in rural and urban settings. This group voice supplements previous knowledge about the experience of living with MND and speaks about the Australian experience. This contribution enhances the international perspective in the MND literature.

The diagnosis story identified concerns about how specialist physicians provided the diagnosis and who seemed to dismiss the person once diagnosed without considering their ongoing support needs. This lack of consideration resulted in unresolved emotional issues for the newly diagnosed person and coloured their future interactions with health professionals. According to the international literature, these same issues
seem to be a continuing problem for people with MND and chronic illnesses. The Australian experience endorses previously identified concerns and thus contributes to the overall request for improvements to the process.

While positive coping strategies have been identified before, this study offers insights into the strategies used by people who have a more negative perception about life with the disease. While these strategies are detailed in other studies about chronic illness and cancer, as reported in the literature, the way people with MND used them is unique. The characteristics of the “hidden MND” illness experience and “bad days” have not previously been identified and seemingly were unknown to health professionals and service providers. This study provides insight into what goes on behind the scenes at home when no-one can see the distressing responses to the disease. This seems to be new information about the illness experience for people with MND.

Although people in the study talked about specific psychosocial needs, each was underpinned by the desire to maintain personal integrity. Participants identified issues such as the desire to have same gender socialisation opportunities and facilities that were more conducive to their needs. However, these issues were highlighted in the main, because they provided a means to maintain a sense of themselves as the persons they always were, despite the ongoing change and adaptation that was part of their day to day lives. The discussion of personal integrity emanating from this study adds to the debate concerning the importance of personal integrity to people with chronic and disabling conditions such as MND.

The usual way, for the people in the study, to negotiate seemed to be via inward self-talk. Typically, intimate carers were involved in negotiations when this was completed and they played the role of enabler. Carers are the people who negotiate with others to implement the choices made. Nevertheless, the ability to negotiate is more complex for people with MND because they generally lack pertinent information to make informed choices.
These findings contribute to the knowledge about negotiation and choice-making for people with terminal illnesses and MND as well as the literature about enablers within the health care system.

In this study effective communication was an issue for most participants. The methods used to include people with impaired communication, which included assistive technology such as Lightwriters and computers, highlight the need for patience and reciprocity in the research relationship. The study demonstrates that people who experience communication difficulties can contribute to qualitative research and group voices.

While this group voice is representative of the study participants, the findings may have resonance for other people diagnosed and living with MND. Although the outcomes contribute to the understanding of the illness experience for others, the significance is moderated by several limitations.

8.5 Limitations of the Study

This study was designed to explore and describe the illness experience of people with MND residing in Victoria, Australia, and how they exercise choice over the way they live. Participants were a homogeneous sample of individuals to the extent that they shared the common experience of being diagnosed and living with MND. While the group who volunteered was drawn from Victoria, the majority came from rural areas, which, as previously discussed, is inconsistent with the statistics that indicate that more people with the disease live in urban areas. The findings represent those people interviewed and while they cannot be generalised to the greater population of people with MND, they certainly appear to resonate with the current literature.

Another unexpected limitation of the study was the participant/researcher relationship. At times the interview process triggered emotional responses from the participants. Emotional distress during and after interviews is a phenomenon that appears to be acknowledged as a part
of the research process because counselling services are always a construction in any human ethics proposals, but little is written about such experiences. For some participants, crying seemed to give them an outlet to relieve the stress associated with their losses and their future with MND. However, on reflection, the emotional impact of dealing with this level of participant distress may have influenced subsequent interviews. That is, interview length and time taken to develop rapport may have unconsciously been shortened.

8.6 Recommendations from the Study

Several recommendations are directed at improving the illness experience for those who are diagnosed with MND, their families, care givers and health professionals. These address acquiring knowledge about the disease and how to live with it, promoting available information, coordination and support following diagnosis, gender implications in care, the importance of care environments and promoting flexibility within the health care system.

8.6.1 Acquisition of knowledge

Although living with MND is hard work, possibilities remain for people with the disease to promote their own wellbeing and integrity. The findings reveal that dependency on others often increases demoralising feelings, loss of dignity and control. To increase independence and promote and maintain personal integrity, it is vital that information is made available about what to expect with the illness and what is “normal” for people with MND. Such information may promote better understanding of the progression of disease and help those with MND to plan their future choices and goals as they live with the illness. Similarly information drawn from people’s illness experiences such as, a written or visual anthology highlighting the strategies that have assisted them to live well with the disease and how they responded positively to particular challenges, may help others find ways to live with the illness.
8.6.2 Promoting available information

It is clear from the findings that there is a need for greater emphasis to be placed on disseminating information that deals with MND. This information has the potential not only to make people aware of the nature of the disease, but also importantly to reduce feelings of isolation and despair. Although neurologists do receive brochures about the support available from the local MND association, it seems that, by not passing it on to patients, they overlook its real value. Emphasising the importance of this information may improve its dissemination and counteract the perception of those being diagnosed that there is little support for them after diagnosis.

8.6.3 Coordination and support following diagnosis

It seems clear that a health professional having in-depth knowledge of the issues facing people with MND is needed to coordinate care from the time of diagnosis until death, and particularly during the initial grieving period for families. While this person could be drawn from any of a number of health care professionals, an advanced practice nurse may be best situated to take on this role, given the respect generally afforded to nurses in the community and the comprehensive nature of their educational preparation. Their role in practice affords them opportunity to undertake a continuing hands-on perspective compared with other health professionals whose involvement may be episodic or may end following diagnosis as with some neurologists.

