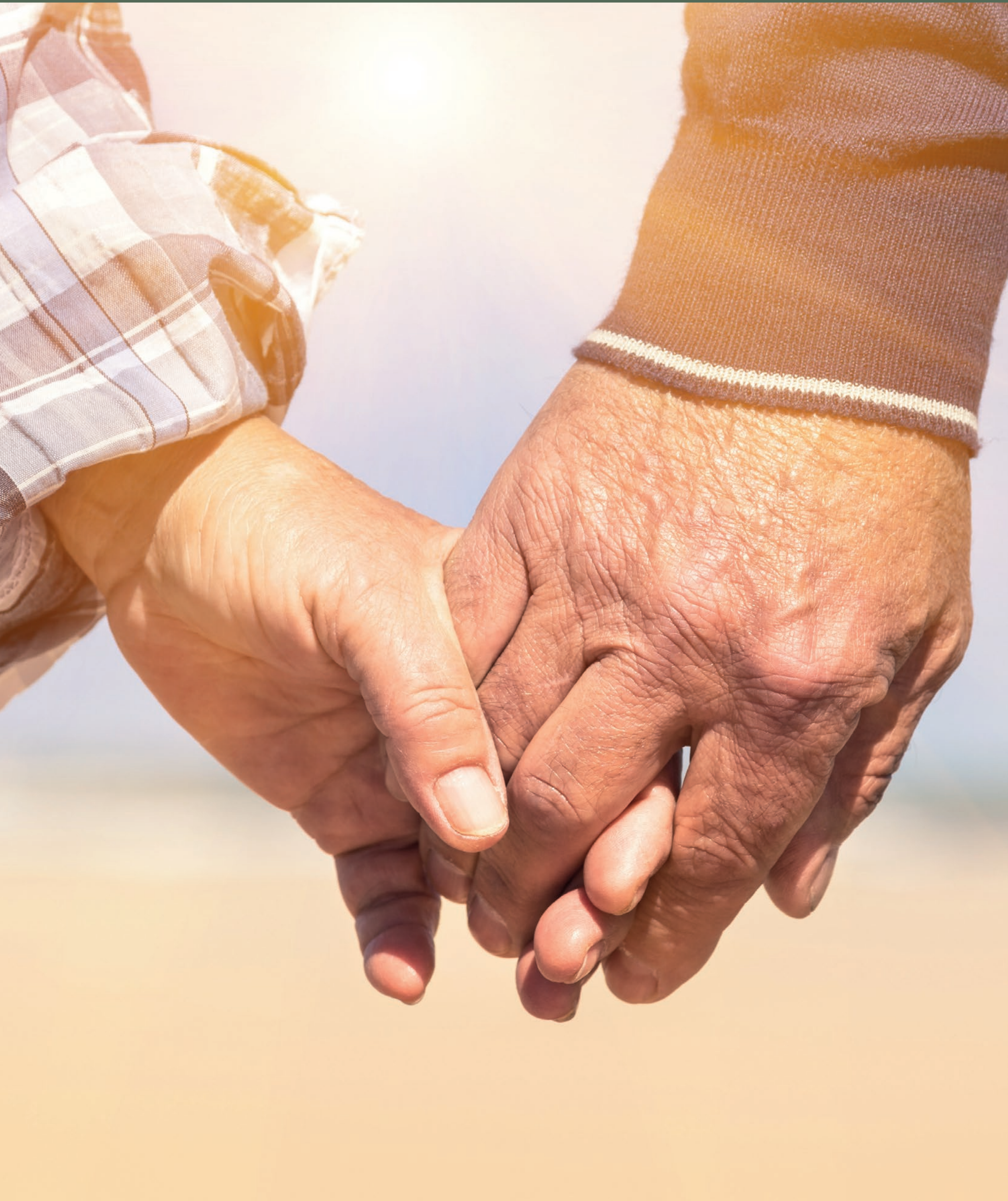
Planning palliative and end of life care with older people with diabetes: information for health professionals



> **[I see death]** ***as a happy deliverance, an inspiration towards happiness of the hereafter, rather than a painful passing away.***
>
> **(Orledge 1979) [1]**

Disclaimer

The suite of information about palliative and end of life care encompasses information for:

1. Older People with Diabetes.
2. Family Members Who Care for Older People with Diabetes.
3. Health Professionals Who Care for Older People with Diabetes.

