Guidelines for managing people with diabetes at the end of life
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FINAL REPORT
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The research was funded by the Nurses Board of Victoria, Ella Lowe Grant
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Yeah, the patients shouldn’t have to worry about it [diabetes care at the end of life] that’s the only thing I would say that it’s [diabetes] not given as high a priority probably as it should be.

You don’t want to go on with endless care... you’ve got to draw a line somewhere but I think I would like to feel comfortable but not be overactive with treatment and I feel that’s not done.

Comments from two people with diabetes receiving palliative care who participated in the interviews.
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List of Abbreviations

ACD  Advanced care directive
AM  Morning
BG  Blood glucose
CAM  Complementary and alternative medicines
CCF  Congestive cardiac failure
DE  Diabetes Educator
DKA  Diabetic ketoacidosis
eGFR *estimated* Glomerular filtration rate
GI  Gastrointestinal symptoms
HONK  Hyperosmolar non-ketotic acidosis
Hypo  Hypoglycaemia
ICU  Intensive care unit
IGT  Impaired glucose tolerance/ glucose intolerance
IM  Intramuscular
IRS  Insulin resistance
IV  Intravenous therapy
MI  Myocardial Infarction
OHA  Oral Hypoglycaemic agents
Mmol/L  millimoles/litre – unit for measuring glucose in blood
PCOC  Palliative care outcomes collaboration
PM  Afternoon
QUM  Quality use of medicines
SVC  Superior vena clava syndrome/obstruction
T1  Type 1 Diabetes Mellitus
T2  Type 2 Diabetes Mellitus
TZD  Thiazolidinediones
UTI  Urinary tract infection
WHO  World Health Organisation
EXECUTIVE SUMMARY

The focus of the project was people with diabetes requiring palliative care in the last stages of life. The main goal during these phases is to improve and maintain the individual’s quality of life and dignity while positively influencing the course of the life limiting illness through appropriately assessing and managing symptoms and contributing disease processes to achieve optimal outcomes. Importantly, palliative care now includes managing chronic diseases such as diabetes. In this context, optimal outcomes include ensuring the patient is comfortable, alleviating pain and unpleasant symptoms, and enabling a peaceful death. That is, managing the comorbid illness (diabetes) as part of caring for people with a progressive life threatening illness where end of life care may be required for days or months. However, diabetes-specific care goals and outcomes at the end of life are not well described.

These Guidelines were developed in accordance with the National Health and Medical Research Council Guidelines for Developing Clinical Practice Guidelines. The process included:

- Establishing an interdisciplinary advisory committee that provided expert advice during the development of the Guidelines.
- Undertaking a comprehensive review of the best available evidence.
- Consulting with key stakeholder consumers: people with diabetes, their carers, and palliative care and diabetes clinicians.
- Undertaking formative evaluation of the draft Guidelines and revising the Guidelines based on the information key stakeholder consumers provided.
- Evaluating the final Guidelines for usability and comprehensiveness in a real life clinical setting.

Aims and objectives

The overall aim of the project was to enhance the quality of palliative care delivered to people with diabetes in the end stages of life.
The specific objectives were to:

- Develop Guidelines for managing diabetes in patients receiving palliative care with a focus on the Palliative Care Outcomes Collaborative (PCOC) end of life stages: stable, unstable, deteriorating, and terminal.
- Implement the Guidelines in a palliative care setting.
- Assess the effectiveness and acceptability of the Guidelines to palliative care clinicians and people with diabetes and their carers and further refine them as appropriate.

Ethics approval to undertake the study was obtained from the Barwon Health Human Research Ethics Committee and written informed consent was obtained from all participants.

**Literature review**

A comprehensive literature review was undertaken but failed to retrieve any randomised control trial evidence on which to base the Guidelines. Ten relevant papers were retrieved and initially evaluated by the research team. Seven of these papers contained useful information and were further evaluated by the Advisory Committee and subsequently used to develop a set of guiding principles to follow as the Guidelines were developed.

The scientific evidence available to inform the development of the proposed Guidelines was of low level and no research was identified with an NHMRC level of evidence greater than level IV. The existing literature does not address the PCOC philosophy or most of the guiding principles used as the contextual framework to guide the development of the current Guidelines. It was largely written by non-diabetes experts, and shows little understanding that monitoring and controlling blood glucose is a key aspect of identifying the cause of and managing unpleasant symptoms, including pain.
**Interviews with patients and family members/carers**

Data were collected during individual face-to-face semi-structured interviews with fourteen patients with diabetes requiring palliative care and ten family members/carers of patients with diabetes requiring palliative care from a large regional palliative care facility. The interviews were audio-recorded and transcribed verbatim after which content analysis was undertaken to identify key themes and issues.

Key findings from the interviews that informed the development of the Guidelines were:

- Continue testing blood glucose until the terminal stage unless otherwise specified in an Advanced Care Directive.
- Continue medicines to control unpleasant hypo/hyperglycaemia until the terminal stage but use them in that stage to promote comfort.
- Medicines may need to changed or adjusted frequently as the person’s condition changes and insulin might be indicated.
- Consider the whole person and individualise their management plan.
- Health professionals should listen to the person with diabetes because they are experts in their disease and recognising symptoms by recognising body cues.
- Health professionals should acknowledge the role of family members/carers in managing the patient’s diabetes as the patient’s health deteriorates, and include family members/carers in discussions about the patient’s care plan.
- Family members/carers may not have previously undertaken tasks such as monitoring blood glucose levels and may lack the necessary knowledge and skills to monitor and interpret blood glucose levels, manage increasing or decreasing blood glucose levels and administer medicines safely and confidently.
- Family members/carers require more information, education and support in relation to managing diabetes in the context of palliative care.
- Family members/carers may feel anxious about their increasing responsibility regarding their care recipient’s diabetes and need support and guidance from health professionals.
Development of the Guidelines and accompanying document

The research team developed the Guidelines in consultation with the Advisory Committee. The Guiding principles, relevant information from the literature review, and the experiences of the Advisory Committee were used to develop the initial draft of the Guidelines. The information obtained from the interviews was included in the second draft of the Guidelines.

The Guidelines describe appropriate treatment for patients with type 1, type 2 and steroid-induced diabetes at the various stages of advanced disease: stable, unstable, deteriorating, and terminal. They are based on the best available evidence at the time they were developed.

An explanatory document to accompany the Guidelines was developed simultaneously with the Guidelines to help palliative care health professionals understand and implement the Guidelines. The document includes a detailed explanation of the conceptual framework and philosophy underlying the Guidelines, an overview of diabetes and the complexity of diabetes management in the context of palliative care. A concise version of the accompanying document was prepared for use in clinical practice.

Evaluation

Three processes were utilised to obtain feedback from palliative care health professionals about the draft Guidelines during the formative and summative evaluation processes:

- An information and discussion session with 21 palliative care health professionals.
- A questionnaire completed by 20 palliative care health professionals working in Barwon Health.
- A brief interview with seven palliative care health professionals after which the draft Guidelines were refined.
- Palliative care health care professionals were invited to use the revised Guidelines to plan care for people with diabetes at the end of life.

The majority of health professionals who responded to the questionnaire (n = 20) found the language in the Guidelines consistent with palliative care language and procedures and with the PCOC palliative care principles. Some respondents and interview
participants suggested the way the Guidelines were presented could be improved. No health professionals interviewed in the third part of evaluation process specifically utilised the Guidelines with a palliative care patient. However, twelve health professionals who completed the questionnaire in the second part of the evaluation applied the Guidelines to at least one patient in a specific PCOC phase. These participants found the Guidelines useful and their comments were generally positive. In particular, respondents indicated that the Guidelines were very helpful when managing patients with diabetes in the terminal PCOC phase.

Refining the Guidelines

The Guidelines were further refined after the evaluation phase. The key changes were as follows:

- A contents page was added to help health professionals easily locate the section of the Guidelines they need.
- Titles on each page were clarified to describe the content of specific pages more clearly.
- The wording within individual sections was revised to ensure it was consistent throughout the Guidelines. For example statements in some text boxes were rewritten as active statements.
- Blood glucose ranges and blood glucose monitoring frequencies were included.
- A skilled graphic designer was employed to ensure the Guidelines were clear, appealing and user-friendly.

Plan for disseminating the Guidelines

The final Guidelines will be disseminated in the following manner:

- They will be officially launched at the Innovations – Updating Professional Practice in Palliative Care Conference in Torquay, Victoria in October 2010.
- Through the CareSearch website, which attracts 100,000 hits per month.
- Presentations or brief summaries to relevant diabetes and palliative care special interest group meetings.
- In newsletters of diabetes and palliative care professional associations.
- At local, state, national and international conferences.
Section 1

INTRODUCTION
INTRODUCTION

The focus of the research was people with diabetes requiring palliative care in the last stages of life, where the goal is to improve and maintain the individual’s quality of life and dignity. That is, managing the comorbid illness (diabetes) as part of caring for people with a progressive life threatening illness where end of life care may be required for days or months. In this context, better patient outcomes include ensuring the patient is comfortable, alleviating pain and unpleasant symptoms, and enabling a peaceful death (Ellershaw, 2003). Importantly, palliative care now includes managing non-life-threatening chronic diseases such as diabetes in the final years (Emanuel, Alexander, Arnold et al., 2004).

However, diabetes-specific palliative care goals and outcomes and diabetes management at the end of life are not well described. People with cancer may decline in a short period of time so that the need for palliative care is obvious. People with diabetes might experience many periods of metabolic instability or deterioration before they enter the terminal stage; thus, the need for palliative care may not be so obvious and could involve short encounters in many unstable episodes.

Palliative care is defined as:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

(World Health Organisation, 2009)

Diabetes management is complex and becomes increasingly complex in the context of palliative care. For example, several symptoms of advanced cancer are similar to those of hyperglycaemia, which complicates care decisions and makes it difficult for health professionals to determine and appropriately manage the underlying cause of the
symptoms, unless blood glucose is monitored (Quinn, Hudson & Dunning, 2006). Likewise, hyperglycaemia causes lethargy and lowered mood, which affects physical comfort, quality of life, and relationships. In addition, some medicines such as glucocorticoids, which are often used in palliative care to control symptoms including pain and nausea in advanced disease, trigger or aggravate hyperglycaemia (Dunning, 1996; Plodkowski & Lee, 2008).

Hypoglycaemia can also occur when people are treated with oral hypoglycaemic agents (OHA) and/or insulin, especially when food intake is affected by their diseases state, fasting for procedures, or as a side effect of medicines. Altered glucose metabolism occurs frequently in the anorexia/cachexia syndrome, which occurs in 40-90% of the cancer palliative care population (CareSearch, 2010). It is difficult to treat hypoglycaemia in patients with poor appetite, nausea or vomiting (McCoubrie, Jeffrey, Paton & Dawes, 2004; Smyth & Smyth, 2005) and OHA and/or insulin is often stopped in these people. However, stopping the OHA or insulin may not be the best management choice because of the resultant hyperglycaemia and its effects. Likewise, there are ethical issues associated with stopping any treatment, even in end of life settings (Ford-Dunn, Smith & Quin, 2006). The wishes of the patient and their family and Advanced Care Directives, if they are available, must be considered (Quinn et al., 2006; Smyth & Smyth, 2005).

Few palliative care and diabetes guidelines address managing diabetes in palliative care situations at the end of life. For example, palliative care guidelines (e.g. Australian Government Department of Health and Ageing, 2006; Qaseem et al., 2008) do not address the impact of diabetes on symptoms or quality of life when people with diabetes develop a life limiting illness and require palliative care. Existing guidelines adopt a broad focus and have not been systematically pilot tested or evaluated (Poulson, 1997; McCoubrie et al., 2004; Ford-Dunn et al., 2006). Anecdotal evidence from consultation within the Australian diabetes and palliative care communities and discussion with the Advisory Committee appointed for the current research indicates that existing guidelines are not well known or used in practice. The complexity of managing diabetes as well as concomitant illnesses requiring palliation and the lack of guidelines make it difficult for palliative health professionals to provide optimal diabetes care and enhance the quality of
life for individuals with diabetes, and for diabetes experts to provide advice about appropriate care (Quinn et al., 2006).

Diabetes is an increasingly common condition and there is good evidence for an association among diabetes, obesity and some forms of cancer. Likewise, people with diabetes with long term complications of diabetes such as end stage renal disease and cardiovascular disease require palliative care. Previous research indicates that current diabetes management in palliative care situations does not have a robust evidence base. However, due to the vulnerable nature of the patients and the ethical issues involved in undertaking research in the area it is difficult to conduct robust randomised controlled trials in end of life care. Thus, all forms of evidence need to be considered when deciding what constitutes ‘evidence’ including observational and qualitative studies and patient and carer wishes.

**Aims and objectives**

The overall aim of the project was to enhance the quality of palliative care delivered to people with diabetes in the end stages of life.

The specific objectives were to:

- Develop guidelines for managing people with diabetes receiving palliative care with a focus on the Palliative Care Outcomes Collaboration (PCOC) (PCOC, 2008) end of life stages: stable, unstable, deteriorating, and terminal.

- Encompass the Liverpool Integrated Care Pathway for the Dying Patient (Kinder & Ellershaw, 2003).

- Implement the Guidelines in a palliative care setting.

- Assess the effectiveness and acceptability of the clinical Guidelines to palliative care clinicians and people with diabetes and their carers (formative evaluation) and further refine them as appropriate.

A staged approach was used to develop Guidelines for managing diabetes at the end of life and the process followed the National Health and Medical Research Council
(NHMRC) *Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines* (NHMRC, 1999) and is described in the following section.

**Design**
Consistent with the NHMRC Guidelines, the current Guidelines were developed with the assistance of an interdisciplinary Advisory Committee that provided expert advice as the Guidelines were developed and evaluated. The Guidelines were based on a comprehensive review of the best available evidence and consultation with people with diabetes receiving palliative care, their carers, and palliative care clinicians. Formative and content evaluation and revision of the Guidelines occurred during their development and the final Guidelines were evaluated in clinical palliative care settings to determine their acceptability, usability, and comprehensiveness in a real life clinical setting. A flowchart depicting the method used to develop and evaluation the Guidelines in presented in Figure 1 on page 12.

The project was undertaken in five stages:

1) **Establishing an Expert Advisory Committee.** An Advisory Committee comprising experts in the fields of palliative care, medical oncology, radiation oncology, nephrology, endocrinology and diabetes management (diabetes educators and endocrinologists) provided advice about the content, design and evaluation process. Members of the Advisory Committee critiqued several iterations of the Guidelines during the development process and reviewed relevant literature. This process encompassed part of the formative evaluation phase of the study.

2) **Literature review.** A comprehensive, structured literature review was conducted to identify whether there were any changes in the management of people with diabetes and advanced disease since the principle researcher and two members of the Advisory Committee undertook the previous literature review in 2006 (Quinn, Hudson & Dunning, 2006). The grey literature was also searched including books written by people who had cared for their relatives in the end stages of life.

3) **Interviews with patients and carers.** Individual interviews were conducted with 14 people with diabetes who required palliative care and 10 family members of people with diabetes who required palliative care. The rich data obtained in the
interviews informed the development of the Guidelines to ensure that the perspectives and preferences of people with diabetes and their family members or carers were addressed.

4) **Development of clinical Guidelines.** Draft clinical Guidelines for managing people with diabetes at the end of life were developed. Formative and content evaluation occurred in this stage.

5) **Evaluating the draft clinical Guidelines.** The draft clinical Guidelines were evaluated in the Palliative Care Service at Barwon Health in Geelong. Palliative care staff commented on the draft Guidelines in the formative evaluation (stage 4) and used the Guidelines to manage people with diabetes requiring palliative care in the stage 5 evaluation process. Some staff also participated in individual interviews as part of the evaluation process. The regularly attended Palliative Care Team weekly case conference meetings, which enhanced the development and evaluation process and aided recruitment into stages 3 and 5.
Figure 1. Flow chart depicting the method used to develop and evaluate the Guidelines.
Section 2

EXPERT ADVISORY COMMITTEE
**EXPERT ADVISORY COMMITTEE**

**Composition of the Advisory Committee**
The researchers invited health professionals with expertise in diabetes management; palliative care, endocrinology and nephrology to join the Advisory Committee, which was established to help guide the project. All the people invited accepted the invitation.

Members of the Advisory Committee were:

Ms Karen Quinn RN, MN, Clinical Education Nurse, Caritas Christi Hospice (St. Vincent’s Hospital, Melbourne) and Nurse Researcher, Centre for Palliative Care Education & Research

Mr Mark Arnold RN, Nurse Unit Manager Palliative Care Inpatient Unit, Barwon Health, Geelong

Ms Pamela Jones RN, RM, B Nsg, CDE, Grad Cert Diabetes Ed, Dip Management, Manager Diabetes Referral Centre, Barwon Health, Geelong

Associate Professor Peter Hudson RN, PhD, St. Vincent’s Hospital, Melbourne

Dr Rob MacGinley, MBBS, FRACP, Nephrologist, Barwon Health, Geelong

Dr Samantha Worboys, MB, BS, FRACP, Endocrinologist, Barwon Health, Geelong

Ms Sharon Anderson, RN, Assoc Nurse Unit Manager, Palliative Care Inpatient Unit, Barwon Health, Geelong

**Role of the Advisory Committee**
The role of the Advisory Committee was to identify and assess relevant literature, provide advice about the draft Guidelines as they were developed and about the evaluation process and agree on the final Guidelines. The Advisory Committee met regularly throughout the project, usually at eight-week intervals. Some members of the Committee participated in the meetings by telephone.

Initially the Advisory Committee assisted the research team to establish the underlying or guiding principles for the Guidelines to ensure they were consistent with palliative care principles and diabetes management philosophy. The palliative care members of the Committee offered advice about the logistics of incorporating diabetes management...
Guidelines into palliative care processes and all members made suggestions about the appropriate design and format for the Guidelines.

The Committee reviewed and provided a structured critique of the relevant literature. Importantly, the Advisory Committee provided feedback about the many iterations of the Guidelines during the formative evaluation phase as the research team developed the content and structure of the Guidelines. The Committee also provided invaluable advice about the accuracy and appropriateness of the content and design of the Guidelines.

**Guiding principles**
The following guiding principles for managing diabetes at the end of life were established in collaboration with the Advisory Committee in the early stages of the project. These guiding principles served as the contextual framework for the Guidelines. They are person-centred and holistic and were derived from the limited available evidence, palliative care philosophy and information developed from the lived experiences of people who cared for their relatives at the end of their lives. Significantly, the issues embodied in the guiding principles also emerged in the interviews with the participants in the current study (see Section 4). These guiding principles formed the contextual framework for the Guidelines.

- Developing a care plan for managing diabetes at the end of life requires a shared understanding about the issues involved and shared, collaborative decision-making by relevant health professionals and patients and/or their carers.
- Diabetes and palliative care should be delivered within a Quality Use of Medicines (QUM) Framework (Pharmaceutical Health and Rational use of Medicines (PHARM) Committee, 2005; National Prescribing Service Limited and Palliative Care Australia, 2009).
- Incorporating diabetes management into the Palliative Care Outcomes Collaborative (PCOC) (PCOC, 2008) framework should enhance the applicability and acceptability of the Guidelines in palliative care settings.
- Only people at the end of life truly know the lived experience of dying.
• Psycho-social-spiritual distress is as painful as physical symptoms and can have just as much impact on the patient and carer’s quality of life.

• Dying is a part of an individual’s spiritual journey in which the individual may search for meaning in their past, present and future lives and utilise hope as part of achieving meaning and purpose in the remainder of their life (undertake a review of their life).

• Time is a valuable commodity when a person is dying.

• Human relationships, including with health professionals, and touch are important.

• Most people require skilled care in the last stages of life. Dying is a complex process that follows a common continuum from stable to unstable, which may be remediable or proceed to the dying terminal stage.

• All carers need to respect the patient’s choices, and where possible, these should be documented in Advanced Care Directives and/or other relevant proxy decision-making documentation.

• Most care can be provided in most settings as long as the health professionals and family providing care have the necessary resources and are adequately educated and supported.

• Changes in the patient’s condition and the families’ ability to manage the patient at home can occur suddenly and strategies and the necessary equipment and medicines to manage such changes need to be in place. Therefore, documented and communicated contingency planning to empower patients, carers and health professionals is critical.

• Current diabetes management strategies emphasise interdisciplinary, collaborative and holistic care in which the patient plays an active role. The patient should continue to be involved in their care according to their physical and mental capabilities during the dying process.

• Cultural beliefs including those concerning death, dying and grieving should be respected.

• Acute illnesses sometimes superimpose on the individual’s existing illness and may require emergency or hospital treatment. Symptom control and quality of
life should still be the focus of care, but relevant treatment of the illness may be warranted. Where relevant, the Liverpool Care Pathway for the Dying Patient should be activated.

- The person’s physical and mental status, projected lifespan, PCOC stage and their Advanced Care Directives usually determine care.

- The last stages of life should be as comfortable and positive as possible to enable people to have ‘a good death’.

- The care provided in the last stages of life can have profound and sometimes lasting effects on everybody involved. Therefore, bereavement support should be offered before and after death.
Section 3

REVIEWING THE LITERATURE
LITERATURE REVIEW

The literature review involved searching key databases, Pubmed, Medline, CINAHL, and CareSearch using the search terms diabetes, palliative care, diabetes/palliative care management/guidelines, life limiting illness, end of life, palliative care principles, symptom control, caregiver, caregiver expectations, spirituality, hope and bereavement and various combinations of these terms. Articles were excluded from the review if they were not published in English. The content of recent palliative care, diabetes, end of life and spirituality publications was examined, unpublished literature was sought from people working in palliative care and diabetes and the reference lists of journal articles and books were examined.

In addition, Australian and international diabetes and palliative care websites were searched for relevant published and unpublished material. No information about diabetes management and palliative care was located. For example, the following key palliative care websites did not mention diabetes management in palliative care settings (accessed 06.01.09): www.palliativecare.org; www.caresearch.com.au; www.palliativecare.org.au; www.health.gov.au—The National Palliative Care Program, Australian Government: Department of Health & Aging; and www.pallcarevic.asn.au.

Although there is a significant body of literature concerning palliative care, mostly focusing on symptom management, no detailed guidelines or guiding principles that foster an appropriate and evidence-based structure for managing people with diabetes requiring palliative care that encompasses quality use of medicines were identified. Only seven papers were identified that specifically addressed diabetes management and palliative care. These publications were subject to a structured critical review, which was undertaken by the Advisory Committee.

The critique of the literature included assessing strengths, weaknesses, quality, relevance to palliative care and diabetes practice and level of evidence using the NHMRC Designation of Levels of Evidence (NHMRC, 1999). The majority of papers were based on expert opinion and clinical experience rather than on research. Thus, the level of evidence of the literature included in the review did not exceed Level IV using the
NHMRC criteria. In addition, several recent relevant papers relied heavily on earlier papers for the information presented. No formal level of evidence is given to expert opinion or anecdotal information (NHMRC, 1999).

**Literature identified**
Nine published articles that focused on managing diabetes at the end of life and one article that focused on various comorbidities including diabetes at the end of life were identified. A detailed summary of the ten papers is presented in Table 1 (pages 26–33).

The evidence base of the available literature is weak. Five papers included one or two case studies in addition to expert opinion (Boyd, 1993; Poulson, 1997; Stevenson, Abernethy, Miller & Carrow, 2004; Tice, 2006; McPherson, 2008), two papers included new data collected from health professionals with diabetes or palliative care experts (Ford-Dunn, Smith & Quin, 2006; Quinn, Hudson & Dunning, 2006), two papers presented expert opinion only (Ford-Dunn & Quin, 2004; Psarakis, 2006), and one paper was a retrospective case note audit of deceased patients with a dual diagnosis of diabetes and cancer (McCoubrie, Jeffrey, Paton & Dawes, 2004).

Seven of the ten articles identified included information that was relevant to the current Guidelines. A summary of the relevant information is presented in Table 2 (pages 34–45) showing general information and information specific to type 1 and type 2 diabetes, separately.

**Limitations of the available literature**
- There is a paucity of published literature about managing diabetes when palliative care is required; the available literature is rarely based on actual data collected by the authors. Several of the most recent articles cite information provided in earlier papers; most relied on the paper published by Poulson (1997).
- The majority of published papers relied on expert opinion and clinical experience or one or two case studies rather than on research data.
- Very little information about the need to adjust diabetes management strategies, sometimes frequently, in the PCOC end of life phases was provided. Frequently, the
only mention of different stages in the dying process was a reference to diabetes management when patients only had weeks, months or days to live.

- Only passing reference was made to steroid-induced diabetes, yet corticosteroids are frequently used in palliative care and are known to cause hyperglycaemia, which in turn causes uncomfortable symptoms and affects quality of life.

- People with diabetes’ management preferences are rarely mentioned.

- Psychosocial dimensions of care are not mentioned.

- Family members/carers needs were rarely addressed except the general need to communicate changes in diabetes management to them. Although some authors did stress the need to consider the wellbeing of family members/carers (McCoubrie et al., 2004) their education needs and contribution to decisions about care were not mentioned.

- The format of the information provided was not helpful. Information was typically presented in dense text, which makes it difficult to identify information relevant to specific situations, and to access ‘at the bedside’. Only one paper presented a summary of information in a format similar to that adopted for the current Guidelines. However, the information was very general and did not address the changing care needs according to the PCOC stages (Tice, 2006).

- No authors acknowledged that diabetes could contribute to or even cause remediable unpleasant symptoms such as pain and contribute to death.

- No information about how to distinguish symptoms of hyperglycaemia or hypoglycaemia from symptoms associated with other disease/s or palliative care treatment was provided.

**Themes emerging in the literature**

A number of themes about managing diabetes in palliative care situations emerged from the available literature. It should be noted that the value of the evidence supporting the themes is compromised by the limitations of the literature and the poor quality of the available literature, as described previously.
Type 1 and type 2 diabetes should be managed differently. There was general consensus in the literature that managing people with type 1 diabetes is different from managing people with type 2 diabetes, particularly in relation to the medicine regimen (e.g., Poulson, 1997; Tice, 2006).

Individualise treatment. Diabetes management needs to be adjusted according to the individual patient’s situation and their preferences and the preferences of their carers when relevant (e.g., Smyth & Smyth, 2005; Ford-Dunn et al., 2006).

The goals of management change when a patient requires palliative care. Some papers specifically mentioned that the goals of diabetes management change from tight glycaemic control to maintaining comfort in the end of life (e.g., Poulson, 1997; Smyth & Smyth, 2005; Tice, 2006). However, ‘end of life’ was a blanket term and did not always distinguish between terminal care and the other stages of the dying process, and ‘tight control’ was not defined.

The need to alter the patient’s medicine regimen. Changes in nutritional intake, the presence of anorexia or nausea and vomiting affect the individual’s medicines regimen (e.g., Poulson, 1997; McCoubrie et al., 2004; Smyth & Smyth, 2005). The amount of detail provided about how to manage medicines in these circumstances varied considerably among authors; only one author mentioned adopting the Quality Use of Medicines framework (Stevenson, Abernethy, Miller & Carrow, 2004). Precautions/contraindications to using oral hypoglycaemic agents (OHAs) in the setting of renal and liver disease and in combination with palliative care medicines were not addressed in significant detail and the safety and benefits of using modern insulin analogues was not included.

Dietary restrictions may be relaxed. A common suggestion was that diabetes dietary restrictions could be relaxed when a person with diabetes has weeks or months to live (e.g., Poulson, 1997; Smyth & Smyth, 2005). However, the suggestion is difficult to interpret, given that current dietary guidelines recommend people with diabetes eat a healthy diet low in saturated fat and high in complex carbohydrate, the same as the rest of the population, rather than ‘a restricted diet.’ Thus, the information the authors used to underpin their dietary recommendations was possibly out-of-date.
A higher blood glucose level is acceptable. However, there was little discussion about what a ‘higher blood glucose level’ was or what constituted an ‘acceptable’ blood glucose level for people with diabetes who were not actively dying (e.g., Boyd, 1993; Poulson, 1997). The suggested ‘acceptable ranges’ varied among authors but most suggested the care focus should change from achieving ‘tight blood glucose control’ to achieving comfort. Some authors indicated that hyperglycaemia causes significant discomfort including acerbating pain. Boyd (1993) suggested a suitable blood glucose range for people with type 1 diabetes was 7–17 mmol/L, while Poulson (1997) suggested 10–15 mmol/L. No author recommended monitoring ketones in the presence of hyperglycaemia in people with type 1 diabetes, yet ketosis causes significant abdominal pain, nausea and vomiting. The criteria authors used to decide on an ‘acceptable blood glucose range’ was unclear.

Blood glucose monitoring. Only Tice (2006) included clear information about the frequency of blood glucose monitoring in different circumstances. Some authors recommended stopping blood glucose monitoring if a patient was unconscious (e.g., McCoubrie et al., 2004) but did not indicate whether blood glucose monitoring should continue if the unconscious state was due to remediable hypo/hyperglycaemia; others suggested discontinuing blood glucose testing when the patient was actively dying (McPherson, 2008).

Prognosis. Poulson (1997) suggested diabetes management should be changed when a patient has only days to live, and this theme emerged in subsequent papers. Smyth & Smyth (2005) and Tice (2006) suggested insulin might be unnecessary when the patient is unconscious or death is imminent. Ford-Dunn et al. (2006) and Quinn et al. (2006) presented data collected from focus groups with health professionals and showed a lack of consensus about blood glucose testing and administering insulin during the last days of life. Poulson (1997) argued that insulin could be considered to be life prolonging therapy when death is imminent and therefore ceased, which shows little understanding of symptom control or insulin action. However, Poulson (1997) did not indicate how to determine when death is ‘imminent’ or the patient is ‘actively dying.’

Communication. Several authors discussed the need to communicate with family members, usually about changes in diabetes management. For example, Smyth and Smyth (2005) indicated the family and interdisciplinary team should be consulted about
decisions to stop intravenous fluids and insulin. However, it was not clear whether diabetes health professionals were included in the interdisciplinary team. Quinn et al. (2006) found palliative care experts rarely referred to diabetes experts and diabetes experts confirmed they were rarely consulted once a patient required palliative care. Stevenson et al. (2004) provided examples of how to discuss changes in diabetes management with patients. But, none addressed family/carer need for advice, support and education when they were caring for the patient at home in the stable and unstable phases of the dying process.

The patient’s wishes. Some authors referred to the need to consider the patient and/or family/carer’s diabetes management preferences (e.g. Boyd, 1993; Tice, 2006) but none discussed Advanced Care Directives. Poulson (1997) did not mention considering the patient’s preferences as part of diabetes management, merely the need to ‘inform’ and ‘reassure’ patients and family members.

Thus, the existing literature does not address most of the guiding principles for managing diabetes at the end of life formulated to guide the development of the current Guidelines. It was largely written by non-diabetes experts, and shows little understanding that monitoring and controlling blood glucose is a key aspect of identifying the cause of and managing unpleasant symptoms, including pain, to achieve a ‘good’ death.

Summary
The scientific evidence available to inform the development of the proposed Guidelines was of low level; most was NHMRC level IV, which limited the current researchers’ ability to adhere to the NHMRC recommendation to base guidelines on level I evidence (NHMRC, 1999). Thus, the available literature was carefully examined and relevant information extracted and discussed with the Advisory Committee and considered in light of the guiding principles.

What needs to be included in clinically useful guidelines?
After considering the literature review, the consensus view of the Advisory Committee was that:
• The Guidelines should commence with a preamble that explains the underlying principles that served as the philosophical and theoretical framework for the Guidelines, why the Guidelines are needed, and how to use them.

• Global statements should be included that stress the importance of:
  - consulting with an interdisciplinary team
  - considering the impact of diabetes on palliative care and vice versa
  - individualising management
  - identifying and incorporating patients’ and family members/carers’ preferences.

• The Guidelines should be easy to use and prepared in a clear format such as a series of flowcharts that include prompts and management options.

• The Guidelines should include definitions of the different end of life stages and information about managing diabetes in each end of life phase, including but not limited to the stage when the person with diabetes is unconscious or actively dying.

• Type 1 and type 2 diabetes should be addressed separately.

• Information about managing steroid-induced diabetes should be included.

• Where appropriate, the Guidelines should provide specific details about diabetes medicines, blood glucose testing and blood glucose levels.

• Frequent instructions or reminders to consult patients about their preferences for diabetes management should be included in the Guidelines. Advanced Care Directives should be included.

• Instructions or reminders to consult family members/carers about the patient’s preferences if the patient cannot be consulted should be included in the Guidelines.

• The Guidelines should include instructions or reminders to consult or refer patients to other health professionals such as diabetes educators and diabetologists when relevant.

• Psychosocial/spiritual needs should be incorporated into the Guidelines.
Table 1. Summary of the relevant literature about managing diabetes in palliative care settings presented in order of the year of publication. (The table continues over 8 pages)

<table>
<thead>
<tr>
<th>Author Country</th>
<th>Purpose</th>
<th>Methods</th>
<th>Data collected or considered</th>
<th>Relevant findings</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Boyd (1993) UK</td>
<td>Discussion and expert opinion. To provide some guidelines for managing diabetes in hospice patients</td>
<td>Case studies n = 2</td>
<td>Case history Medicines Blood glucose levels (BGL)</td>
<td>When to cease blood glucose monitoring (BGM) and administering insulin is challenging at the end of life Modify DM management as condition deteriorates. Tight glycaemic control unnecessary, suggested BG range 7–17 mmol/L.</td>
<td>IV</td>
</tr>
<tr>
<td><em>Diabetes mellitus in hospice patients: some guidelines</em></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Poulson (1997) Canada</td>
<td>Discussion and expert opinion. To discuss issues in the management of diabetes in patients with advanced cancer and suggest guidelines for maintaining glycaemic control</td>
<td>Case studies (n = 2)</td>
<td>Case history Medicines BGL Medicinal effects on BGL as patient’s condition deteriorates or as patient requires medicines to manage palliative condition</td>
<td>Hypoglycaemia and hyperglycaemia can impair quality of life (QOL), alter mental status and interfere with interactions with family members. Extremes of BG levels can be predicted and prevented without excessive monitoring/intervention. Goal of care depends on prognosis (phase) and the type of diabetes. Factors that can interfere with glycaemic control include: anorexia, nausea and vomiting, disordered gastrointestinal (GI)</td>
<td>IV</td>
</tr>
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</table>
### Table 1. Summary of the relevant literature about managing diabetes in palliative care settings presented in order of the year of publication (Continued).