Debriefing support is required when the MND diagnosis is finalised to prevent long-term reliving of the diagnostic process. Health professionals need to be acutely aware that there are likely to be negative and detrimental feelings associated with the diagnosis of a terminal illness. Formal debriefing may assist to address such issues.
8.6.4 Gender implication in care

The men and women in the study confided that they welcomed the opportunity to have same gender socialisation opportunities such as men talking with men about “men’s business” and women browsing in the shops with other women. It appears that care providers need to consider these important needs when allocating care resources.

8.6.5 Importance of care environments

Various aspects within the environments in which people with MND live, need to be addressed. There are particular concerns about hospitalisation and having environments that are both conducive to reducing physical symptoms and safe.

Hospitalisation

Hospitalisation seems to be an issue for most people with the disease. The care in hospitals was reported, at times, as unsafe and neglectful, which appeared to reflect an uncaring attitude. Admission for respite care often led to increased stress levels, and feelings of being unwell and out of sorts on the return home. Findings suggest that nurses and other health professionals need to take time to understand what people with communication difficulties are saying. Second guessing may often cause angst in people with the disease and leading to their being viewed as “difficult” patients. Understanding the hidden strategies that people with MND use can enable health professionals to facilitate sensitive, supportive and innovative care of people with MND and their families.

Promoting calm

Sometimes the involvement of many support services and carers may increase stress levels and promote tension within a person’s environment. The findings suggest that environments in which people with MND are cared for and live need to be calm, quiet and stress-free because such conditions seem to reduce the body’s physical responses to the illness.
Safety issues

The findings reveal that safety issues are often a forgotten aspect of this progressive disease. Service providers need to address such issues for people experiencing increasing levels of disability. The experience of “wake-up calls” and crises exposed important safety aspects for people with MND and their families. Health professionals need to understand and anticipate responses to such issues for people who live at home. Because of the progressive nature of the disease, there is increased potential for accidents and lapses of awareness, as carer burdens increase. Safety is particularly important for those who live alone and like to keep their belongings within easy reach. The findings identify a specific concern for fire safety.

8.6.6 Promoting systemic flexibility

Several issues associated with government policies were uncovered in the study. Some regulations within the healthcare system appear rigid, not taking into account individual needs. These include the refunding of costs associated with self-transportation, policies that govern the distribution of funds to support people living in their own homes, funds for holidays, and the “No-Lift” health and safety policy in health care institutions. Government bodies need to make funding policies more transparent and accessible for people with MND. Because life with the disease is limited, services need to be made available when required and not delayed by waiting lists. Further, the policy implementations need to be flexible enough for individual needs to be addressed. This is especially vital for those people who live in aged care and nursing home facilities because their socialisation opportunities are often restricted because of institution policies as well as by the limitations of their physical disabilities.

8.7 Further Research

Suggestions for further research focus on aspects that are complementary to this current study. The illness experience was mainly drawn from people who lived and were cared for at home. In general, their
experiences pertaining to short hospital stays for diagnostic tests and respite care were expressed in derogatory terms, often perceived as detrimental to participants’ psychological and physical health. For a more comprehensive perspective, the experience of hospitalisation and respite care needs further investigation across a larger sample.

The models and the substantive theory that together explain what it is like to live with MND, require further investigation from two perspectives. First the efficacy of the models needs to be tested to ascertain their usefulness as tools to guide health professionals, service providers and care institutions in striving to provide optimal care. Second, the relevance of the substantive theory requires trialling with a larger sample of people with MND, other neurodegenerative diseases and other chronic illnesses. Such assessment will complement further development towards a formal theory that explains the illness experience of people diagnosed with terminal diseases such as MND.

8.8 Conclusion

The aim of this study was to explore the life-worlds of people diagnosed and living with MND in Victoria, Australia. A grounded theory methodology provided the philosophical underpinnings with which to analyse the data, to understand the illness experience and interactions that people with the disease have with others and the meanings they attached to those interactions. The purpose was to identify how people diagnosed with the disease negotiate with others to exercise their choices in life and to provide them with a way of articulating their stories.

The findings evolved into three conceptual models that represented different aspects of living with MND. They were the “diagnosis story”, the “ongoing change and adaptation” decision-making model and the basic social process of “maintaining personal integrity”. Each conceptual model was integral to the story about what it is like to live with MND and how individuals negotiate with others for their choices in life. These models
underpin a substantive theory of “maintaining personal integrity in the face of ongoing change and adaptation”.

The major finding was that, in the absence of any guidelines on how to live with MND, participants based their decisions and choices on maintaining their personal integrity. The experience was a personal journey that evolved as a continuous and cyclical decision-making process in response to changes that were consequential of the disease and the illness experience. As the body deteriorated, negotiation about choices became an internal discussion using self-talk. Negotiation occurred with intimate carers who then acted as enablers and advocates to make choices happen with others. Others included those people and services outside of their home or personal environment – friends, health professionals, service providers, state and government funding bodies and volunteers.

There is a need to improve care during the period of diagnosis and to ensure that information is available to support people’s journey with MND. Although it is a shattering and demeaning disease that is terminal, living with life goals is possible by seeking “positivity”, achievable activities, quiet and stress-free environments and interaction with supportive people who respect an individuals’ need for maintaining personal integrity. Such issues are reflected in the writing of one of the participants, Thomas, who offered this message to others living with MND.

*Love, follow your heart!*  
*Living is making the most out of every moment!*  
*Do “IT” now!*  
*Share “IT” with your Love!*  
*Problems become insurmountable because that’s how we choose to see them!*  
*Seek out what you can do, rather than focus on what you can’t do!*  
*Attempt to be aware, avoid being arrogant!*  
*Aim for balance, hope for harmony!*  
*Don’t try and win every war. The Winner is not always the Victor!*  
*Be Kind, include yourself!*  
*Quality of Life is paramount, Dignity supreme!*


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Awards given for achievement

KARREN Owens of Fern-tree Gully, and Susan King of Knoxfield were presented with their accolades at Deakin University’s Institute of Disability Studies awards night last week.