The information was designed to be used with other relevant guidelines and policies for managing older people with diabetes receiving palliative and end of life care. The authors and Advisory Groups who developed the suite of information are not responsible for any actual care provided on the basis of the information and disclaim liability and responsibility to any person for the consequences of anything done or omitted by any person relying wholly or partially on the whole or part of the suite of information. It is essential that the information is used within relevant acts and regulations, local policies, guidelines, service structures and resources and within the Health Professional's level of knowledge and competence and their roles and scopes of practice.

Conflict of interest

The authors and members of the Advisory Groups have no conflict of interest to declare with respect to commercial enterprises, governments and non-government organisations. Diabetes Australia Research Trust Grant Program (DARP) funded the development of the suite of information. No fees were paid to the authors or the Advisory Groups in connection with the information except Sally Buchanan-Hagen who was employed through the DARP grant as research assistant.

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Copyright

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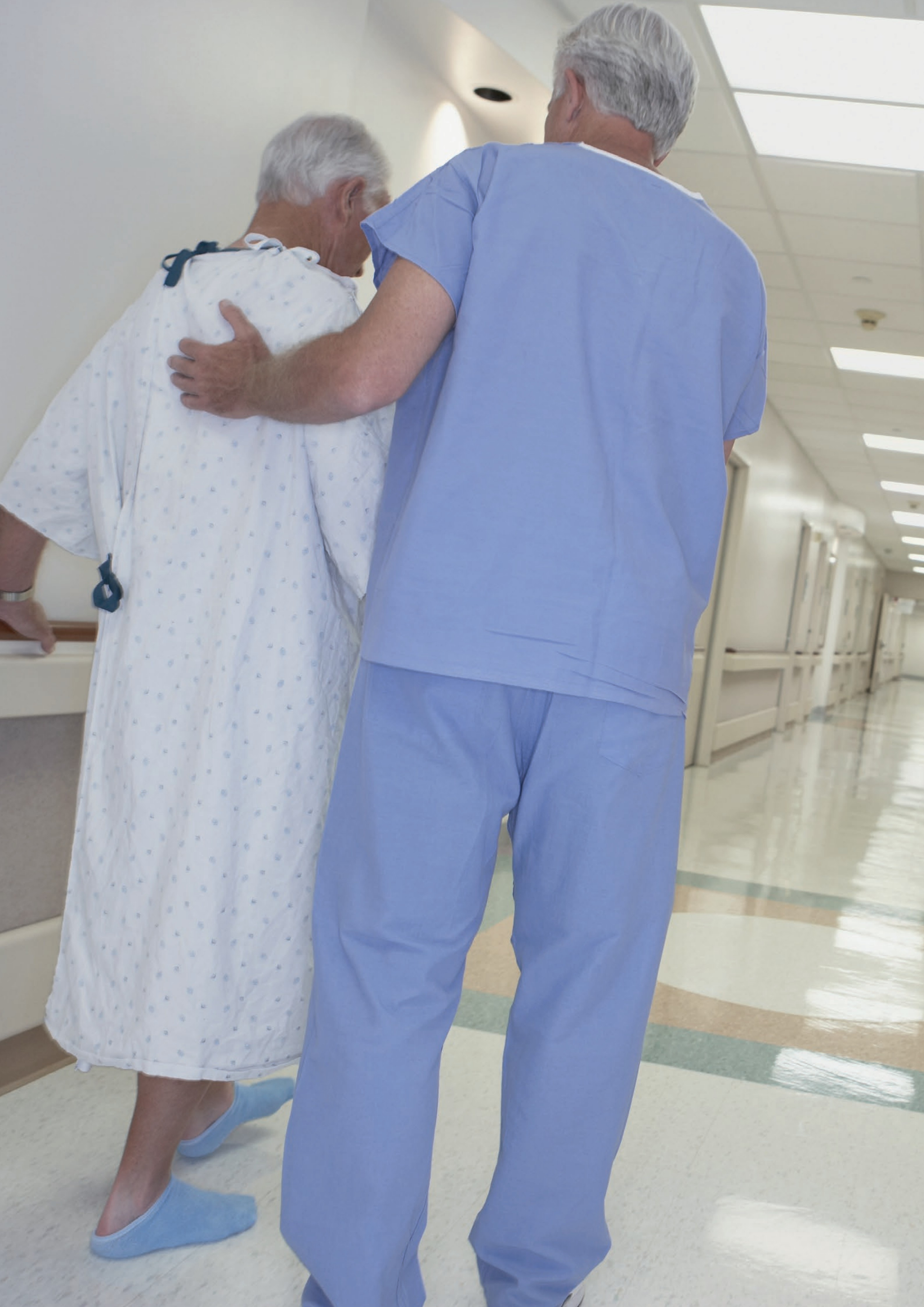