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</tr>
</thead>
<tbody>
<tr>
<td>Poulson, 1997 (Cont.)</td>
<td>without excessive interventions</td>
<td></td>
<td>BGL raised by medicines in most patients with diabetes and cancer</td>
<td>motility, bowel obstruction, stress, infection and some medications (i.e. steroids, diuretics). Organ failure such as hepatic and renal failure can affect the metabolism and duration of action of OHAs and glucose intolerance can be attributed to the metabolic consequence of cancer. Further abnormalities include: increased hepatic glucose production, failure to adapt to starvation, increased Cori cycle activity, increased lactate production, aberrant skeletal muscle glucose utilisation, aberrant production of counter-regulatory hormones and other alterations under investigation.</td>
<td>III</td>
</tr>
<tr>
<td>Stevenson, Abernethy, Miller &amp; Carrow (2004) Australia</td>
<td>To discuss key considerations for competent care of people with life</td>
<td>Discussion and expert opinion; case study (n = 1)</td>
<td>Pharmacological and non-pharmacological management of common chronic</td>
<td>Regular review of both the life limiting illness and the comorbidity is essential as both can change over time. Quality use of medicines is a responsibility of all clinicians.</td>
<td>IV</td>
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Table 1. Summary of the relevant literature about managing diabetes in palliative care settings presented in order of the year of publication (Continued).

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<tbody>
<tr>
<td>Managing comorbidities in patients at the end of life</td>
<td>limiting illnesses and chronic comorbidities.</td>
<td></td>
<td>conditions in patients at the end of life.</td>
<td>Adjusting medications in accordance to whole body changes should be an active process rather than in response to adverse events.</td>
<td>N/A</td>
</tr>
<tr>
<td>NOTE: This paper is not specific to diabetes</td>
<td></td>
<td></td>
<td>Metabolism Pathophysiology of death Prognostication Measure of benefit Aims of the intervention Psychological concerns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ford-Dunn &amp; Quin (2004) UK Management of diabetes in the terminal phase of life</td>
<td>To determine management strategies for managing diabetes in the terminal phase of life</td>
<td>Review of literature/expert opinion (Refers to Poulson, Boyd)</td>
<td>Dilemma of withdrawing/ceasing treatments in the dying phase</td>
<td>Current practice—little consistency, management varies depending on setting, type of diabetes and experience of health professional. Current evidence limited. May be difficult for patient, family and/or health professionals to accept less tight control of BG.</td>
<td>N/A</td>
</tr>
<tr>
<td>McCoubrie, Jeffrey, Patton, Dawes (2004)</td>
<td>To establish how diabetes is managed in patient with</td>
<td>Retrospective case note audit of deceased patients</td>
<td>Type of diabetes, date of diagnosis, details of diabetes monitoring</td>
<td>There is a lack of consistency in approach to diabetes treatment, monitoring, specialist palliative care involvement or informing patients and their family regarding care decisions.</td>
<td>IV</td>
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<tr>
<td>UK</td>
<td>Managing diabetes mellitus in patients with advanced cancer: a case note audit and guidelines</td>
<td>advanced cancer and diabetes mellitus</td>
<td>from a single health facility with dual diagnosis of diabetes and cancer over a 12-month period. Sample 42 deceased patients (14.6% of all cancer deaths) 8 – T1, 34 – T2</td>
<td>and management, use of steroids and involvement of other professionals around time of death. Whether diabetes monitoring continued, reduced or discontinued and how close to death these changes occurred. Whether decisions were discussed with patients and family.</td>
<td>The type of diabetes, the presence or absence of symptoms, the likely prognosis and the conscious level of the patient should govern treatment and monitoring decisions. See details in Table 2.</td>
</tr>
<tr>
<td>Ford-Dunn, Smith &amp; Quin (2006)</td>
<td>To form consensual expert opinion on the management of</td>
<td>Semi-structured postal questionnaire based around three</td>
<td>Diabetes management, frequency of BG monitoring, glycaemic</td>
<td>Consultant diabetologists and palliative care physicians seemed to agree to cease treatment and management of type 2 diabetes during the terminal phase.</td>
<td>IV</td>
</tr>
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<tr>
<td><strong>UK</strong></td>
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<tr>
<td>Management of diabetes during the last days of life: attitudes of consultant diabetologists and consultant palliative care physicians in the UK</td>
<td>diabetes during the terminal phase.</td>
<td>clinical situations.</td>
<td>threshold for intervention, additional comments/opinions</td>
<td>Consultant diabetologists and palliative care physicians seemed uncertain of the ethics of withdrawing a life sustaining medication and the unanswered question of benefit vs. burden of treatment for the management of type 1 diabetes during the terminal phase. Individualised treatment with guidelines adjusted according to patient/carer preference and the views of the staff.</td>
<td>IV</td>
</tr>
<tr>
<td><strong>Tice (2006)</strong></td>
<td>USA</td>
<td></td>
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<tr>
<td>Diabetes Management at the end of life</td>
<td>To explore the appropriateness of shifting the goal of diabetes therapy from tight control of blood sugar to maintaining comfort and enhancing quality</td>
<td>Case study n = 1</td>
<td>Discusses: shifting the goal of therapy from tight glycaemic control to maintaining comfort and QOL; Hypoglycaemic/ Hyperglycaemia; transitioning to comfort care.</td>
<td>Transitioning to comfort care: the key to balancing the goals of comfort and blood glucose control at end of life is to focus on the patient’s symptoms and prognosis.</td>
<td>IV</td>
</tr>
</tbody>
</table>

Suggested management of diabetes at end of life:
Acceptable BGL range 8.3–13.8 mmol/L.

See details in Table 2.
Table 1. Summary of the relevant literature about managing diabetes in palliative care settings presented in order of the year of publication (Continued).

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<tr>
<td>Quinn, Hudson &amp; Dunning (2006) Australia <em>Diabetes management in patients receiving palliative care.</em></td>
<td>To describe the current practices of doctors and nurses caring for patients with diabetes and advanced disease.</td>
<td>Two phase study consisting of two focus groups - one metropolitan and one regional (purposive sample of care providers) and a cross sectional survey.</td>
<td>Clinical experiences of doctors and nurses when caring for patients with diabetes and advanced disease. Decision making criteria of doctors and nurses caring for patients with diabetes and advanced disease. Whether the management of people with diabetes varies according to diabetes type.</td>
<td><strong>Focus group:</strong> Lack of guidelines for practice. Stage of illness influences BG management. Existence of specific issues to type one and type 2 and steroid-induced diabetes. Expressed concern about how much discomfort finger pricking causes. A great deal of palliative care interventions are far more uncomfortable or invasive than monitoring blood glucose. Significance of communicating with and educating patients and families. General lack of referral to expert professional colleagues. <strong>Cross sectional survey</strong> Despite most respondents indicating they had some experience with diabetes in end of life care and that the care was average to good (self-rated), there appeared to be several inconsistencies in diabetes management in patients with advanced disease. Significantly there was a lack of confidence to care for a patient with diabetes with advanced disease, difficulties in diagnosing</td>
<td>IV</td>
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Table 1. Summary of the relevant literature about managing diabetes in palliative care settings presented in order of the year of publication (Continued).

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<tbody>
<tr>
<td>Quinn et al. (2006) Cont.</td>
<td></td>
<td>40% response rate</td>
<td></td>
<td>diabetes at the end of life, a lack of referrals to diabetes experts, lack of awareness of how often patients on corticosteroids had abnormal BG levels and lack of knowledge about the types of diabetes.</td>
<td></td>
</tr>
<tr>
<td>Psarakis (2006) USA</td>
<td>Clinical challenges in caring for patients with diabetes and cancer</td>
<td>Discussion and expert opinion</td>
<td>Pre-existing renal, cardiac or neuropathic complications</td>
<td>Chemotherapeutic agents can exacerbate renal, cardiac or neuropathic conditions; treatment must be based on the clinical picture.</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Glucocorticoids</td>
<td>Screening and routine monitoring of diabetes - treatment of hyperglycaemia depends on type of diabetes, severity of the elevated BG levels, dose and duration of therapy. Consider changing from OHAs to insulin and/or increasing insulin doses.</td>
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<tr>
<td></td>
<td></td>
<td>Tube feeding and total parenteral nutrition</td>
<td>Hyperglycaemia is a frequent complication. Consider insulin. Common adverse drug reactions—screen, monitor, consider antiemetic therapy.</td>
<td></td>
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</tr>
</tbody>
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Table 1. Summary of the relevant literature about managing diabetes in palliative care settings presented in order of the year of publication (Continued).

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<tbody>
<tr>
<td>Psarakis (2006) Cont.</td>
<td></td>
<td></td>
<td></td>
<td>Less stringent but should not be ignored. Consider patient and family wishes; re-evaluate and revise with each change in patient’s clinical condition.</td>
<td></td>
</tr>
<tr>
<td>McPherson (2008) USA</td>
<td>To review therapeutic goals for terminally ill patients with diabetes</td>
<td>Discussion and expert opinion; case study n = 1</td>
<td>Need for relevant therapeutic goals at the end of life</td>
<td>Tight BG control is an unrealistic goal for patients with a terminal illness and may cause unacceptable symptoms such as hypoglycaemia. For terminally ill patients the glycosylated haemoglobin (HbA1c) level no longer provides useful information. The most important goal for an end stage patient with diabetes is to prevent symptoms related to hyperglycaemia and/or hypoglycaemia.</td>
<td>IV</td>
</tr>
<tr>
<td>Authors</td>
<td>Form of guidelines &amp; source</td>
<td>Relevant factors included</td>
<td>Specific guidelines or recommendations</td>
<td>Level of evidence</td>
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<tr>
<td>Boyd (1993)</td>
<td>Brief guidelines in text.</td>
<td>Based on two case studies and diabetes literature.</td>
<td>Decisions concerning withdrawing of BG monitoring and reducing/ceasing medicines may be difficult</td>
<td>IV</td>
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<tr>
<td></td>
<td></td>
<td>BGL Medicines End of life stage</td>
<td>Modify diabetes management plans are appropriate in hospice patients</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Tight glycaemic control unnecessary emphasis on avoiding hypoglycaemic and symptomatic hyperglycaemia</td>
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<td></td>
<td></td>
<td>Determine suitable BG target range</td>
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<td>BGL twice per day (BD)</td>
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<td></td>
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<td></td>
<td>Give 4 units short acting insulin if BGL &gt; 17mmol/L</td>
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<td></td>
<td>Suitable BG range: 7–7 mmol/L</td>
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<td>Administer insulin where patient truly insulin dependant.</td>
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<td>Insulin administration appropriate</td>
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<td></td>
<td></td>
<td>Consider conscious level, symptoms, patient and families’ wishes, provide adequate explanation and support</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Relax dietary restrictions</td>
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<td></td>
<td>Review OHA regularly and gradually withdraw as patient’s oral intake reduces, as patient loses weight or as condition deteriorates; consider OHA dose reductions.</td>
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<td></td>
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<td></td>
<td>Consider short acting OHAs to reduce risk of hypoglycaemia.</td>
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<td></td>
<td></td>
<td></td>
<td>Monitor side effects of OHAs with a view to dose</td>
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</tbody>
</table>
Table 2. Summary of key papers that suggested guidelines or recommendations for managing people with diabetes and advanced cancer or advanced terminal illness at the end of life presented in order of the year they were published (Continued).

<table>
<thead>
<tr>
<th>Authors</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Boyd (1993) Cont.</td>
<td></td>
<td>Important – avoiding hypo-glycaemia and symptomatic hyperglycaemia, relaxing dietary restrictions, maintain skin/feet integrity, early identification of candida &amp; other infections and monitoring effects of corticosteroids</td>
<td>General: Monitor symptoms consider consciousness level, patient and family wishes Type 1: Provide support/education to family members/carers Type 2: reduction/ceasing. Recognise and accept relatives views on the patients diabetes management</td>
<td></td>
</tr>
<tr>
<td>Poulson (1997)</td>
<td>In text and table for monitoring and managing</td>
<td>Type of diabetes: Anticipated prognosis Treatment needs to be individualised. Tight glycaemic control not</td>
<td>Absolute requirement for insulin to prevent the development of fatal ketoacidosis. Suggested BG range 8–15mmol/L, unless symptomatic.</td>
<td>IV</td>
</tr>
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Table 2. Summary of key papers that suggested guidelines or recommendations for managing people with diabetes and advanced cancer or advanced terminal illness at the end of life presented in order of the year they were published (Continued).

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</tr>
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<tbody>
<tr>
<td>Poulson (1997) Cont.</td>
<td>diabetes. Based on clinical experience, two case studies, and cancer, diabetes and medical literature.</td>
<td>End of life stage Appetite/weight BGL</td>
<td><strong>General</strong></td>
<td><strong>Type 1</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Important however essential to avoid hypo/hyperglycaemia. Maintain BGL in an acceptable range with a minimum of monitoring. Dietary restrictions no longer required. Careful explanation to patient and family; provide reassurance and education. Reassure patients and family that reduced dietary restrictions and monitoring, and higher BGL reflects shift of therapy toward quality of life. Suggested short-acting insulin</td>
<td>Suggested BG range 10–15 mmol/L, unless symptomatic. If stable nutritional status, maintain previous insulin regimen, monitor BGL twice daily before meals every 3 days. If reduced appetite, monitor fasting BG daily for 3 days and reduce insulin if indicated. If severe anorexia and/or vomiting, change to short-acting insulin. Once stable dose established, intermediate-acting insulin. Monitor BG twice daily. Maintain adequate insulin to avoid ketosis (0.3-0.4 units/kg/24hr).</td>
</tr>
</tbody>
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<tr>
<td>Poulson</td>
<td></td>
<td>dose (units) for post prandial BGL:</td>
<td>Patients with no oral intake still require baseline insulin to prevent ketosis. Need to anticipate patient’s insulin requirements and match insulin dose accordingly.</td>
<td></td>
</tr>
<tr>
<td>(1997) Cont.</td>
<td></td>
<td>BGL 10–15 6 units</td>
<td>As death becomes imminent insulin could be considered as life prolonging therapy emphasising the necessity of discussions re withdrawing treatments with family; cease BG monitoring at this stage.</td>
<td></td>
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<tr>
<td></td>
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<td>BGL 15.1–18 8 units</td>
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<td></td>
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<td>BGL 18.1–22 10 units</td>
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<td>BGL &gt;22 12 units</td>
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<td>Glucocorticoids can affect glycaemic control in patients with diabetes but the affect varies with the individual. Patients with Type 2 may develop hyperglycaemia and require insulin. Patients with type 1 may require insulin dose increases. Intensive BG monitoring is warranted.</td>
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<td></td>
<td>infection or serious stress factors present. Monitor BG every two days “and hypoglycaemic treatment initiated if the clinical assessment suggests that hyperglycaemia is contributing significantly to patient distress” (p. 344) [NOTE, this is confusing and could mean use OHA/insulin to control hyperglycaemia OR treat hyperglycaemia].</td>
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<tr>
<td></td>
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<td></td>
<td>Relax dietary restrictions and adjust OHA/insulin accordingly.</td>
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</table>
Table 2. Summary of key papers that suggested guidelines or recommendations for managing people with diabetes and advanced cancer or advanced terminal illness at the end of life presented in order of the year they were published (Continued).

<table>
<thead>
<tr>
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<th>Relevant factors included</th>
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<th>Level of evidence</th>
</tr>
</thead>
</table>
Involvement of specialist palliative care teams – early referral to palliative and diabetes teams may facilitate a more palliative approach to care.  
Early involvement and updating of patients and families so they can make decisions concerning their care.  
Weeks/months to live: Consider referral to specialist palliative care and or diabetes | Patient with weeks/months to live  
Insulin required to prevent ketoacidosis  
Weight loss or reduced calorie intake due to nausea or vomiting may indicate an insulin dose reduction  
Patient with days to live:  
If conscious and symptomatic of hyperglycaemia, use short acting  
Patients with days to live:  
If conscious and symptomatic of hyperglycaemia, use short | IV |
Table 2. Summary of key papers that suggested guidelines or recommendations for managing people with diabetes and advanced cancer or advanced terminal illness at the end of life presented in order of the year they were published (Continued).

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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>General</td>
<td></td>
</tr>
<tr>
<td>McCoubrie et al. (2004)</td>
<td></td>
<td></td>
<td>team</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Maintain BG range at 10–20 mmol/L</td>
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<tr>
<td></td>
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<td></td>
<td>Reduced calorific intake and weight loss significantly lowers BG</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Avoiding hypoglycaemia paramount</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Relax dietary restrictions</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Early identification and treatment of oral Candida</td>
<td></td>
<td></td>
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<tr>
<td></td>
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<td>insulin when BG &gt;20 mmol/L.</td>
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<tr>
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<td></td>
<td>If patient is unconscious, stop all oral and hypoglycaemic medication and BG monitoring.</td>
<td></td>
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<td>Discuss with relatives.</td>
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<tr>
<td></td>
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<td></td>
<td>acting insulin when BG &gt;20 mmol/L.</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>If patient is unconscious, stop all oral and hypoglycaemic medication and BG monitoring.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Discuss with relatives.</td>
<td></td>
</tr>
<tr>
<td>Smyth &amp; Smyth (2005)</td>
<td>Recommendations in text.</td>
<td>Type of diabetes Appetite/weight</td>
<td>Early stages of the palliative illness conventional diabetes management and care are</td>
<td>IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Lack of appetite and weight loss, nausea and vomiting:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Lack of appetite and weight loss:</td>
<td></td>
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</tr>
</tbody>
</table>
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<thead>
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<th>Specific guidelines or recommendations</th>
<th>Level of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smyth &amp; Smyth (2005)</td>
<td>Based on palliative care, diabetes and cancer literature. (Cites Poulson, 1997)</td>
<td>Loss, Nausea/vomiting, Palliative drugs, End of life stage</td>
<td>General: management and care are acceptable. As the palliative disease progresses and prognosis becomes worse, it becomes more important to manage the acute and distressing short term complications of diabetes (hypo/hyperglycaemia, DKA, HONK) rather than the long term complications. Later stages of terminal illness – it is reasonable to relax glycaemic control; aiming for BG range of 5-15mmol/L may help avoid hypoglycaemia without leading to hyperglycaemia. Type 1: A reduction in dietary intake may increase the risk of a hypo, insulin may need to be changed or reduced. Specific management strategies may be introduced including administering antiemetics, encouraging small frequent meals and sugary drinks that will provide valuable caloric intake as well as preventing hypoglycaemia. Type 2: A reduction in dietary intake may increase the risk of hypoglycaemia, OHAs/insulin may need to be changed, reduced or ceased. If nausea and vomiting prevent patient from eating and BGL continue to rise, insulin and intravenous fluids may be required. Patients treated with corticosteroids who have type 2 diabetes usually managed with diet and/or OHA may require insulin treatment to control hyperglycaemia.</td>
<td></td>
</tr>
</tbody>
</table>

Care of the dying
Table 2. Summary of key papers that suggested guidelines or recommendations for managing people with diabetes and advanced cancer or advanced terminal illness at the end of life presented in order of the year they were published (Continued).

<table>
<thead>
<tr>
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<th>Level of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smyth &amp; Smyth (2005)</td>
<td></td>
<td>hyperglycaemia.</td>
<td>Insulin will usually be needed to prevent ketosis but there is seldom a need for an intensive insulin regime and frequent monitoring.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Minimise investigations.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Patient comfort and carer well-being should be the holistic and therapeutic goals.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>When lack of appetite or anorexia present, allow patient to eat previously avoided foods e.g. ice cream.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reassure family this is not ‘giving up’. Consult a dietitian to devise a suitable diet – patient may need supplements.</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>The effect of corticosteroids on glycaemic control varies with individuals – important to monitor glycaemic control in all</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>OHAs will normally be stopped. If insulin is used the does can be reduced or stopped.</td>
<td></td>
</tr>
</tbody>
</table>
Table 2. Summary of key papers that suggested guidelines or recommendations for managing people with diabetes and advanced cancer or advanced terminal illness at the end of life presented in order of the year they were published (Continued).

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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>General</td>
<td>Type 1</td>
</tr>
<tr>
<td>Ford-Dunn, Smith &amp; Quin (2006)</td>
<td>Brief guidelines in text. Based on expert opinion from 217 palliative care consultants and 111 diabetes consultants (UK)</td>
<td>Type of diabetes End of life stage Need for individualised treatment with guidelines adjusted according to patient/carer preference</td>
<td>Patients receiving corticosteroids. Use once daily long-acting or twice daily intermediate-acting insulin to prevent hyperglycaemia with minimum monitoring and adverse effects. One-half to two-thirds of the usual dose of insulin, and monitor BGL daily. When patient is in terminal phase and oral intake is minimal, cease OHA and/or insulin and BGL monitoring. It may be appropriate to check BGL and act accordingly if patient has symptoms of hyperglycaemia or unresolved in clinical condition changes.</td>
<td>IV</td>
</tr>
<tr>
<td>Ford-Dunn et al. (2006) Cont.</td>
<td>Table provides detailed guidelines for drug therapy and blood glucose monitoring.</td>
<td>Type of diabetes Stable nutritional status Weight loss/anorexia</td>
<td>The goal of therapy shifts from tight glycaemic control to maintaining comfort and enhancing quality of life. Begin discussing and educating patient and family members</td>
<td>Stable nutritional status: maintain current drug therapy; BG monitoring every 3rd day, test twice a day pre meals and as required depending on symptoms. Weight loss/anorexia: reduce</td>
</tr>
<tr>
<td>Tice (2006)</td>
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</tbody>
</table>

Managing Diabetes at the End of Life Copyright 2010
Table 2. Summary of key papers that suggested guidelines or recommendations for managing people with diabetes and advanced cancer or advanced terminal illness at the end of life presented in order of the year they were published (Continued).

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</tr>
</thead>
</table>
Blood glucose > 250 mg/dl (13.8 mmol/L)  
End of life stage regarding future need to allow blood glucose to run higher before need to change management. Instructions for treating hypoglycaemia. | **General**  
Insulin dose based on BGL.  
Consider changing to intermediate acting from long acting insulin; BG monitoring—twice daily. Once stable resume every 3rd day as above.  
**Nausea and vomiting:** change to short acting insulin. Once stable change to intermediate acting; BG monitoring—twice daily. Once stable resume every 3rd day as above.  
**BG > 13.8 mmol/L:** adjust short acting insulin. Once stable, change to intermediate acting. BG monitoring—twice daily. Once stable resume every 3rd day as above. | **Type 1**  
Oral medication dose by 50%; BG monitoring—weekly fasting x3, then 1–2/month unless symptomatic.  
**Nausea and vomiting:** discontinue oral agents while symptomatic; BG monitoring—fasting every other day. Once stable resume weekly fasting x 3 then 1–2/month.  
**BG > 13.8 mmol/L:** short acting insulin 2–4 doses/day. Change to intermediate acting when stable; BG monitoring—2–4/day before scheduled insulin dose. Taper to daily | **Type 2**  
Insulin dose based on BGL.  
Consider changing to intermediate acting from long acting insulin; BG monitoring—twice daily. Once stable resume every 3rd day as above.  
**Nausea and vomiting:** change to short acting insulin. Once stable change to intermediate acting; BG monitoring—twice daily. Once stable resume every 3rd day as above.  
**BG > 13.8 mmol/L:** adjust short acting insulin. Once stable, change to intermediate acting. BG monitoring—twice daily. Once stable resume every 3rd day as above. |
Table 2. Summary of key papers that suggested guidelines or recommendations for managing people with diabetes and advanced cancer or advanced terminal illness at the end of life presented in order of the year they were published (Continued).

<table>
<thead>
<tr>
<th>Authors</th>
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<th>Relevant factors included</th>
<th>Specific guidelines or recommendations</th>
<th>Level of evidence</th>
</tr>
</thead>
</table>
| McPherson (2008) | Brief, in text. Based on diabetes literature. | Type of diabetes
Diet
End of life stage | **General**

Tight glycaemic control is an unrealistic goal for patients with a terminal illness and may in fact cause unacceptable symptoms such as hypoglycaemia.

The most important goal—prevention of symptoms related to hypo/hyperglycaemia.

Need to help families to be above.

**Actively dying** (last few days to last week of life): consider discontinuing medicines.

Discontinue BG monitoring—discontinue if insulin stopped.

**Type 1**

If patient has stable nutritional status and good quality of life—continue usual diabetes management.

If patient has consistent but declining appetite – consider switching to daily or twice daily intermediate or long acting insulin.

If the patient has erratic oral intake – consider using rapid IV

**Type 2**

If patient has stable nutritional status and good quality of life—continue usual diabetes management.

If the patient has consistent declining appetite and weight loss consider discontinuation of diabetes therapies or reduction of OHAs by 50% (e.g. insulin, sulphonylurea agents, glitinides). | IV |

**Form of guidelines & source**

47
Table 2. Summary of key papers that suggested guidelines or recommendations for managing people with diabetes and advanced cancer or advanced terminal illness at the end of life presented in order of the year they were published (Continued).

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<tr>
<td></td>
<td></td>
<td></td>
<td>General</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>acting insulin after meals.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>If the patient is actively dying (days to one week pre death)—consider discontinuing insulin therapy.</td>
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<tr>
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<td></td>
<td></td>
<td>If the patient has erratic meal intake—consider glitinide after meals based on carbohydrate intake.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Actively dying – consider discontinuing therapy.</td>
<td></td>
</tr>
<tr>
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<td></td>
<td>Communication and goal setting with the patient’s family, and all providers is central to avoiding unnecessary pain and adverse effects from diabetes medicines.</td>
<td></td>
</tr>
</tbody>
</table>
Section 4

INTERVIEWS WITH PATIENTS AND CARERS
INTERVIEWS WITH PATIENTS AND CARERS

Ensuring the diabetes management preferences of patients with diabetes requiring palliative care and the views of their family members or carers were included in the Guidelines was an important component of the Guideline development process. Significantly, a consultation report about the quality use of medicines in palliative care, published during the later phase of the current project, strongly supported the need to ask patients and carers about their expectations and concerns regarding their care at the end of life (National Prescribing Service Limited and Palliative Care Australia, 2009). However, little information about these issues with respect to diabetes care was identified in the literature. Therefore, a qualitative study was undertaken to explore the care preferences of people with diabetes and family members or carers when palliative care was required.

**Aims**

The aims of collecting qualitative data from patients and family members/carers were to:

- Explore the past and current experiences of patients requiring palliative care in relation to managing their diabetes.
- Identify the preferences of people with diabetes requiring palliative care regarding how they wanted their diabetes managed at the end of life.
- Identify the views of family members or carers of people with diabetes requiring palliative care about managing their loved one’s diabetes at the end of life.
- Explore the experiences and needs of family members or carers of people with diabetes requiring palliative care to assist them to help the individual manage their diabetes and/or undertake diabetes management tasks such as managing medicines and monitoring blood glucose.

**Method**

Data were collected during individual face-to-face semi-structured interviews with fourteen people with diabetes requiring palliative care and ten family members/carers of people with diabetes requiring palliative care from a large regional palliative care facility.
Ethics approval was obtained from the Barwon Health Human Research Ethics Committee and written informed consent was obtained from all participants. The interviews were audio-recorded and transcribed verbatim after which content analysis was undertaken to identify key themes and issues.

**Recruitment**

Eligible participants were recruited from a large regional palliative care facility. The inclusion criteria were:

- aged older than eighteen years
- people with diabetes requiring palliative care services in stable, unstable, and deteriorating PCOC phases
- family members/carers of people with diabetes receiving palliative care or who required palliative care in the past
- able to converse in English. The researchers acknowledge that people who were not able to converse in English could have different points of view and needs, but felt having an interpreter present was not feasible and could inhibit discussion given the sensitivity of the topic and the vulnerability of the participants.

People with diabetes requiring palliative care services and their family members/carers were invited to participate in the research project by palliative health professionals employed in various clinical palliative care locations within Barwon Health. The research team provided these health professionals with information and education about the study and the recruitment procedure at the commencement of the study. Where appropriate, palliative health professionals initiated a conversation with the patient and/or family member/carers to determine their interest in participating in an individual interview to explore their experiences of and their diabetes management preferences at the end of life.

Palliative care staff provided patients and family members or carers who expressed an interest in participating with an information package consisting of a participant information document, consent form, researcher contact details and a reply paid envelope. The patient and family member/carer were asked to mail the completed contact details form to the researchers’ office after which the researcher contacted the
patient and/or family members to explain the research project, what participation would involve, and schedule a time for the interview.

The initial response to the recruitment procedure was low. In order to facilitate recruitment, the research team submitted an ethics amendment to enable the researcher to contact potential participants by telephone after the palliative care health professional had given them the information package. The amendment was approved, which enabled the researcher to provide a more comprehensive explanation of the research aims and explain what participation involved, which enhanced participation.

**Procedure**

The study was conducted between March and September 2009. Fourteen patient interviews and ten family member/carer interviews were conducted in that six-month period. These people lived in Geelong and surrounding rural areas. The same researcher conducted all the interviews. Participants were provided with a Participant Information and Consent Form prior to the interview and the researcher clarified any questions before commencing the interviews. The interviews were tape recorded with participant’s consent and were guided by a series of questions relevant to the Guiding Principles and informed by the literature review (see appendices A and B).

Most participants preferred to be interviewed in their homes; however, one interview was conducted in a hospice and one in a palliative care unit. The researcher established rapport with the patient and family member/carer and was considerate of the participant’s condition and ability to be interviewed. For example, being cognisant of signs of fatigue, pain or emotional distress. Family member/carer interviews were either conducted following the patient’s interview or scheduled for a future convenient date/location. On three occasions, patients rescheduled their interviews due to deterioration in their condition, symptom issues or because of an unforeseen appointment for a medical intervention. However, all participants who needed to reschedule the interview indicated they wanted to participate at another time. The researcher remained in contact with the patient and family member/carer and considered the appropriateness of arranging another interview time.

During the interviews the patients were asked about their past and present diabetes
management and their diabetes management preferences as their condition changed. The family members/carers were asked about their perceptions of the impact diabetes had on the patient’s comfort and lifestyle and the role they had played in assisting the patient to manage their diabetes in the past and currently, during the patient’s life limiting illness. The researcher referred to the questions throughout the interviews (see appendices A and B) when interviewing both patients and family members/carers and encouraged the participants to provide as much detail about their diabetes management as possible. The duration of the interviews ranged from 35 to 90 minutes.

Detailed field notes were compiled during and at the completion of each interview to capture non-verbal language and to note the researcher’s assumptions about and interpretation of the information presented (reflexivity). These field notes and the interview transcripts were discussed with the other researchers to note emerging themes, inform subsequent interviews and to reduce researcher bias.

**Data Analysis**

The interviews were tape-recorded and transcribed verbatim. Two researchers listened to the interviews several times, separately and then met to discuss their interpretation of the data and reach consensus about the content. The interview data were collated and presented on a computer disk and in written form. Content analysis of the data was undertaken using the Ritchie and Spencer Framework method (1994) to identify key themes. The framework method comprises five stages:

- Becoming familiar with the data—the researchers immerse themselves in the transcripts and notes from the interviews and list key ideas and emerging recurrent themes.
- Identifying a thematic framework—identifying all the issues, concepts and themes by which the data can be examined and referenced.
- Indexing—applying the index or thematic framework systematically to the data by annotating the transcripts with codes.
- Charting—rearranging the data according to the appropriate part of the thematic framework to which they relate, and forming charts.
- Mapping and interpreting the data—using the charts to define concepts and map the range and nature of phenomena and find associations among themes (Pope, Ziebland & Mays, 2000).
The results of the data analysis from the interviews conducted with patients are presented first, followed by the results of the interviews conducted with family members or carers.

**Results 1: Interviews with people with diabetes**

*Participant Characteristics*

Fourteen people with diabetes requiring palliative care services were interviewed. As Table 3 (page 52) demonstrates, participants were aged between 58 and 84 years. Twelve people had type 2 diabetes and two had type 1 diabetes. The majority had a principal diagnosis of cancer and several comorbidities; only one person had a non-malignant life limiting illness (see Table 3 on the next page).

Table 4 on page 53 presents participant demographic data. Eleven people were male and three were female. Ten were married and indicated they relied on the help of a carer; three patients indicated they were divorced/widowed and had no significant carer. Significantly, twelve people were receiving care at home; only two people resided in a health care facility.

Ten of the fourteen people with diabetes requiring palliative care services indicated there were no significant issues affecting their ability to continue to manage their diabetes independently at the time of the interview; however, four acknowledged their ability to self-manage their diabetes was declining: three of the four cited vision deficits and one cited dexterity deficits as the main reasons for their declining self-care ability.
Table 3. Principal diagnosis and comorbidities of people with diabetes receiving palliative care who participated in the interviews (n = 14).