Ms Owens received the JC Paul Duerrloth Memorial Award for her determination and persistence in completing a bachelor of applied science, after chronic back pain caused her to defer her degree for one semester.

Ms King received a PhD scholarship from the School of Nursing in collaboration with the Institute of Disability Studies; Bethlehem Griffiths Foundation; Bethlehem Hospital and Motor Neurone Disease Association of Victoria.

The three-year scholarship will allow Ms King to complete further studies.

Knox achiever

KNOXFIELD resident Susan King (pictured) has been given a scholarship to research her PhD on motor neuron disease.

Ms King, 48, was awarded a PhD scholarship from Deakin University’s School of Nursing to spend three years researching support services for people with the degenerative disease and how they felt these services could be expanded.

The PhD is also supported by the Institute of Disability Studies, the Bethlehem Griffiths Foundation, Bethlehem Hospital and the Motor Neurone Disease Association of Victoria.

Ms King said there was no known cure for the disease and there was a lot to learn about it. She said she was excited at the prospect of the research.

"I will be interviewing people diagnosed with motor neurone disease to better understand their service and support requirements," she said. "The study will give them a voice."

She said about 230 people living in Victoria suffered from motor neurone disease, and people with it had a life expectancy of one to five years.

She said there was research on palliative care and support services, but there had not been a lot of study done on how people with the disease viewed this care.
Appendix B - Participant Information Sheet

Deakin University School of Nursing, Bethlehem Health Care, MNDAV
Participant Information Sheet

Negotiating Life Choices: Living with Motor Neurone Disease

Dear

My name is Susan King and I am a PhD/research student. On behalf of Bethlehem Health Care, Motor Neurone Disease Association of Victoria (MNDAV) and Deakin University School of Nursing, I would like to invite you to participate in an innovative study. The research supervisors are Dr Jan Browne (Senior Research Fellow, Deakin School of Nursing/Bethlehem Health Care) and Assoc Prof Barrie O’Connor (Disability Studies Unit, School of Health Sciences, Deakin University).

This study aims to describe and explore the experiences of people living with MND to gain a clearer understanding of their emotional and social support requirements, how they view the care they are currently receiving from the various support services they access, and how they would like their care to occur in the future. The outcome of the study will provide information for education of carers who provide care to people living with MND.

Information for the study will be collected in one interview. The interview will take about one hour and will be conducted at a time and place suited to you. Interviews can be broken up into short sessions if an hour is too long for you.

I will conduct the interview. I am independent of the care or services provided to you by Bethlehem Hospital and MND Association of Victoria. Your participation in the study is entirely voluntary and you are free to withdraw at any time without any impact on your care.

Before the interview starts, I will talk through the Participant Information Sheet with you until you are satisfied that you understand it. I will answer all your questions about the study. You will be asked to agree verbally to participate in the study. Your consent will be recorded on tape before the interview commences. The interview will be tape recorded and then typed out word for word. Your name will not be typed from the audiotape, instead your interview will be given a false name in the written record. You are welcome to read a copy of the interview transcript to be read to you if you prefer.

The interview will be like a normal conversation. The opening request is ‘Tell me about what has been happening for you since you were diagnosed with MND?’ The aim is for you to talk about what is most important to you as a person living with MND, which will help us to obtain information about issues central to the research.

Participants will also be invited to keep a written or audiotaped diary of their experiences. Written and audio-taped diary information will be handled in the same manner as interview transcripts. That is, your false name will be used on the transcript and any other person, institution or service identified will be given a code name thus ensuring confidentiality.
To better understand the various types of support services you receive, I will request a copy of any written material you may have about the support services you receive. This might include service plans, schedules of visits by support services, therapy programs, or self-help strategies that are owned and held by you that relate to your actual use of services. Service providers will not be approached for this material. Please note medical records are not requested. In instances where such materials may be incorporated into the results and final publication of thesis by way of example, your anonymity and that of your service providers will be ensured.

If you become unwell during the interview, the interview will stop immediately. It will be postponed to a later time if you wish to continue to participate. Should you become distressed during the interview or want an opportunity to talk about it after the interview, a counsellor from Bethlehem Health Care or an independent counsellor will be made available at your request. In addition, Pastoral Care services at Bethlehem Health Care will be available for post interview debriefing should you wish to use their services.

Publication of the study will ensure anonymity of participants. False names will be used in the write-up of all results and on all written information. Data will be securely stored according to Deakin University guidelines for a minimum of six years. Your contact details will be kept separate from the interview information and only the student who conducted the interview and the Chief Investigators, Dr Jan Browne and Assoc Prof Barrie O’Connor will have access to contact details. You, or a person nominated by you, will receive a summary of the study findings. On request, a copy of the full research report will be provided free of charge to participants.

Should you have any questions about this research, please feel free to contact the Research Officer: Susan King  
School of Nursing  
Deakin University  
221 Burwood Hwy  
BURWOOD VIC 3125
Or the Chief Investigators:  
Dr Jan Browne  
Senior Research Fellow  
Bethlehem Health Care  
476 Kooyong Rd  
CAULFIELD VIC 3162  
Phone: 03 9596 2853  
Or 9244 6608  
e-mail: jlbrowne@deakin.edu.au  
Professor Barrie O’Connor  
Director  
Disability Studies Unit  
School of Health Sciences  
Deakin University  
221 Burwood Hwy  
BURWOOD VIC 3125

Yours faithfully

Susan King

Should you have any concerns about the conduct of this research project, please contact the Secretary, Ethics Committee, Research Services, Deakin University, 221 Burwood Highway, BURWOOD VIC 3125. Tel (03) 9251 7123 (International +61 3 9251 7123).