Introduction

Diabetes is the most common chronic disease associated with complications such as cardiovascular disease, renal disease, neuropathy, sensory changes, frailty, dementia and some forms of cancer. Multimorbidity is common. All of these comorbidities, independently and collectively, affect independence and quality of life and reduce life expectancy. Proactive planning for palliative and end of life care can improve outcomes for older people with diabetes and families and be rewarding for health professionals.

Most deaths in western society occur in hospital. Thus, many people's knowledge and experience of death comes from vicarious experience from the news, television and movies. Health professionals are more accustomed to witnessing death in hospitals, often in stressful circumstances. Thus, death has become a 'medicalised' state that needs to be prevented or 'cured' if possible. That is, death is no longer seen as a normal part of life; the public and many health professionals do not see 'normal death' often enough to witness and recognise its patterns [2].

The information in this book is part of a suite of information developed to help health professionals, older people with diabetes and their family members discuss palliative and end of life care in a proactive, timely manner.

Health professionals, older people with diabetes and their families share the responsibility for making decisions about care. Health professionals have specific responsibilities concerning medical decision making [3].

Care decisions become more difficult and stressful for everybody in life-threatening situations and emergencies. Planning ahead of time can help reduce such stress for everybody. Sometimes intensive treatment might not be beneficial. It might prolong life, but not necessarily the life the individual would choose.

It is important to acknowledge that many people, including health professionals, find it difficult to discuss end of life issues. Knowing the older person with diabetes's values, preferences and goals is very important when helping them make decisions about their care at any time, not just at end of life.

Every encounter with an older person with diabetes is an opportunity to discuss palliative and/or end of life care - try not to miss these precious opportunities.

Culture influences peoples' values, beliefs and social norms throughout life and shape their decision-making style and will influence the way they regard palliative and end of life care. Many religions believe in some form of existence after death, some believe in reincarnation, some believe death is unconscious sleep and some believe death is God's will/plan or that it is part of life [4, 5].

Deciding to start palliative care to improve comfort and quality of life depends on the likely benefits and risks of any treatment, the degree of pain and suffering, the stage of the illness and how long the person is likely to live (prognosis).

Prognostication is difficult. Usually the person does not want an accurate prediction. They want some idea of their life expectancy so they can complete 'unfinished business'. However, some indicators of shortened life expectancy that can help health professionals discuss life expectancy are described on pages 10 and 11.

Palliative and end of life care are important aspects of quality evidence-based care and are relevant to all standards but are particularly relevant to standard 5, the Comprehensive Care Standard in the 2nd edition of the National Safety and Quality Health Service Standards (2017) [6].

The National Framework for Advance Care Directives was endorsed by the Australian Health Ministers' Advisory Council in 2011 [7] and describes the objectives policies and practices health professionals and organisations should aim for. The Victorian Health Priorities Framework 2012-2022 guides advance care planning [8].