<table>
<thead>
<tr>
<th>Age</th>
<th>Diagnosis</th>
<th>Type of diabetes</th>
<th>Comorbidities</th>
</tr>
</thead>
<tbody>
<tr>
<td>58</td>
<td>Metastatic Neuroendocrine Carcinoma</td>
<td>type 2</td>
<td>Depression Hypertension Encephalopathy</td>
</tr>
<tr>
<td>58</td>
<td>Advanced oesophageal cancer with pulmonary metastases.</td>
<td>type 2</td>
<td>Dysphagia Anxiety Depression</td>
</tr>
<tr>
<td>60</td>
<td>Pancreatic cancer</td>
<td>type 2</td>
<td>Not stated</td>
</tr>
<tr>
<td>60</td>
<td>Metastatic breast cancer</td>
<td>type 1</td>
<td>Osteoarthritis Asthma Eczema Cervical spondylosis Right mastectomy</td>
</tr>
<tr>
<td>62</td>
<td>Metastatic breast cancer</td>
<td>type 2</td>
<td>Non-alcoholic steatohepititis Oesophageal varices Uterine fibroids Large bowel obstruction</td>
</tr>
<tr>
<td>65</td>
<td>Bowel cancer</td>
<td>type 2</td>
<td>Hypertension</td>
</tr>
<tr>
<td>67</td>
<td>Squamous cell tongue</td>
<td>type 1</td>
<td>Cirrhosis of liver Chronic Pancreatitis Malnutrition Chronic obstructive airways disease Nephrolithotomy</td>
</tr>
<tr>
<td>74</td>
<td>Lung cancer</td>
<td>type 2</td>
<td>Hypertension Chronic obstructive pulmonary disease Depression</td>
</tr>
<tr>
<td>78</td>
<td>Lung cancer</td>
<td>type 2</td>
<td>Hypertension Hyperlipidemia</td>
</tr>
<tr>
<td>78</td>
<td>Pancreatic cancer</td>
<td>type 2</td>
<td>Ischaemic heart disease Irritable bowel syndrome Chronic back pain Macular degeneration</td>
</tr>
<tr>
<td>79</td>
<td>Metastatic colo-rectal cancer</td>
<td>type 2</td>
<td>Hearing/vision deficits</td>
</tr>
<tr>
<td>81</td>
<td>Malignant thoracic mesothelioma</td>
<td>type 2</td>
<td>Gastro oesophageal reflux disease Percutaneous transluminal coronary angioplasty Ischaemic heart disease Obesity Gout</td>
</tr>
<tr>
<td>83</td>
<td>End stage congestive cardiac failure</td>
<td>type 2</td>
<td>Gout Chronic renal impairment</td>
</tr>
<tr>
<td>84</td>
<td>Adenocarcinoma of the lower oesophagus</td>
<td>type 2</td>
<td>Hypertension Depression/anxiety</td>
</tr>
</tbody>
</table>
Table 4. Demographic data of people with diabetes requiring palliative care who participated in the interviews (n = 14).

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Marital status</th>
<th>Residential location</th>
<th>Advanced Care Directive</th>
</tr>
</thead>
<tbody>
<tr>
<td>58</td>
<td>Female</td>
<td>Married</td>
<td>Home</td>
<td>Not stated</td>
</tr>
<tr>
<td>58</td>
<td>Male</td>
<td>Married</td>
<td>Home</td>
<td>Yes</td>
</tr>
<tr>
<td>60</td>
<td>Male</td>
<td>Divorced/widowed</td>
<td>Home</td>
<td>Not stated</td>
</tr>
<tr>
<td>60</td>
<td>Female</td>
<td>Divorced/widowed</td>
<td>Home</td>
<td>No</td>
</tr>
<tr>
<td>62</td>
<td>Female</td>
<td>Married</td>
<td>Home</td>
<td>Yes</td>
</tr>
<tr>
<td>65</td>
<td>Male</td>
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Key Themes

Five key themes were identified:

1. living with diabetes
2. the way health professionals manage diabetes
3. the interaction between diabetes and other illnesses
4. managing diabetes when the patient is very ill
5. plans for the future.

In addition, participants suggested information they felt should be included in the Guidelines. Quotes from participants are presented in italics with the interview number in parentheses.

Living with diabetes

The main issues emerging from the interviews with people with diabetes about living with diabetes at the end of life was ambivalence about how big an impact diabetes has, an accepting attitude towards having diabetes, and the substantial impact of hypoglycaemia and hyperglycaemia on wellbeing and quality of life, and well being and quality of life generally. These sub-themes are grouped under the headings of:

- it’s no big deal—or is it?
- you just have to live with it
- the impact of hypoglycaemia and hyperglycaemia.

It’s no big deal—or is it?

Nine of the fourteen participants commented that diabetes did not have a big effect when they were first diagnosed; but seven of the nine commented about the changes the diagnosis of diabetes caused in their lives, which represented a major impact on the lives of some participants. Not surprisingly, the main changes participants described related to what they could eat and drink followed by changes in lifestyle and activities.

Three participants who indicated having diabetes did not affect them much in general commented:
It doesn’t seem to bother me … as long as I keep my [blood glucose] in range…it doesn’t bother me … Oh, I had to go on a diet…a food diet…you know…and go on the medication, and everything just seemed to fall into place. (P 5)

Well diabetes itself … it’s never been a big problem for me. (P 6)

[Effect of diabetes] Not a terrible lot … no … not a terrible lot … no … not much at all. (P 13)

In contrast, participants who indicated diabetes had a big impact on their lives commented:

…and it [diabetes] certainly has a lot to do with the pain in my feet … I get very painful feet and ankles … really painful … if they [nurses] lift my feet up … awww I go through the roof … but if they handle me by the heel I’m alright … if they grab me but the ankles ohhhh, … talk about hurt. (P 8)

…buggered me up actually … I had to be at a certain place at a certain time … I had to know where my needle was … in the end I had one in the car and one where I sit at night times … evenings … amongst the table in other words … yeah its stuck in my head trying to think of this other bloody needle. (P 4)

Two other participants, who initially indicated that diabetes did not affect them much, later commented on the significant ways it had affected them. Pairs of quotes from some of these participants included:

It obviously still affects what I eat … what I can and can’t eat … but I don’t feel that it affects me in any way. (P 3)

Well it does it affects what you eat … obviously you can’t drink [alcohol] … well you can, but it’s wiser not too … yeah it affects a lot of your life … it would be easier if I didn’t have it. (P 3)

And
Basically ... I did the exercise I took the pills ... I tried to restrain the diet ... otherwise it didn’t really affect my life at all ... (P 11)

...there was a constant battle to get the hyper down or the actual blood readings below 10 ... I mean you really had to be very strict to get it down below 8. (P 11)

You just have to live with it

Participants generally accepted the diagnosis of diabetes and the self-care tasks they needed to undertake to manage it. Only one participant commented about how much he disliked pricking his finger to check his blood glucose and that he also hated ‘the needle’ (insulin). For example, participants who accepted the diabetes self-care tasks commented:

Well its just something I have to do ... I think you’ve got to be pragmatic about these things and its something you have to do ... its just what you do. (P 3)

No, I might be one of them queer buggers but I never worry about things...you know...if it’s there it’s there...so you accept it. (P 5)

Well you’ve just got to wear it ... not much you can do about it ... as I say if the researchers come up with something brilliant ... I’d be the first to applaud and use their new system ...but until that happy day, we’re stuck with the finger prick and the pills. (P 12)

Get it [blood glucose testing, insulin] over and done with and that’s it. (P 14)

The impact of hypoglycaemia and hyperglycaemia

The effects of hypoglycaemia and hyperglycaemia emerged as an important theme from the interview data. The sub-themes identified were that both states are very unpleasant but the symptoms and effects varied among individuals: that is, participants tried to avoid blood glucose levels in the high or low ranges; and with time, participants believed they knew when a hypoglycaemic or hyperglycaemic event
was imminent or had started because of the symptoms they experienced (listened to body cues).

**How it feels.** Ten participants vividly described what it feels like to ‘have a hypo’ (hypoglycaemia) or hyperglycaemia and stressed how unpleasant these states and the accompanying symptoms and emotional effects were. The symptoms of hypo/hyperglycaemia participants experienced varied among individuals, but, by listening to their body cues and testing their blood glucose, they were able to accurately recognise high or low blood glucose levels, as the following quotes illustrate:

*The lips went numb and … I got the shakes … that was before … I’d realised what I’d got [hypoglycaemia] …. And I went back to bed again and the next minute I found myself on the floor and I don’t know … I wouldn’t have a clue how I got there … on the floor.*  
(P 5)

*[Hypoglycaemia] I would go to put my foot to the floor and it would be jumping and shaking and my son would be saying ‘mum, test your sugars [glucose]’.*  
(P 9)

*[When the blood glucose is high] Yes it makes you feel terrible, to me if its above 12 you start to feel itchy, ants crawl all over your face … and a little bit dizzy … and the vision gets a little bit impaired, its terrible.*  
(P 6)

Participants dreaded hypoglycaemia or hyperglycaemia and the symptoms and described them as something to avoid. Participants described how frightening hypoglycaemia and hyperglycaemia were and were keen to avoid further episodes:

*Well it did frighten me, I’ll admit it [hypoglycaemia]. I never want to feel that way.*  
(P 5)

*Yeah … two tests a day … yeah … I didn’t want that [hypo] to happen again.*  
(P 12)
Warning signs. Participants did not always recognise the cause of hypo/hyperglycaemia symptoms the first time they experienced them, but with time, by listening to body cues and experiencing these states, most were able to recognise the warning signs. Listening to body cues and blood glucose testing enabled participants to appropriately manage the episode. For example:

... and then with the years going by through those things [symptoms] I managed to discover that if I feel that sensation of ants crawling and that, I knew that the blood sugar level is high and if I felt faint that it is too low. (P 6)

Whenever I have a low I get dizzy I act quickly, and take something ... sweet biscuit, a glass of coke .... (P 8)

She’ll [wife] be able to tell if I’m about to have a hypo ’cause she said I get this vacant look in my eyes. (P 9)

Now I understand them [hypos] I can keep them off before they get serious... I can feel my sugars getting low ... I’ll get shaky if I get below 4 ... or if I get above 12 then ... I start to sweat ... so it’s a matter of learning which way you’re going, I think. (P 13)

The way health professionals manage diabetes
Participants had mixed views about health professionals’ approach to diabetes management. The sub-themes emerging from the data reflected negative experiences with health professionals particularly in acute care settings, but experiences with specialist health care professionals were more positive. Many also felt health professionals did not treat the whole person by acknowledging the importance of diabetes and did not listen to the patient. These sub-themes are grouped under the headings of:
- they bugger it up
- positive experiences
- listen to the patient.
They bugger it up
A number of participants described negative experiences with health professionals whilst in an acute care setting, and suggested diabetes was not given enough attention when they were admitted for other illnesses. Problems managing medicines and appropriate food for people with diabetes were discussed:

You sort of find you keep stable and it’s good, stable [blood glucose] but when you go into hospital its erratic cause they bugger it up… It’s really frustrating; I joke with [husband] and say oh well here we go back into hospital bloody sugars will be up the tree. (P 1)

…that’s the only thing I would say that it’s [diabetes] not given as high a priority probably as it should be … I think they should be made very aware of the diabetes … … we all should be confident knowing that you come into hospital and that you’re unwell but that the diabetes will not be forgotten and that you don’t have to worry about it … that the kitchen is aware, the staff are aware …. (P 3)

But they messed me up [blood glucose] in hospital … they had me taking little bits of this and little bits of that [insulin ‘top up’ doses]. (P 8)

They treated the diabetes like it wasn’t a part of me… but then that’s what they do … they’re looking at the illness [cancer], not the person … and it’s [diabetes] a big part of me. (P 9)

Positive experiences
However, participants also described more positive experiences with health professionals in acute care, most of which occurred when specialists, particularly diabetes specialists, were involved in their care:

… and the endocrinologist was a great help, he was very good indeed … so it didn’t take me [long] … it took me about a month I suppose to get stabilised again. (P 3)
They had a diabetes educator in there who helped me a lot and I stayed in hospital for a week because I went through the thing of having the big fluid drop [intravenous infusion] or whatever it is … and I was right then. (P 9)

… because we came to an agreement that while I was outside, doing my lifestyle stuff he’d [specialist] knew I’d play up [not adhere to advice] but when I go to hospital that’s when he [diabetes specialist] I had to put up with …[I had to] take his line … and we’ve been together for about 13 years … a happy little couple. [P 10]

Other specialists also received praise, for example:

Once it [blood glucose] was up and [Palliative care nurse] was on the ball….she said ‘you need to be seen’….you know ‘we need to do something about this’… she’s on the ball [palliative care nurse]. (P 1)

Listen to the patient

Seven participants stated that health professionals should listen to what the person with diabetes tells them and consider the person as a whole. Many participants were frustrated that most health professionals did not seem to listen or acknowledge their diabetes expertise:

Well I would like to think that people would listen to what I’m saying from my, from what my body’s experiencing….I think that’s important… my body tells me that I, I don’t need to take that much insulin or I need more insulin and I adjust accordingly. (P 2)

Well I would expect the nurse to come in and see me … to see the person, to see what they’ve [the patient] been doing such and such at home and to listen to them …. (P 7)
What happened to me at the hospital was they treated the diabetes like it wasn’t a part of me … but then that’s what they do … they’re looking at the illness, not the person. (P 9)

One participant commented that there should be more communication among different health professional disciplines. The participant was particularly referring to communication between health professionals treating cancer and those managing diabetes.

…there should be a little bit of communication between the diabetes side and the cancer side … about what is the best diet to have … that actually joins the two together … the diabetes and the cancer side should get together to actually talk to the dietician … and come up with a menu or a diet they see suits both sides … (P 11)

The interaction between diabetes and other illnesses

An important theme emerging from the data was people with diabetes were aware of the effect other illnesses had on their blood glucose and consequently, their diabetes management. Twelve of the fourteen patients interviewed commented that their other illness or illnesses affected their blood glucose levels and required changes to their usual diabetes management regimens. They noted it was more difficult to keep the blood glucose levels in an acceptable range when they were ill.

Participants described how treatments and medicines prescribed for their other illness caused ‘problems with their diabetes’, and how the symptoms associated with their other illness complicated their diabetes management. For example, chemotherapy caused problems such as nausea, vomiting and hyperglycaemia; and diminished appetite could cause hypoglycaemia and affect their diabetes medicines regimen.

Chemotherapy. Four participants described the problems they experienced managing their diabetes as a result of having chemotherapy for their other illness.

When I first had chemotherapy … they put me in hospital two days before I would have normally would have gone in so that they could set themselves up
and ... gauge how the effect would be on my blood sugars. So that cost me about three days in hospital. (P 10)

After chemo the blood sugar levels go out of sight ... I mean out of control ... we had levels at one stage up to 27 ... I was still alive and lucid ... that was in the evening and the next morning it was down to 2.4 ... so ... in that period initially after chemo ... say for four days it’s irregular ... but then it’s alright. (P 11)

Medicines required to treat their other illnesses also caused problems.

Other medicines and diabetes. Participants described how some medicines prescribed for their other illness affected their blood glucose levels and diabetes management, in particular, some participants mentioned corticosteroids such as prednisolone:

   Some of the drugs they give you for palliative care, they interfere with the blood sugar. It’s a complicated subject isn’t it? (P 8)

   Diabetics can’t take prednisolone, that’s all there is to it. (P 9)

Symptoms of the other illness. Some participants said the symptoms associated with their other illness affected their blood glucose levels and their ability to manage their diabetes. Most notably vomiting, nausea and a reduced appetite affected their blood glucose levels:

   But because of the location of the stent umm [patient had a gastrointestinal stent], until such time as, umm I can get my eating regiment together umm, I’ve been vomiting on a regular basis ... I’ve therefore desisted from injecting [insulin]. (P 2)

Diabetes management was affected by the medicines and interventions required for the person’s life limiting illness and diabetes management required significant alterations.
Changes in diabetes management. Changes in diabetes medicines were usually needed, sometimes frequently, because of the impact of other illnesses and their management, on blood glucose levels. Participants described complex adjustments to their medicine regimens. It should be noted that people with diabetes using insulin often adjust their own insulin doses. The first and third of the following three comments represent health professional participants who had diabetes and were receiving palliative care:

When I was having chemo…the three days I was having chemo they [doctors] wanted me to have 20 units in the morning and 10 units at night because of the dexamethasone. But obviously I won’t be doing that now because with this oral chemo I’m not having steroids so I assume that’s right - I don’t take the evening insulin its alright my sugars are alright. It was three yesterday in the morning and five today. (P 1)

… umm, initially It was via oral medication, umm, but its advanced now to the stage that I’m on two different types of insulin, but that’s only been the occasion, ahh well first of all, only I would say 12 months ago, I was introduced to Lantus, which is, from my understanding a long – sorry a 24 hour acting, has a 24 hour action and recently, since my last hospitalisation, I’ve been put on novorapid, which is a quick acting, umm insulin. (P 2)

Well six or seven [blood glucose level] I think if I can, when I was having the chemotherapy [specialist] said he wasn’t concerned about it if it went into the low teens … I used a bit more Novorapid then … I tried to keep up with it but it is a bit hard to do … the Novorapid worked quite well … When you needed it … so I’d bump the Lantus up … to a total of 28 to 30 [units]. (P 7)

These comments also demonstrate that people with diabetes acquire considerable expertise in managing their diabetes and insight into their disease. Significantly, the relationship between diabetes and their other illness was extremely complex for some participants, including those participants accustomed to adjusting their medicines.

What’s what? Four participants described the inter-relatedness between diabetes and
other illnesses, three of these participants discussed their experiences and one suggested some health professionals may have difficulty understanding the cause of the symptoms if they do not test blood glucose levels regularly. For example:

*But they think I am an unusual case because the tumour began on my pancreas … so they think …what came first the diabetes or the tumour, we don’t know and I was diagnosed straight away as a type 1. (P 3)*

*… but when I started with the cancer [treatment] and just before my cancer [diagnosis], because we thought [why isn’t the medicine working] … autonomic nerve disorder or something else but [the doctors] found out it was the cancer …*

One participant found it difficult to distinguish the symptoms of hyperglycaemia from cancer-related symptoms:

*It’s hard to say what causes all the symptoms I’ve got. I don’t know what’s what. I don’t know which is diabetes and which is this cancer or what. I don’t know. (P 14)*

Most participants found the effects of their other illness made managing diabetes more difficult, but two participants found their blood glucose levels were lower because they lost weight as a result of the other illness and their diabetes was, in fact, better controlled.

*Managing diabetes when the patient is very ill*

Participants were clear about how they would like their diabetes managed, whether they wanted active management, and who should provide diabetes care if they were too unwell to undertake self-care. Responses about diabetes management were coded according to how active participants wanted their diabetes management to be. The sub-themes identified were not mutually exclusive, although the majority of participants were generally aligned with either an active or a less active approach to managing their diabetes. The sub-themes identified were:
- actively managing diabetes
- the middle ground
- no active management
- who should decide?

**Actively managing diabetes**

Ten of the 14 participants indicated diabetes should be actively managed at the end of life: two of these mentioned the need to consider diabetes as a cause of symptoms, four indicated it was important to continue managing diabetes to make the person comfortable, and four indicated their existing diabetes management should be continued.

*Consider diabetes as a cause of symptoms.* Two participants indicated health professionals should be aware that symptoms could be related to the patient’s diabetes, which suggests an active approach to managing diabetes that includes blood glucose monitoring to assess the impact of illness on metabolic control whenever the patient is unwell.

> Yes they [health professional’s] should be aware [of the impact of diabetes] because it can easily get confused with other symptoms so whether people could have a hypo … be prepared to do a [blood glucose] test whenever … you know if the person’s not feeling well …to diagnose what’s gone wrong. (P 3)

*Maintain comfort.* Participants stressed the importance of identifying and preventing/managing the unpleasant symptoms associated with hypoglycaemia and hyperglycaemia. For example:

> I can’t imagine if you are dying and you’ve got a blood sugar of 30 and no one’s treating it, I can’t sort of accept that, I mean you don’t want to go on with endless care … but I think I would like to feel comfortable. (P 1)

> Oh, yeah, I would prefer to be monitored just to make sure. I don’t want another of them hypos again. (P 5)
Leave everything alone. Four participants wanted to continue their existing diabetes management regimen in the last palliative care phases (active management). One person said:

And provided …the monitoring stays reasonable … leave everything alone … like I said before if it ain’t broke don’t fix it. (P 11)

I don’t know how you could improve it any. The present set up is pretty good. (P 13)

The middle ground

Five of the 14 participants took the ‘middle ground’. They wanted their diabetes managed when they were very ill, but suggested management could be less rigorous, for example accept a wider blood glucose range, and perform blood glucose monitoring less frequently. Two other participants suggested they wanted active management, two participants did not want active management, and one participant wanted both active and no active management depending on the likely outcome of the episode. Comments included:

… and they want me to eat and then they send you that other gruel to eat cause you’re diabetic … it’s not worth it … what’s more important, eating [and] putting four to five kilos on, maybe having a little more adjustment to the insulin and that will affect my eyes … neuropathy and all this type of thing but who cares …. (P 10)

Yes, and if his [blood glucose level] is 24 well that’s a different story … well he needs insulin … if it’s in the low teens just don’t get too excited about it. (P 7)

No active management

Three participants explicitly stated that, in certain circumstances, they would not want their diabetes management to continue. The circumstances included if they were unconscious and when death was imminent.
If I am unconscious. Three participants indicated that they would not want anything done to manage their diabetes if they are unconscious or ‘non-compos’ for example:

I would see no point to tight glycaemic control … the focus should be on making life as comfortable as possible… no I couldn’t see the point [of tight control]… maybe because I’m almost 70 I feel like that but, and maybe because I’ve had the experiences I’ve had … I wouldn’t see the point to it really … and then if I’m unconscious, well don’t do anything …. (P 9)

... but when you get to the non-compos stage I don’t think it matters. (P 7)

If I am on the way out. Two participants also suggested when they are in the process of dying they would not care whether their diabetes was managed or not:

I would just think ‘if you have to give me some insulin, give me eight units’. I don’t know what … but why bother and go through all that … even though it’s [diabetes] a large part of me … I wouldn’t want it to be the dominating factor if I’m heading out the door. (P 9)

Who should decide?

Eleven participants indicated either health professionals or family members/carers could make the management decisions if they were very ill and dying.

Health professionals and family/carers. Most of these eleven participants suggested health professionals and family members or carers could jointly make decisions for them.

I’ll just leave that with [specialist] and X, my wife. (P 10)

Only three participants suggested only health professionals should decide, for example:
Well I say you’ve got to trust the doctors and that. Well, … I haven’t been to bloody university or anything like that to know exactly what’s going on … so let’s go with the professionals. (P 4)

Other participants wanted to be involved in decision-making.

*Listen to me.* Seven participants explicitly stated they wanted to have a say in how their diabetes was managed when they are very ill, or at least to have their wishes respected. Some explained why they should be listened to, but acknowledged the important role of health professionals:

> Well I’d like them [health professionals] to respect ummm, my thoughts. I’m obviously guided by professionals but umm, I think that given that I’ve been a diabetic for three and a half years, and … I’ve experienced the progression of the diabetes that, I’d like to think that … my thoughts would be respected. (P 2)

> I would like to have a say (P 6)

**Planning for the future**

All participants were asked about their plans for diabetes management when their condition deteriorated; nine were specifically asked about Advanced Care Directives and they all said they had not thought about these issues or completed Advanced Care Plans regarding their diabetes management. For example:

> I’ve never really thought about it … (P 11)

Only one participant indicated she had prepared an Advanced Care Directive that included her diabetes management preferences for the future:

> You would put it in your Advanced Care Plan, we’ve done that, umm and let everyone know your feelings…you know so your doctors that are all looking after your [husband] know what you want… (P 1)
This participant elaborated on why she felt it was important to ensure her diabetes management preferences are known:

*And with the diabetes perhaps the health care professional has not had diabetes so doesn’t know what the feeling of hyperglycaemia is like.* (P 1)

One other participant said he was thinking about ‘something like an advanced plan’ and one was interested in the idea and indicated she would like to ‘do something like that’ and asked the researcher where to find out more about Advanced Care Directives.

**Patient participants’ suggestions for the Guidelines**

Participants were asked whether they had any suggestions about what to include in the Guidelines for managing diabetes at the end of life. Three participants suggested health professionals need to be more aware of diabetes when developing palliative care management plans, two participants suggested people’s needs should be considered individually, and two suggested health professionals need to listen to the patient. One participant suggested including diabetes management preferences in Advanced Care Directives.

Participants indicated information about food and new advances in diabetes management should be included in the Guidelines and they welcomed the idea of Guidelines for managing diabetes at the end of life ‘it is a good idea to get the knowledge together.’

Participants who suggested that health professionals should be ‘more aware of diabetes’ commented:

*I mean I think they [health professionals] should be made very aware of the diabetes … I don’t think that sometimes they’re aware enough and they should be.* (P 3)

*The ordinary nursing staff, who are very good, are given a little bit more familiarity with what’s in those tubes [intravenous tubes] and what/how they[the person with diabetes] react … if the patient’s asleep he might be*
hypo ... or the other, ... so I think a little bit broader education ... on the diabetes side, the patient might not be well enough to have his insulin or eat his meal.... (P 7)

Participants also stressed the need to consider each person individually:

_Umm, not really, I’m quite happy that each case has got to be considered on its individual merits having regard to whatever the diagnosis or the prognosis is._ (P 2)

Other participants wanted to make sure health professionals using the Guidelines would listen to what the patient with diabetes said:

_Well see, one of the things I was going crook about was how the team at the hospital didn’t take any notice of what I [said] …_ (P 9)

The participant who already had prepared an Advanced Care Directive suggested the diabetes management Guidelines could be included in the Directive. It appeared that this participant was prompted to include diabetes in her Advanced Care Directive by the invitation to take part in the current research:

_I would like to see it as the Advanced Care Directive, possibly it could be included because I don’t think you would routinely include that [diabetes management preferences] it’s only that I have diabetes and I knew about your research otherwise that would never have come up_ (P 1)

The following comment from one participant who liked the idea of putting all the information together concludes this section:

_I think it’s a good idea to get something like that [the Guidelines] organised ... because I think before [there] hadn’t been enough knowledge of what care you can get and what is available ... I think it is a great idea …_ (P 13)
Results 2: Interviews with family members/carers

Participant Characteristics

Ten family members of people with diabetes receiving palliative care were interviewed. As Table 5 on the next page demonstrates, eight participants were female and two were male. All were spouses of a person with diabetes receiving palliative care. Two participants’ spouses had died: one died prior to the study and one patient had participated in an interview and died before the study was completed. Eight participants were caring for their ill spouse at home at the time of the interview. In order to reduce the stress and keep the interviews focused on the topic (caring for a dying family member) the interviewer did not ask personal details such as age but all participants were of a similar age to their spouses whose ages ranged between 58 and 84 years.

The duration of the semi-structured interviews ranged from approximately thirty minutes to one and a half hours. As with the patient interviews, the same researcher conducted all family member/carer interviews. On nine occasions the researcher had met the family members/carers prior to the patient’s interview, which provided a valuable opportunity to build rapport and discuss the family member’s/carer’s involvement in the project, and for the researcher to respond to any questions about the study from family members/carers.

All the family member/carers were willing to participate in the research and were eager to describe their experiences and their perceptions of the effect diabetes has or had on their spouse and the subsequent effects on themselves. Family members/carers described their spouse’s diabetes management before the diagnosis of their life limiting illness and the subsequent changes to their spouse’s diabetes management as a result of the life limiting illness including medicines, functional decline, loss of motivation, and depression.
Table 5. Relevant information about family members/carers of people with diabetes receiving palliative care who participated in the interviews (n = 10).

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However, some family members/carers indicated they were uncertain and confused about their spouse’s future diabetes management when death was days away. Their concerns were related to the care their spouse received from health professionals, for example the possibility that medicines and blood glucose monitoring would be ceased, or their spouse would commence insulin. Family members/carers also
expressed concerns about how they would manage their spouses’ diabetes, for example managing hypoglycaemia and hyperglycaemia and performing ‘technical’ tasks such as ‘finger pricking’ and administering insulin they had not previously performed.

Family members/carers described very personal experiences at an extremely emotional time as their loved one neared death. Significantly, five key themes emerged from the interviews.

Key Themes
The five key themes that emerged from the interviews with family members/carers were:
1. the effects of diabetes on partner and self
2. witnessing distress/being distressed (distress caused by hypo/hyper/medicines)
3. increasing burden of care
4. recognising ‘I’m out of my depth—I need help’
5. being uncertain about diabetes management when spouse neared the end of life.

These themes are discussed in the following section and illustrated using quotes from participants, which are presented in italics with the interview number in parentheses. In addition, family members/carers suggested some information they would like included in the guidelines.

Effects of diabetes on partner and self
Family members/carers of people with diabetes described varying effects of diabetes on their spouse and themselves. Participants explained the effects of diabetes on their spouses and themselves at the time diabetes was first of diagnosed, the processes involved in adjusting to diabetes, and the escalating effects of diabetes in light of the life limiting illness. These sub-themes are grouped under the headings of:
- diabetes at diagnosis
- adjusting to life with diabetes.
Diabetes at diagnosis

Seven of the ten family members/carers described the effect of diabetes on their spouse and themselves at diagnosis as being minimal; however, five of the seven described some significant issues that suggested otherwise. For example, the difficulty of managing ‘dietary restrictions’:

*Nothing really ... the only thing is ... for a start off he ... I couldn’t get him to understand that dieting would have helped ...*(C 9)

*Well it’s [diabetes] made him think a lot more about what he eats ... that’s the main thing ...*(C 10)

For another participant, the complexity of managing a spouse’s diabetes who was a shift worker was an issue:

*The major impact would be ...taking adequate food at the appropriate time ... having access to the proper food. (C 5)*

Two participants described significant behaviour changes and physical effects on their spouse resulting from the diagnosis of diabetes.

*Well when he found out he had diabetes, he was very aggressive ... and he couldn’t adjust to the eating habits, and ... It’s hard to explain ... because he really didn’t, couldn’t realise how serious diabetes is ...*(C 2)

*He had a lot of intercurrent infections, and was often very tired and so when he was diagnosed it sort of all fitted into place ... he was just having these ongoing sort of colds and cold sores and he was overweight and he was feeling tired and ... passing all the urine ... (C 7)*

Two family members/carers described positive effects on their spouse and themselves following the diagnosis of diabetes. One participant said she was more mindful about her health and lifestyle and the health and lifestyle of her spouse.
It’s more a positive effect in the sense that ... we were probably both a bit overweight ... we probably thought we ate quite well but ... when you sat down and looked at it we needed to make some modifications to our diet ... it encouraged us to exercise more regularly ... so they were good things that came about as a result from it ... [C 7]

I think it probably had a positive effect ... we became more aware of the need to monitor what we ate ...[C 5]

**Adjusting to life with diabetes**

The family members/carers indicated they adopted a supportive role helping their spouse to adjust to life with diabetes when initially diagnosed. Their comments related to taking on an active and supportive role and working together as a team are grouped together. Comments relating to assisting their spouse to integrate diabetes management strategies into a daily routine are grouped together; and comments from two participants who were anxious about adjusting to life with diabetes are grouped together.

**Working together—working as a team.** Five participants described ‘working together’ and ‘teamwork’ as central to supporting their spouse to manage his or her diabetes. The participants described being in the background, providing active support, encouragement and incorporating lifestyle changes. One participant said working as a team was the usual way the participant and their spouse worked, thus they worked as a team to manage diabetes:

*We always worked as a team looking after each other ... it just became a reflex just like caring for anyone else ...*[C 5]*

Teamwork was described as making joint decisions and altering their own diet and lifestyle to demonstrate understanding. Examples of comments concerning working together include:

*I would watch what we were cooking and how much fat and oil and whatever we were using and ... just keep an eye on what he was having because he did*
love lots of butter, lots of cream, lots of ‘wrong things’ … so I managed to gradually change all that and it did help with his … he became stabilized … quite stable with his blood sugars … took a while though …[C 4]

I suppose in thinking about managing the diabetes it’s part of the whole helping B care for himself of which I have taken on quite a bit of that role in a supportive way … I haven’t just tried to take over … I’ve tried to, him and I do it together … so he does his blood sugars quite regularly and then we’ll talk about adjusting his medication depending on what his blood sugars are. [C 7]

A sense of routine. Three participants described helping to integrate their spouse’s diabetes management activities into regular, everyday tasks. These participants indicated that, once their spouse had a routine, the demands of managing their diabetes seemed more achievable.

Comments included:

... Cause I got ... the insulin that I organise for him night and morning ... it’s a regular thing that as soon as I get up and have my shower ... I produce the ... his blood machine and the insulin and ... then about 5 pm each night it’s just a regular thing that I do... it’s part of the routine now ... I think we’re such creatures of habit that things ... once things ... get into a routine I haven’t got any problems ... [C 10]

... So I’ve always paid attention to that ... I’ve encouraged us to exercise regularly but he does that as well ... so yeah, I’ve tried to encourage him as much as possible to take control of it ...[C 7]

When discussing routine diabetes management support strategies, one participant described reminding, prompting and encouraging her spouse to undertake diabetes self-management tasks including blood glucose testing and remembering to take his medicines. When asked how she felt about the role she replied:

*It doesn’t worry me doing it* [reminding, prompting and encouraging him to undertake diabetes self-management tasks including blood glucose testing and
taking medicines] ... he’s been part of my life for so long now ... we’re sort of more or less like one ...[C 8]

However, one participant indicated it was challenging for her spouse to develop a diabetes self-management routine.

But I think for him its been difficult because it’s meant quite a lot more of a routine and for someone like him who travels for 5 weeks ... goes away for 5 weeks and comes home for 5 weeks ... his life is very much ... I shouldn’t say unstructured but ... Yeah ... and so to have to take blood sugars and do all of those things ... so in some ways some people might say he’s been a bit non–compliant but he’s been as compliant as he possibly can given the person that he is ...[C 7]

**Anxiety about adjusting.** Two participants described heightened levels of anxiety about their ability to adjust to their spouse’s diabetes management routine. Both participants described complicating factors that affected their spouse’s ability to cope with the diagnosis of diabetes and the requisite self-care management strategies.