This research is funded by the Australian Research Council, Strategic Partners in Industry – Research and Training Scheme, Bethlehem Griffiths Foundation, Bethlehem Health Care and the Motor Neurone Disease Association of Victoria (2001-2003).
Appendix C – Requesting Participants through the MND Newsletter

Negotiating life choices: Living with Motor Neurone Disease
An invitation to tell your story

My name is Susan King, a PhD student undertaking a project on negotiating life choices. My supervisors are Dr Jan Browne (Research Fellow, School of Nursing, Deakin University/Bethlehem Hospital) and Prof Barrie O’Connor (Director, Institute of Disability Studies, Deakin University).

This study aims to explore the experiences of people living with MND. It seeks to gain a clearer understanding of emotional and social support requirements, and how you are able to work with others to have your choices fulfilled.

If you would like to hear more about this study, please leave your name and contact telephone number on 03 9244 6527. Or return this form to me at the address below and I will contact you.

Susan J. King
C/o Institute of Disability Studies
Faculty of Health and Behavioural Sciences
221 Burwood Hwy
Burwood 3125

NAME: ....................................................................................................................... 

CONTACT PHONE NUMBER: ...................................................................................

This project is funded and supported by The Australian Research Council, Deakin University, Bethlehem Griffiths Research Foundation, Bethlehem Hospital and the Motor Neurone Disease Association of Victoria.

Negotiating life choices: Living with Motor Neurone Disease
An invitation to tell your story

My name is Susan King, a PhD student undertaking a project on negotiating life choices.

My supervisors are Dr Jan Browne (Research Fellow, School of Nursing, Deakin University/Bethlehem Hospital) and Prof Barrie O’Connor (Director, Institute of Disability Studies, Deakin University).

This study aims to explore the experiences of people living with MND.

It seeks to gain a clearer understanding of emotional and social support requirements, and how you are able to work with others to have your choices fulfilled.

Or return the form on the flyer with this issue to:

Susan J. King
C/o Institute of Disability Studies
Faculty of Health and Behavioural Sciences
221 Burwood Hwy
Burwood 3125

This project is funded and supported by The Australian Research Council, Deakin University, Bethlehem Griffiths Research Foundation, Bethlehem Hospital and the Motor Neurone Disease Association of Victoria.

If you would like to hear more about this study, please leave your name and contact telephone number on - 03 9244 6527.

MND NEWS

September-October 2001
Appendix D: Verbal Consent Form

DEAKIN UNIVERSITY ETHICS COMMITTEE
VERBAL CONSENT FORM:

I, of

Hereby consent to be a subject of a human research study to be undertaken by Susan King, a PhD candidate being supervised by Professor Barrie O'Connor and Dr Jan Browne in the Faculty of Health and Behavioural Sciences at Deakin University and I understand that the purpose of the research is to explore the experiences of people living with MND to better understand their perceptions of the care they receive and their service and support requirements. The study outcomes will underpin evidence-based strategies to guide people with MND in negotiating their desired end-of-life conditions, identify directions for community support organisations, and develop education programs for carers who work in this area. An example of a question you maybe asked is “Have you talked with anyone about how you would prefer to be cared for? Would you tell me about this conversation?”

I acknowledge

1. That the aims, methods, and anticipated benefits, and possible risks/hazards of the research study, have been explained to me.

2. That I voluntarily and freely give my consent to my participation in such research study.

3. I understand that aggregated results will be used for research purposes and may be reported in scientific and academic journals.

4. I also understand that if I provide documentation that is included in any aggregated results for research purposes and reported in scientific and academic journals, that my anonymity and that of the service provider will be ensured.

5. Individual results will not be released to any person except at my request and on my authorisation.

6. That I am free to withdraw my consent at any time during the study, in which event my participation in the research study will immediately cease and any information obtained from me will not be used.

Verbal agreement was obtained on Audio Tape Number: Date:

Interviewer Signature: Date:

NOTE: This form is to be read and explained to the participant, their questions answered, and the interviewer to sign that verbal, audiotaped consent has been obtained.

NOTE: In the event of a minor's consent, or person under legal liability, please complete the Ethics Committee's "Form of Consent on Behalf of a Minor or Dependent Person"
Appendix E - Deakin Ethics Approval

Research Services
Office of the Pro Vice-Chancellor (Research) (Melbourne Campus)

MEMORANDUM

TO: Prof Barrie O'Connor & Susan King
Institute of Disability Studies
Melbourne

FROM: Secretary, Deakin University Human Research Ethics Committee (DUHREC)

DATE: 16 October 2001

SUBJECT: PROJECT: EC 250-2000 (Please quote this project number in future communication)
NEGOTIATING LIFE CHOICES, LIVING THE LAST MONTHS OF LIFE WITH MOTOR NEURONE DISEASE

This application was considered by the Committee on 19 February 2001.

APPROVAL HAS BEEN CONFIRMED FOR MS SUSAN KING, UNDER THE SUPERVISION OF DR JAN BROWNE, NURSING AND PROF BARRIE O'CONNOR, INSTITUTE OF DISABILITY STUDIES, TO UNDERTAKE THIS REVISED PROJECT FROM 25 MAY 2001 TO 31 DECEMBER 2003.