The guidance in this suite of information and the Guidelines for Managing Diabetes at the End of Life (2010) [9] (currently under review) were designed to help older people with diabetes and to help health professionals deliver quality palliative and end of life care for/with older people with diabetes and their families.

Other useful documents are listed under resources on page 18 and include:

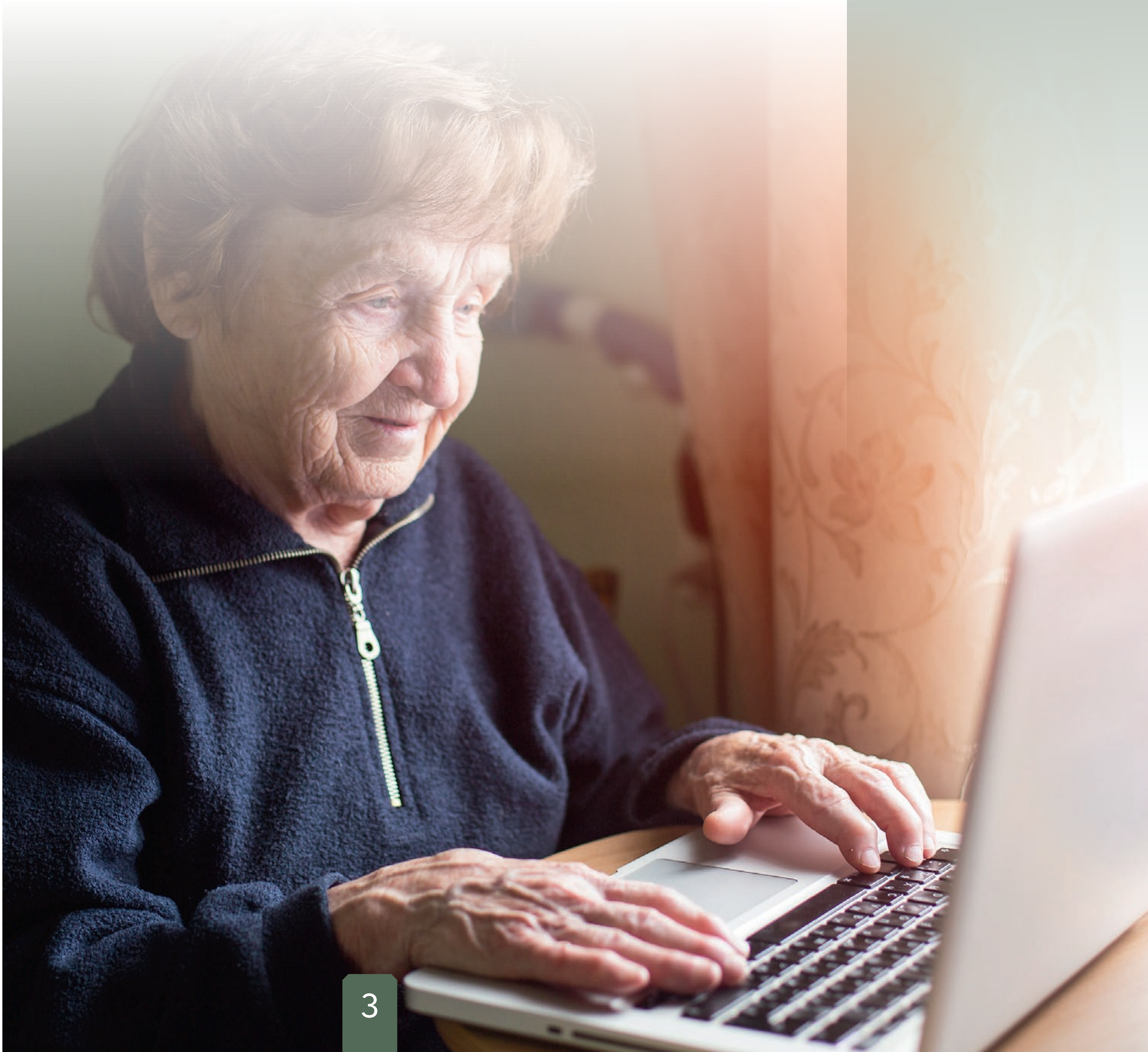
- *The Medical Treatment Act* 1988.
- *Guardianship and Administration Act* 1986.
- Charter of Human Rights and Responsibilities 2006.
- The Australian Commission on safety and Quality in Health Care National Safety and Quality Health Service (NSQHS) Standards 2nd Edition 2017, which are expected to be completely implemented by 2019 [6].