The first participant said her husband had significant mental health issues when he was diagnosed with diabetes and commented:

Well ... he had a mental illness as well ... he had paranoid schizophrenia ... and he’d had that for about ten–fifteen years so he had episodes of delusional disorders ... and so because of that ... he was unable to see reality in a situation and ... he couldn’t see the importance of following a strict diet and regularly checking his blood sugars ... and he’d get a bit aggressive if I tried to encourage him or force him into taking his blood sugars so ... that was a bit difficult for a while ...[C 4]

The second participant’s wife was diagnosed with diabetes and cancer at the same time, which created stress, anxiety and uncertainty for both partners. The participant was not concerned about managing diabetes at diagnosis or later. He said:
We found out on the same day that she had diabetes, that she had a tumour on the pancreas and one on the liver ... so ... that was such a shock ... the diabetes did sort of become secondary ...[C 6]

Witnessing distress/being distressed—effects of diabetes during life limiting illness

The effects of diabetes on their spouse overwhelmed participants during their spouse’s life limiting illness. Seven of the ten participants reported their stress levels escalated and their anxiety and worry increased as their spouse’s illness progressed and they undertook more of the diabetes self-care tasks such as blood glucose monitoring and managing medicines. Participants felt distressed when their spouse experienced diabetes-related symptoms such as hypo/hyperglycaemia and did not know how to help their spouse. These sub-themes are grouped under the headings of:
- it’s a worry
- hypoglycaemia/hyperglycaemia.

It’s a worry

A sub-theme emerging from the interview data was the constant worry family/members endured due to the effects of diabetes on their spouse’s life limiting illness.

Comments included:

Well it’s ... it’s a worry ... you know when I go shopping or I sort of go out somewhere and I think ‘oh, did he take his insulin or did he help himself to a cuppa’ ... that worries me ... when I go out because many time I get very angry and I come home and I see the cup is still standing there. [C 2]

Yeah, I mean I was always ... I guess you are always aware of ... you know I used to check his book to see what his blood sugars were cause I was always anxious that ... and to see what he’d eat ... what effect it would have on his blood sugars ... just in case he was hypo or hyper ... whatever ... because he didn’t experience it so he didn’t realise how bad it could be ... [C 4]
A lack of knowledge about the impact of the life limiting illness and its treatment on their spouse’s diabetes added to the negative affect the family member/carer experienced:

_So at the moment it’s confusing for us … we don’t know what’s causing what symptom …_ [C 3]

**Hypoglycaemia/hyperglycaemia**

**Negative emotions.** Four participants described their distress at witnessing their spouse having a ‘hypo’ or ‘hyper’. In many instances the family member/carer had no previous experience managing hypoglycaemia and felt isolated because most hypoglycaemic episodes occurred at home. Four participants said they were ‘frightened’ and ‘scared’ their spouse would have a ‘hypo’ or ‘hyper.’

Comments included:

 Well it scares me, and then I get very angry with him…[seeing her husband having a hypo] …[C 2]

_He doesn’t demonstrate clearly that he’s hypo or hyper … it’s the blood sugar machine [blood glucose meter] that tells you that … it doesn’t have such a huge impact but it … it does worry me that he’ll have a whopping hypo. [C 7]

_Not knowing what is happening._ One participant gave a vivid account of her husband experiencing a hypo and the participant did not know what was happening.

 Well, it happened in the night and I just think … he went like … like a dream and he was probably talking in his dream and … then I thought ‘oh, he fell out of bed’ and I got out of bed and went to him … and I thought no, he’s not right there’s something wrong here … and that’s when I panicked … and I couldn’t lift him up … so I thought well, I’ll call my friends and … they came … and I said ‘I’ll phone for the ambulance’ and they came … I didn’t know what it was … to be honest and it never dawned on me that it was his sugar … [C 1]
Two participants described instances where they were concerned about their spouse’s health and thought their spouse was having a hypo so they tested their spouse’s blood glucose. Comments were:

*There were occasions when her blood sugars were low … we just used to do that by checking with the glucometer [blood glucose meter] and if it was a 3 or so when she woke up I’d make sure she got something to eat pretty quickly … [C 5]*

*He did have a lot of light headed episodes … and … then … this was after he was diagnosed with cancer … he had a few episodes like that when I insisted that I take his blood sugars … [C 4]*

**Increase in hypoglycaemia and hyperglycaemia.** Two participants commented on the effects of diabetes and the life limiting illness on their spouse’s blood glucose levels. They indicated that the blood glucose was more erratic and unpredictable and episodes of hypoglycaemic or hyperglycaemia occurred frequently.

*I suppose that is what we’re still trying to get our head around … it would appear that his … with cancer he’s having more hypoglycaemic episodes … well he’s started having more hypoglycaemic episodes because it’s affected his eating … the cancer affected his eating … and as he ate less and couldn’t deal with as much food … and he was still taking the same sorts of medications because they didn’t know he had cancer … he was having hypoglycaemic episodes and we don’t know whether he was hypoglycaemic or hypotensive … at times it’s hard to tell … [C 3]*

One participant (a nurse) specifically mentioned her distress seeing her spouse develop hyperglycaemia due to diabetogenic medicines prescribed to manage his life limiting illness.

*One of the most challenging things has been … with having chemotherapy is the prednisolone and what that does to his blood sugars … and I don’t know if he told you about a night that his blood sugar was 27 and … I was actually going*
Increasing burden of care/stress

A significant issue emerging from the interview data concerned the increasing burden of care on family members/carers as their spouse’s life limiting illness progressed. Seven of the ten participants described how they had assumed increasing responsibility for managing their spouse’s diabetes and other illnesses and discussed their concerns about the increasing responsibility of the ‘new role’ for which they were unprepared. Participants’ comments are grouped together as:

- care tasks
- being housebound
- emotional response to new role
- what will happen if I get sick?

Participants provided details about their new care tasks.

Care tasks

The family members/carers described the many care tasks they performed as their spouse’s condition deteriorated. These tasks included attending to personal hygiene needs, assisting with meals and nutrition, administering medicines including diabetes medicines and pain relief, attending medical appointments with their spouse and generally being present for their spouse.

Comments included:

*Oh, yeah, yeah ... yeah I have too ... because there are many thing he can’t do now ...like I help him ... he puts his pants and that on himself ... but the socks is a struggle ... cause when he bends down ... you know to put the socks on ... he gets out of breath straight away ... and I help him in the shower ... what I never did before ... it’s just little things ... you know but I’m ... well I thinks*
it’s important for him that I help him in that way … but I do everything I can … [C 2]

The time taken to perform these tasks was substantial and affected the time the carer was able to spend on their own interests and responsibilities:

Well I just put it down to … by the time I’ve got up and I help him have a wash … cause when he’s having a wash I have to hold him cause he said when he puts his head down he goes dizzy … so he has a wash … I help him to have a wash … wash his body and back … and then … put his shirt on … have to button his shirt for him … cause he’s a bit shaky … then I give him his breakfast … then I clean up and maybe I have to go to the shops … come back … then it’s lunch time … I give him his lunch … and before I know it … you know the day’s gone … and there’s things I can see wanting doing in the house and I think ‘ gee I’ll have to do that’ but I don’t get time … cause I’m with him … all the time… [C 4]

The repercussions of their spouse’s increasing care needs included restrictions on the participants’ activity.

**Being housebound**

Two of the ten participants briefly alluded to experiencing isolation due to a combination of their spouse’s health decline and their own increasing anxiety to leave their spouse alone. Comments included:

Well if he doesn’t go out, I don’t go out … [C 2]

One participant elaborated on why she did not leave her spouse alone:

He was in terrible pain and I didn’t like to leave the house and leave him alone I wanted someone he with him … worried when I wasn’t here … because at the time I didn’t know what was going on and I didn’t know what was likely to happen when I was out the door … [C 9]
Emotional response to new role

The emotional response of individual family members/carers to the increased needs of their spouse varied greatly. Negative emotions were related to feeling inadequate and wishing they could perform their new role differently:

Yeah … so … so sometimes I feel angry and inadequate and … and sometimes I feel like I’m chasing my own tail trying to look after him in that I’m forever picking up the pieces rather than being proactive … I’m being reactive … [C 3]

Negative emotional responses also reflected a carer’s reaction to the loss of freedom imposed on the family member/carer by their new role:

I felt trapped a lot of the time … you know, because I found towards the last few weeks I had to stay home all the time, I didn’t like to leave him because he … was getting a little bit disorientated, at times not a lot but he tried to do things for himself and he was very fragile and unsteady on his feet and I was worried … what’s going to happen if he falls … so someone had to be here all the time … so that … does limit the time that I could go out ……[C 4]

Another family member/carer acknowledged the difficulty they experienced undertaking their new role, but also indicated that they felt privileged to be doing it:

It’s about the time that it takes to deal with that [diabetes management] … and I’m not complaining I actually feel fairly privileged that I can care for him, that’s something that I can do for us … so in some ways it’s a privilege to do that it’s just juggling all the hats that you have to wear and the time, the nature of the time. [C 7]

It was apparent from one participant’s comments (a health care worker) that role conflict affected her emotional response to the new care tasks she was taking on. This participant was apprehensive about taking over her spouse’s diabetes self-management tasks including blood glucose monitoring. She indicated she wanted her
role to remain as his wife; yet she understood she needed to know about and undertake blood glucose monitoring.

Umm … how do I feel … not exactly thrilled … because …. Because I do work in the medical system … for me part of the juggle is … being his wife and not predominately his nurse … so I have to be careful that I don’t … that, that sort of medical background that I have doesn’t dominate our relationship … so for me taking that on would be fine I can do it … it’s not that I can’t do it, I can do it… but it would just be one thing that I would do which would be sort of more part of that medical care of him … I mean I’ll do it … that’s why I asked him to show me how to do it … with the machine … in case I ever need to know how to do it … [C 7]

What will happen if I get sick?

Family members/carers were concerned about what would happen to their spouse if they were unable to look after them. They worried about who would undertake the diabetes management task they now performed for their spouse. For example:

The only thing is if I’m too sick to do it or something like that … like I keep pretty well but I run on a pace maker and I have an artificial valve in my heart … and they’ve sort of given me 8 more years of life … 9 more years now but … coming up to 9 … since they did my heart operation … but … and I had cancer at the same time … so … he’s sort of been more my … looking after me more than I’ve been looking after him until the last 12 months or so … [C 9]

Another participant discussed what would happen if she was not able to be there for her husband, and was more specific about who would be appropriate to assist him manage his diabetes:

... I think if need be I could get the support … I wouldn’t be happy about just getting a friend to pop in and do it because … I’d like someone who’s done it before because I know the first day I started pricking the finger I was rather hopeless. [C 10]
Recognising ‘I’m out of my depth—I need help’

Several family members/carers indicated they would need advice and education when their spouse was nearing death. Comments included:

*I think I’d need a bit of assistance ... yes I would ... yes I would need assistance from someone ... but as I say it would have to be a professional ...* [C 1]

*Well like I said how long I can manage it myself, I don’t need any help but when it comes to the stage that I really need somebody well I would like that somebody is there for me ... you know ...* [C 4]

One family member/carer explained why they needed education and advice help:

*Because the other day when he needed me to be able to do it, I didn’t really know what to do ...* [C 3]

Another participant mentioned he or she might need help as their spouse approached the terminal stage but did not really know until he or she was in that situation:

*Well, maybe I need some help ... I don’t know ... until it gets to the stage ...* [C 2]

Uncertainty concerning diabetes management when spouse approached the end of life

The language family members/carers used when they were asked about managing diabetes when their spouse approached the end of their life suggested many were uncertainty about the issue. Some family members/carers indicated they preferred to continue diabetes management. Comments were grouped as:

- wanting diabetes management to continue
- being guided by others
- letting go.
Wanting diabetes management to continue

Three family members/carers indicated they thought diabetes management should continue, typically to increase their spouse’s comfort and reduce the risk of diabetes-related symptoms and illnesses:

*I would think to continue with it … I wouldn’t like to think he was stopped and take sick … again and go through all that trauma …* [C 1]

*Nearer toward the end of life … I’m trying to think of the way to say this … I want him to be comfortable … and if it means continuing with the monitoring to keep him comfortable then I think that’s really important …* [C 7]

One participant gave contradicting responses to the question about continuing diabetes management when her spouse was close to death revealing a level of uncertainty about what would be best for his/her spouse. Initially the participant responded:

*Oh … it wouldn’t worry me [to cease diabetes management]… so long as he was being looked after and was well … so long as he’s not suffering in any way from it …* [C 9]

Only minutes later she stressed the importance of actively managing her spouse’s diabetes to maintain his comfort:

*No I don’t think I’d like them [BG testing and medicines] to be stopped because I think that would only make him feel worse …* [C 9]

Two participants believed blood glucose monitoring should be continued because it provides important information about their spouse’s condition:

*’Cause I feel it’s a guide … you know too … at least if you can test … his sugar you know what it’s … what’s happening … I guess if you didn’t do it you’d just have to guess and I think it’s much better to keep on doing the*
testing ... and you know where you are ... I mean it’s showing you isn’t it in a tangible way ... what’s happening ........ [C 10]

Oh well I would tell them [health professionals] that it is necessary [insulin and blood glucose monitoring] ... because otherwise they’ve got no idea ... if his sugar level is high or if its too low or whatever I mean you have to do that ...  [C 2]

The latter participant indicated she would be guided by other people when making the decision to continue or cease her spouse’s diabetes management.

Being guided by others

Two participants said they would rely on other people to tell them what to do and when to cease blood glucose monitoring if their spouse was near the end of life. Comments included:

Well I don’t know ... I really don’t know but I think it would help him and its necessary ... I would do it [blood glucose monitoring] until somebody tells me otherwise ...  [C 2]

Another participant stated:

So if ... that was what the palliative care people recommended I would trust them because they’re the experts and I would say ok, that’s fine lets give it a go and see how it goes but if they said to me that they think it’s really important for his comfort that we continue with that then I’d be guided by them ...  [C 7]

Letting go

Two family members/carers spoke about stopping active diabetes management as ‘letting go’. One suggested letting go would be difficult:

... and I suppose it’s that letting go of something that’s become part of your life ... that’s become routine ... seeing that the first thing that B does when he wakes up is do a blood sugar and we talk about what that is and ... then work
Another participant described feeling that her spouse wanted to let go:

*I think he wants to just let go of the diabetes control even though he might feel lousy ... and I don't know whether doing that is exacerbating the cancer or the cancer's exacerbating the feelings of just wanting to let go of the control ... but he's certainly ... for quite some time now he hasn't wanted to test himself or take his insulin ...*[C 3]

The participant continued to prepare the self care equipment for her husband but left the decision about blood glucose testing/taking medicines to him. It was not clear from her comments whether the she accepted the situation, was resigned to it, or passively resisted the situation. Nor was it clear whether she had discussed ‘letting go’ with her husband.

*So now I just put everything in front of him and if he chooses to use it he uses it, if he doesn’t he doesn’t ...*[C 3]

**Suggestions family members/carers made about the type of information they would like included in the guidelines**

Significantly, all family members/carer offered valuable suggestions about the type of information they would like included in the Guidelines. Many felt they were inexperienced to take on diabetes self-care tasks and/or to support their spouse with their diabetes management in the context of a life limiting illness. They were concerned about performing technical tasks such as blood glucose testing and administering insulin, which many had never performed before.

They also worried about being able to interpret/respond to blood glucose readings and appropriately manage symptoms of hypoglycaemia and hyperglycaemia. They described feeling anxious, overwhelmed and initially incapable of taking in vast
quantities of information about diabetes management because they were coping with the emotional and physical impact of knowing their spouse was dying.

The three major themes identified from the interview data were:
- education, guidance and support
- individualised, inclusive approach with carer
- meeting patient care needs if carer unavailable.

A need to know more about how to care for their spouse and support to do so was an important theme emerging from the data.

**Education, guidance and support**

Primarily, family members/carers suggested health professionals needed to provide clear and concise explanations about how to manage diabetes in the presence of a life limiting illness. The sentiment was exemplified by the following comment:

*That’s the most important thing I think in explaining things properly*  (C 2)

Family members/carers discussed their escalating frustration about not being able to manage or cope with their spouse’s diabetes management in the presence of a life limiting illness when they had not previously undertaken many diabetes management tasks. They wanted specific education, guidance and support for carers to be a leading consideration in the Guidelines.

Comments included:

*I almost need a list of things to go through, so yes a bit of education, a bit of guidance is probably what the carer needs … I’m not a health care professional so I really don’t know what to do when things go wrong … I almost need a checklist of … you know what to do next …*  (C 3)

*Education and counselling …*  (C 4)
Another family member/carer suggested:

*Some written guidelines for the carer ... would be really helpful.* (C 7)

This statement echoes an earlier comment from the same participant:

*If there was a suggested treatment plan that would be really helpful because one of the ... one of the scary things about ... it's that sort of watching and waiting approach ... is that you might not have it right ...* [C 7]

**Individualised, inclusive approach with carer**

Four of the ten family members/carers discussed the need for the Guidelines to encourage an individualised and inclusive approach to the patient and family member/carer when managing diabetes at the end of life.

*Consider individual needs.* Family members/carers discussed the importance of identifying the most appropriate care for each individual patient. Comments included:

*You just have to take the approach of each individual client ...* (C 5)

*... It is a good idea to talk to the carer as well ... and say ... 'what can we do for you' ... 'cause I assume there are some people that are quite frightened ... because it all came in a rush for us ...* (C 6)

The importance of including both the patient and the carer in discussions about care plans was also articulated.

*A shared responsibility.* One family member/carer reiterated that the patient’s diabetes management at the end of life as a shared responsibility that incorporated the family member/carer as active participants in the care. This sentiment echoes the discussion about ‘team work’ discussed earlier. Significantly, the participant’s responses suggested that although she wanted to share responsibility for care decisions, she also wanted to defer to health professionals advice to avoid self-blame and distress if her decisions ‘don’t work.’:
... through communication and consultation and that I'm not left with the responsibility of it ... that's what ... I don't want the responsibility of it ... I think that's what it is ... yes ... because if something doesn't work then I don't want to be left blaming myself because of that ... (C 7)

And,

That the care plan is negotiated with the carer and the patient ... I suppose that the guidelines are based on what evidence there is ... yeah and I just think having guidelines would be a really good thing to have ... and that it's done ... when those guidelines are being considered in regards to a patient that, that's communicated to the patient and their carer ... (C 7)

Participants suggested the Guidelines should encompass the need to assess the individual patient’s and carer’s diabetes management capabilities when care plans are prepared for patients being managed at home.

Mirroring care to reflect patient’s capability and willingness. One family member/carer suggested the Guidelines should reflect care that is consistent and achievable in all settings, to enable an easier transition from home to health facility and vice versa. The participant described the need to focus on the patient’s ‘best possible outcomes,’ indicating the importance of developing patient-centred care goals to enhance quality of life, as opposed to prescriptive medical/nursing goals.

Her comments included:

I think it really important that in care it has to mirror what s been happening at home... and some ... strategies devised to get it as good as it can be knowing that that’s what’s going to happen at home rather than have the ideal situation because the person’s compliant and the nursing staff are good at their job and you have really good control and then you go home and to a disaster ... (C 3)

And,

To work out ‘what is this person willing to do’ once they leave the hospital setting ... and then as I said before ... once that’s established they you can
develop the prescription level according to his best possible outcome, even though it’s not medically the soundest … (C 3)

Meeting patient care needs if carer unavailable

Two of the ten family members/carers suggested including ‘contingency planning’ in the Guidelines; for example, information about what to do if the family member/carer becomes unwell or is no longer able to care for the patient. This suggestion is consistent with the participants’ concerns about what would happen if they could not care for their spouse. One participant said:

I think to be able to have some sort of help if I’m not there to do it (C 9)

When asked what would help to support the carer, another participant responded:

Just that … I guess we’d have help if I happened to … not be available [inferring significant illness or death] … you know Mr M would need some help.  [C 10]

Discussion

The participants

The participants with diabetes were willing to discuss their diabetes and palliative care despite having a limited life expectancy and being unwell. Similarly, family members/carers were willing to be interviewed for the project despite the many demands on their time and the difficulties they were experiencing. Participants provided moving and useful information about the complexity of managing diabetes in the presence of a life limiting illness. The recruitment process was complex and time consuming due to the vulnerability of the target participants and the intricacies of involving busy palliative care health professionals in the recruitment process. The researcher had prior experience with palliative patients and used flexible and innovative skills to involve palliative care heath professionals by establishing relationships, attending bi-weekly palliative care meetings and maintaining contact by email and telephone.
Participants were from different backgrounds and age groups and some had sensory disabilities. In addition, the palliative care phase they were in, as defined by Palliative Care Outcomes Collaboration (PCOC, 2008), at the time of the interview varied; all four PCOC phases were represented. Some participants were undergoing treatment for cancer and were reasonably well at the time of the interview. Others were very unwell and were interviewed while they were in hospital. Sadly, four people who participated in the interviews and contributed important information, passed away before the Guidelines were completed.

The interviews

Interviewing people receiving palliative care presented an unusual situation for one of the researchers. Palliative patients and their family members/carers live with the diagnosis of a life limiting illness and often have complex needs and symptom management requirements. Most patient interviews were conducted in the patient’s homes and many were in a very poor health and in bed when they were interviewed, thus, they were extremely vulnerable (Koffman et al., 2009). Nevertheless, they were keen to ‘be heard’; therefore, it was particularly important that the interviews were conducted sensitively and with compassion. It was also important that the researcher was able to debrief with the rest of the research team and to balance discussing her concerns about the patient or carer that emerged during the interview with the treating palliative care staff when relevant, with respecting the individual’s confidentiality.

The tapes and transcripts of the interviews demonstrate that the researcher quickly established a good rapport with each individual and was extremely mindful of their particular situations. It is clear that the patients were very happy to discuss their health and quite sensitive topics. The field notes the researcher recorded contemporaneously with each interview indicate that several interviews were very difficult for her due to the patient’s sensory deficits or because the patient was in pain during the interview but wanted to continue the interview despite their obvious discomfort.
Participants’ diabetes management preferences

While patient participants’ specific diabetes management preferences varied, there were common views about how diabetes should be managed. Significantly, the patient participants in the current study wanted an individualised, collaborative, consistent approach to managing their diabetes. They wanted relief from distressing symptoms, including hypoglycaemia and hyperglycaemia, and flexible approaches to managing their medicines and blood glucose monitoring. Some participants were happy to leave decisions to health professionals, but some specified that health professionals should be competent and ‘know what they are doing’ with regards to managing diabetes.

Participants indicated health professionals should listen to the patient because they are ‘experts in their bodies and their diabetes.’ Interestingly, people with diabetes interviewed for the current project experienced a variety of symptoms of hypoglycaemia and hyperglycaemia. The symptoms varied among participants and in some cases were different from common ‘textbook’ symptom lists that health professionals rely on to detect blood glucose levels in the high and low ranges. People with diabetes learn to recognise body cues associated with hypo/hyper-glycaemia; these cues/symptoms often change over time with increasing duration of diabetes or be masked by other diseases or medicines. For example, people with type 1 diabetes can experience hypoglycaemic unawareness due to autonomic neuropathy and other causes including frequent episodes of hypoglycaemia (Schwab, Menche, Schmeisl & Lohse, 2004). Frequent episodes of hypoglycaemia also reduce the individual’s ability to detect hypoglycaemia symptoms (brain desensitisation). The brain no longer signals for adrenaline release and the upregulation of brain glucose transporters, which lowers the glycaemic threshold at which people recognise hypoglycaemic symptoms (Cryer, 1997).

Significantly, people with diabetes and their family members/carers are afraid of hypoglycaemia and the threat to their safety, which includes death (Egi, Bellomo, Stachowski et al., 2010). The unpleasant effects of hypoglycaemia often persist after the blood glucose is corrected, but can recur if treatment is inadequate and in some cases become chronic (Dunning, 2009).
OHA-induced hypoglycaemia is hard to detect and usually occurs more slowly and produces different symptoms from insulin-induced hypoglycaemia. Likewise, it often takes longer to resolve, especially if renal disease is present. Hyperglycaemia also causes unpleasant symptoms such as lethargy, low mood, nausea and vomiting and exacerbates pain that may not be adequately relieved if the underlying cause is not identified (Campbell, 2007). Blood glucose monitoring is necessary to detect hypoglycaemia if the individual has hypoglycaemic unawareness or is cognitively impaired and cannot respond to or indicate they are hypoglycaemic.

Most participants accepted blood glucose monitoring as part of their life with diabetes and indicated it helped them manage symptoms and medicines. Health professionals in Quinn et al.’s (2006) study indicated that finger pricking in the last days of life might be distressing for the patient. However, only one patient participant in the current study expressed a strong dislike of finger pricking, which was present regardless of his palliative care status. Health professionals need to reflect on their own concerns about blood glucose monitoring and discuss the issue with patients with diabetes or family members/carers before making a decision to stop testing. The notion that blood glucose testing is an unnecessary and painful intervention needs to be reassessed in light of other more invasive and unpleasant palliative care interventions.

Only one patient participant in the current study had formulated an Advanced Care Directive. She had not included her diabetes management preferences until she agreed to participate in the study. Health professionals are in an ideal position play an active role advising palliative care patients to formulate an Advanced Care Directive early in the course of their patient’s disease. Health professionals could counsel palliative care patients to include their diabetes management preferences in their Advanced Care Directives. For example, the patient’s views on continuing blood glucose monitoring could be specified in the Advanced Care Directives.

The perspective of family members/carers

The family members/carers interviewed in the current study discussed the impact of the new diabetes management tasks they undertook when their care recipient’s health deteriorated. They articulated a need for more education and support to help them in
their new role, and some described feeling ‘out of their depth’ and expressed uncertainty about how the patient’s diabetes should be managed in the context of other life limiting illnesses. Family members/carers also wanted to be included in decision-making and discussions about the care of the patient with diabetes.

Health professionals and diabetes management in palliative care

Some participants felt health professionals did not give diabetes enough attention once the patient required palliative care. Quinn et al. (2006) conducted focus groups with diabetes and palliative care specialists to discuss end of life issues. The diabetes health professionals indicated they did not receive referrals from palliative care health professionals and the latter indicated they did not often refer palliative care diabetes patients to diabetes specialists. Significantly, rural palliative care participants in Quinn et al’s study indicated they did not know how to access diabetes experts or information.

Diabetes experts may not have a good understanding of palliative care. Collaborative health professional education programs could foster collaborative relationships and improve knowledge and understanding regarding managing people at the end of life and result in improved patient outcomes.

In summary, the following conclusions were drawn from the interview data about study participants’ preferences about managing diabetes when palliative care is required.

Conclusions

• Each person with diabetes needs to be treated individually. There was a wide variation in how patient participants responded to having diabetes, the extent to which diabetes and their other illness/es were inter-related, and how actively they preferred to have their diabetes managed when they are very ill.
• Patient participants described a variety of symptoms of hypoglycaemia and hyperglycaemia that were not always consistent with textbook lists, which could make it very difficult for health professionals to recognise hypoglycaemia or hyperglycaemia in patients with diabetes requiring palliative care.
• Patient participants found hypoglycaemia and hyperglycaemia very uncomfortable and they wanted to avoid these events. Similarly, family members/carers commented on their concern about their spouse experiencing these events.

• Significantly, the majority of patients indicated change was needed in their diabetes management as a result of their other life limiting illness/es. They were aware of the complexity of the interaction between the treatment/medicines they needed to manage their other illness and their diabetes medicines. Likewise they were aware of the impact of medicines such as glucocorticoids on their blood glucose levels and wanted their blood glucose monitored and controlled to prevent hypo/hyperglycaemia.

• Patient participants accepted the tasks involved in managing their diabetes, for example, testing their blood glucose levels. Only one of the 14 patients interviewed indicated he disliked pricking his finger to test his blood glucose. This finding suggests health professionals need not be concerned about blood glucose monitoring causing pain or distressing patients.

• Some patients felt health professionals do not pay sufficient attention to their diabetes and do not know enough about diabetes management. They described inconsistencies in how health professionals managed diabetes in different health care settings.

• Patients were frustrated when health care professionals did not pay attention to the patient’s views about how to manage their diabetes. Seven of the 14 patient participants specifically indicated that they wanted health professionals to listen to them.

• Patient participant’s preferences for diabetes management when they are very ill varied. Some wanted very active management; some wanted less active management, and some thought diabetes management could be stopped when they were no longer conscious. Some patients stressed the need to be kept comfortable, especially when they were close to death. Identifying and acknowledging the patient’s diabetes management preferences is extremely important.

• Generally, the patients interviewed were unaware of Advanced Care Directives, which suggests they need information from health professionals about the option of preparing Advanced Care Directives that could include diabetes management.
• Family members/carers took on an increasing role regarding diabetes management for the person with diabetes requiring palliative care as the patient’s life limiting illness progressed.

• While family members/carers responded differently to the demands of their new role, it was apparent that it had a substantial impact on them. Many experienced difficulties and were anxious about performing specific diabetes care tasks. Some were also concerned about leaving their care recipient alone.

• Most family members/carers interviewed indicated they needed more information and education about managing diabetes and also wanted health professionals to include them in discussions about care plans with the patient.

These data provided very useful information to include in the Guidelines. Significantly, they are consistent with the guiding principals developed as the conceptual framework for the Guidelines.

**Key findings that informed the development of the Guidelines**

• Continue testing blood glucose until the terminal stage unless otherwise specified in an Advanced Care Directive.

• Continue medicines to control unpleasant hypo/hyperglycaemia until the terminal stage but use them in that stage to promote comfort.

• Medicines may need to changed or adjusted frequently as the person’s condition changes and insulin might be indicated.

• Consider the whole person and individualise their management plan.

• Health professionals should listen to the person with diabetes because they are experts in their disease and recognising symptoms by recognising body cues.

• Health professionals should acknowledge the role of family members/carers in managing the patient’s diabetes as the patient’s health deteriorates, and include family members/carers in discussions about the patient’s care plan.

• Family members/carers may not have previously undertaken tasks such as monitoring blood glucose levels and may lack the necessary knowledge and skills to monitor and interpret blood glucose levels, manage increasing or decreasing blood glucose levels and administer medicines safely and confidently.

• Family members/carers require more information, education and support in relation to managing diabetes in the context of palliative care.
• Family members/carers may feel anxious about their increasing responsibility regarding their care recipient’s diabetes and need support and guidance from health professionals.
Section 5

DOCUMENT TO ACCOMPANY THE GUIDELINES
INTRODUCTION

In the course of the formative evaluation of the Guidelines it became apparent that a detailed explanation of the framework and philosophy underlying the Guidelines, an overview of diabetes, and an explanation about the complexities of managing diabetes in the context of palliative care was needed to help palliative care and diabetes health professionals understand and implement the Guidelines. Therefore, a document to accompany the Guidelines was developed simultaneously with the Guidelines—the accompanying document. The accompanying document is presented in the following section. A shorter version of the accompanying document that could easily be used in clinical situations was also prepared and is described in a later section of the report and presented in Appendix C.
**Background**

The project to develop guidelines for managing diabetes at the end of life originated from collaboration between diabetes and palliative care clinicians. The project was designed to address the critical need for clear guidelines for managing people with diabetes requiring palliative care.

Palliative care is defined as:

> An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

(World Health Organisation, 2009)

The goal of palliative care is to achieve the best quality of life for patients and their families. Most people gradually deteriorate towards the active dying phase after a period of illness: less than 10% die suddenly or unexpectedly (Emanuel et al. 2008). However, people with chronic diseases such as diabetes may have many episodes of the unstable Palliative Care Outcomes Collaboration (PCOC, 2008) phase before they enter the final end of life stage.

A detailed report about the development of the Guidelines, including a literature and interviews with people with diabetes requiring palliative care and their carers, was prepared. The following sections provide information about the philosophical and theoretical frameworks used to underpin the Guidelines and detailed background information about managing diabetes in people requiring palliative care.

**The Palliative Care Outcomes Collaboration framework**

The Palliative Care Outcomes Collaboration (PCOC, 2008) palliative care phases and the Quality Use of Medicines (QUM) Framework (PHARM Committee, 2005) were used as the underlying conceptual framework for the Guidelines.
The five palliative care phases are:

1. stable
2. unstable
3. deteriorating
4. terminal
5. bereaved.

The phases are not necessarily sequential and an individual patient can move between the phases (PCOC, 2008). There is no defined duration of the phases or for the entire dying entire process.

Separate Guidelines for managing diabetes are provided for each PCOC phase with the exception of the bereaved phase. In addition, guidelines for managing people, with and without diabetes, who are prescribed corticosteroid medicines are included.

A definition of each phase is presented in the following section based on the PCOC definitions (PCOC, 2008).

**Phase 1: STABLE**
All people not classified as unstable, deteriorating or terminal.

The person’s symptoms are adequately controlled using their established management plan but interventions to maintain symptom control and quality of life have been planned.

The family/carers’ situation is relatively stable and no new issues are apparent. Any needs are addressed in the established plan of care.

**Phase 2: UNSTABLE**
The person develops a new unexpected problem or a rapid increase in the severity of existing problems, either of which requires an urgent change in current management or emergency treatment. The person could restabilise or deteriorate.
The family/carers experience a sudden change in their situation requiring urgent intervention by members of the multidisciplinary team.

**Phase 3: DETERIORATING**
The person’s existing symptoms *gradually worsen* or they develop **new but unexpected problems**. These require specific plans of care and regular review but **not urgent or emergency treatment**.

The family/carers experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the person they are caring for. This requires a planned support program and counselling as necessary.

**Phase 4: TERMINAL**
Death is likely in a matter of days and no acute intervention is planned or required. However, frequent, usually daily, interventions aimed at physical, emotional and spiritual comfort is required.

The typical features of a person in the terminal phase include some or all of the following:

- profound weakness
- essentially bed bound
- drowsy for extended periods
- disorientated for time and has a severely limited attention span
- increasingly disinterested in food and drink
- finding it difficult to swallow medicines.