The approval given by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the application and approval. It is your responsibility to contact the Secretary immediately should any of the following occur:
• Serious or unexpected adverse effects on the participants
• Any proposed changes in the protocol, including extensions of time.
• Any events which might affect the continuing ethical acceptability of the project.
• The project is discontinued before the expected date of completion.
In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

Victoria Emery
Secretary, DU-HREC
(03) 9251 7123
vemery@deakin.edu.au
1 February 2001

Ms Susan King
Student Researcher
School of Nursing
Deakin University
221 Burwood Highway
BURWOOD VIC 3125

Dear Susan,

I am pleased to advise that at its meeting held on Thursday 1 February 2001, the Research and Ethics Committee of Bethlehem Hospital granted approval for the conduct of your study titled - "Negotiating Life choices: Living with Motor Neurone Disease".

For reference purposes please note the following number, which is to be quoted on all communications regarding this project - 00120701.

In addition please note the following standard conditions that apply when such ethics approval has been granted by Bethlehem Hospital -

1. Ethical approval is granted for a two year period effective from 1 February 2001;

2. Immediate notification to Bethlehem Hospital's Research & Ethics Committee of any adverse affects on human subjects;

3. In the reporting of all adverse events, the Chief Investigator shall be required to explain in their opinion the significance of the event(s) being reported;

4. The immediate notification to Bethlehem Hospital Research & Ethics Committee of any unforeseen events that may affect the continuing ethical acceptability of the project;

5. Approval to be sought from Bethlehem Hospital's Research & Ethics Committee of any proposed modifications to the project; and

6. Submission of report at the completion of the project, with an interim report being provided at the expiration of the first 12 months and each 12 month period thereafter should the study be in excess of one year's duration.

"A Community of Carers Expressing Love in Action"
Please do not hesitate to contact me if you have any queries regarding this approval.

Yours sincerely

JEANNY GOOLD
Director of Nursing

JG ml
Appendix G - Template for fieldnotes

Interview context

Date:
Name (pseudonym):
Context of interaction
Accompanying person, if any
First impression:

A. Substantive issues

1. People, activities, settings:
   Descriptions of informants
   Short biographical history relevant to study
   Age:
   Sex:
   Relationship status:
   Type of living:
   Occupation or previous occupation:
   Diagnosis ie bulbar or spinal MND:
   Visible deficits:
   Equipment related to the participants care or social well-being:
   Service accessibility and services accessed:

   Description of settings

   Sensory perceptions: what does the setting look, smell, sound and feel like?
   Sketch of seating arrangements and furniture:

   Details of actions of participant and interviewer

   Description of researcher’s behaviour in field:
   R’s role in the field and influence on informant, their behaviour and comments
   Words and actions in the context in which they occurred:
   Details of participant’s behaviours and actions which are not visible in the transcript,
   including non-verbals: facial and physical expressions, perceptions. [these help to clarify
   what is being said – eg laughing, crying]

   Personal impressions of situations
Placing what happened within the context of your perceptions.
Your assumptions and how these change throughout the study.
Good points or tactics in the interaction
Points that could be improved in future interactions.
Did I listen and not talk over the participant?

2. The social experience of doing research
Getting in

What strategies were used to get informant to agree to be interviewed?
What promises did you make?
How did you present the research?
How much did you disclose about the research?
How did you present yourself?
Phone conversations (before and after interview)?

Establishing and maintaining relations

How did you establish rapport?
How did the relationship develop?
What interactions took place?
Were there any problems in developing trust?

Learning the ropes

What did you learn about people in this setting?
How did you become familiar with the participants world and view?
What special knowledge did you need to learn to fit in with this setting eg re: vocabulary, relationship networks, self presentation and management tactics?

Getting out

Did you keep your promises?
How did you negotiate return?
Follow-up & on-going contact plans?
B Methodological issues

Selection of informants
Who did you interview?
Why did you select this participant?
Who has not been included in the sampling framework?
Relevance of informant to theory building?
Which specific type of a phenomenon does this participant represent?
Who do you need to compare this participant with?
What contrasts in participants are needed to clarify the analysis and obtain saturation of the emerging categories?

Problems encountered
Difficulties using tape recorder eg informant’s objections, flat batteries, informant sensitivity to the presence of the recorder!
Difficulty with communication eg equipment, speech, ventilator.

Analysis of questions and questioning strategies
Did your questions work for you?
If yes, Why?
If no, what happened?
What are the consequences for your research findings?
What can you do next time?
Did you follow the recursive method?
Were you reflective?
Did you probe deeply, or merely slim the surface?
What issues do you need to follow up in subsequent talks with this participant and with other participants?

Ethical issues
What ethical dilemmas arose?
How did you deal with these?

Ideas for improvements on method and questions, alternative research designs that may work better.
Appendix H – Poster

Poster presented at the 13th International Symposium on ALS/MND, Melbourne, Australia in 2002.


**P78 CHALLENGING THE BARRIERS: CREATING OPPORTUNITIES FOR PEOPLE LIVING WITH ALS/MND TO PARTICIPATE IN QUALITATIVE RESEARCH**

King SJ, Browne JL, O’Connor B  
1 School of Nursing, 2 School of Nursing/Bethlehem Health Care Research Partnership, Disability Studies Unit, School of Health Sciences, Deakin University, Burwood, Victoria, Australia

**Objective**

What can a researcher do when seeking to record the views of a group of people living with ALS/MND whose capacity to communicate is often severely impaired due to their condition? This paper reports on the methodological challenges faced in the first 10 interviews with 6 participants of a qualitative grounded theory research project. The study aims to explore and describe the experiences of people living with ALS/MND and to identify what they see as their psycho-social needs to live their life as they wish.

**Methods**

Individuals diagnosed with ALS/MND who live in metropolitan, regional and rural areas within the state of Victoria, Australia were interviewed. The criteria for selection were that they should be able and willing to communicate in English, whether verbally or with communication aids.

Participants were recruited through collaboration with providers of neurological care and support groups. Data for this study were mainly collected using in-depth interviews. Additional data for analysis were gathered from diaries, e-mail correspondence and primary sources such as care plans. Literature and photographs. The collaborative and responsive methods used to collect the data are described.