In addition, the new Victorian 'Assisted Dying' legislation will be introduced in 2019 [10]. Health professionals need to reflect on their personal feelings about the legislation and how they will respond to people with diabetes who request help to end their life.

Other states such as the ACT are beginning to explore whether assisted dying legislation has a place in their states.

It is essential to ask about, be respectful of and sensitive to the person's cultural and religious beliefs and ceremonies about death and dying.

It is important that health professionals acknowledge that their own religious and cultural beliefs and customs and experiences influence the way they view palliative and end of life care and death and their willingness to discuss these issues with older people with diabetes and their families.



What is Palliative care?

Palliative care is not only concerned with dying [13]. It refers to an approach that focuses on relieving pain and suffering and maintaining function and independence to achieve dignity and quality of life. It can be commenced at any time in the diabetes disease trajectory, including at diagnosis [1]. Palliative care no longer only refers to the terminal stage of life [3].

Why commence palliative care?

Implementing palliative care early can reduce pain and suffering, improve function and quality of life, and may increase life expectancy [3,9]. Palliative care has an important role in improving the dying experience for the individual, their families and health professionals. Likewise, it is an essential aspect of safe, quality care [6].

When could palliative care be implemented?

Palliative care can be implemented at any time, but consider the benefits of palliative care for people with diabetes aged 65 and older:

- At every consultation.
- During the Annual Cycle of Care.
- During 75-Year Health Checks.
- Before, during and after admission to hospital
- Before or soon after admission to a residential aged care facility (RACF).

People with diabetes and the following conditions or situations that are associated with increased risk of further morbidity and mortality could benefit from *early* palliative care and planning for their end of life:

- Multiple comorbidities including cardiovascular disease especially heart failure, renal disease and associated anæmia, liver and gastrointestinal problems [11, 12, 13].
- Polypharmacy [14].
- Long term high HbA1c, which is associated with complications and causes unpleasant symptoms
- Long duration of diabetes.
- Low HbA1c; the latter is associated with hypoglycæmia [15].
- Sarcopenia and frailty, and the associated nutrition deficits, weight loss, falls and mental and social consequences [14].
- Cancer [16] - some cancers are associated with diabetes, survival depends on the type of cancer and the stage of the disease.
- Cognitive changes or dementia [17]
- Falls.
- Frequent admissions to hospital or the Emergency Department (ED).
- Vascular disease of the lower limbs.
- Admission to an RACF.

What can health professionals do?

Be prepared to discuss palliative and end of life care at every consultation. Prepare for planned discussions by having all the relevant information to hand and ensure there is a private, quiet environment.

Consider whether the individual is able to provide informed consent.

Understand your responsibilities when helping older people with diabetes complete an Advance Care Directive (ACD) and the witnessing requirements, including understanding the difference between a Values Directive and Instructional Directive and the type of information included in each type of directive.

The following Victorian State Government website can be a useful guide when helping older people with diabetes develop an ACD: https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning.

Information to document in an ACD includes treatment the person wants to receive and treatment they do not want to receive.

Understand the importance of considering the individual's and their families' dignity. Dying has a personal effect on emotional, social, cultural and spiritual dignity. Dignity Therapy and life story/narratives are programs that can be used with palliative care and ACDs; to help individuals maintain self-respect, hope and a sense of control over their dying by learning to live in the moment [18,19] and reduce distress [20].