The family/carers recognise that death is imminent and care is focussed on ensuring comfort and emotional and spiritual care as a prelude to bereavement.

**Phase 5: BEREAVED**
The individual died and the carers are grieving. A planned bereavement support program is available in many palliative care services including referral for counselling as necessary.
**Diabetes and palliative care**

Diabetes is a complex multifaceted disease of disturbed glucose homeostasis. Normal glucose metabolism is finely balanced among glucose uptake and glucose utilisation, production and storage (Table 6 on the next page). However, glucose enters cancer cells down a concentration gradient rather than being insulin-mediated and the metabolism favours lactate production, which is used in the liver for gluconeogenesis, which increases blood glucose levels. Lactate production may also increase the risk of lactic acidosis especially in people with type 2 diabetes taking Metformin. There is an association between some forms of cancer such as breast, pancreas, liver and kidney, and diabetes and obesity. Weight loss associated with cancer often leads to malnutrition, reduced immunity and affects normal cell functioning.

In addition, renal disease is a significant complication of diabetes and influences the choice of medicines, many of which are excreted via the kidney, and care must be taken to protect the kidney if radio-contrast media are used. People with a long duration of diabetes may have autonomic neuropathy, which can lead to unrecognised hypoglycaemia and gastric stasis. The latter can complicate medicine-induced constipation, and nausea and lead to unstable blood glucose levels and nutrient malabsorption, which complicates the nutritional status and contributes to falls.

Hypoglycaemia produces unpleasant symptoms and affects cognitive functioning. People with liver disease and limited nutritional reserves are not able to mount an effective counter-regulatory response to hypoglycaemia and glucagon injections may not be effective in these people. In addition, the counter-regulatory response to hypoglycaemia decrease in type 1 diabetes: glucagon and adrenaline secretion diminishes; thus, the early warning signs are lost (Cryer, 1997). Hypoglycaemia can occur when people are on glucose lowering medicines, have renal or liver disease and inadequate carbohydrate intake.

Hyperglycaemia produces unpleasant symptoms, which can be mistaken for other causes. It affects mood, quality of life and cognitive functioning. Significantly, type 2 diabetes is a progressive disease of beta cell decline and insulin is needed in 75% of people to control blood glucose, and thus symptoms.
Table 6. Normal glucose metabolism: a fine balance among glucose uptake, glucose utilisation, production and storage.

<table>
<thead>
<tr>
<th>Circulating blood glucose (Available fuel)</th>
<th>Hepatic glycogen stores (Stored fuel)</th>
<th>Longer term</th>
</tr>
</thead>
<tbody>
<tr>
<td>After food—the post prandial state</td>
<td>Fasting state and between meals</td>
<td></td>
</tr>
<tr>
<td>Glucose enters the bloodstream after food is digested in the GIT and stimulates the pancreas to secrete insulin (glucose-mediated insulin release).</td>
<td>Counter-regulatory hormones e.g. glucagon, adrenaline, cortisol, and growth hormone release glucose stores from the liver and muscle between meals, overnight and when fasting.</td>
<td>In the longer term glucose is manufactured in the liver from protein and fat stores (gluconeogenesis and glycogenolysis). Thus, protein and fat are important fuel substrates.</td>
</tr>
<tr>
<td>The intestinal incretin hormones also play a role in insulin release when the BG rises after food.</td>
<td>Insulin is required for the glucose to enter the cells. It attaches to the insulin receptors on the cell membranes (insulin binding).</td>
<td>Insulin is needed for the new glucose to enter the cells. If insulin is lacking or the individual has insulin resistance the glucose does not enter the cells and hyperglycaemia and hyperlipidaemia occur.</td>
</tr>
<tr>
<td>Insulin attaches to the insulin receptors on the cell membranes (insulin binding).</td>
<td>Insulin initiates a cascade of intracellular events that enables glucose to enter the cells.</td>
<td></td>
</tr>
<tr>
<td>Insulin initiates a cascade of intracellular events that enables glucose to enter the cells.</td>
<td>Inside the cell the glucose is used for immediate energy production or stored for longer term use.</td>
<td></td>
</tr>
<tr>
<td>Inside the cell the glucose is used for immediate energy production or stored for longer term use.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
A summary of the short and long term complications of diabetes is provided in Table 7. Many of these are present before diabetes is diagnosed thus non-diabetics at risk of type 2 diabetes are likely to have impaired glucose intolerance and complications such as cardiovascular disease.

Table 7. The short term and long term complications of diabetes.

<table>
<thead>
<tr>
<th>Short term complications</th>
<th>Long term complications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypoglycaemia</td>
<td>(1) Microvascular disease</td>
</tr>
<tr>
<td>Hyperglycaemia, if not corrected can lead to:</td>
<td>- retinopathy</td>
</tr>
<tr>
<td>- ketoacidosis</td>
<td>- nephropathy (eGFR &lt; 60ml/min)</td>
</tr>
<tr>
<td>- hyperosomolar states</td>
<td>(2) Macrovascular disease</td>
</tr>
<tr>
<td>Active infection</td>
<td>- cardiovascular disease</td>
</tr>
<tr>
<td></td>
<td>- cerebrovascular disease</td>
</tr>
<tr>
<td></td>
<td>- intermittent claudication</td>
</tr>
<tr>
<td></td>
<td>(3) Neuropathy</td>
</tr>
<tr>
<td></td>
<td>- peripheral</td>
</tr>
<tr>
<td></td>
<td>- autonomic</td>
</tr>
<tr>
<td></td>
<td>- responsible for gastroparesis and hypoglycaemia unawareness</td>
</tr>
<tr>
<td>(4) Periodontal disease</td>
<td></td>
</tr>
<tr>
<td>(5) Anxiety and depression and burnout</td>
<td></td>
</tr>
</tbody>
</table>

People may already have diabetes when they enter palliative care or may develop diabetes during palliative care, often as a consequence of treatment with diabetogenic medicines. A number of factors are known to increase the risk of people developing diabetes.
Risk factors for type 1 and type 2 diabetes

People most at risk of developing type 2 diabetes:

- family history of diabetes
- have the metabolic syndrome (a cluster of risk factors for cardiovascular disease and type 2 diabetes)
- are aged over 50 years (but prevalence is increasing in younger people)
- have close relatives with type 1 or type 2 diabetes
- are overweight
- are women who had gestational diabetes or gave birth to large babies
- belong to Asian, Pacific Islander or Australian Aboriginal ethnic groups
- have hepatitis C
- have schizophrenia
- have pancreatic cancer
- are using immunosuppressive therapy and/or
- take diabetogenic medicines (Diabetes Australia, 2009b; Dunning, 2009).

People most at risk of developing type 1 diabetes:

- genetic predisposition
- pancreatectomy or other significant pancreatic disease or trauma.

Diagnostic criteria

The criteria for diagnosing diabetes are presented in Figure 2 (next page). Fasting plasma glucose is the preferred diagnostic test, but any of the three tests are acceptable.
Figure 2. Criteria for diagnosing diabetes (venous plasma glucose levels in mmol/L) (Based on Diabetes Australia, 2009b). The OGTT is rarely required and is contraindicated if the blood glucose is already high.

**Overview of diabetes management**

In general, diabetes management involves an appropriate diet and activity for both type 1 and type 2 diabetes even when medicines are needed. Managing diabetes involves:

- Lifestyle changes particularly for type 2 diabetes.
Medicines:

- Type 1 diabetes – insulin
- Type 2 diabetes oral hypoglycaemic agents, incretin mimetics and/or insulin.
  
  Note: beta cell function declines over time in type 2 diabetes and approximately 75% eventually need insulin.

- Managing blood glucose, lipids and blood pressure.
- Regular medicines review.
- Regular monitoring by health professionals to identify and manage the short and long term complications of diabetes.
- Diabetes education including educating significant others.
- Self-care by the patient, with support from family/carer.

**Hyperglycaemia and hypoglycaemia**

Two conditions commonly associated with diabetes are hyperglycaemia, a symptom of uncontrolled diabetes, and hypoglycaemia, a side effect of glucose lowering medicines, especially sulphonylureas and insulin.

**Hyperglycaemia**

Under usual circumstances, many people with type 2 diabetes do not experience the symptoms of hyperglycaemia until their blood glucose levels are extremely high. Common symptoms of hyperglycaemia include:

- feeling excessively thirsty
- frequently passing large volumes of urine
- feeling tired
- blurred vision
- infections e.g. thrush, cystitis, wound infections
- lowered mood
• weight loss in the longer term (Diabetes Australia, 2009a).

**Hypoglycaemia**

Hypoglycaemia, also called a ‘hypo’, low blood glucose, or insulin reaction, occurs when the blood glucose level falls below 3.5 mmol/L. Symptoms of hypoglycaemia vary from person-to-person, however, common feelings are:

- weakness, trembling or shaking
- sweating
- light headedness
- headache
- dizziness
- difficulty concentrating
- tearful/crying
- behaviour change
- irritability
- hunger
- numbness around the lips and fingers (Diabetes Australia, 2009a).

Hypoglycaemia unawareness may be present especially in people with long-standing type 1 diabetes. This means they may not recognise the early adrenergic symptoms of hypoglycaemia. In addition, symptoms may be masked by analgesia, delirium and other cognitive changes and cancer-related autonomic neuropathy. Significantly, people with diabetes and their family members/carers are often very fearful of hypoglycaemia and the consequences, which includes death.

**The Quality Use of Medicines framework**

The Quality Use of Medicines (QUM) Framework (PHARM Committee, 2005) is the recommended Australian framework for making medicines-related decisions and was used when formulating these Guidelines (see Figure 3, page 114). The safe and effective use of medicines is extremely important at the end of life (National Prescribing Service Limited and Palliative Care Australia, 2009).
The factors to consider when determining a diabetes medicine regimen for people with diabetes receiving palliative care, if medicines are indicated, are:

- Insulin doses may need to be adjusted frequently.
- Patients on metformin who develop nausea and vomiting especially the elderly, those on diabetogenic medicines, and those with reduced renal function, liver, cardiac and respiratory disease, and people who are not eating, may be at risk of lactic acidosis, a relatively rare but serious adverse event. Significantly, most reported cases of lactic acidosis associated with metformin occurred in people with known contraindications (Australian Adverse Drug Reactions Advisory Committee, 2001). Therefore, metformin may not be the best choice.
- Insulin mimetics can induce weight loss and nausea, therefore, they may be contraindicated.
- Thiazolidinediones contribute to weight gain due to fluid retention and may be contraindicated.
- Diuretics can exacerbate dehydration and increase blood glucose levels.
- Corticosteroids, and atypical antipsychotics are frequently used in palliative care and other disease processes and increase blood glucose levels.
- Glucagon used to treat severe hypoglycaemia usually increases blood glucose quickly. A second dose can induce nausea but may be ineffective in emaciated people with reduced glycogen stores. This means if oral glucose treatment of hypoglycaemia and intramuscular (IM) glucagon are ineffective or contraindicated, intravenous (IV) dextrose may be required.
- Some oral nutrition supplements affect blood glucose levels, often leading to hyperglycaemia.
- The patient may be using complementary medicines (CAM) and other CAM therapies. If so, determine why the person is using CAM, what they are using, and whether CAM is appropriate i.e. the benefits outweigh the risks and there is evidence for its use.
• CAM medicines may interact with conventional medicines. However, some non-medicine CAM therapies can relieve symptoms such as stress and pain and may be safer than medicines.

• CAM use should be included in the management plan and monitored.

• Opioids and other psychoactive medicines can mask hypoglycaemia.
Figure 3. Quality Use of Medicines Framework for managing diabetes at the end of life.
**Corticosteroid medicines**

Corticosteroid medicines are an essential part of the management of several disease processes such as haematological malignancies, inflammatory diseases, allergies and shock. However, long term use and high doses predispose people to insulin resistance (IRS), glucose intolerance (IGT) and steroid-induced diabetes; and causes hyperglycaemia and the resultant symptoms in people with diagnosed diabetes. IRS and IGT can occur within 48 hours of commencing steroids, especially in at-risk individuals and those with diabetes. People should be informed they could develop diabetes when diabetogenic medicines are prescribed.

Several mechanisms have been proposed for the diabetogenic effects of steroids. These include:

- Enhancing gluconeogenesis by upregulating key regulatory hormones that contribute to hyperglycaemia such as glucose-6-phoshatase and phosphoenolpyruvate carboxylase.
- Suppressing insulin release from the beta cells.
- Inducing peripheral insulin resistance by inhibiting production of glucose transporters in adipose and skeletal muscle cells.

Both fasting and post prandial blood glucose levels are affected.

These proposed mechanisms of action suggest the key areas to target when developing strategies to manage IGT, IRS, and steroid-induced diabetes. However, the effect on blood glucose depends on the biological action of the specific corticosteroid medicine and the period of time it is used for as well as the individual’s personal risk of developing diabetes. Hyperglycaemia usually occurs when doses of Prednisolone or equivalent medicines exceeds 7.5 mg/day. In contrast, short courses may not cause hyperglycaemia or only have a short term effect on the blood glucose.

Corticosteroids can also mask the signs and symptoms of infections, which often do not present in the usual way in people with diabetes and can be difficult to detect. The skin can become thin and fragile and prone to tears. If not managed, these effects can cause considerable discomfort and distress. Corticosteroids also have variable
effects on bone formation and reduce calcium absorption from the intestine, which predisposes susceptible individuals to osteoporotic fractures and pain. Mental changes can also occur ranging from mild psychosis to significant pathology. These effects can be distressing for the individual and carers.

**Managing medicine-induced diabetes in palliative care patients**

Balancing the need for corticosteroid medicines with their effects on glucose homeostasis is multifactorial and challenging and is affected by individual susceptibility, meal schedules, whether dosing is intermittent or continuous and the diabetogenic effects of the individual medicines. Table 8 (next page) outlines an appropriate diabetes management strategy for people with medicine-induced diabetes.

**Palliative care symptoms and diabetes**

Sub-optimal symptom control can be due to the diabetes or the life-threatening primary illness or both. Distinguishing between cause and effect can be difficult. Symptoms not caused by diabetes can have significant effects on diabetes management. Table 9 (pages 118–121) outlines the relationships between common palliative care symptoms and diabetes.
Table 8. Managing medicine-induced diabetes.

| 1. Pre-prescription evaluation | • Screen for diabetes risk factors. |
|                              | • Complete assessment and medical history. |
|                              | • Undertake a comprehensive medicine review including self-prescribed and complementary medicines. |
|                              | • Provide education and counselling about weight, diet and activity. |
|                              | • Select the most appropriate medicine and use the least diabetogenic medicine for shortest duration, if possible (Quality Use of Medicines principles). |
|                              | • Monitor blood glucose regularly. |
| 2. Individualise therapy     | • Choose an appropriate medicine (as above). |
|                              | • Reduce diabetogenic medicine doses as soon as possible. |
|                              | • Set blood glucose target and commence relevant oral hypoglycaemic agents (OHAs) or insulin, if indicated e.g. blood glucose consistently > 7 mmol/L. |
|                              | • Target post-prandial blood glucose levels, use long acting insulin analogue. Add prandial insulin (meal time) use rapid acting analogue if indicated. |
| 3. Monitor                   | • Self-blood glucose testing regularly. |
|                              | • Test ketones if person has type 1 and blood glucose is high. |
|                              | • The need to continue corticosteroids. |
|                              | • Reduce OHA/insulin doses as steroid doses are reduced. |
|                              | • Monitor physical and mental status. |
Table 9. The relationship between common palliative care symptoms and diabetes. (Table continues over 4 pages)

<table>
<thead>
<tr>
<th>Common palliative care symptoms</th>
<th>Impact on diabetes management</th>
<th>May be diabetes-related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain (acute/chronic)</td>
<td><strong>Increased:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- somnolence or confusion/cognitive impairment due to pain/analgesia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- risk of hyperventilation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- hyperglycaemia</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Reduced:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- intake</td>
<td>- Peripheral vascular disease</td>
</tr>
<tr>
<td></td>
<td>- mobility</td>
<td>- Amyotrophy</td>
</tr>
<tr>
<td></td>
<td>- sleep</td>
<td>- Peripheral neuropathy</td>
</tr>
<tr>
<td></td>
<td>- self-care ability</td>
<td>- Myocardial Infarction (MI)</td>
</tr>
<tr>
<td></td>
<td>- quality of life</td>
<td>- Tissue glycosylation (e.g. carpal tunnel syndrome)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Ketoacidosis (abdominal pain)</td>
</tr>
<tr>
<td>Depression/anxiety</td>
<td><strong>Increased:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- fatigue</td>
<td>- Associated with diabetes especially hyperglycaemia</td>
</tr>
<tr>
<td></td>
<td>- lethargy, change in performance status</td>
<td>- Renal disease</td>
</tr>
<tr>
<td></td>
<td>- risk of DKA, HONK</td>
<td>- Corticosteroid medicines</td>
</tr>
<tr>
<td></td>
<td>- social isolation</td>
<td>- Hypoglycaemia symptoms can be mistaken for anxiety</td>
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<td></td>
<td><strong>Reduced:</strong></td>
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<tr>
<td></td>
<td>- self-care ability, disinterest increased risk of hyperglycaemia</td>
<td></td>
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<td></td>
<td>- confidence</td>
<td></td>
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<td></td>
<td>- inadequate nutrition increased risk of hypoglycaemia</td>
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<td></td>
<td>- effects on communication and self-care</td>
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<tr>
<td>Oral Pathology (oral and maxillofacial pathology)</td>
<td><strong>Increased:</strong></td>
<td></td>
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<tr>
<td></td>
<td>- pain</td>
<td>- Diabetic ketoacidosis (DKA), hyperosmolar states (HONK) may lead to dry mouth,</td>
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<tr>
<td></td>
<td>- dry mouth</td>
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<td></td>
<td>- inadequate nutrition, inappropriate</td>
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<tr>
<td>Common palliative care symptoms</td>
<td>Impact on diabetes management</td>
<td>May be diabetes-related</td>
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<tr>
<td>Mucositis, ulcers, dry mouth</td>
<td>weight loss, cachexia, hypoglycaemia if on OHA/insulin</td>
<td>lead to dry mouth, thirst and clinical dehydration</td>
</tr>
<tr>
<td></td>
<td>Reduced:</td>
<td>- Risk of dental caries and oral pathology</td>
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<tr>
<td></td>
<td>- intake</td>
<td>- Risk of hypoglycaemia if on OHAs or insulin</td>
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<td></td>
<td>- self-care deficits</td>
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<td></td>
<td>- mood</td>
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<td>Nausea/vomiting</td>
<td>Increased:</td>
<td>- May be due to gastric autonomic neuropathy</td>
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<td></td>
<td>- confusion</td>
<td>- Renal disease</td>
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<tr>
<td></td>
<td>- lethargy</td>
<td>- Hyperglycaemia – DKA, HONK</td>
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<tr>
<td></td>
<td>- disinterest</td>
<td>- Medicines:</td>
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<tr>
<td></td>
<td>- pain/discomfort</td>
<td>- Metformin</td>
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<td></td>
<td>- inadequate nutrition → weight loss, cachexia, hyperglycaemia</td>
<td>- Byetta</td>
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<td></td>
<td>- hypoglycaemia if on OHA/insulin</td>
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<td>- dehydration and electrolyte imbalance</td>
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<td>- risk of ketoacidosis</td>
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<td></td>
<td>Reduced:</td>
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<td></td>
<td>- intake</td>
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<td></td>
<td>- energy, depleted energy stores</td>
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<tr>
<td>Delirium</td>
<td>Increased:</td>
<td>- May be due to many factors including hyper and hypoglycaemia</td>
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<td></td>
<td>- cognitive impairment</td>
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<td></td>
<td>Reduced:</td>
<td></td>
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<tr>
<td></td>
<td>- ability to communicate and detect signs/symptoms of hypo/hyperglycaemia</td>
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<td></td>
<td>- self-care ability</td>
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### Common palliative care symptoms

<table>
<thead>
<tr>
<th>Common palliative care symptoms</th>
<th>Impact on diabetes management</th>
<th>May be diabetes-related</th>
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</thead>
<tbody>
<tr>
<td><strong>Sepsis</strong></td>
<td></td>
<td>- May be silent in diabetes (urinary tract infection (UTI), MI)</td>
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<tr>
<td></td>
<td></td>
<td>- May precipitate DKA, HONK</td>
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<tr>
<td><strong>Acute Dyspnoea</strong></td>
<td><strong>Increased:</strong></td>
<td><strong>Increased:</strong></td>
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<td></td>
<td>- hypoxia contributing to confusion</td>
<td>- confusion</td>
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<tr>
<td></td>
<td><strong>Reduced:</strong></td>
<td>- energy requirements</td>
</tr>
<tr>
<td></td>
<td>- self-management capacity</td>
<td>- pain</td>
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<tr>
<td></td>
<td>Note: MI often silent in diabetes</td>
<td>- difficulty interpreting elevated white cell count, which could be caused by hyperglycaemia, sepsis, or other factors</td>
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<tr>
<td></td>
<td></td>
<td>- bone marrow failure</td>
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<td></td>
<td><strong>Reduced:</strong></td>
<td>- intake increased DKA, HONK risk</td>
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<tr>
<td></td>
<td>- hypoglycaemia</td>
<td>- quality of life</td>
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<td></td>
<td>- hyperglycaemia</td>
<td>- wound healing</td>
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<td></td>
<td>- MI</td>
<td>- Hypoglycaemia</td>
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<td></td>
<td></td>
<td>- DKA, HONK, Lactic acidosis</td>
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<tr>
<td><strong>Diabetes Emergencies</strong></td>
<td><strong>Examples:</strong></td>
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<tr>
<td></td>
<td>- Hypoglycaemia</td>
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<td></td>
<td>- Hyperglycaemia</td>
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<td></td>
<td>- MI</td>
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<td>Common palliative care symptoms</td>
<td>Impact on diabetes management</td>
<td>May be diabetes-related</td>
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<tr>
<td>Oncology Emergencies</td>
<td>Examples:</td>
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<tr>
<td></td>
<td>- Spinal Cord Compression</td>
<td>- Hypoglycaemia</td>
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<td>(corticosteroids) and acute</td>
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<td></td>
<td>immobility</td>
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<td></td>
<td>- Superior vena clava (SVC)</td>
<td>- DKA, HONK, Lactic</td>
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<tr>
<td></td>
<td>obstruction</td>
<td>acidosis</td>
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<td></td>
<td>(acute dyspnoea and delirium)</td>
<td>high dose of corticosteroids</td>
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<tr>
<td></td>
<td>- Febrile neutropenia</td>
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<td></td>
<td>- Major bronchial obstruction</td>
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<td></td>
<td>(dyspnoea and use of corticosteroids)</td>
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**Considerations when using the Guidelines**

The key themes that emerged from the interviews with patients and their family members/carers that were conducted to ensure the guideline development process was consistent with NHMRC recommendations and people with diabetes and their relatives’ voices were heard, follow. Importantly, these themes are consistent with the guiding principles developed as the conceptual framework for the Guidelines development project.

- Care should be individualised for each patient because the situation, diagnosis and responses of each individual are unique.
- Patients want a consistent approach to their diabetes management. When they are cared for by health professionals they want their diabetes management to be consistent with their usual self-management practices, and they want different health professionals to be consistent in how they manage the patient’s diabetes.
- Comfort is very important to patients and interview participants stressed that they want their diabetes managed to prevent unpleasant symptoms of hypoglycaemia and hyperglycaemia.
• Most patients want some say in how their diabetes is managed, but are happy for experienced health professionals to work with their family/carers to make decisions when they are no longer able to do so, if they have not communicated their wishes in an Advanced Care Directive.

• Family members/carers need education about managing diabetes as the patient’s health deteriorates and the family member/carer takes on new responsibilities.

**General considerations—diabetes and all palliative care phases**

**Goal of care**

• Symptom management and support for the patient. Manage diabetes using the Guidelines for each PCOC phase in people diagnosed with diabetes. Identify diabetes or impaired glucose tolerance in non-diabetics for example, those on corticosteroids to enable appropriate timely care and symptom control.

• Consider the patient’s wishes and choices when making decisions about diabetes management.

• Discuss changes in diabetes management with other relevant health professionals, the patient and family members/carers.

• Include diabetes management in care plans and advanced care planning directives.

• Provide education to the patient and their family members or carers concerning the focus of care, which focuses on preventing symptoms of hypo/hyperglycaemia and their consequences and enhancing quality of life. However, long term diabetes complications may be present and affect palliation, general care plan, medicine choice, and contribute to or be the cause of symptoms. Therefore, they must be identified and managed.

• Involve an interdisciplinary health team to foster inclusive, collaborative goals of care (endocrinologist, diabetes educator, palliative care specialists—medical/nursing; psychologist; social worker; occupational therapist; physiotherapist; pastoral care worker) and communication.

• In addition to the tools already used to assess patients, assess whether the patient has diabetes and/or the signs and symptoms of diabetes.
• Blood glucose monitoring is an important decision-making tool rather than an unnecessary intervention.
• Admissions may be needed for acute illnesses.

**Stable phase**

**General considerations**

• The goals of care are symptom management and support for the patient and carers to maintain independence and self-care capacity as long as possible.

• Determine the cause of the symptoms and whether diabetes is causing or exacerbating symptoms.

• The stable phase represents a ‘window of opportunity’ to identify, acknowledge and document patient’s wishes for current and future diabetes management. Initiate Advanced Care Planning including preferences for future diabetes management

• Assess carer’s capacity to provide care and their need for diabetes education.

• Management begins with a thorough clinical assessment and medicines review during which the patient’s and carer’s level of understanding and current treatment regimen is evaluated.

• If the patient’s blood glucose pattern is stable and in an acceptable range (4-8 mmol/L) continue current treatment regimen. The assessment should include documenting the presence of long term complications and a medication review. Liver/renal disease may mean OHAs and some other medicines are contraindicated. Determine whether the patient is using complementary medicines (CAM) or other CAM therapies and their safety and efficacy and potential interactions with conventional medicines.
• The patient’s diet may need to be revised and supplements may be needed particularly if anorexia or cachexia is present. The patient and carers may need significant explanation and education if the diet changes significantly from the diet they have been familiar with for many years.

• Glucocorticoids induce glucose intolerance and insulin resistance and may cause blood glucose levels to rise. People prescribed these medicines often need insulin to control blood glucose levels and diabetes symptoms. The effect of corticosteroids on glycaemic control varies with individual corticosteroid medicines and among individuals.

• Other medications can cause hyperglycaemia, for example, atypical antipsychotics, thiazide diuretics and octreotide (a somastatin analogue).

• Blood glucose monitoring is advisable to identify hyperglycaemia early and manage it to reduce the impact of diabetes-related symptoms on pain, mood and quality of life and prevent consequences such as DKA, HONK and lactic acidosis.

• Blood glucose testing for patients who are not on corticosteroids could be once to twice a day. Increase the frequency of blood glucose monitoring if symptoms develop or the patient becomes ill. In the stable phase this might be every 2–4 hours depending on the type of diabetes. Patients with type 1 diabetes should also be tested for ketones.

• If the patient is on corticosteroids refer to Part 3 of the Guidelines.

Case study

“A” is a 78-year-old woman with severe dementia and type 2 diabetes. She lives in a residential aged care facility and requires full nursing care including continence management. She has no Advanced Care Plan. She previously had very limited intake, which became much worse in the last three months, and her family have requested a palliative approach.
Managing Diabetes at the End of Life

• Ascertain whether there is an Enduring Medical Power of Attorney (EMPOA) or limitation of treatment order. An Advanced Care Plan is vital to establish the boundaries of care and help health professionals respect the individual’s wishes.

• “A” may need insulin to prevent hyperglycaemia if oral medicines are stopped. Insulin should be considered with the other ‘core’ out-of-hours emergency medicines to ensure it is available as part of the contingency plan as part of the discussion with other health professionals, in particular with her General Practitioner. Including insulin in the ‘core’ medicines list should minimise the risk of an inappropriate/unwanted out-of-hours admission to hospital.

Unstable phase

General considerations

• The goal of care is to rapidly identify the cause/causes of the instability, treat the cause/s if possible, manage symptoms and support the patient and his or her carers.

• Consider whether the phase is likely to revert to stable or continue to the deteriorating or terminal phases.

• Determine the cause of symptoms and whether hypo/hyperglycaemia could be causing or exacerbating symptoms. Monitor BGLs regularly for example every four hours while her condition is unstable.

• Provide education to the patient and his or her family members or carers about the focus of care, which should be on preventing symptoms of hypo/hyperglycaemia and their consequences and enhancing quality of life. However, short and/or long term complications may be present and affect palliative care, medicine choice and contribute to or be the cause of symptoms. Therefore, ideally, they should be identified and managed.
• Review her medicines regimen, including any CAM treatments and self-prescribed medicines she might be using, considering her complication status and BGL pattern, and potential medicine interactions.

• Several symptoms of advanced cancer are similar to those of hyperglycaemia. It is important to consider diabetes as a possible cause of symptoms. Blood glucose monitoring is important to determine whether diabetes is involved.

• If changes in symptoms are due to intercurrent illness, treat the cause and/or consider whether an emergency department or hospital admission is needed. Consider the possibility that DKA could occur in type 1 diabetes and test for ketones. Blood ketone testing is preferred over urine ketone testing.

• The patient’s diet may need to be revised and supplements may be needed particularly if anorexia or cachexia is present. The patient and carers may need significant explanation and education if this is a radical change from the diet they have been familiar with for many years.

• Ascertaining the patient’s and family’s wishes is vital to determine the boundaries of investigating the primary disease and progressive co-morbidities. Using disease-specific prognostic tools when they are available, these tools can also assist health professionals obtain informed consent from the patient or carers. General prognostication such as functional status prior to the period of instability might help determine the appropriate approach.

Case study

“B” is a 60-year-old woman with renal failure, cardiovascular disease (NYHA stage IV) and type 1 diabetes. Her weight has decreased from 80 kg to 65 kg over the last six months. B is unstable due to increasing dyspnoea at rest, a prolonged episode of chest pain, and delirium. She has been taking regular long acting opioids (morphine). B has an Advanced Care Plan (ACP).

• Consider what symptoms represent and what can and cannot be controlled or reversed. There are many causes of delirium.
• Determine whether the ACP covers her diabetes management preferences or the contingency that this may represent acute on chronic renal impairment?
• B’s symptoms, including delirium, may be due to hyperglycaemia leading to dehydration, or hypoglycaemia including nocturnal hypoglycaemia, and she may need acute complex management.
• B’s dose or choice of opioid may change depending on the degree and rapidity of her renal function decline and further renal impairment.
• Her 19% recent weight loss is a very significant prognostic factor and needs to be considered when formulating a management plan as well as considering her pre-existing diabetes and renal impairment.
• If renal and diabetic causes are excluded, a host of other factors that could cause or contribute to the presenting picture including opioid toxicity, hypoxia, stroke, thromboembolism and ketoacidosis need to be considered.
• Determining the venue of immediate care and the degree of intervention is complex and may require a senior clinician’s guidance.

**Deteriorating phase**

**General considerations**

• The goal of the deteriorating phase is to support and comfort the patient and carers, maintain comfort, dignity and autonomy as long as possible and maximum comfort.

• Generally, do not cease insulin for patients with type 1 diabetes in this phase but dose reductions may be indicated.

• Check the patient’s Advance Care Plan if they have one. If not, ascertain their wishes as a matter of urgency.

• Provide education for the patient and their family members or carers about the focus of care, which should be on preventing symptoms of hypo/hyperglycaemia and their consequences and enhancing quality of life.
However, short and long term diabetes complications may be present and affect palliative care and medicine choice and contribute to or be the cause of symptoms. Therefore, ideally they should be identified and managed.

- Weight loss, lack of appetite and decreasing performance status are the main expected issues in this phase. Maximising and maintaining as much function as possible may require a multimodality approach including nutritional supplements, exercise including resistance training and orexigenic medications that can alter glucose metabolism and diabetes management. Examples include glucocorticoids and agents such as megestrol acetate. The diabetes management plan will need to be revised if these interventions are used.

- The patient’s diet may need to be revised and supplements may be needed particularly if anorexia or cachexia is present. The patient and carers may need significant explanation and education if this is a radical change from the diet they have been familiar with for many years.

- Several symptoms of advanced cancer such as dry mouth and polydipsia are similar to the symptoms of hyperglycaemia. It is important to consider diabetes as a possible cause of symptoms, which, if corrected will enhance comfort. Blood glucose monitoring is important to determine whether diabetes is involved.

- If changes in symptoms are due to intercurrent illness, consider whether treatment and/or an emergency department or hospital admission is needed.

- A patient with diabetic ketoacidosis (DKA) or hyperosmolar non-ketotic (HONK) coma may not actually be in a coma. If these conditions are present insulin is generally needed.

- Ketone testing is important in type 1 diabetes during illness and hyperglycaemia to detect DKA early. DKA can contribute to pain and cognitive changes. Insulin doses may need to be increased to manage ketosis.
Case study

“C” is a 65-year-old male with metastatic non-small cell lung cancer. He has cachexia and is taking dexamethasone. He has steroid-induced diabetes. C has no Advanced Care Plan.

- Determine the patient’s wishes and suggest he develops an ACP.
- C may need insulin when on high dose Dexamethasone. Note the syndrome of cancer cachexia may increase insulin resistance.
- C’s insulin doses and dose frequency will need to be carefully titrated when his Dexamethasone dose is weaned or increased.
- Regular blood glucose monitoring will provide important information on which to base insulin dose adjustments.
- The patient and carers may need diabetes education because Mr C’s diabetes is a very ‘new’ diagnosis. Education should include blood glucose testing and medicines management. They may be distressed at dealing with a new illness in addition to the primary lung cancer. It may all feel ‘too much;’ support and counselling may be needed.

Terminal phase

General considerations

- The goal of the terminal phase is to maximise comfort and ensure a peaceful transition to death.
- Very limited or no oral intake is often a sign that death may be close. Providing mouth care may be the major comfort measure.