**Results**

Key concerns when interviewing people living with ALS/MND include accessing a sample, and recording and transcribing slurred speech and electronic voices. Obtaining and recording data through in-depth interviewing techniques with individuals with decreasing ability to communicate is challenging. With collaboration and lateral thinking, it is possible for people with ALS/MND to participate in qualitative research.

**Conclusions**

People living with ALS/MND form a group whose symptoms may create difficulties in communication. For this reason they are usually excluded from any research that requires collection of verbal data. This study concludes that individuals with ALS/MND can contribute to research; however, their contribution requires participant–researcher collaboration and perseverance. The processes used in this study, can be used to facilitate research participation across a broad range of people living with communication challenges.

**Acknowledgements**

This project is funded and supported by The Australian Research Council, Deakin University, Bethlehem Griffiths Research Foundation, Bethlehem Health Care and Motor Neurone Disease Association of Victoria.
Challenging the barriers
Creating opportunities for people living with ALS/MND to participate in qualitative research

1. Introduction
Research interviews pose challenges for people with ALS/MND and researchers. This poster describes methodological challenges faced in the first 10 interviews with six participants of a qualitative grounded theory research project in Victoria, Australia. The project titled 'Negotiating life choices: living with ALS/MND' explores what people living with ALS/MND identify as the two most neglected in qualitative research.

As ALS/MND progresses, an individual's ability to communicate may decline. Research that involves interviewing individuals with such communication difficulties is, in the main, neglected (Thorne & Paterson, 2000). This study ensures people with ALS/MND have a rarely heard voice in qualitative research.

2. Research process
Method: Grounded theory exploration of participants’ lived experiences.
Participants: Individuals diagnosed and living with ALS/MND.
Recruitment: Advertisements in public interest, snowball sampling, direct mail to clients in metropolitan and rural areas of Victoria, Australia.
Data: Transcribed audiotaped in-depth interviews, diaries, songs, prose, letters.

3. Addressing challenges with tips for researchers
- Sound quality of recording: External microphones enhance audio-recording of electronic voices.
- Electronic devices such as lightimers and computers disrupt conversational flow and spontaneity.
- Altered speech and electronic voices are very difficult to transcribe.
- Getting the right story when emotional expressions do not convey true feelings—either extremes of laughing and crying or laughing when feeling sad and crying when feeling happy.
- Before the interview ask if the participant experiences extremes of confusion in expressing their feelings.
- Pause for the participant to gain composure.
- Clarify what the feeling the person is actually expressing.
- Ask the participant if they would like to change the subject.

4. Conclusion
- Individuals living with ALS/MND are a group of people whose symptoms may create significant communication difficulties.
- For this reason, they are often excluded from research that requires collection of verbal data.
- People with ALS/MND can contribute to qualitative research.
- Collecting interview data requires participant and researcher collaboration and perseverance.
- Tips described above are useful to all researchers to ensure that the stories of people who live with communication challenges can be heard.

5. References

This project is funded and supported by the Australian Garners Council, Deakin University, Neuroscience Research Australia, Brain Research Foundation, and the Motor Neurone Disease Association of Victoria. Susan King is a joint recipient of the Australian Academy Award in 2002.
Appendix I – Poster

Poster presented at the 14th International Symposium on ALS/MND, Milan, Italy, 2003


**P199 LIVING WITH ALS/MND - ‘BAD DAYS’**

King SJ*, Browne JL*, O’Connor B*

*School of Nursing, Deakin University, Burwood, Victoria, Australia, School of Nursing/Bethlehem Health Care Research Partnership, Deakin University, Burwood, Victoria, Australia, Disability Studies Unit, School of Health Sciences, Deakin University, Burwood, Victoria, Australia

E-mail address for correspondence: king@deakin.edu.au

Objective

Previous studies have looked at positive coping strategies of people living with ALS/MND. In a qualitative grounded theory study 'Negotiating life choices: living with ALS/MND', data analysis revealed aspects of living with the disease that some prefer to keep private. Overall, the study aimed to capture and describe the experiences of people diagnosed and living with ALS/MND as well as to identify how they negotiated with others to live their life as they wished. This paper reports on the findings of this project in relation to the less talked-about aspect of 'bad days'.

**Methods**

Twenty-five individuals diagnosed with ALS/MND who lived in metropolitan, regional and rural areas within the state of Victoria, Australia were interviewed from 2001 to 2003. Participants were recruited through extensive advertising campaigns in health-care and community support organisations. The criteria for selection were that they were able and willing to communicate in English whether verbally or with communication aids. Data included transcripts of in-depth interviews, participant photographs, care plans, reflections and stories, prose and songs that had meaning for participants, researcher field notes and reflections. A grounded theory approach was used for data analysis. The computer software QSR NVivo was used to manage the data collected for the project.

**Results**

Analysis of the data revealed aspects of living with ALS/MND that were private. Among them were the 'bad days' which participants were keen to hide. ‘Bad days’ are not talked about in public. The image shown to the public by most participants is one of coping well, of smiling and not complaining, or complaining with a smile. Intimate carers experienced 'bad days' with the person living the disease, in private. Those who lived alone occasionally revealed 'bad days' to those who happened to come along.

**Conclusions**

This study draws attention to the need for emotional support services for people with ALS/MND and their carers in recognition of the emotional impact of living with a progressive terminal illness that has no predetermined longevity. The existence of ‘bad days’ needs to be acknowledged and addressed for the well-being of the person and the circle of carers to promote living satisfactorily.