Consider holding a case conference to discuss the individual's health status and the benefits of palliative care with the individual, relevant carers and family members.

Other health professionals can be included in the case conference, provided the older person with diabetes is not 'outnumbered' or feels intimidated.

Prepare for the consultation by having all the relevant information available, preparing the individual and their family and creating a welcoming, respectful, private environment. People like to feel the consultation is for them and about them.

Undertake regular comprehensive assessments that encompass changing life expectancy and/or refer the individual for a geriatric and/or palliative care assessment.

Consider spirituality, which is a key aspect of dignity and personhood. It is one of the six domains of quality and supportive care [21,22].

Undertake a medicines review and stop any unnecessary medicines and medicines that are contraindicated or unlikely to benefit the person in their remaining lifetime. Refer to the Beers Criteria [23], STOP/START Guidance [24] and/or Rowett et al. [25].

You do not have to be old or a patient to develop an ACD.

Health professionals could consider their own values, preferences and goals and document an Advance Care Directive for themselves.

It is important to ask about complementary medicines and therapies (CM) as part of the review [26]. Some CM can be beneficial, e.g. meditation, Cognitive Behaviour Therapy (CBT), Tai Chi and music, and can improve quality of life and reduce the medicine burden.

It is important to assess family carer's health, wellbeing and their care burden. The Needs Assessment Tool for Carers (NAT-C Caring for You) can be helpful [27]. However, astute observation and sensitive questions can be just as valuable and probably more likely to achieve personalised care.

Undertake relevant risk assessments to help decide care, for example, falls, hypoglycaemia, pain, medicine adverse event, admission to hospital, and assess functional and self-care capacity.

Decide blood glucose, HbA1c and blood pressure ranges and other care goals with the individual considering their safety, values, goals, care preferences and their life expectancy. Personalised care might involve changing the focus on 'tight blood glucose control' to blood glucose target ranges that focus on safety, comfort and quality of life.

A safe blood glucose range for comfort and quality of life is generally between 6-11 mmol and HbA1c 7% - 8% [9,13].

Manage hyperglycaemia because it produces uncomfortable symptoms and affects cognition, problem-identification and decision-making and contributes to electrolyte dysfunction, dehydration and delirium. If the person cannot swallow oral glucose lowering medicines or they are contraindicated, a daily dose of long acting insulin can be used to manage hyperglycaemia and its consequences, in which case it has a palliative role managing unpleasant symptoms.

Health Professionals need to be able to educate family and other carers about how to recognise and act on signs of deterioration. Significantly, symptoms of heart attack, hypoglycaemia and infections are often atypical. Thus, people need relevant information about how to recognise these emergencies and what to do if they occur. Such information could be included in or replace their 'Sick Day' Care Plan.

Advance Care Directives

An Advance Care Directive has three parts:

The person's personal details.

Values directive

A part for the person to write their values, care preferences and goals to help family members make decisions for the person if they are unable to decide for themselves.

Instructional directive

A part where the person writes down what treatment they want or do not want so health professionals understand the person's preferences.

See https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning [28].

An Advance Care Directive is a legal document and must be signed and witnessed. It is essential to consider cultural and religious beliefs about death and dying and be sensitive to these issue.

Advance care directives can help Health Professionals and families make best interest decisions for the older person with diabetes when they do not have the capacity to decide for themselves.

Initiate conversations by asking 'good' questions

Ask 'good' questions to clarify older people with diabetes' values, goals and preferences to support dignity at end of life. Offering reassurance might not be helpful. It is more helpful to encourage people to express their fears and concerns.

Be quiet and listen to the answer.

Recognise and respond to verbal, non-verbal and emotional cues during discussion but check your assumptions.

Some questions include the following but they should not be used as a 'tick box' list and they must be personalised:

- What do I need to know about you to help me give you the best possible care?
- What things make your life worth living/matter to you? (Rather than using the term 'quality of life').
- What does 'suffering' mean to you?
- What does a 'good death' mean to you?
- What does a 'dignified death' mean to you?
- Follow up with relevant probing and clarifying questions but do not interrupt the person while they are thinking or talking.