- Decisions should be made about which medicines can be stopped and whether blood glucose testing should be continued or stopped, explored. Check the patient’s Advance Care Plan if they have one. If not, ascertain their wishes as soon as possible.
• A patient with diabetic ketoacidosis (DKA) or hyperosmolar non-ketotic (HONK) coma may have an impaired conscious state. These states should be excluded as the cause of ‘the terminal phase’ and treated to manage symptoms.

• Glucocorticoids may no longer confer any symptom or quality of life benefit and could be ceased.

Case study

“D” is a 40-year-old woman with breast cancer and depression. D has type 1 diabetes and no Advanced Care Plan.

• Determining D’s judgement regarding the boundaries of care may be difficult due to her depression and no pre-morbid ACP.

• The duration of the terminal phase may influence the approach to managing her diabetes care. If she dies in a matter of a few hours the issue may not arise, but some people can remain in the terminal phase for days and insulin or other interventions may be needed to promote comfort. The ethical considerations may be complex and need a multi-disciplinary approach and senior clinicians discussing the issues with her family so they can make a substituted judgement.

• Consider whether D’s depression can be treated in the timeframes indicated by your prognostication, or whether it is caused or affected by her blood glucose levels.

• Her insulin requirements may change dramatically and she may need a more flexible dose regimen.

• Blood glucose and ketones monitoring will help plan care to prevent short-term symptoms and ease her discomfort.

• All oral medicines may need to be rationalised with a view to stopping them.

Full case study

“E” is a 55-year-old male with colorectal cancer and long standing type 2 diabetes
E lives alone with his dog. He is Italian and has limited English. He presented with rectal bleeding and was diagnosed with metastatic colorectal cancer (bulky liver metastases) following palliative bypass surgery during which widespread peritoneal seeding was noted. He often experiences nausea and vomiting, he has had peripheral diabetic neuropathy (PDN) for over 20 years. He has episodes of angina and erectile dysfunction.
E has not told his health care professionals that he takes some complementary medicines (CAM). He consumes 10–20 standard units of alcohol per day and probably drank more in the past.

Shortly after being admitted to a community palliative care program he phoned complaining of severe abdominal pain associated with nausea and vomiting. He has been reluctant to monitor his blood glucose in the past and is reluctant to do it now. He does not want to come into hospital, which was suggested by the community nurse. He is drowsy and relatively immobile.

**Unstable phase**

Key issues:

- Exclude hyperglycaemia as a cause of his symptoms.
- Determine what his current diabetes medicine regimen is and whether he takes his medicines. There could be interactions with his CAM medicines. Some OHA may be contraindicated given his alcohol intake.
- The long standing alcohol intake may have caused liver disease and nutritional deficiencies.
- His social isolation means that supporting his care requirements or new diabetes regimen will be very difficult even with frequent community nursing visits.
- Clinically, he appears to have a sub-acute bowel obstruction. He is not able to take any oral intake. E thinks he is dying.
- After explaining that his symptoms might improve with simple non-surgical approach he agrees to a hospital admission if his dog can be cared for. His PDN has worsened with recent (weeks) of non-adherence to his adjuvant analgesics. He will need:
- IV fluids.
- Intravenous infusions to deliver analgesics and anti-emetics.
- He may be prescribed high dose corticosteroids.
- He may need an insulin infusion and then regular insulin doses while he is on glucocorticoids.
- Medicines to prevent alcohol withdrawal symptoms.

E’s symptoms settle with the regimen described above and after five days he insists on returning home on BD insulin after meeting the diabetes team once and the diabetes educator once more.

**Stable Phase**

Once home he is well supported by the community care team and a further outpatient visit to the diabetes educator. He is able to stop his dexamethasone and his OHAs and regular analgesia for PDN are recommenced. He admits the major reason he wants to return home is his dog.

Key issues:

- Careful monitoring during corticosteroid dose titration.
- Significant education was required when he commenced insulin
- It is important to explore his wishes in general and that an ACP is started.
- Social work involvement is important to help address social interventions and to discuss his preferences for his pet’s care into the future.
- Contingency medications, care plans, and orders need to be in place.

He remains well for three months following an endocrinology review and his cancer is relatively indolent, with stable liver disease and no major episodes of obstruction, on an oral chemotherapy regimen.

**Deteriorating phase**

Over the next few months E complains of increasing abdominal distension and becomes jaundiced. He notes his muscles are wasted. His nausea increases in frequency and his appetite diminishes. He is re-commenced on Dexamethasone to
improve his appetite, wellbeing and nausea. He is given some nutritional supplements. His alcohol intake reduces dramatically. He admits he feels depressed. He finally agrees to complete his advanced care plan.

Key issues:

- His weight is unlikely to reflect his muscle mass due to probable ascites.
- His caloric intake may be dramatically reduced (alcohol and general intake).
- BGL monitoring is required when he commences glucocorticoids.
- Insulin may be required when on glucocorticoids but the doses may be lower than before due to his weight loss and other factors.
- Contingency plans that reflect his ACP should be in place.
- Consider the effects of acute alcohol withdrawal.
- An appetite stimulating antidepressant (many suppress appetite) may be part of a treatment plan for his depression.
- Discussion regarding his preferences for venue of terminal care should be finalised and the timing of when his dog should be moved to the home that agreed to adopt it, explored.
- If the decision is to treat his anorexia/cachexia, the ramifications for his diabetes management should be considered.
- If he is deemed to be clinically depressed this may effect whether his ACP was based on informed consent from a competent individual.

Terminal Phase

A few weeks later E becomes drowsy, bed-bound, confused and is noted to be much more jaundiced with obvious hepatic asterixis (liver flap). He outlined in his ACP (he was not thought to be clinically depressed when he made it) that when this occurred he wished to be admitted to the local palliative care unit for terminal care and that his dog should go to the home that agreed to adopt it. He confessed he has an estranged son and asks to see the priest despite letting his faith lapse.

Key issues:

- Oral medications should be rationalised and it is likely that most, if not all, oral medicines could be stopped.
- Routine blood tests may indicate whether this is truly a terminal event and exclude reversible causes.
- Blood glucose monitoring will guide what type of insulin regimen he will need, although his ACP stated that in the terminal stages he wanted comfort measures only.
- Regular antipsychotic medicines may help control the symptoms of delirium.
- He may need higher doses of sedatives to reduce terminal restlessness based on his long standing alcohol history.
- His estranged family should be contacted and supported as needed.
- His spiritual requests should be respected and the priest contacted.
- Symptoms of alcohol withdrawal should be monitored and PRN medications to reduce the discomfort provided if needed.

E dies 36 hours later in the company of his adult son having required medicines through a syringe driver to manage his agitation.
Section 6

THE DRAFT GUIDELINES
THE DRAFT GUIDELINES

The final draft of the Guidelines for managing diabetes at the end of life is presented on the following pages. The document consists of three separate sections:

- screening for diabetes
- managing diabetes in the PCOC phases of stable, unstable, deteriorating and terminal
- managing medicine-induced diabetes in patients requiring palliative care.

The draft Guidelines are shown on pages 138 to 144. They are the result of many iterations. Features of the section about managing diabetes in the PCOC phases include a consistent format presenting general considerations, information about assessing and managing diabetes in separate columns, and include notes highlighting the differences in managing type 1 and type 2 diabetes for each PCOC phase rather than providing separate guidelines for type 1 and type 2 diabetes for each PCOC phase. However, the section about medicine-induced diabetes does present separate information for people with type 1 and type 2 diabetes, based on the recommendation of the Advisory Committee.

A succinct version of the accompanying document to the Guidelines was compiled to support health professionals to use the Guidelines in clinical practice. The brief accompanying document comprised (see Appendix C):

- A brief outline of diabetes management.
- A description of hyperglycaemia and hypoglycaemia.
- Information about corticosteroid medicines.
- Details about the Quality Use of Medicines (QUM) Framework and its application to managing diabetes at the end of life. The QUM Framework figure in Appendix C is an early representation of the Framework.
- A detailed table presenting the relationship between common palliative care symptoms and diabetes.
- A list of abbreviations and symbols used in the Guidelines.
All people referred to palliative care regardless of PCOC* stage – KNOWN TO HAVE DIABETES

*Palliative Care Outcomes Collaboration (PCOC)

- Comprehensive assessment
- Assess presence of diabetes risk factors
- Undertake a comprehensive medicine review
- Assess for occult infections

**HAS DIABETES**

Using diabetogenic medicines:
- Steroids
- Antipsychotics
- OR
- Using other medicines known to increase blood glucose:
- Thiazide diuretics
- Sympathomimetics
- Pentamidine
- Diltiazem/phenytoin
- Calcium channel blockers
- Enzyme nutrition supplements e.g. Glucerna

**USING DIABETOGENIC MEDICINES**
- Review need to continue diabetogenic medicines
- Adjust/commence diabetogenic medicines to control hyperglycaemic symptoms and promote comfort
- Monitor according to steroid medicine guidelines but individualise according to Advanced Care Directive and PCOC phase
- Provide education about steroids and diabetes
- Consider adrenal suppression and hypercalcaemia as complicating factors if steroids are needed in the long term
- Assess enteral feeds – may lack carbohydrate and therefore contribute to lethargy OR may be high caloric and contribute to hyperglycaemia
- Readjust diabetes medicines if steroids are ceased and when weaning the dose to avoid hypoglycaemia

**NOT KNOWN TO HAVE DIABETES**

**SEE NEXT PAGE**

**USUAL DIABETES MANAGEMENT**
- Diabetes management and education according to relevant diet and activity guidelines
- Adjust diabetes medicines as appropriate
- Consider referring to:
  - Treating Specialist
  - Endocrinologist
  - Diabetes Educator
  - Dietitian
  - Dentist
  - Podiatrist

Guidelines for managing diabetes at the end of life DRAFT flowcharts 7-12-09 NOT FOR DISSEMINATION
All people referred to palliative care regardless of PCOC stage - NOT KNOWN TO HAVE DIABETES

- Comprehensive assessment
- Assess presence of diabetes risk factors
- Undertake a comprehensive medicine review
- Assess for occult infections

**NOT KNOWN TO HAVE DIABETES**

**Using diabetogenic medicines**

**AND**
- Random blood glucose ≥ 11.1 mmol/L
- Fasting blood glucose ≥ 7.0 mmol/L

**YES**

**Random blood glucose ≥ 11.1 mmol/L**
- or
**Fasting blood glucose ≥ 7.0 mmol/L**

**YES**

Three or more diabetes risk factors present:
- Family history
- Ethnicity (e.g., Asian, Pacific Islander, Australian Aboriginal)
- Overweight, especially central obesity
- Over age 50
- History of gestational diabetes
- Schizophrenia
- Pancreatic cancer
- AND/OR
- Hyperglycaemic symptoms present

**YES**

**USING DIABETOGENIC MEDICINES**

- Provide education about steroids and diabetes
- Review need to continue diabetogenic medicines
- Monitor according to steroid medicine guidelines but individualise according to Advanced Care Directive and PCOC phase
- Commence diabetes medicines to control hyperglycaemic symptoms and promote comfort
- Assess enteral feeds — may lack carbohydrate and therefore contribute to lethargy OR may be high calorie and contribute to hyperglycaemia
- Consider adrenal suppression and hypercalcaemia as complicating factors if steroids are needed in the long term
- Adjust diabetes medicines if steroids are ceased and when weaning the dose to avoid hypoglycaemia

**COMMENCE DIABETES MANAGEMENT**

- Diabetes management and education according to relevant diet and activity guidelines
- Commence diabetes medicines if appropriate
- Consider referring to:
  - Endocrinologist
  - Diabetes Educator
  - Dietitian
  - Dentist
  - Pediatrician

**CONTINUE SCREENING**

- Monitor blood glucose levels especially fasting and towards the end of the day
- Monitor for hyperglycaemic symptoms

---

Guidelines for managing diabetes at the end of life DRAFT flowcharts 7-12-09 NOT FOR DISSEMINATION

---

Managing Diabetes at the End of Life Copyright 2010
### PHASE: STABLE

<table>
<thead>
<tr>
<th>Diabetes Approach</th>
<th>Assessment</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review/document diabetes management plan</td>
<td>• Review medicines using Quality Use of Medicines (QUM) framework (see page 3 accompanying document)</td>
<td>Provide information/discuss management with patients and family members/carers</td>
</tr>
<tr>
<td>Document presence of diabetes-related symptoms (see Table 1)</td>
<td>• Ascertain whether patient is using complementary medicines and other therapies</td>
<td></td>
</tr>
<tr>
<td>Document diabetes short and long term complication status</td>
<td>Assess presence of diabetes-related symptoms</td>
<td></td>
</tr>
<tr>
<td>Ascertain self-care capacity and carer involvement and capacity</td>
<td>Assess diabetes complications:</td>
<td></td>
</tr>
<tr>
<td>Consult with GP, diabetes educator, endocrinologist</td>
<td>Short term</td>
<td>TYPE 2</td>
</tr>
<tr>
<td>Check continuing and planned treatments e.g. dialysis, chemotherapy, radiotherapy, surgery</td>
<td>Hypoglycaemia</td>
<td>• Are oral hypoglycaemic agents (OHAs) still appropriate?</td>
</tr>
<tr>
<td>Prioritise, update or commence Advanced Care Directive that includes diabetes management</td>
<td>Hyperglycaemia</td>
<td>• Simplify regimen if possible</td>
</tr>
<tr>
<td></td>
<td>Active infection</td>
<td>• Consider using insulin – may be required if altering/ceasing OHAs and/or to control symptoms</td>
</tr>
<tr>
<td></td>
<td>Long term</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(1) <strong>microvascular</strong> disease</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• retinopathy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• nephropathy (eGFR &lt; 60ml/min)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(2) <strong>macrovascular</strong> disease</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• cardiovascular disease</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• cerebrovascular disease</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• intermittent claudication</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(3) neuropathy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• peripheral</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• autonomic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o responsible for gastroparesis and hypoglycaemia unawareness</td>
<td></td>
</tr>
</tbody>
</table>

*Information relates to patients with type 1 or type 2 diabetes, unless otherwise stated

Guidelines for managing diabetes at the end of life DRAFT flowcharts 7-12-09  NOT FOR DISSEMINATION
PHASE: UNSTABLE

**Type 1 and Type 2 Diabetes**

<table>
<thead>
<tr>
<th>Diabetes Approach</th>
<th>Assessment</th>
<th>Management</th>
</tr>
</thead>
</table>
| Review/document diabetes management plan | Assess symptoms:  
- Pain  
- Nausea/vomiting  
- Oral intake/pathology  
- Delirium  
- Infection – occult or overt sepsis  
- Depression/anxiety  
- Acute dyspnoea  
- Polyuria, oliguria, thirst  
- Anorexia  
- Cachexia  
- Decreasing performance status | **Initiate management strategies:**  
- Monitor BG up to 4/day to determine whether symptoms are diabetes-related or contribute to the unstable state  
- Blood glucose targets: Fasting 6-8 mmol/L, Postprandial 6-11 mmol/L  
- Initiate or change medicines if indicated:  
  - Increase or decrease dose  
  - Alter dose interval  
  - Consider initiating insulin  
- Ensure emergency medicines are available  
- Provide diabetes management contingency plans for patient and family/carer |
| Document presence of diabetes-related symptoms (see Table 1) |  
- Consider diabetes as a cause of the symptoms (table 1) | **Type 1**: Monitor blood ketones  
**Type 2**: Consider introducing insulin |
| Document diabetes short and long term complication status |  
- Consider the impact of the symptoms on diabetes (table 1) |  
- Treat underlying cause of the emergency  
- Is admission to hospital (and/or ICU depending on prognosis) necessary?  
- Consider referring to endocrinologist  
- Provide education if medicines change  
- Manage comfort and support family  
- Monitor response |
| Ascertain self-care capacity and carer involvement and capacity |  |  
- Manage comfort and support family  
- Monitor diabetes status  
- Consider initiating management strategies (see above) |
| Consult with GP, diabetes educator, endocrinologist |  |  |
| Check continuing and planned treatments e.g. dialysis, chemotherapy, radiotherapy, surgery |  |  |
| Prioritise, update or commence Advanced Care Directive that includes diabetes management |  |  |

*Information relates to patients with type 1 or type 2 diabetes, unless otherwise stated*
**PHASE: DETERIORATING**

**Diabetes Approach**
- Review/document diabetes management plan
- Document presence of diabetes-related symptoms (see Table 1)
- Document diabetes short and long term complication status
- Ascertain self-care capacity and carer involvement and capacity
- Consult with GP, diabetes educator, endocrinologist
- Check continuing and planned treatments e.g. dialysis, chemotherapy, radiotherapy, surgery
- Prioritise, update or commence Advanced Care Directive that includes diabetes management

**Assessment**
- Consider in particular:
  - Anorexia
  - Cachexia
  - Decreasing performance status
- Also assess symptoms:
  - Pain
  - Nausea/vomiting
  - Oral intake/pathology
  - Delirium
  - Infection – occult or overt sepsis
  - Depression/anxiety
  - Acute dyspnoea
  - Polyuria, oliguria, thirst

  - Consider diabetes as a cause of the symptoms (table 1)
  - Consider the impact of the symptom/s on diabetes (table 1)

**Management**
- Re-evaluate diabetes management strategies:
  - BG and ketone monitoring is still useful to determine whether ketosis exists but may not be as frequent (1-2/day)
  - New blood glucose targets < 10 mmol/L fasting
  - Ensure medicines are optimal for this phase – cease unless using to promote comfort

**TYPE 2**: consider introducing insulin to promote comfort
- Treat the underlying cause
- Is admission to hospital necessary?
- Consider referring to endocrinologist
- Manage comfort
- Monitor response

- Manage comfort
- Consider initiating management strategies (see above)
- Implement additional support/education for family/carers

*Information relates to patients with type 1 or type 2 diabetes, unless otherwise stated*
**PHASE: TERMINAL**

<table>
<thead>
<tr>
<th>Diabetes Approach</th>
<th>Assessment</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review/document diabetes management</td>
<td>• Assess need to treat short term diabetes complications to achieve comfort</td>
<td><strong>Focus of diabetes management is on comfort</strong></td>
</tr>
<tr>
<td>Carer involvement may increase</td>
<td>• Refer to Advanced Care Directive</td>
<td></td>
</tr>
<tr>
<td>Communicate with GP, palliative care specialist team</td>
<td>• Identify carer/family bereavement risks</td>
<td></td>
</tr>
<tr>
<td>Prioritise or update Advanced Care Directive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consider implementing the Liverpool Care Pathway</td>
<td><strong>Assess and manage:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Pain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Nausea/vomiting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Oral comfort</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Delirium</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Infection – occult or overt sepsis to alleviate symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Depression/anxiety</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Acute dyspnoea</td>
<td></td>
</tr>
</tbody>
</table>

*Information relates to patients with type 1 or type 2 diabetes, unless otherwise stated.*

Guidelines for managing diabetes at the end of life DRAFT flowcharts 7-12-06  NOT FOR DISSEMINATION
Managing steroids and other diabetogenic medicines in palliative care patients with **TYPE 1 DIABETES**

<table>
<thead>
<tr>
<th>Diabetes Approach</th>
<th>Assessment</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short course not causing symptoms or ketosis may not require regimen changes but effects on blood glucose often occur after 1-2 doses</td>
<td>• Revise medicine regimen: if possible avoid other diabetogenic medicines or use lowest possible dose</td>
<td>• Increase insulin dose if BG &gt; 10 mmol/L, especially if ketones are present.</td>
</tr>
<tr>
<td>Courses &gt; three days usually require regimen changes</td>
<td>• Collaborative team meeting with specialists – Palliative, DE, endocrinologist, and patient and family/carers</td>
<td>• Patients in ICU or fasting will require an insulin infusion</td>
</tr>
</tbody>
</table>
| Long term steroid use can:  
  • cause hypercalcemia  
  • suppress the hypothalamic-pituitary-adrenal axis  
  Both states can complicate management but may not be relevant depending on the prognosis | • Patient/carer education requirements  
  - Appropriate medicine self-management (when, how, why, interactions, side effects)  
  - BG testing  
  - Increased risk of hypoglycaemia if hypo unawareness is present especially when weaning or ceasing steroids  
  • BG monitoring: consider increasing frequency while on diabetogenic medicines  
  • Diet and exercise routines – food choices should not be limited if the person is cachectic or anorexic | • Use subcut insulin if eating |
| | | • Usually prandial doses need to be adjusted because the post prandial BG tends to increase. |
| | | • Food choices should not be limited. |
| | | • If on enteral feeds consider the effect of the carbohydrate content on BG and the need to provide energy |
| | | • Monitor and record BG before meals and before bed |
| | | • Monitor blood ketones if BG >15 mmol/L. |
| | | • BG often peaks early PM and tends to fall overnight, therefore an AM dose may be effective |
| | | • Manage hyperglycaemia and hyperglycaemia |
| | | • Revise patient and carer knowledge and provide education especially managing hyperglycaemia if managed at home |
| | | • Consider need for access to ‘on call/after hours’ support |
Managing steroids and other diabetogenic medicines in palliative care patients with **TYPE 2 DIABETES** or **PREVIOUSLY UNDIAGNOSED DIABETES**

<table>
<thead>
<tr>
<th>Diabetes Approach</th>
<th>Assessment</th>
<th>Management</th>
</tr>
</thead>
</table>
| Short course not causing symptoms or hyperosmolar non-ketotic acidosis (HONK) may not require regimen changes but effects on BG often occur after 1-2 doses | - Revise medicine regimen: if possible avoid other diabetogenic medicines or use lowest possible dose for the shortest possible time  
- Collaborative team meeting with specialists – Palliative, DE, endocrinologist and oncologist, and patient and family/carers  
- Oral hypoglycaemic agents may need to be altered  
- Consider commencing insulin if BG is consistently > 11 mmol/L  
- Patient/carer education requirements  
  - Appropriate medicine self-management (when, how, why, interactions, side effects); hypoglycaemia management  
  - BG testing  
- Diet and exercise routines – food choices should not be limited if the person is cachectic or anorexic  
- BG monitoring: consider increasing frequency while on diabetogenic medicines | - Consider insulin preparations  
Prebreakfast long acting analogue such as Lantus or protaphane  
Premixed insulin before lunch e.g., mixtard 30/70  
- Patients in ICU or fasting may require an insulin infusion  
- Food choices should not be limited  
- If on enteral feeds consider the effect of the carbohydrate content on BG and the need to provide energy  
- Monitor and record BG before meals and before bed  
- Manage hyperglycaemia and hypoglycaemia  
- Revise patient and carer knowledge especially managing hyperglycaemia if managed at home  
- Consider need for access to ‘on call/after hours’ support |

People with T2 can develop ketoacidosis during significant illnesses  
Courses > three days usually require regimen changes

Long term steroid use can suppress the hypothalamic-pituitary-adrenal axis  
This can complicate management but may not be relevant depending on the prognosis
Section 7

EVALUATING THE GUIDELINES
EVALUATING THE GUIDELINES

Processes utilised to evaluate the Guidelines

Three processes were utilised to obtain feedback about the draft Guidelines from palliative care health professionals during the formative and summative evaluation processes:

• An information and discussion session with palliative care health professionals.
• A questionnaire distributed to palliative care health professionals working in Barwon Health, Geelong.
• Interviews with palliative care health professionals after the draft Guidelines were refined and the health care professionals had the opportunity to use them to plan care for people with diabetes at the end of life.

1. Formative Evaluation

Information and discussion session

Method

Twenty-nine health care professionals (HPs) working in palliative care in Barwon Health were invited to attend an information and discussion session concerning the development of Guidelines for managing people with diabetes requiring palliative care. The HPs received a personalised information package containing an explanation of the research project, a letter inviting them to information session, a copy of the draft Guidelines, the draft information to accompany the Guidelines, and a brief questionnaire about the Guidelines.

The information session was held in the McKellar Centre (where the palliative care team meeting takes place) immediately after a regular palliative care team meeting on November 4th, 2009. Inpatient and community palliative care teams attend the regular meetings. Fifteen palliative care beds are located in The McKellar Centre. The researchers introduced the research and progress to date prior to guiding an open forum discussion about the draft Guidelines. Two researchers took notes to record the discussion.
A total of 21 palliative health professionals attended the information session comprising:

- ten nurses
- two doctors
- two Department of Health Representatives (these people attended the regular team meeting and were invited to stay for the information session. They did not receive information packages prior to the meeting because the researcher’s did not know they would be present
- seven Medical students undertaking clinical placement attended but did not receive information packages prior to the meeting because the researchers did not know they would be present.

**Results**

The discussion was interactive, open and wide ranging and included many aspects of palliative care and diabetes management, thus the notes from the discussion were not amenable to thematic analysis. A summary of the discussion is presented as general comments and comments specifically about the Guidelines.

General comments about managing diabetes at the end of life:

- HPs identified two groups of diabetes patient’s requiring palliative care:
  i. Preterminal—in which HPs are ‘more proactive in blood glucose control.’
  ii. End stage or terminal—where HPs stated they became ‘neglectful’ about monitoring and treating diabetes.’

- HPs indicated it is very complex managing diabetes at the end of life and made statements such as should I ‘do BG monitoring … it’s painful’ and ‘manage symptoms as we [HPs] perceive them.’

- HPs asked ‘does BG control equal better symptom control?’ and questioned the need to ‘change established practice.’ However, established practice is possibly ad hoc based on the previous experience of the researchers.
• HPs acknowledged the significant effect of corticosteroids noting ‘I know it will increase blood glucose, therefore, we should test more.’ and ‘it is one of the accepted side effects [of the medication].’

• HPs recognised the need to ‘find a balance to find the best outcome’ and mentioned times such as when ‘the patient may not be eating’ as significant.’

• Some HPs agreed to ‘go with the best interest of the patient’ but did not say how to identify or achieve the ‘best interest of the patient.’

• HPs noted the complexities of managing diabetes in care settings in which palliative care is provided and stated that an inpatient setting has more staff, control, and routine as opposed to the home setting where carers are often informal and often do not have medical/nursing backgrounds.

Specific comments about the Guidelines included:

• A senior Community Palliative Care nurse stated:

  The Guidelines are great … [they] identify things that can identify diabetic situations at home… sometimes diabetes can be seen as less problematic when it might not be … [I] found it [Guidelines] helpful to guide me …[they] seem a bit overwhelming but then once it [information] settles … comprehension is good.

• Participants indicated ‘[The Guidelines provide] a sharper focus to identify issues that can affect diabetes management at home because diabetes management is seen as the least important.’

• A community palliative care nurse liked the presentation of the ‘unstable’ type 1 and 2 management Guidelines, however, she questioned community nurses’ ability to test for ketones and thought the explanation about ketone testing in the accompanying document could be clearer.

• HPs agreed the language in the Guidelines was appropriate and ‘made sense.’

• One senior medical officer asked where the Guidelines will ‘fit’ in other settings:

  Barwon Health versus other facilities… other facilities do not have the community resources we have … however, at least the Guidelines may alert HPs to the issues surrounding diabetes management.
He then commented that, in remote areas ‘[the Guidelines may] help HPs know where to refer.’

- A senior medical officer asked whether hypercalcemia needed to be included in the Guidelines and suggested a clearer explanation about the issue was needed in the accompanying document.

- HPs agreed that ‘often GPs manage diabetes at the end of life … and the care is often ad hoc.’

- One HP recommended including a podiatrist in the list of HP specialists to refer the patient to.

**Questionnaires distributed to palliative care health professionals**

**Method**

The researchers developed a questionnaire specifically for the study to evaluate the Guidelines after HPs comments raised in the discussion group were included. The questions addressed the content, presentation and style of the Guidelines; information in the Guidelines that was not useful and information that was missing; and feedback based on their use of the Guidelines with at least one patient with diabetes requiring palliative care. The questionnaire is presented in Appendix D. The questionnaire in general performed well. Missing data were limited, responses to individual questions were appropriate suggesting the questions were clear and participants took the time to provide detailed responses to the open questions.

The researcher distributed the questionnaire and information package to 22 palliative HPs who regularly attended the palliative care team meetings, prior to the information session. The charge nurse of the Palliative Care Unit in the McKellar Centre distributed the questionnaire and information package to seven HPs working in the unit. Due to an oversight, and unknown to the researchers, these packages did not include the brief accompanying information document that provides essential information about the Guidelines. A further four health professionals who commenced working in palliative care after the information session was held were provided with the package and educated about the Guidelines by the researcher.
Results

At the conclusion of the information and discussion session, 16 completed questionnaires were placed in the sealed box provided by the researchers. An additional four questionnaires were returned to the researcher or to the research office. Thus, twenty completed questionnaires of the 33 distributed were returned, giving a response rate of 61%.

The majority of respondents were nurses (n = 17), two were doctors and one worked in allied health. Three respondents had worked in palliative care for less than one year, three for two to five years, nine for six to nine years, four for ten years or more, and one respondent did not answer the question.

The first nine questions concerning the Guidelines related to the design, language and consistency with palliative care principles. Respondents were asked to rate their response according to a Likert scale. The responses to these nine questions are summarised in Table 10 on page 151.

Palliative care HPs were generally positive about the Guidelines. The majority strongly agreed or agreed that the language used in the Guidelines was consistent with palliative care language (90%), and 85% strongly agreed or agreed that the Guidelines were consistent with palliative care procedures. Seventy five percent of respondents liked the design of the Guidelines, only 25% reported they were difficult to follow in some places but most did not provide a reason. It was some concern that 20% partially agreed with the statement ‘I find the language in the Guidelines difficult to understand’ but did not explain why. Thus, it was difficult to take these comments into consideration when the draft Guidelines were revised.
Table 10. Responses made by HPs to questions about the design and language of the Guidelines and their consistency with palliative care principles (n = 20).

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
<th>Missing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq (%)</td>
<td>Freq (%)</td>
<td>Freq (%)</td>
<td>Freq (%)</td>
<td>Freq (%)</td>
<td>Freq (%)</td>
</tr>
<tr>
<td>I like the design of the Guidelines</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>9</td>
<td>6</td>
<td>0</td>
</tr>
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<td>(25%)</td>
<td>(25%)</td>
<td>(5%)</td>
<td>(45%)</td>
<td>(30%)</td>
<td></td>
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<tr>
<td>The Guidelines are difficult to follow</td>
<td>5</td>
<td>9</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(25%)</td>
<td>(45%)</td>
<td>(5%)</td>
<td>(20%)</td>
<td>(5%)</td>
<td></td>
</tr>
<tr>
<td>The language used in the Guidelines is appropriate</td>
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<td>2</td>
<td>1</td>
<td>9</td>
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<td></td>
<td>(10%)</td>
<td>(5%)</td>
<td>(5%)</td>
<td>(45%)</td>
<td>(40%)</td>
<td></td>
</tr>
<tr>
<td>The colours used in the Guidelines make the information easy to read</td>
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<td>1</td>
<td>4</td>
<td>4</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>(5%)</td>
<td>(20%)</td>
<td>(20%)</td>
<td>(50%)</td>
<td>(5%)</td>
<td></td>
</tr>
<tr>
<td>I find the design of the Guidelines confusing</td>
<td>6</td>
<td>7</td>
<td>4</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(30%)</td>
<td>(35%)</td>
<td>(20%)</td>
<td>(15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The Guidelines are easy to follow</td>
<td>0</td>
<td>4</td>
<td>3</td>
<td>8</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(20%)</td>
<td>(15%)</td>
<td>(40%)</td>
<td>(25%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I find the language in the Guidelines difficult to understand</td>
<td>7</td>
<td>6</td>
<td>3</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(35%)</td>
<td>(30%)</td>
<td>(15%)</td>
<td>(20%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The language used in the Guidelines is consistent with palliative care language</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>12</td>
<td>6</td>
<td>0</td>
</tr>
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<td></td>
<td>(10%)</td>
<td>(20%)</td>
<td>(60%)</td>
<td>(30%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The Guidelines are consistent with palliative care procedures</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>10</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(5%)</td>
<td>(5%)</td>
<td>(5%)</td>
<td>(50%)</td>
<td>(35%)</td>
<td></td>
</tr>
</tbody>
</table>

* Percentage totals may not sum to 100 due to rounding of decimal places for clarity.
When asked whether the Guidelines contained any information that is not needed, most respondents indicated all the information was relevant (see Table 11). Thirty per cent of respondents suggested some other information that could be included in the Guidelines: two people suggested including a glossary of abbreviations, one suggested including the frequency of screening patients with diabetes risk factors, one suggested including when to discontinue lipid lowering medicines and one suggested including a podiatrist on the list of specialist health professionals to refer patients to. Significantly, several respondents suggested discussing what care they want with the patient and relatives should be the first priority.

Table 11. Responses HPs made to questions about the Guidelines (n = 20).

<table>
<thead>
<tr>
<th>Question</th>
<th>NO Freq (%)</th>
<th>YES Freq (%)</th>
<th>Missing Freq (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q10. Do the Guidelines contain any information that is not needed?</td>
<td>16 (80%)</td>
<td>1 (5%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Q11. Is there any other information that should be included in the Guidelines?</td>
<td>10 (50%)</td>
<td>6 (30%)</td>
<td>4 (20%)</td>
</tr>
<tr>
<td>Q12. Are the Guidelines consistent with the PCOC palliative care principles?</td>
<td>0 (0%)</td>
<td>17 (85%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Q13. Do you feel it will be feasible to apply the Guidelines in routine clinical practice?</td>
<td>2 (10%)</td>
<td>17 (85%)</td>
<td>1 (5%)</td>
</tr>
</tbody>
</table>

* Percentage totals may not sum to 100 due to rounding of decimal places for clarity.
Most respondents thought the Guidelines were consistent with the PCOC palliative care Guidelines and that the Guidelines would be feasible to apply in clinical practice (see Table 11 on page 152). Four respondents commented about the feasibility of applying the Guidelines in clinical practice. Two of these suggested the Guidelines could be simplified but did not say how, one suggested doctors would be confused by the Guidelines but did not say how or why, and one that HPs needed education about managing diabetes.