**Acknowledgement**

This project is funded and supported by The Australian Research Council, Deakin University, Bethlehem Griffeth Research Foundation, Bethlehem Health Care and Motor Neuron Disease Association of Victoria. Susan King is a joint recipient of the Nina Bascombe Award 2002.

**References**

Living with ALS/MND – “Bad days”

1. Introduction
Previous studies have looked at the positive coping strategies of people living with ALS (Young & McAlonan, 1993). This analysis in the research project ‘Negotiating life choices: living with ALS/MND’ revealed aspects of living with the disease that some preferred to keep private. This study explored and described the experiences of people living with ALS/MND in order to identify how they negotiated with others, so to live life as they wished. One aspect that was often hidden was “bad days”. This paper charts typical decisions by people living with ALS/MND for coping with “bad days” and the possible consequences of the decisions when “bad days” are not acknowledged.

2. Research process
Method: Grounded theory exploration of participants’ lived experiences
Participants: 20 individuals diagnosed & living with ALS/MND
Recruitment: Extensive advertising campaigns through health care services in urban & rural areas of Victoria, Australia
Data: Transcribed audio taped interviews; participant photos, case notes, reflections & stories; songs, poems, letters, researcher reflections & memos.

3. Preamble to results
Living with ALS/MND was about “negotiating change and adaptation”. Not knowing what would and could happen in the future was met with uncertainty. One aspect or living that participants endeavoured to maintain was their personal integrity and their sense of self in the face of uncertainty. This was the basis for negotiating adaptation strategies. A strategy for maintaining personal integrity was to ensure and protect a positive public image. Thus, distancing and unglittered experiences were often hidden from the public view and kept at home, as with “bad days”.

4. “Bad days” definition
“Bad days” happened when participants experienced changes that had a detrimental effect on them and their life perspective. Changes could be physical, emotional or environmental events that were unexpected. “Bad days” were described as “black”.

5. Hiding “bad days” – consequences
Positive: From participants’ perspective
- Maintains public view of coping well
- Do not feel isolated
- Family cope better if person is perceived to be coping well by family

Negative: From carers’ and support workers’ perspectives
- Limits support services at critical times
- Increases stress on carers & family
- Real story not revealed

6. Implications for intervention
- It can be helpful to provide support in a more flexible manner for people with ALS/MND so that their needs in recognition of the emotional impact of living with a progressive disease can be better met.

7. Conclusion
Negotiating life choices: living with ALS/MND has raised the need for more flexible and innovative support services for people living with ALS/MND and their carers to recognize the emotional impact of living with a progressive disease.

8. References

Appendix J– Poster


P156 LIVING WITH ALS/MND: ‘ONGOING CHANGE AND ADAPTATION’ MODEL

King SJ1, Duke MM1, O’Connor B2, Browne J2

1School of Nursing, 2School of Nursing/Galley Health Care Bethlehem Research Partnership, 3School of Health and Social Development, Faculty of Health and Behavioural Sciences, Deakin University, Burwood, Victoria, Australia

E-mail address for correspondence: king@deakin.edu.au

Background: People diagnosed with ALS/MND have different illness experiences. Living with the disease and navigating health care services change as the disease progresses. Research in ALS/MND is mainly concerned with causes, care and psychological studies that contribute to the understanding of the disease. Other research seeks to improve life with assistive technologies and techniques. However, there is a lack of research about the illness experience as reported by people living with the disease.

Objectives: This paper presents findings of the research project ‘Negotiating life choices living with ALS/MND’. Analysis of the data revealed two models that elucidated the illness experience: ‘The Diagnosis Story’ and ‘Living with ALS/MND’. The key concepts of the second model are presented.

Methods: Twenty four people diagnosed and living with ALS/MND were interviewed for this qualitative study. A grounded theory approach was used for data collection, analysis and model development. The computer software Nvivo was used to manage the data, which included in-depth interviews with participants and key informants, field notes and electronic correspondence as well as prose, stories, songs and photographs provided by participants.

Results: Living with ALS/MND evolved as a decision-making process linked to ‘ongoing change and adaptation’. The seven processes were perceived change, reacting to change, selecting adaptation strategies, adjusting to change, affecting well-being and facing another change when the process was repeated. Whatever the change – physical, psychological, emotional or environmental – the same steps were followed in incorporating it into their lives. Passive and active strategies were linked to altering support structures enabling participants to live their life. Participants made decisions and negotiated choices based on their need to maintain personal integrity, which had three dimensions – feelings, image and control. Feelings were associated with not being embarrassed or humiliated, but worthwhile, respected, cared for and loved. Image was associated with the participants’ sense of importance to project a positive public image and not show the ‘bad days’. Control was associated with taking charge of the MND, being able to make choices, having them enacted, and making future plans for care associated with their deteriorating body. These dimensions promoted participants’ perceptions about their self-esteem, self-worth, identity and personal integrity in the face of ‘ongoing change and adaptation’.

Discussion and conclusions: The model, ‘Living with ALS/MND’, highlights strategic areas for health professionals to purposefully intervene to improve care. In addition, the model assists people diagnosed and living with ALS/MND to understand quality of life issues for themselves. The model developed from this project has relevance in understanding decision-making processes by people with other fatal illnesses.

Acknowledgements: This project was funded and supported by The Australian Research Council, Deakin University, Bethlehem Grifiths Research Foundation, Calvary Health Care Bethlehem and Motor Neurone Disease Association of Victoria. Susan King won a joint recipient of the Nina Bincombe Award 2002 and 2004.
"Ongoing change and adaptation" model

1. Introduction
People diagnosed and living with ALS/MND travel different pathways as the disease progresses. This study sought to explore and understand what it is like to live with ALS/MND and how people with the disease negotiate with others for their choices in life.

This poster presents a model of decision-making about "ongoing change and adaptation" that participants revealed as living with ALS/MND.