Respondents were asked to ‘think of a patient with diabetes you have cared for who is in one PCOC phase. Apply the relevant section of the Guidelines and note where the Guidelines were useful and how they could be improved’. Different phases were specified on individual questionnaires and randomly allocated to HPs so information could be collected about all four PCOC phases. Responses from the 12 people who answered this section of the questionnaire are presented in Table 12 on page 154 on the following two pages.
Table 12. Comments HPs made about the Guidelines after applying them to patients with diabetes in various end of life phases (n = 12).

<table>
<thead>
<tr>
<th>PCOC Phase</th>
<th>HP comments after using Guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable</td>
<td>Covered all aspects of their care concisely and with good explanations and reasons.</td>
</tr>
<tr>
<td>Unstable</td>
<td>Guidelines are relevant to the client diabetic group. The flowcharts were user friendly. However, referring to table 1 [in the accompanying document] was time consuming because of the wealth of information it provided. Guidelines very useful, great assessment prompts. Are tables going to be included in draft as references? Prompts useful in assessment to think outside the box in relation to diabetes and other symptoms and how they are related.</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>Seems ok. If deteriorating likely to enter the terminal phase next. Why consider referral to endocrinologist at this stage?</td>
</tr>
<tr>
<td>Terminal</td>
<td>Type 2 diabetes patient the Guidelines were very useful. Especially so that MOs can cease management. However, some dilemmas re: hypos in type 1 diabetes patients. After reviewing the Guidelines and applying them to a patient I have cared for in the terminal phase of their illness, I found the Guidelines to be useful and consistent with the care that was provided for this patient. Assessment of patients with diabetes is an ongoing and always reportable to the treating team. Easy to follow; prompts what to do. The main trouble with diabetes management at end of life/pall care is...</td>
</tr>
</tbody>
</table>
that doctors don’t always write appropriate orders i.e. they use sliding scale insulin orders and the staff do not know how to follow them. Education is the key and these Guidelines (while very informative) seem to make it harder. Inpatient care is very different from community care.

I applied the Guidelines on a terminal patient—easy to use the Guidelines except patient changed from one phase to the other, fluctuating status. These changes then made the Guidelines difficult to use.

The patient I was considering was in the terminal phase. The Guidelines seemed logical and easy to follow.

Participants were asked to list three pieces of information they had learned by using the Guidelines and attending the information session. The most frequent types of information they listed related to the:

- Need to consider medical conditions other than the primary diagnosis.
- Impact of corticosteroids and some other medicines on blood glucose levels.
- How to manage steroid-induced diabetes.
- Common symptoms that could be diabetes related but are not recognised as such.
- Risk factors of diabetes.
- Need to treat the patient as a whole.
- Side effects of diabetes medicines.
- Improved understanding of diabetes management at end of life.
- Importance of the Quality Use of Medicines framework and reviewing medicines.
2. Summative Evaluation

Interviews with palliative care health professionals

Method

A total of 34 palliative care health professionals working in Barwon Health were invited to use the revised draft Guidelines with patients with diabetes requiring palliative care over a period of eight weeks. After eight weeks, an email was sent these HPs inviting them to participate in a brief interview with the researcher to discuss the Guidelines. The interviews were conducted face-to-face at a time and location suitable for the health professional using a structured interview schedule (see Appendix E). The researcher wrote notes during each interview.

Results

Seven palliative care health professionals agreed to be interviewed, giving a response rate of 21%. Most participants were female (n = 6), and most were nurses (n = 6). One participant was a doctor. None of the HPs interviewed utilised the Guidelines in caring for a patient with diabetes over the eight week evaluation period. The HPs, however, spent some time reading and considering the Guidelines.

The Guidelines in general. All seven participants felt the design of the Guidelines was good or very good, five felt the wording was good or very good and two felt the document was too long. Participants commented throughout the interview about the Guidelines in general. Positive comments about the Guidelines included:

I think the Guidelines are great … have been lacking for a long time. (HP 6)

Easy to follow but quite complex. (HP 5)

Flows well, easy to understand, a lot to it, but information is relevant. (HP 4)

One participant made less positive comments about the Guidelines for example:

It read like a medical text book … I would prefer to refer to a text. (HP 3)
The preference for using a text presents a difficulty because the information presented in the Guidelines is not available in any text book the researchers identified. It appears that the participant was generally not in favour of guidelines:

*I don’t find Guidelines in general overly helpful.* (HP 3)

However, this participant made other comments about the content of the Guidelines that were at odds with these two statements:

*This document is almost a good reference document for a registrar but too involved for general staff … if you added 3 or 4 pages it could be an advanced guide/course for palliative care registrars.* (HP 3)

In contrast, another participant asked whether doctors would use the Guidelines:

*I don’t think doctors will like them [the Guidelines] … I find it hard to get doctors to respond [to new information].* (HP 6)

*Further education needed.* The preceding comment and other participants’ comments indicate there is a need to educate palliative care HPs about the way diabetes affects other health problems and the difficulty determining whether symptoms are related to diabetes or to other illnesses, for example:

*Too much information … diabetes is not the focus for community palliative care … although it is important to manage. … I do agree that we need to care for people with diabetes but we have to address palliative symptoms first.* (HP 1)

The comment shows the participant did not understand that symptoms could be due to diabetes and highlights the need for education about diabetes in palliative care settings.

When asked why they had not used the Guidelines, participants indicated they had time constraints, had not cared for an appropriate patient in the evaluation time frame or found the Guidelines too long. Health professionals who were not able to use the
Guidelines during the evaluation indicated they would use the Guidelines in the future. Some participants suggested they would use the Guidelines if the person had a longer term life expectancy or if diabetes symptoms were present, but did not see the point in the deteriorating or terminal phases.

For example, participants indicated they would use the Guidelines:

- If I had a patient with longer term prognosis or if there was a patient and we had ‘ruled out’ ‘normal’ things causing symptoms. (HP 5)

- If the patient with diabetes had symptom issues. (HP 4)

These comments illustrate that participants focus on short duration life-limiting illnesses and may not consider the different effects of chronic disease on the dying process and the likelihood of periods of stability and instability that frequently occur in chronic diseases before the deteriorating and terminal phases.

**How to improve the Guidelines.** Several participants suggested the Guidelines could be reduced or put onto a single poster, which would encourage their use:

- Simplified Guidelines … a real simple checklist … not too involved. (HP 1)

Another suggestion was that the Guidelines and the brief accompanying document could be more ‘user friendly’:

- More user friendly … if there’s too much reading people will shelve it … to put into clinical practice it has to be user friendly. (HP 7)

Other participants suggested that, over time, the Guidelines will be incorporated into practice, and education about how to use the Guidelines would assist that process, and that the Guidelines should be included in the electronic records system to facilitate their use.
Final comments from participants. The researcher’s request for any final comments elicited some interesting responses. Two participants mentioned they were more aware about the importance of HP collaboration and working with other health professionals such as diabetes educators increased after reading the Guidelines.

Summary
Importantly, the majority of questionnaire respondents found the language in the Guidelines consistent with palliative care language and procedures and with the PCOC palliative care principles. Some questionnaire respondents and interview participants noted problems with the presentation of the draft Guidelines and wanted them to be more user friendly. The researchers anticipated that these problems would be addressed once a graphic designer developed the layout and design of the Guidelines.

Some respondents suggested there was a need to include additional information in the Guidelines such as a list of abbreviations and a table presenting information about symptoms. One HP distributed a small number of packages to other HPs and these packages did not include the brief accompanying information document that provides essential information about the Guidelines. It is possible that the participants requesting additional information did not receive the accompanying document. These respondents’ comments highlighted the value of including the accompanying information with the final Guidelines. Some HPs who were interviewed commented that the Guidelines and accompanying document were too long and contained too much information. However, the questionnaire data suggest the information in the Guidelines is in fact necessary, and many participants indicated they learnt new facts about diabetes after using the Guidelines and accompanying document.

One HP interviewed in the summative evaluation phase commented that the Guidelines could almost be an advanced diabetes guide for palliative care registrars, further supporting the educational value of the Guidelines.

Some interview participants did not appear to understand the significance of diabetes in the context of palliative care and suggested palliative care was their first priority. These responses highlight the importance of educating HPs about diabetes management
in palliative care, particularly about the effect of diabetes on other health problems and the difficulty establishing the cause of some symptoms that may be related to diabetes or to the other illnesses. For example, the similarity between the signs of hyperglycaemia and the indicators that a patient is entering the terminal PCOC phase could be communicated to palliative care HPs.

Interestingly, one HP suggested the Guidelines are too involved for ‘general staff’, while another HP commented that it is hard to get doctors to respond to new information. Such comments are contrary to the collaborative approach to palliative care that is part of the underlying principles of palliative care and of the Guidelines. Strategies to promote interdisciplinary collaboration could be introduced into the education provided to HPs when the Guidelines are implemented.

None of the HPs interviewed in the third part of evaluation process utilised the Guidelines with a palliative care patient for various reasons. However, twelve HPs who completed the questionnaire in the second part of the evaluation applied the Guidelines to at least one patient in a specific PCOC phase. These participants found the Guidelines useful and their comments were generally positive. In particular, respondents indicated the Guidelines were very helpful when managing patients with diabetes in the terminal PCOC phase.

A final comment from one of the health professionals interviewed about the Guidelines is an appropriate conclusion to this report.

*Guidelines in palliative care ... the right answer is, what the patient wants.*
Section 8

REFINING AND
DISSEMINATING THE
GUIDELINES
REFINING THE GUIDELINES

A number of changes were made to the draft Guidelines when the researchers discussed the HPs’ comments. The next step in the Guidelines development process was obtaining expert advice on the presentation of the Guidelines from a graphic designer. A graphic designer was consulted and designed the content of the draft Guidelines into a completely new format and layout. Throughout the design process the graphic designer consulted with the research team and requested some changes to the wording in the draft documents. The researchers made changes where appropriate and forwarded the revised Guidelines to the designer for further work.

The final Guidelines and accompanying document are visually appealing, clear and easy to follow. The substantial redesign of the Guidelines should facilitate their use in clinical practice.

The key changes to the Guidelines were:

- A contents page was added to direct the health professional to the section they need.
- The titles on each page that describe the content of specific pages were clarified.
- The language within individual sections was revised to ensure it was consistent throughout the Guidelines, for example statements in some text boxes were rewritten as active instructions.
- Suggested BGL ranges and BGL monitoring frequencies for specific situations were included.
- The final Guidelines document and accompanying document are presented in Appendices F and G respectively.
PLAN FOR DISSEMINATING THE GUIDELINES

The final Guidelines will be disseminated in the following manner:

- The Guidelines for Managing Diabetes at the End of Life will be officially launched at the *Innovations – Updating Professional Practice in Palliative Care* Conference in Torquay, Victoria in October 2010. Copies of the Guidelines will be available to conference attendees.

- Through the CareSearch website, which attracts 100,000 hits per month.

- In relevant diabetes and palliative care special interest group meetings.

- In newsletters of diabetes and palliative care professional associations.

- At local, state, national and international conferences, some of which have already occurred:
  - ADEA Victorian Branch Conference: The hemisphere of Diabetes, 5th June 2010, Harmonising care of people with diabetes requiring palliative care.
  - Palliative Care Victoria 7th Biennial Conference: Palliative Care—Extending the Reach, 23rd July 2010, Diabetes and end of life care—gathering evidence to guide care.
Section 9

REFERENCES
REFERENCES


Pharmaceutical Health and Rational use of Medicines (PHARM) Committee (2005)
The quality use of medicines in diabetes. PHARM.


Section 10

APPENDICES
Appendix A: Interview questions for patients

Interview questions – Patients

What effect does having diabetes have on your health now?

How is your diabetes monitored? How do you feel about that?

What type of medicines do you take now? How do you feel about that?

Who helps you to manage your diabetes now?

Who would you like to help you manage your diabetes in the future?

What are your preferences for your diabetes care in the future? For example what do you think about having your diabetes monitored in the future?

What do you think about taking diabetes medicines in the future?

How do you feel about having some say about how your diabetes is managed in the future when you may become very ill?

How could that be done – how could you be given some say in your diabetes management?

Who would you like to make decisions for you about how your diabetes is managed in the future?

Do you have any questions or comments?
Appendix B: Interview questions for family members/carers

Interview questions for family members/carers

1. Think about the person you care for who has a serious illness and diabetes.
2. What effect do you think having diabetes has on them?
3. What effect does their diabetes have on you?
4. What role have you played in helping them to manage their diabetes in the past?
5. How do you help them to manage their diabetes now?
6. How do you feel about doing that?
7. What effect does it have on your lifestyle?
8. How would you feel if you were told you did not need to do that any more?
9. How do you feel about having some say about how their diabetes is managed in the future when they may become very ill?
10. How could that be done—how could you be given some say in their diabetes management?
11. When would you feel it was all right to have diabetes monitoring stopped?
12. When would you feel it was all right to have diabetes medication stopped?
13. Do you have any questions or comments?
Appendix C: DRAFT VERSION Brief document to accompany guidelines

Brief information to accompany the

Guidelines for Managing Diabetes at the End of Life

Outline of diabetes management

In general diabetes management involves an appropriate diet and activity for both type 1 and type 2 diabetes even when medicines are needed. Managing diabetes involves:

- Lifestyle changes particularly for type 2 diabetes.
- Medicines:
  - Type 1 diabetes—insulin
  - Type 2 diabetes oral hypoglycaemic agents and/or insulin.
    Note beta cell function declines over time and approximately 75% of people with type 2 diabetes need insulin.
- Managing blood glucose, lipids and blood pressure.
- Regular medicines review.
- Regular monitoring by health professionals to identify and manage the short and long term complications of diabetes.
- Diabetes education including educating significant others.
- Self-care by the patient, support from family/carer.
Hyperglycaemia and hypoglycaemia

Two conditions commonly associated with diabetes are hyperglycaemia, a symptom of diabetes, and hypoglycaemia, a side effect of glucose lowering medicines, especially sulphonylureas and insulin.

Hyperglycaemia

Under usual circumstances, many people with type 2 diabetes do not experience the symptoms of hyperglycaemia until their blood glucose levels are extremely high. Common symptoms of hyperglycaemia include:

- Feeling excessively thirsty
- Frequently passing large volumes of urine
- Feeling tired
- Blurred vision
- Infections e.g. thrush, cystitis, wound infections
- Lowered mood
- Weight loss in the longer term (Diabetes Australia, 2009a).

Hypoglycaemia

Hypoglycaemia, also called a ‘hypo’, low blood glucose or insulin reaction, occurs when the blood glucose level falls below 3.5 mmol/L. Symptoms of hypoglycaemia vary from person-to-person, however, common feelings are:

- Weakness, trembling or shaking
- Sweating
- Light headedness
- Headache
- Dizziness
- Difficulty concentrating
- Tearful/crying
- Behaviour change
- Irritability
- Hunger
- Numbness around the lips and fingers (Diabetes Australia, 2009a).

Hypoglycaemia unawareness may be present, especially in people with long-standing type 1 diabetes. This means they may not recognise the symptoms of hypoglycaemia. In addition, symptoms may be masked by analgesia, delirium and other cognitive changes and cancer-related autonomic neuropathy. Significantly, both people with diabetes and their family members/carers are often very fearful of hypoglycaemia and its consequences.

**Corticosteroid medicines**

Corticosteroid medicines are an essential part of the management of several disease processes such as haematological malignancies, inflammatory diseases, allergies and shock. However, long term use and high doses predisposes people to insulin resistance (IRS), glucose intolerance (IGT) and steroid-induced diabetes and causes hyperglycaemia and the resultant symptoms in people with diagnosed diabetes. IRS and IGT can occur within 48 hours of commencing steroids, especially in at risk individuals and those with diabetes. People should be informed they could develop diabetes when diabetogenic medicines are prescribed.
The Quality Use of Medicines framework

The Quality Use of Medicines (QUM) Framework (PHARM Committee, 2005) is the recommended Australian framework for making medicines-related decisions and is used in formulating these guidelines (see Figure 1, next page).

The factors to consider when determining diabetes medicine regimen for people with diabetes receiving palliative care, if medicines are indicated are:

- Insulin doses may need to be adjusted frequently.
- Patients on metformin who develop nausea and vomiting especially the elderly, those on diabetogenic medicines, and those with reduced renal function, liver, cardiac and respiratory disease, and people who are not eating may be at risk of lactic acidosis, a rare but serious adverse event. Therefore, metformin may not be the best choice.
- Insulin mimetics can induce weight loss and nausea, therefore, they may be contraindicated.
- Thiazolidinediones contribute to weight gain due to flued retention and may be contraindicated.
- Diuretics can exacerbate dehydration and increase blood glucose levels.
- Corticosteroids, and atypical antipsychotics are frequently used in palliative care and other disease processes and increase blood glucose levels.
- Glucogen used to treat severe hypoglycaemia usually increases blood glucose quickly. A second dose can induce nausea but may be ineffective in emaciated people with reduced glucogen stores. This means if oral glucose treatment of hypoglycaemia and IM glucagon are ineffective or contraindicated, IV dextrose may be required.
- Some oral nutrition supplements affect blood glucose levels, often leading to hyperglycaemia.
- The patient may be using complementary medicines (CAM) and other CAM therapies. If so, determine why the person is using CAM, what they are using, and
whether CAM is appropriate i.e. the benefits outweigh the risks and there is
evidence for its use.

- CAM medicines may interact with conventional medicines. However, some non-
  medicine CAM therapies can relieve symptoms and may be safer than medicines.
- Opioids and other psychoactive medicines can mask hypoglycaemia.
Figure 1: QUM Framework for managing diabetes at the end of life.
Palliative care symptoms and diabetes

Sub-optimal symptom control can be due to the diabetes or the life threatening primary illness or both. Distinguishing what is cause and effect can be difficult. Symptoms not caused by diabetes can have significant effects on diabetes management. Table 1 (next pages) presents the relationships between common palliative care symptoms and diabetes.
Table 1: The relationship between common palliative care symptoms and diabetes

<table>
<thead>
<tr>
<th>Common palliative care symptoms</th>
<th>Impact on diabetes management</th>
<th>May be diabetes-related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain (acute/chronic)</td>
<td>Increased:</td>
<td>- Peripheral vascular disease - Amyotrophy - Peripheral neuropathy - Myocardial Infarction (MI) - Tissue glycosylation (e.g. carpel tunnel syndrome) - Ketoacidosis (abdominal pain)</td>
</tr>
<tr>
<td></td>
<td>- somnolence or confusion/cognitive impairment due to pain/analgesia - risk of hyperventilation - hyperglycaemia</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- intake</td>
<td>- Peripheral vascular disease - Amyotrophy - Peripheral neuropathy - Myocardial Infarction (MI) - Tissue glycosylation (e.g. carpel tunnel syndrome) - Ketoacidosis (abdominal pain)</td>
</tr>
<tr>
<td></td>
<td>- mobility</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- sleep</td>
<td>- Peripheral vascular disease - Amyotrophy - Peripheral neuropathy - Myocardial Infarction (MI) - Tissue glycosylation (e.g. carpel tunnel syndrome) - Ketoacidosis (abdominal pain)</td>
</tr>
<tr>
<td></td>
<td>- self-care ability</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- quality of life</td>
<td>Reduced:</td>
</tr>
<tr>
<td>Depression/anxiety</td>
<td>Increased:</td>
<td>- Associated with diabetes especially hyperglycaemia - Renal disease - Corticosteroid medicines - Hypoglycaemia symptoms can be mistaken for anxiety</td>
</tr>
<tr>
<td></td>
<td>- fatigue</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- lethargy, change in performance status</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- risk of DKA, HONK</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- social isolation</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>Reduced:</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- self-care ability, disinterest increased risk of hyperglycaemia</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- confidence</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- inadequate nutrition increased risk of hypoglycaemia</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- effects on communication and self-care</td>
<td>Reduced:</td>
</tr>
<tr>
<td>Oral Pathology (oral and maxillofacial pain)</td>
<td>Increased:</td>
<td>- Diabetic ketoacidosis (DKA), hyperosmolar states (HONK) may</td>
</tr>
<tr>
<td></td>
<td>- pain</td>
<td>Reduced:</td>
</tr>
<tr>
<td></td>
<td>- dry mouth</td>
<td>Reduced:</td>
</tr>
<tr>
<td>Common palliative care symptoms</td>
<td>Impact on diabetes management</td>
<td>May be diabetes-related</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-------------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td><strong>pathology</strong>&lt;br&gt;Mucositis,&lt;br&gt;ulcers, dry mouth</td>
<td>- inadequate nutrition, inappropriate weight loss, cachexia, hypoglycaemia if on OHA/insulin&lt;br&gt;<strong>Reduced:</strong>&lt;br&gt;- intake&lt;br&gt;- self-care deficits&lt;br&gt;- mood</td>
<td>lead to dry mouth, thirst and clinical dehydration&lt;br&gt;- Risk of dental caries and oral pathology&lt;br&gt;- Risk of hypoglycaemia if on OHAs or insulin</td>
</tr>
<tr>
<td><strong>Nausea/vomiting</strong></td>
<td><strong>Increased:</strong>&lt;br&gt;- confusion&lt;br&gt;- lethargy&lt;br&gt;- disinterest&lt;br&gt;- pain/discomfort&lt;br&gt;- inadequate nutrition → weight loss, cachexia, hyperglycaemia&lt;br&gt;- hypoglycaemia if on OHA/insulin&lt;br&gt;- dehydration and electrolyte imbalance&lt;br&gt;- risk of ketoacidosis&lt;br&gt;<strong>Reduced:</strong>&lt;br&gt;- intake&lt;br&gt;- energy, depleted energy stores</td>
<td>- May be due to gastric autonomic neuropathy&lt;br&gt;- Renal disease&lt;br&gt;- Hyperglycaemia – DKA, HONK&lt;br&gt;- Medicines:&lt;br&gt;- Metformin&lt;br&gt;- Byetta</td>
</tr>
<tr>
<td><strong>Delirium</strong></td>
<td><strong>Increased:</strong>&lt;br&gt;- cognitive impairment</td>
<td>- May be due to many factors including hyper and hypoglycaemia&lt;br&gt;<strong>Reduced:</strong>&lt;br&gt;- ability to communicate and detect signs/symptoms of hypo/hyperglycaemia&lt;br&gt;- self-care ability</td>
</tr>
<tr>
<td>Common palliative care symptoms</td>
<td>Impact on diabetes management</td>
<td>May be diabetes-related</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>------------------------------</td>
<td>------------------------</td>
</tr>
</tbody>
</table>
| **Sepsis**                      |                              | - May be silent in diabetes (urinary tract infection (UTI), MI)  
                                            - May precipitate DKA, HONK |
| **Acute Dyspnoea**              | **Increased:**               | **Increased:**         |
|                                 | - hypoxia contributing to confusion | - confusion  
                                             - energy requirements  
                                             - pain  
                                             - difficulty interpreting elevated white cell count, which could be caused by hyperglycaemia, sepsis, or other factors  
                                             - bone marrow failure |
|                                 | **Reduced:**                 | **Reduced:**           |
|                                 | - self-management capacity | - intake increased DKA, HONK risk  
                                             - quality of life  
                                             - wound healing |
<p>| <strong>Diabetes Emergencies</strong>        | <strong>Examples:</strong>                | <strong>- Hypoglycaemia</strong>    |
|                                 | - Hypoglycaemia              | <strong>- DKA, HONK, Lactic acidosis</strong> |</p>
<table>
<thead>
<tr>
<th>Common palliative care symptoms</th>
<th>Impact on diabetes management</th>
<th>May be diabetes-related</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Oncology Emergencies</strong></td>
<td><strong>Examples:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Spinal Cord Compression</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(corticosteroids) and acute mobility</td>
<td>Hypoglycaemia</td>
</tr>
<tr>
<td></td>
<td>- Superior vena clava (SVC) obstruction</td>
<td>DKA, HONK, Lactic acidosis</td>
</tr>
<tr>
<td></td>
<td>(acute dyspnoea and delirium) – high dose of corticosteroids</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Febrile neutropenia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Major bronchial obstruction (dyspnoea and use of corticosteroids)</td>
<td></td>
</tr>
</tbody>
</table>
List of Abbreviations and symbols

↑ Increased
↓ Decreased
≥ Equal to, or greater than
> Greater than
≤ Equal to, or less than
< Less than
ACD Advanced care directive
AM Morning
BG Blood glucose
CAM Complementary and alternative medicines
CCF Congestive cardiac failure
DE Diabetes Educator
DKA Diabetic ketoacidosis
eGFR estimated Glomerular filtration rate
GI Gastrointestinal symptoms
HONK Hyperosmolar non-ketotic acidosis
Hypo Hypoglycaemia
ICU Intensive care unit
IGT Impaired glucose tolerance/ glucose intolerance
IM Intramuscular
IRS Insulin resistance
IV Intravenous therapy
MI Myocardial Infarction
OHA Oral Hypoglycaemic agents
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mmol/L</td>
<td>millimoles/litre – unit for measuring glucose in blood</td>
</tr>
<tr>
<td>PCOC</td>
<td>Palliative care outcomes collaboration</td>
</tr>
<tr>
<td>PM</td>
<td>Afternoon</td>
</tr>
<tr>
<td>QUM</td>
<td>Quality use of medicines</td>
</tr>
<tr>
<td>SVC</td>
<td>Superior vena clava syndrome/obstruction</td>
</tr>
<tr>
<td>T1</td>
<td>Type 1 Diabetes Mellitus</td>
</tr>
<tr>
<td>T2</td>
<td>Type 2 Diabetes Mellitus</td>
</tr>
<tr>
<td>TZD</td>
<td>Thiazolidinediones</td>
</tr>
<tr>
<td>UTI</td>
<td>Urinary tract infection</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
</table>
Appendix D: Questionnaire for health care professionals

Brief questionnaire about *Managing diabetes at the end of life* guidelines

Please read the *Managing diabetes at the end of life* guidelines and then answer the following questions. Your answers are anonymous and confidential. We are not collecting any information that can identify you.

Please rate the *Managing diabetes at the end of life* guidelines by circling one number on the scale next to the statement that best reflects your point of view.

The numbers mean:

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Somewhat disagree</td>
<td>Neither agree nor disagree</td>
<td>Somewhat agree</td>
<td>Strongly agree</td>
</tr>
</tbody>
</table>

1. I like the design of the guidelines

2. The guidelines are difficult to follow

3. The language used in the guidelines is appropriate

4. The colours used in the guidelines make the information easy to read

5. I find the design of the guidelines confusing

6. The guidelines are easy to follow

7. I find the language in the guidelines difficult to understand

8. The language used in the guidelines is consistent with palliative care language

9. The guidelines are consistent with palliative care procedures
10. Do the guidelines contain any information that is not needed? (Tick one)

☐ YES       ☐ NO

If YES, please tell us what information is not needed:

______________________________________________________________________________________________

______________________________________________________________________________________________

11. Is there any other information that should be included in the guidelines? (Tick one)

☐ YES       ☐ NO

If YES, please tell us what other information is needed:

______________________________________________________________________________________________

______________________________________________________________________________________________

12. Are the guidelines consistent with the PCOC palliative care principles?

☐ YES       ☐ NO

If NO, please tell us why not:

______________________________________________________________________________________________

______________________________________________________________________________________________
13. Do you think it will be feasible to apply the guidelines in routine clinical practice?

☐ YES ☐ NO

If NO, please tell us why not:

__________________________________________________________________________________

__________________________________________________________________________________

14. Please write any other comments you would like to make about the guidelines.

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

15. Please think of a patient with diabetes you are caring for or have cared for. Determine the PCOC phase (Stable, Unstable, Deteriorating or Terminal). Go to the relevant part of the guidelines, and apply the guidelines to that patient’s situation. When you apply the guidelines to a specific patient, think about how useful the guidelines were, and whether they could be improved.

Please comment about using the guidelines for the patient you selected, noting the PCOC phase of the patient:

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________
16. Please list three pieces of information you learned by participating in this activity.

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________

17. Have you attended any diabetes education programs in the last two years? If YES, please list the name of the program/s.

________________________________________________________________________________________

18. Please tick your profession.

☐ Nurse     ☐ Allied Health     ☐ Doctor     ☐ Other

19. How long have you worked in palliative care? _________________

20. What age group are you in?

☐ 20 – 29     ☐ 30 – 39     ☐ 40 – 49     ☐ 50 – 59     ☐ 60+

Thank you for taking the time to complete this questionnaire. We value your feedback.

Please bring your completed questionnaire to the MDT meeting on November 4th and place it in the sealed box at the door.
Appendix E: Interview schedule – Health professionals

Managing diabetes at the end of life

Interview schedule – Health professionals

Version 1, Dated 22/9/09

1. Are you aware of the Guidelines for Managing Diabetes at the End of Life that we developed recently? (circle one response)
   YES  NO

2. Have you used the guidelines with any patients receiving palliative care?
   YES  NO

If YES ask Questions 3 to Question 13. If NO, go to Question 14.

3. With how many patients did you use the guidelines?
   ____________________

4. What Palliative Care Outcomes Collaboration (PCOC) palliative care phase were the patients in?

<table>
<thead>
<tr>
<th>Phase</th>
<th>Number of patients with whom you used the guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable</td>
<td>-----</td>
</tr>
<tr>
<td>Unstable</td>
<td>-----</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>-----</td>
</tr>
<tr>
<td>Terminal</td>
<td>-----</td>
</tr>
</tbody>
</table>

5. Were the guidelines helpful?  YES  NO

6. If so, please tell me how they were helpful.
   ____________________________________________________________________________
7. Did you have problems using the guidelines? If so, what were they?

_________________________________________________________________

_________________________________________________________________

8. What information was most useful?

_________________________________________________________________

9. What information in the guidelines was least useful?

_________________________________________________________________

10. Is there any information that could be omitted? If so, what information?

_________________________________________________________________

11. Is there any information that needs to be added? If so, what information?

_________________________________________________________________

Please rate the following (circle one response):

12. The design of the guidelines

Very Poor / Poor / Good / Very Good / Excellent

13. The wording used in the guidelines

Very Poor / Poor / Good / Very Good / Excellent

14. Ease of use in clinical situations

Very Poor / Poor / Good / Very Good / Excellent Go To Question 17
If NO

15. If you did not used the guidelines, please say why?
__________________________________________________________

__________________________________________________________

16. When would you consider using the guidelines?

__________________________________________________________

17. What would make it more likely that you would use the guidelines?
__________________________________________________________

__________________________________________________________

ALL 18. Please suggest any changes that you think would improve the guidelines.
__________________________________________________________

__________________________________________________________

18. Do the guidelines need to include specific target ranges for BG ranges .....?

__________________________________________________________

19. Do you have any other comments?

__________________________________________________________

__________________________________________________________

THANK PARTICIPANT FOR THEIR TIME AND SUPPORT
Appendix F: FINAL VERSION Guidelines for managing diabetes at the end of life
Guidelines for
MANAGING DIABETES
AT THE END OF LIFE

Trisha Dunning
Peter Martin
Sally Savage
Nicole Duggan
Yeah, the patients shouldn’t have to worry about it… that’s the only thing I would say that it’s [diabetes] not given as high a priority probably as it should be.

You don’t want to go on with endless care… you’ve got to draw a line somewhere but I think I would like to feel comfortable but not be overactive with treatment and I feel that’s not done.

Comments people with diabetes receiving palliative care made during individual interviews conducted as part of the consumer consultation process as the Guidelines were developed.
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ACKNOWLEDGEMENTS

The research was funded by the Nurses Board of Victoria through the Ella Lowe Grant.

The research team gratefully acknowledges the important contribution of the patients with diabetes receiving palliative care services and their family members/carers who participated in the project, the health professionals who assisted with recruitment and completed the questionnaire, and the Advisory Committee for their expert advice. We thank Michelle Roberts for her graphic design work.
FOREWORD

The prevalence of diabetes is increasing and people with diabetes are living longer, however, they frequently have significant complications of diabetes and other comorbidities that affect their quality of life and require palliation. The focus of diabetes management in palliative care settings may need to change from tight metabolic control to prevent medium to long term diabetic and organ disease to managing symptoms, maximising quality of life and achieving a peaceful death.

Often health professionals believe monitoring blood glucose levels and continuing diabetes medicines, especially insulin, represents intrusive disease-modifying treatment. However, hypo- and hyperglycaemia produce unpleasant symptoms that affect comfort and quality of life and can exacerbate pain. The 'textbook' symptomatic presentations of these metabolic derangements may not be present or be hard to distinguish from symptoms due to another life threatening illness unless blood glucose monitoring occurs. Likewise, medicines, including insulin, may be required to control hyperglycaemia. Hyperglycaemia occurs as a result of medicines such as corticosteroids, commonly used in palliative care contexts, and physical stressors such as dehydration and pain as well as psychological stress and depression, and can lead to ketoacidosis or hyperosmolar states and unnecessary hospital admissions.

There is very little 'gold standard' evidence for managing diabetes at the end of life mainly because dying people are a very vulnerable group and recruitment is difficult. Thus, it was difficult to identify any Level I evidence to support the care suggested in the Guidelines. However, an expert interdisciplinary advisory group consisting of palliative care and diabetes clinicians reviewed the existing literature and provided expert comment during the development of the guidelines. In addition, people with diabetes at the end stages of life and their family members were interviewed. The majority indicated they preferred an individualised approach including monitoring their blood glucose and continuing their diabetes medicines including insulin to prevent excursions in blood glucose until they were actively dying and unconscious.

We are very grateful to these people for willingly and openly discussing such an emotive topic, at such a difficult time for the patients and their carers, and the valuable insights all the contributors provided. We commend the guidelines to you in their name and honouring the memories of those who are no longer with us.

Trisha Dunning

Peter Martin
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<td>Index</td>
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<td>Part 2, Diabetes Management</td>
<td>4</td>
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<td>Part 3, Managing Steroids</td>
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### LIST OF ABBREVIATIONS AND SYMBOLS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Increased</td>
<td></td>
</tr>
<tr>
<td>Decreased</td>
<td></td>
</tr>
<tr>
<td>≥</td>
<td>Equal to, or greater than</td>
</tr>
<tr>
<td>&gt;</td>
<td>Greater than</td>
</tr>
<tr>
<td>≤</td>
<td>Equal to, or less than</td>
</tr>
<tr>
<td>&lt;</td>
<td>Less than</td>
</tr>
<tr>
<td>ACD</td>
<td>Advanced Care Directive</td>
</tr>
<tr>
<td>AM</td>
<td>Morning</td>
</tr>
<tr>
<td>BG</td>
<td>Blood glucose</td>
</tr>
<tr>
<td>CAM</td>
<td>Complementary and alternative medicines</td>
</tr>
<tr>
<td>CCF</td>
<td>Congestive cardiac failure</td>
</tr>
<tr>
<td>DE</td>
<td>Diabetes Educator</td>
</tr>
<tr>
<td>DKA</td>
<td>Diabetic ketoacidosis</td>
</tr>
<tr>
<td>eGFR</td>
<td>Estimated Glomerular filtration rate</td>
</tr>
<tr>
<td>GI</td>
<td>Gastrointestinal symptoms</td>
</tr>
<tr>
<td>HONK</td>
<td>Hyperosmolar non-ketotic acidosis</td>
</tr>
<tr>
<td>Hypo</td>
<td>Hypoglycaemia</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive care unit</td>
</tr>
<tr>
<td>IGT</td>
<td>Impaired glucose tolerance/glucose intolerance</td>
</tr>
<tr>
<td>IM</td>
<td>Intramuscular</td>
</tr>
<tr>
<td>IRS</td>
<td>Insulin resistance</td>
</tr>
<tr>
<td>IV</td>
<td>Intravenous therapy</td>
</tr>
<tr>
<td>MI</td>
<td>Myocardial Infarction</td>
</tr>
<tr>
<td>OHA</td>
<td>Oral hypoglycaemic agents</td>
</tr>
<tr>
<td>mmol/L</td>
<td>Millimoles/litre – unit for measuring glucose in blood</td>
</tr>
<tr>
<td>PCOC</td>
<td>Palliative Care Outcomes Collaboration</td>
</tr>
<tr>
<td>PM</td>
<td>Afternoon</td>
</tr>
<tr>
<td>QUM</td>
<td>Quality use of medicines</td>
</tr>
<tr>
<td>SVC</td>
<td>Superior vena cava syndrome/obstruction</td>
</tr>
<tr>
<td>T1</td>
<td>Type 1 Diabetes Mellitus</td>
</tr>
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<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
</table>
Guidelines for managing diabetes at the end of life

The guidelines use the Palliative Care Outcomes Collaboration (PCOC) palliative care phases of stable, unstable, deteriorating and terminal.

**STABLE PHASE:** The person's symptoms are adequately controlled on their established management plan but interventions to maintain symptom control and quality of life have been planned.

**UNSTABLE PHASE:** The person develops a new unexpected problem or a rapid increase in the severity of existing problems.

**DETERIORATING PHASE:** The person's existing symptoms gradually worsen or they develop new but unexpected problems.

**TERMINAL PHASE:** Death is likely in a matter of days and no acute intervention is planned or required.

**HOW TO USE THESE GUIDELINES**

**PART 1**

Part 1 is a SCREENING PROCESS for all people when they are first referred to palliative care regardless of PCOC phase.

Use Part 1, Section A if they are known to have diabetes.

Use Part 1, Section B if their diabetes status is unknown.

**PART 2**

Part 2 is the recommended DIABETES MANAGEMENT at each PCOC phase.

Determine the PCOC phase of a palliative care patient and use the appropriate section.

Use Part 2, Section A for stable phase.

Use Part 2, Section B for unstable phase.

Use Part 2, Section C for deteriorating phase.

Use Part 2, Section D for terminal phase.

**PART 3**

Part 3 is recommendations for MANAGING STEROIDS and other diabetogenic medicines (as listed on Page 2 of the accompanying document) in palliative care patients. People requiring palliative care who are prescribed steroid medicines and some other medicines may develop diabetes.

Use Part 3, Section A for type 1 diabetes.

Use Part 3, Section B for type 2 or previously undiagnosed diabetes.
Screening process for all people when they are first referred to palliative care, regardless of PCOC* phase

**KNOWN TO HAVE DIABETES**

- Undertake a comprehensive assessment
- Assess presence of diabetes risk factors (refer to Part 1, Section B)
- Undertake a comprehensive medicine review
- Assess for occult infections

Is the person using diabetogenic medicines?
- Steroids
- Antipsychotics

Or using other medicines known to increase blood glucose?
- Thiazide diuretics
- Sympathomimetics
- Pentamidine
- Diltiazem/phenoxybenzamine
- Calcium channel blockers
- Enteral nutrition supplements e.g. GlucaMax

If the person is using diabetogenic medicines:
- Review need to continue diabetogenic medicines
- Adjust/commence oral hypoglycaemic agents (OHAs) or insulin to control hyperglycaemic symptoms and promote comfort
- Monitor according to Managing Steroid Guidelines (refer to Part 3, Section A/B) but individualise according to Advanced Care Directive and PCOC phase
- Provide education about steroids and diabetes
- Consider adrenal suppression and hypercalcaemia as complicating factors if steroids are needed in the long term
- Assess enteral feeds – may lack carbohydrate and therefore contribute to lethargy OR may be high calorie and contribute to hyperglycaemia
- Readjust OHAs/insulin doses if steroids are ceased and when weaning the dose to avoid hypoglycaemia

If the person is NOT using diabetogenic medicines:
- Provide usual diabetes management and education according to relevant diet and activity guidelines
- Adjust OHAs/insulin as appropriate
- Consider referring to:
  - Treating Specialist
  - Endocrinologist
  - Diabetes Educator
  - Dietitian
  - Dentist
  - Podiatrist

*Palliative Care Outcomes Collaboration (PCOC)
Guidelines for managing diabetes at the end of life

Screening process for all people when they are first referred to palliative care, regardless of PCOC* phase

**Diabetes Status Unknown**

- Undertake a comprehensive assessment
- Assess presence of diabetes risk factors
- Undertake a comprehensive medicine review
- Assess for occult infections

**Is the person using diabetogenic medicines AND has hyperglycaemia?**

- Provide education about steroids and diabetes
- Review need to continue diabetogenic medicines
- Monitor according to steroid medicine guidelines but individualise according to Advanced Care Directive and PCOC* phase
- Commence OHA/insulin+ to control hyperglycaemic symptoms and promote comfort
- Assess enteral fluids – may lack carbohydrate, which can contribute to lethargy OR may be high calorie and contribute to hyperglycaemia
- Consider adrenal suppression and hypercalcaemia as complicating factors if steroids are needed in the long term
- Adjust OHA/insulin if steroids are ceased and when weaning the dose to avoid hypoglycaemia

**Does the person have hyperglycaemia?**

- Commence diabetes management and education according to relevant diet and activity guidelines
- Commence OHA/insulin+ if appropriate
- Consider referring to:
  - Treating Specialist
  - Endocrinologist
  - Diabetes Educator
  - Dietitian
  - Dentist
  - Podiatrist

**Are three or more diabetes risk factors present?**

- Family history
- Ethnicity (e.g. Asian, Pacific Islander, Australian Aboriginal)
- Overweight, especially central obesity
- Over age 50
- History of gestational diabetes
- Schizophrenia
- Pancreatic cancer

AND/OR are hyperglycaemic symptoms present?

- Continue screening
- Monitor blood glucose levels especially fasting and towards the end of the day
- Monitor for hyperglycaemic symptoms

* (Palliative Care Outcomes Collaboration (PCOC)
** Random venous blood glucose > 11.1 mmol/l or fasting blood glucose > 7.0 mmol/l
* Oral hypoglycaemic agents/insulin
**Recommended diabetes management for Type 1 and Type 2 Diabetes**

**PCOC** PHASE: STABLE

**DIABETES APPROACH**
- Review/document diabetes management plan including medicines: insulins, oral hypoglycaemic agents (GHA)/incretins
- Document presence of diabetes-related symptoms (see Table 1 in accompanying document)
- Document diabetes short and long term complication status
- Ascertains self-care capacity and carer involvement and capacity
- Consult with GP, diabetes educator, endocrinologist
- Check continuing and planned treatments e.g. dialysis, chemotherapy, radiotherapy, surgery
- Review or commence Advanced Care Directive that includes diabetes management
- Provide information/discuss management with patients and family members/carers

**ASSESSMENT**
- Review medicines using Disability Use of Medicines (DUM) framework (see page 3 accompanying document)
- Ascertain whether patient is using complementary medicines and/or other therapies
- Caution with renally excreted medicines and eGFR < 60ml/min
- Assess presence of diabetes-related symptoms
- Assess diabetes complications:
  - Hypoglycaemia
  - Hyperglycaemia
  - Active infection
  - Long term
    - (1) Microvascular disease
      - Retinopathy
      - Nephropathy
    - (2) Macrovascular disease
      - Cardiovascular disease
      - Cerebrovascular disease
      - Intermittent claudication
    - (3) Neuropathy
      - Peripheral
      - Autonomic (responsible for gastroparesis and hypoglycaemia unawareness)

**MANAGEMENT**

**TYPE 1**
- Continue usual management
- Insulin regimen might need to be adjusted

**TYPE 2**
- Decide whether oral hypoglycaemic agents (OHAs) are still appropriate
- Simplify medicines regimen if possible
- Consider using insulin - may be required if altering/causing OHAs and/or to control symptoms

**NOTE:** For all PCOC phases when patient is on OHAs and Incrins
- Risk of hypoglycaemia is increased with sulphonylureas if renal or liver disease is present
- Metformin and alpha-glucosidase inhibitors can exacerbate gastrointestinal (GI) symptoms, nausea, vomiting, diarrhoea
- Metformin increases the risk of lactic acidosis and should be stopped temporarily if radio-contrast media are used in investigative procedures
- Incretin mimetics cause nausea, vomiting, weight loss and reduce appetite
- Be aware of relevant contraindications e.g. Thiazolidinediones (TZDs) e.g. oedema, congestive cardiac failure (CCF)
- Consider the side effects of medicines chosen e.g. Metformin (GI symptoms), opioids (opioid-induced bowel dysfunction, neurotoxic changes, masks hypoglycaemia)

*Information relates to patients with Type 1 or Type 2 Diabetes unless otherwise stated

**PCOC** Part-Time Care Outcomes Collaboration (PCOC)

© Copyright 2010
Recommended diabetes management for Type 1 and Type 2 Diabetes

**PCOC** PHASE: UNSTABLE

**DIABETES APPROACH**

- Review/document diabetes management plan including medicines: insulins, OHA/s, incretins
- Document presence of diabetes-related symptoms (see Table 1 in accompanying document)
- Document diabetes short and long term complication status
- Ascertain self-care capacity and carer involvement and capacity
- Consult with GP, diabetes educator, endocrinologist
- Check continuing and planned treatments e.g. dialysis, chemotherapy, radiotherapy, surgery
- Revise or commence Advanced Care Directive that includes diabetes management
- Provide information/discuss management with patients and family members/carers

**ASSESSMENT**

**Assess symptoms:**
- Pain
- Nausea/vomiting
- Oral intake/pathology
- Delirium
- Infection – occult or overt sepsis
- Depression/anxiety
- Acute dyspnoea
- Polyuria, oliguria, thirst
- Anorexia
- Cachexia
- Decreasing performance status

Consider diabetes as a cause of the symptoms
Consider the impact of the symptoms on diabetes
(See Table 1 in accompanying document)

** Decide whether symptoms represent a diabetes, oncology or other emergency **

**Initiate management strategies:**
- Monitor BG up to 4/day to determine whether symptoms are diabetes-related and/or contribute to the unstable state
- Blood glucose targets: Fasting 6-8 mmol/L, Postprandial 6-11 mmol/L
- Initiate or change medicines if indicated:
  - Increase or decrease dose
  - Alter dose interval
- Ensure emergency medicines are available
- Provide diabetes management contingency plans for patient and family/carer

**TYPE 1: Monitor blood ketones**
**TYPE 2: Consider introducing insulin**

**If an emergency:**
- Treat underlying cause
- Decide whether admission to hospital (and/or ICU depending on prognosis) is necessary
- Consider referring to endocrinologist
- Provide education if medicines change
- Manage comfort and support family
- Monitor response

**If not an emergency:**
- Manage comfort and support family
- Monitor diabetes status
- Consider initiating management strategies (see left)

*Information relates to patients with Type 1 or Type 2 Diabetes unless otherwise stated
**Palliative Care Outcomes Collaboration (PCOC)**
Managing Diabetes at the End of Life  Copyright 2010

Diabetes Management for Type 1 and Type 2 Diabetes

**PCDC** PHASE: DETERIORATING

- **DIABETES APPROACH**
  - Review/document diabetes management plan including medicines: insulins, OHAs/Incretins
  - Document presence of diabetes-related symptoms (see Table 1 in accompanying document)
  - Document diabetes short and long-term complication status
  - Ascertain self-care capacity and carer involvement and capacity
  - Consult with GP, diabetes educator, endocrinologist
  - Check continuing and planned treatments e.g. dialysis, chemotherapy, radiotherapy, surgery
  - Revise or commence Advanced Care Directive that includes diabetes management
  - Provide information/discuss management with patients and family members/caregivers

- **ASSESSMENT**
  - Consider in particular:
    - Anorexia
    - Cachexia
    - Decreasing performance status
  - Assess symptoms:
    - Pain
    - Nausea/vomiting
    - Oral intake
    - Oral pathology
    - Delirium
    - Infection — occult or overt sepsis
    - Depression/anxiety
    - Acute dyspnoea
    - Polyuria, oliguria, thirst
  - Consider diabetes as a cause of the symptoms
  - Consider the impact of the symptoms on diabetes
    (See Table 1 in accompanying document)
  - Decide whether symptoms represent a diabetes, oncology or other emergency

- **MANAGEMENT**
  - Re-evaluate diabetes management strategies
    **NOTE:**
    - BG and ketone monitoring is still useful to determine whether ketosis exists but may be less frequent (1-2/day)
    - New blood glucose targets < 10 mmol/L fasting
    - Ensure medicines are optimal for this phase — cease unless using to promote comfort
  - If an emergency:
    - Treat the underlying cause
    - Decide whether admission to hospital is necessary
    - Consider referring to endocrinologist
    - Manage comfort
    - Monitor response
  - If not an emergency:
    - Manage comfort
    - Consider initiating management strategies (see left)
    - Implement additional support/education for family/caregivers

*Information relates to patients with Type 1 or Type 2 Diabetes unless otherwise stated
**PCDC** (Palliative Care Outcomes Collaboration)
Recommended diabetes management for Type 1 and Type 2 Diabetes*

**DIABETES APPROACH**
- Review/document diabetes management including medicines: insulins, OHAs/incretins with a view to ceasing
- Note: Caregiver involvement may increase
- Communicate with GP, palliative care specialist team
- Implement Advanced Care Directive
- Consider implementing the Liverpool Care Pathway
- Provide information/discuss management with patients and family members/careers

**ASSESSMENT**
- Assess whether short-term diabetes complications need to be treated to achieve comfort
- Refer to Advanced Care Directive
- Identify caregiver/family bereavement risks
- Assess and manage to alleviate symptoms
  - Pain
  - Nausea/vomiting
  - Oral comfort
  - Delirium
  - Infection – occult or overt
  - Depression/anxiety
  - Acute dyspnea

**FOCUS OF DIABETES MANAGEMENT IS ON COMFORT**

**MANAGEMENT**

<table>
<thead>
<tr>
<th>Re-evaluate diabetes management strategies:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Consider patient and caregiver preferences for diabetes management</td>
</tr>
<tr>
<td>- Consider ceasing BG monitoring – check Advanced Care Directive and/or discuss with caregiver if patient has not given instructions to ensure monitoring is consistent with the patient’s wishes</td>
</tr>
<tr>
<td>- Decide whether care is provided in home/hospital care</td>
</tr>
</tbody>
</table>

*Information relates to patients with Type 1 or Type 2 Diabetes unless otherwise stated

**PCOC** **PHASE:** TERMINAL

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*Note: Medicines may not be appropriate except to achieve comfort. Rationalise medicines and stop any that are unnecessary*
Managing steroids and other diabetogenic medicines in palliative care patients

TYPE 1 DIABETES

DIABETES APPROACH

- Short course not causing symptoms or ketosis may not require regimen changes but effects on blood glucose often occur after 1-2 doses
- Courses > three days usually require regimen changes

NOTE:
- Long term steroid use can:
  - cause hypercalcaemia
  - suppress the hypothalamic-pituitary-adrenal axis
- Both states can complicate management but may not be relevant depending on the prognosis

ASSESSMENT

- Revise medicine regimen: if possible avoid other diabetogenic medicines or use lowest possible dose
- Conduct a collaborative team meeting with specialists – Palliative, diabetes educator, endocrinologist, and patient and family/caregivers
- Ascertain patient/carer education requirements – Appropriate medicine self-management (when, how, why, interactions, side effects)
  - BG testing
  - Increased risk of hypoglycaemia if hypoglycaemia unawareness is present especially when weaning or ceasing steroids

MANAGEMENT

- Increase insulin dose if BG > 10 mmol/L especially if ketones are present.
- Note: Patients in ICU or fasting may require an insulin infusion
- Use subcut insulin if eating
- Adjust prandial doses because the post prandial BG tends to increase.
- Consider the effect of the carbohydrate meal content on BG and the need to provide energy if patient is on enteral feeds

- Commence BG monitoring – consider increasing frequency while on diabetogenic medicines (e.g. 3-4/day)
- Revise diet and exercise routines but note food choices should not be limited if the person is cachectic or anorexic
- Monitor and record BG before meals and before bed
- Monitor blood ketones if BG >15 mmol/L
- Manage hyperglycaemia and hypoglycaemia
- An AM insulin dose may be needed because BG often peaks early PM and tends to fall overnight
- Revise patient and carer knowledge and provide education especially managing hyperglycaemia if managed at home
- Consider need for access to ‘on call’/after hours’ support
Managing steroids and other diabetogenic medicines in palliative care patients

TYPE 2 DIABETES or previously undiagnosed diabetes

**Diabetes Approach**

- Short course not causing symptoms or hyperosmolar non-ketotic acidosis (HONK) may not require regimen changes but effects on BG often occur after 1-2 doses
- People with Type 2 can develop ketoacidosis during significant illnesses
- Courses > three days usually require regimen changes

**NOTE:**
Long term steroid use can suppress the hypothalamic-pituitary-adrenal axis.
This can complicate management but may not be relevant depending on the prognosis

**Assessment**

- Revise medicine regimen: if possible avoid other diabetogenic medicines or use lowest possible dose for the shortest possible time
- Conduct a collaborative team meeting with specialists – Palliative, diabetes educator, endocrinologist and oncologist, and patient and family/carers
- Oral hypoglycaemic agents may need to be altered
- Consider commencing insulin if BG is consistently > 11 mmol/L

- Ascertain patient/carer education requirements – Appropriate medicine self-management (when, how, why, interactions, side effects); hypoglycaemia management
- BG testing
- Revise diet and exercise routines but note food choices should not be limited if the person is cachectic or anorexic
- Commence BG monitoring – consider increasing frequency while on diabetogenic medicines (e.g. 3-4/day or fasting and pre-prandial meals)

**Management**

- Consider insulin preparations
  - Prebreakfast long acting analogue such as lantus or protaphane OR
  - Premixed insulin before lunch e.g. mixard 30/70
- Note: Patients in ICU or fasting may require an insulin infusion
- Consider the effect of the carbohydrate meal content on BG and the need to provide energy if patient on enteral feeds

- Monitor and record BG before meals and before bed
- Manage hyperglycaemia and hypoglycaemia
- Revise patient and carer knowledge especially managing hyperglycaemia if managed at home
- Consider need for access to ‘on call/after hours’ support
BRIEF INFORMATION TO ACCOMPANY THE
Guidelines for managing diabetes at the end of life

OUTLINE OF DIABETES MANAGEMENT
In general diabetes management involves an appropriate diet and activity for both type 1 and type 2 diabetes even when medicines are needed. Managing diabetes involves:

- Lifestyle changes particularly for type 2 diabetes
- Medicines:
  - Type 1 diabetes – insulin
  - Type 2 diabetes oral hypoglycaemic agents and/or insulin
    Note: beta cell function declines over time and approximately 75% of people with type 2 diabetes need insulin
- Managing blood glucose, lipids and blood pressure
- Regular medicines review
- Regular monitoring by health professionals to identify and manage the short and long term complications of diabetes
- Diabetes education including educating significant others
- Self-care by the patient, support from family/carer

HYPERGLYCAEMIA AND HYPOGLYCAEMIA
Two conditions commonly associated with diabetes are hyperglycaemia, a symptom of diabetes, and hypoglycaemia, a side effect of oral hypoglycaemic agents, especially sulphonylureas and insulin.

Hyperglycaemia
Under usual circumstances, many people with type 2 diabetes do not experience the symptoms of hyperglycaemia until their blood glucose levels are extremely high. Common symptoms of hyperglycaemia include:

- Feeling excessively thirsty
- Feeling tired
- Infections e.g. thrush, cystitis, wound infections
- Weight loss in the longer term

Hypoglycaemia
Hypoglycaemia, also called a ‘hypo’, low blood glucose or insulin reaction, occurs when the blood glucose level falls below 3.5 mmol/L in people on DHA or insulin. Symptoms of hypoglycaemia vary from person-to-person, however, common feelings are:

- Weakness, trembling or shaking
- Light headedness
- Dizziness
- Tearful/crying
- Irritability
- Numbness around the lips and fingers

Hypoglycaemia unawareness may be present, especially in people with long-standing type 1 diabetes. This means they may not recognise the symptoms of hypoglycaemia. In addition, symptoms may be masked by analgesia, delirium and other cognitive changes and cancer-related autonomic neuropathy. Significantly, both people with diabetes and their family members/carers are often very fearful of hypos and their consequences.
CORTICOSTEROID MEDICINES

Corticosteroid medicines, more specifically the glucocorticoids (often referred to as steroids), are an essential part of the management of several disease processes such as haematological malignancies, inflammatory diseases, allergies and shock. However, long term use and high doses predisposes people to insulin resistance (IRS), glucose intolerance (IGT) and steroid-induced diabetes and causes hyperglycaemia and the resultant symptoms in people with diagnosed diabetes. IRS and IGT can occur within 48 hours of commencing steroids, especially in at risk individuals and those with diabetes. People should be informed they could develop diabetes when diabetogenic medicines are prescribed.

THE QUALITY USE OF MEDICATION FRAMEWORK

The Quality Use of Medicines (QUM) Framework (PHARM Committee, 2005) is the recommended Australian framework for making medicines-related decisions and was used to formulate these guidelines (see Figure 1, next page).

Factors to consider when determining diabetes medicine regimen for people with diabetes receiving palliative care – if medicines are indicated

- Insulin doses may need to be adjusted frequently.
- Patients on metformin who develop nausea and vomiting especially the elderly, those on diabetogenic medicines, and those with reduced renal function, liver, cardiac and respiratory disease, and people who are not eating may be at risk of lactic acidosis, a rare but serious adverse event. Therefore, metformin may not be the best choice.
- Insulin mimetics can induce weight loss and nausea and may be contraindicated.
- Thiazolidinediones (TZDs) contribute to weight gain due to fluid retention and may be contraindicated.
- Diuretics can exacerbate dehydration and increase blood glucose levels.
- Corticosteroids are antidiabetic and can reduce effectiveness of blood glucose-lowering medications.
- Hyperglycaemia usually increases blood glucose quickly. A second dose can induce nausea but may be ineffective in ameliorating hypoglycaemia. This means if oral glucagon is ineffective or contraindicated, IV dextrose may be required.
- Some oral nutrition supplements affect blood glucose levels, often leading to hypoglycaemia.
- The patient may be using complementary medicines (CAM) and other CAM therapies. If so, determine why the person is using CAM, what they are using, and whether CAM is inappropriate i.e. the benefits outweigh the risks and there is evidence for its use.
- CAM medicines may interact with conventional medicines. However, some non-medicine CAM therapies can relieve symptoms and may be safer than medicines.
- Opioids and other psychoactive medicines can mask hyperglycaemia.
FIGURE 1: Quality Use of Medicines Framework for managing diabetes at the end of life

**EARLY IDENTIFICATION OF DIABETES**

If the patient is on corticosteroids or diabetogenic medicines:
- Conduct diabetes risk assessment
- Review medicines, including complementary medicines
- Provide appropriate medicine and/or lifestyle advice
- Monitor—blood glucose, ketones
- Check for signs and symptoms of diabetes, increased blood glucose
- Oral health check

Diabetes present as existing diagnosis or develops during palliative care process

Refer all patients with diabetes to:
- Diabetes specialist
- Diabetes educator
- Dietitian
- Other health professionals as indicated

- Determine whether medicines are needed to manage diabetes
- Conduct a medicines review encompasses:
  - Type 1—Insulin
  - Type 2—GLP or insulin, depending on the physical assessment renal, liver, respiratory, and gastrointestinal factors that could affect medicine pharmacokinetics and pharmacodynamics.
  - For patients on diabetogenic medicines, consider whether they can be stopped or doses or dose intervals adjusted or an alternative formulation can be used.
- Consider the need for other medicines to manage other conditions including the indication for palliative care, which could be diabetes-related e.g. end-stage renal disease.

Is the patient taking any medicines to manage diabetes?

**YES**

- Consider self-care potential
- Determine whether oral route possible or another route is indicated, e.g. insulin infusion?
- Consider the complexity of regimen, is insulin simplest choice?
- Provide education including 'sick day care'
- Develop medicine management plan, a plan for monitoring outcomes and for stopping medicines when indicated, develop Advanced Care Directives (ACD)

**NO**

- Decide alternative management strategies relevant to PCOC phase
- Medicines may need to be ceased for patients in the terminal phase but may be needed to maintain comfort and control symptoms
- Consider Advanced Care Directives (ACD)
### PALLIATIVE CARE SYMPTOMS AND DIABETES

Sub-optimal symptom control can be due to the diabetes or the life-threatening primary illness or both. Distinguishing cause and effect can be difficult. Symptoms not caused by diabetes can have significant effects on diabetes management. Table 1 (next page) presents the relationships between common palliative care symptoms and diabetes.

#### Table 1: The relationship between common palliative care symptoms and diabetes

<table>
<thead>
<tr>
<th>COMMON PALLIATIVE CARE SYMPTOMS</th>
<th>IMPACT ON DIABETES MANAGEMENT</th>
<th>MAY BE DIABETES-RELATED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain (acute/chronic)</td>
<td>Increased:</td>
<td>- Peripheral vascular disease</td>
</tr>
<tr>
<td></td>
<td>- Somnolence or confusion/cognitive impairment due to pain/anaesthesia</td>
<td>- Amyotrophy</td>
</tr>
<tr>
<td></td>
<td>- Risk of hyperventilation</td>
<td>- Peripheral neuropathy</td>
</tr>
<tr>
<td></td>
<td>- Hypoglycaemia</td>
<td>- MI</td>
</tr>
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<td></td>
<td>Redced:</td>
<td>- Tissue glycosisation</td>
</tr>
<tr>
<td></td>
<td>- Intake</td>
<td>(e.g. carpal tunnel syndrome)</td>
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<tr>
<td></td>
<td>- Mobility</td>
<td>- Karacioclds (abdominal pain)</td>
</tr>
<tr>
<td></td>
<td>- Sleep</td>
<td>- Associated with diabetes especially hypoglycaemia</td>
</tr>
<tr>
<td></td>
<td>- Self-care ability</td>
<td>- Renal disease</td>
</tr>
<tr>
<td></td>
<td>- Quality of life</td>
<td>- Steroid medicines</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Hypoglycaemia symptoms can be mistaken for anxiety</td>
</tr>
<tr>
<td>Depression/anxiety</td>
<td>Increased:</td>
<td>- DKA, HONK may lead to dry mouth, thirst and clinical dehydration</td>
</tr>
<tr>
<td></td>
<td>- Fatigue</td>
<td>- Risk of dental caries and oral pathology</td>
</tr>
<tr>
<td></td>
<td>- Emotional change in performance status</td>
<td>- Risk of hypoglycaemia if on OHA's or Insuline</td>
</tr>
<tr>
<td></td>
<td>- Risk of DKA, HONK</td>
<td>- Hypoglycaemia if on DKA/HONK</td>
</tr>
<tr>
<td></td>
<td>- Social isolation</td>
<td>- May be due to gastric autonomic neuropathy</td>
</tr>
<tr>
<td>Oral Pathology (oral and maxillofacial pathology — WGO): Macoetha, slurs, dry mouth</td>
<td>Increased:</td>
<td>- Renal disease</td>
</tr>
<tr>
<td></td>
<td>- Pain</td>
<td>- Hyperglycaemia — DKA, HONK</td>
</tr>
<tr>
<td></td>
<td>- Dry mouth</td>
<td>- Medicines:</td>
</tr>
<tr>
<td></td>
<td>- Inadequate nutrition, inappropriate weight loss, cachexia</td>
<td>- Metformin</td>
</tr>
<tr>
<td></td>
<td>- Hypoglycaemia if on OHA/Insuline</td>
<td>- Byetta</td>
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<tr>
<td>Nausea/vertigo</td>
<td>Increased:</td>
<td>- Intake</td>
</tr>
<tr>
<td></td>
<td>- Constipation</td>
<td>- Energy, depleted energy stores</td>
</tr>
<tr>
<td></td>
<td>- Lethargy</td>
<td>- Disinterest</td>
</tr>
<tr>
<td></td>
<td>- Distress</td>
<td>- Palp/discomfort</td>
</tr>
<tr>
<td></td>
<td>- Inadequate nutrition — weight loss, cachexia, hypoglycaemia</td>
<td>- Hypoglycaemia — DKA, HONK</td>
</tr>
<tr>
<td></td>
<td>- Hypoglycaemia if on OHA/Insuline</td>
<td>- Dehydration and electrolyte imbalance</td>
</tr>
<tr>
<td></td>
<td>- Dehydration and electrolyte imbalance</td>
<td>- Risk of ketosids</td>
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<td></td>
<td>Redced:</td>
<td>- Intake</td>
</tr>
<tr>
<td></td>
<td>- Energy</td>
<td>- Energy, depleted energy stores</td>
</tr>
</tbody>
</table>

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Table 1 (continued): The relationship between common palliative care symptoms and diabetes

<table>
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<th>COMMON PALLIATIVE CARE SYMPTOMS</th>
<th>IMPACT ON DIABETES MANAGEMENT</th>
<th>MAY BE DIABETES-RELATED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delirium</td>
<td>Increased:</td>
<td>- May be due to many factors including hyper and hypoglycaemia</td>
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<td></td>
<td>- cognitive impairment</td>
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<td></td>
<td>Reduced:</td>
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<td></td>
<td>- reduced ability to communicate and detect signs/symptoms of hypo/hyperglycaemia</td>
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<td></td>
<td>- lower self-care ability</td>
<td></td>
</tr>
<tr>
<td>Sepsis</td>
<td>Increased:</td>
<td>- May be silent in diabetes (UTI, MI)</td>
</tr>
<tr>
<td></td>
<td>- confusion</td>
<td>- May precipitate DKA, HONK</td>
</tr>
<tr>
<td></td>
<td>- energy requirements</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- pain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- difficulty interpreting elevated white cell count, which could be caused by hyperglycaemia, sepsis, or other factors</td>
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<td>- bone marrow failure</td>
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<td></td>
<td>Reduced:</td>
<td></td>
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<tr>
<td></td>
<td>- intake increased DKA, HONK  risk</td>
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</tr>
<tr>
<td></td>
<td>- reduced quality of life</td>
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<tr>
<td></td>
<td>- reduced wound healing</td>
<td></td>
</tr>
<tr>
<td>Acute Dyspnoea</td>
<td>Increased:</td>
<td>- Tachypnoea may be due to DKA and resultant metabolic acidosis</td>
</tr>
<tr>
<td></td>
<td>- hypoxia contributing to confusion</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reduced:</td>
<td>- Kussmaul breathing in early stages of DKA could be mistaken for Cheyne-Stokes respiration</td>
</tr>
<tr>
<td></td>
<td>- self-management capacity</td>
<td>- Consider lactic acidosis if taking Methotrexate</td>
</tr>
<tr>
<td></td>
<td>Note: MI often silent in diabetes</td>
<td></td>
</tr>
<tr>
<td>Diabetes Emergencies</td>
<td>Examples:</td>
<td>- Hypoglycaemia</td>
</tr>
<tr>
<td></td>
<td>- Hypoglycaemia</td>
<td>- Hyperglycaemia</td>
</tr>
<tr>
<td></td>
<td>- Hypoglycaemia</td>
<td>- MI</td>
</tr>
<tr>
<td>Oncology Emergencies</td>
<td>Examples:</td>
<td>- Hypoglycaemia</td>
</tr>
<tr>
<td></td>
<td>- Spinal Cord Compression (glucocorticoids) and acute immobility</td>
<td>- DKA, HONK, Lactic acidosis</td>
</tr>
<tr>
<td></td>
<td>- SVC obstruction (acute dyspnoea and delirium) - high dose of glucocorticoids</td>
<td></td>
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<tr>
<td></td>
<td>- Febrile neutropenia</td>
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</tr>
<tr>
<td></td>
<td>- Major bronchial obstruction (hypoxia and use of glucocorticoids)</td>
<td></td>
</tr>
</tbody>
</table>
SUGGESTED READING

Palliative Care Resources


Diabetes Management Resources


End of Life Resources