2. Research process
Method: Grounded theory approach to explore participants' voiced experiences
Participants: 25 individuals diagnosed and living with ALS/MND
Recruitment: Extensive advertising through health-care services in urban and rural areas of Victoria
Data: 32 transcribed, audio-taped, in-depth interviews; participant photographs, care plans, reflections and stories, songs, prose and letters, researcher fieldnotes.

3. Findings
Participants revealed that living with ALS/MND was about "ongoing change and adaptation". The basis for deciding choices concerned with ongoing change was maintaining personal integrity in the face of the continuing decline of body functions.

The process of maintaining included regaining, sustaining and promoting personal integrity.

Dimensions of personal integrity were feelings, control and image.

4. Implications for practice
For people with ALS/MND:
A guide for understanding and making clearer what is happening as they live with ALS/MND and exploring possible consequences of decision-making.

For carers and health service providers:
A guide for understanding the reasons behind some of the decisions made by people with ALS/MND and promoting their efforts in maintaining their personal integrity.
Appendix K– Poster

Poster presented at the 16th International Symposium on ALS/MND, Dublin, Ireland, 2005.


P175 LIVING WITH ALS/MND: MAINTAINING PERSONAL INTEGRITY IN THE FACE OF ONGOING CHANGE AND ADAPTATION

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Background: The progressive death of motor neurons causes difficulties with mobility, communication, breathing and nutrition for people diagnosed with ALS/MND. While most research focuses on the disease progress, little is known of the illness experience.

Objectives: The aim of this study was to explore and describe what it is like to live with ALS/MND and identify how people with the disease negotiate with others for their choices in life. The purpose was to give people with the disease a rarely heard voice in qualitative research.

Method: A grounded theory approach was used to explicate the life world of people diagnosed and living with ALS/MND. Sample size was 25 people with the disease from rural and urban areas. Data sources were 33 transcribed in-depth interviews; written stories, prose, songs and books important to the people and researcher field notes. The data were analysed using constant comparison analysis and managed with the software program N-Vivo.

Results: Analysis revealed a story of being diagnosed that was integral to understanding the illness experience of ALS/MND. Living with the disease involved the development of a decision-making process to cope with the ongoing changes that emanated from the disease’s progression. The pattern was cyclic and repetitive. The basic social process that underpinned the decision-making while living with the disease was that of maintaining personal integrity. Living with ALS/MND was revealed as maintaining personal integrity in the face of “ongoing change and adaptation”. Facets of personal integrity were feelings, image and control. Strategy types for maintaining personal integrity were protecting, regaining and sustaining. Contextual aspects that influenced the processes were past experiences of the health care system and socioeconomic factors. The threats participants experienced as they endeavoured to maintain personal integrity were impaired communication, “bad days”, and health professionals and service providers. Overall, participants said it was “hard work” to live with ALS/MND.

Discussion and conclusions: Laughing, denying, withdrawing and thinking creatively were important tactics used in maintaining personal integrity, but such strategies were mostly misunderstood by, or invisible to, the nurses and health care professionals who cared for the participants. As such this study revealed the hidden ALS/MND illness experience, which until now has been unacknowledged and not included in care management plans. Implications are that better understanding by health professionals of the hidden experiences will enable them to facilitate sensitive, supportive and innovative care of people with ALS/MND and their families.

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Living with ALS/MND

Maintaining personal integrity in the face of ongoing change and adaptation

1. Introduction

The progressive death of motor neurons causes difficulties with mobility, communication, breathing and nutrition for people diagnosed with ALS/MND. While most research focuses on the disease progress, little is known of the illness experience.

The conceptual model of the substantive theory that emerged from the grounded theory study “Negotiating Life Choices: Living with ALS/MND” is presented.

2. Study Aims

- To explore and describe what it is like to live with ALS/MND.
- Identify how people with the disease negotiate with others to exercise choice in the way they wish to live life.
- To hear the rarely heard voice of people diagnosed and living with ALS/MND.

3. Research Process

Method
- The tenets of grounded theory (Glaser & Strauss, 1967)
- N-Vivo software to manage data (Bazeley & Richards, 2006)
- Conceptual modelling to facilitate understanding of dense theories (Soutierre, Britt & Mariner, 2001)

Participants
- 51 individuals diagnosed and living with ALS/MND

Recruitment
- Extensive advertising through health-care services in urban and rural areas of Victoria, Australia

Data
- 33 transcribed, audio-taped, in-depth interviews; participant photographs, care plans, reflections and stories; songs, prose and letters; researcher fieldnotes

4. Findings

Three constructs were explicated.
- “The Diagnosis Story”
- A decision-making model of “ongoing change and adaptation”
- A basic social process and core theme of “maintaining personal integrity”

Together they told the story of what it is like to live with ALS/MND and how people with the disease exercised their choices in life.

The substantive theory emerged as “maintaining personal integrity in the face of ongoing change and adaptation”. Negotiation to exercise choice is implicit. Elements that impact on the process are threats, and internal and external moderators.

5. Implications for Practice

Often strategies such as laughing, denying, withdrawing and thinking creatively are misunderstood or invisible to health professionals who care for people with ALS/MND.

The hidden ALS/MND illness experience of the detrimental outcomes of the diagnosis process, “bad days” and negative effects of the disease process, all threaten the process of maintaining personal integrity. Better understanding of these hidden aspects by health professionals, will facilitate sensitive, supportive and innovative care of people with ALS/MND and their families.

6. Conclusion

Although ALS/MND is a shattering and demeaning disease that is terminal, living with life goals is possible by seeking “positivity”, achievable activities, quiet and stress-free environments and interaction with supportive people who respect an individual’s need for maintaining personal integrity.

7. References


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