Encourage the individual to document an ACD and other relevant documents such as a will, nominate a medical decision-maker to make decisions when they are unable to decide for themselves, and various types of powers of attorney such as a financial power of attorney.

Consider referring the individual to an Advance Care Planning program where experts can help them think through and document their values, goals and care preferences.

Ask the person about their preferred place to receive palliative care and to die. For example, at home, in hospital or in an RACF.

Discuss the implications for family members if the individual elects to stay at home such as the emotional effects of watching them suffer, the physical effects of providing care such as heavy lifting that might be required and religious needs. For example some religions require the environment to be cleansed after death [29].

If the person wants to die at home refer them and their family to other relevant health professionals such as community palliative care, their GP and/or programs such as dignity therapy program and life narratives.

Document the discussion in the relevant medical records and communicate it to other relevant care providers, the individual and their family.

Most older people have reduced capacity to make decisions for a while before they die. It is important to give people time to develop an Advance Care Directive: initiating conversations early can allow them time to think about their values and care preferences.

Remind the individual/family that they should keep a copy of their signed, dated and witnessed ACD and give copies to their doctor, medical decision-maker, paramedic service and/or place in their electronic medical record, especially when travelling interstate and overseas. Australian states and territories often have different regulations and laws.

Be aware that older people with chronic diseases who are depressed may have suicidal thoughts. Older people who think about suicide may not share their intentions in advance [30]. Statements such as ‘put me out of my misery’ and talking about wanting to die could be a warning sign and should be taken seriously and explored with the individual and/or their family.

The ACD does not have to be completed all at once. The content of the discussion can be tailored to their stage of life and disease trajectory.

Give the individual a copy of the Palliative and End of Life Care Information for Older people with Diabetes and/or the Information for Family Members.

Allow the person time to consider the information and their values and life and care goals and to discuss issues with relevant others.

That is:

- Begin a conversation.
- Follow up at an appropriate time.
- Initiate the Advance Care Directive when relevant.

If the health professional does not feel confident to develop an ACD with the individual and/or their family refer them to an Advance Care Planning Program in their area.

Having a conversation about end of life care is an important gift you can give to the individual and their family.

What is end of life care?

End of life care refers to care of people likely to die in the following 12 months [31,32]. End of life care is often divided into five related but non-sequential phases:

1. Stable.
2. Unstable.
3. Deteriorating.
4. Terminal, when death is imminent.
5. Bereavement [31].

When could end of life care be implemented?

It is difficult to predict when a person will die. Although, people often ‘know’ when they are approaching the end of their life.

Some signs the person could be entering the last stage of life include:

- Answering ‘no’ to the ‘surprise question’: Would I be surprised if this person died in the next few months?
- Answering ‘no’ indicates it is time to plan for their palliative and/or end of life care. If the answer is ‘yes’ there is more time to plan end of life care with the person [32].
- If the person has an ACD make sure it still meets their values, goals and care preferences and was communicated to relevant people. If not, help them make a new ACD and destroy ALL copies of the existing ACD.

Some general indicators of declining life expectancy are described in the GSF [32]. Others include:

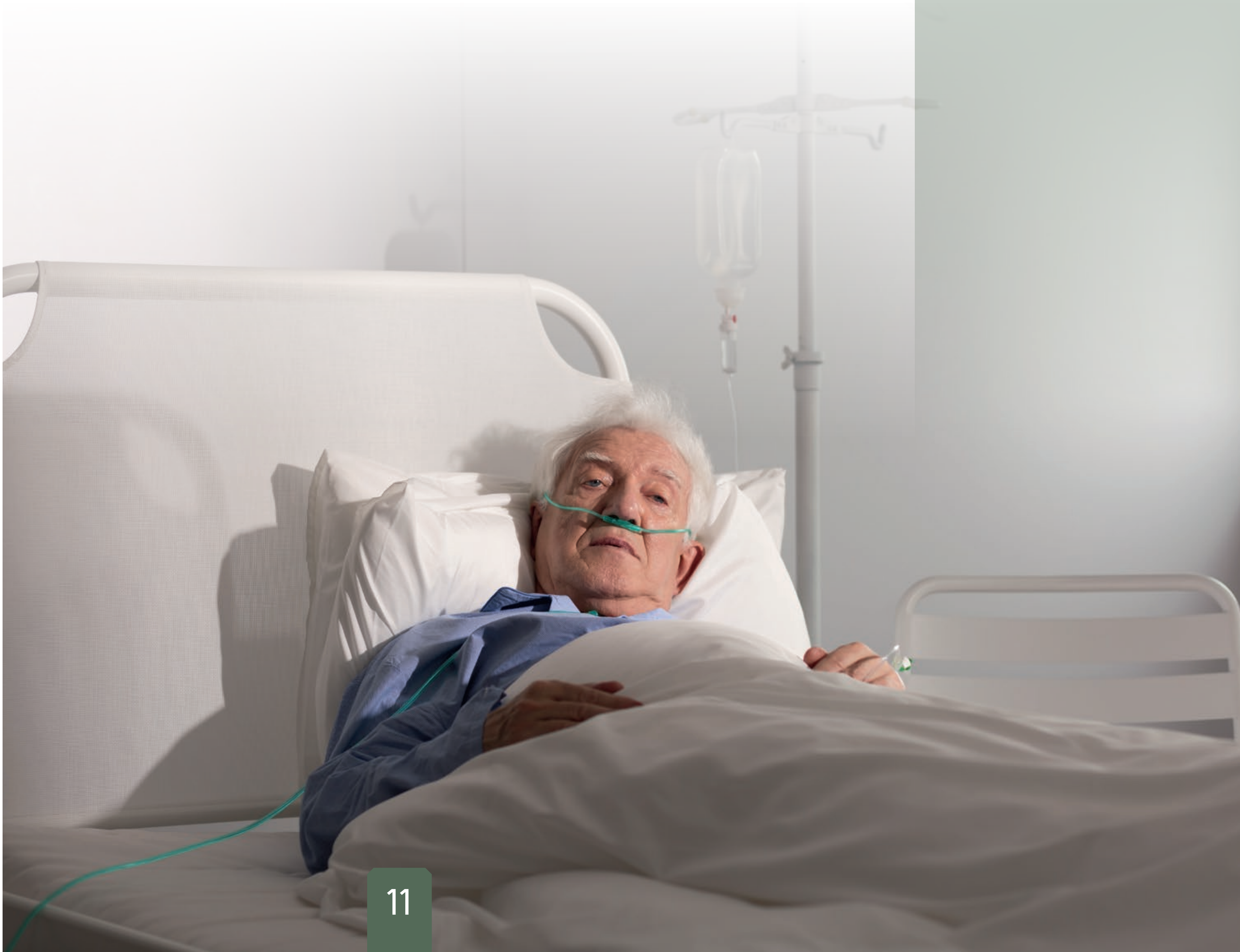
- Increasing frailty for example slow walking speed and malnutrition. [33,34]
- Several unplanned ED visits or hospital admissions.
- Several comorbidities [11,35].
- Advanced renal and cardiovascular disease [12, 32].
- The person has lost the will to live, especially if they wish to live <5 years [36].
- Self-reported health. It is more useful to ask about future health expectations than current health status e.g. in the next 5–10 years [37].

Diabetes-related signs and symptoms of reducing life expectancy

Reduced life expectancy is associated with both low and high HbA1c and with a rapid reduction in HbA1c [38].

One or more of the following:

- Long-standing hyperglycæmia, HbA1c consistently > 7.5% [9,11,13].
- Low HbA1c and hypoglycæmic unawareness [15,38,39].
- Hypotension: postural hypotension increases the risk of falls [42].
- Lower limb and foot disease [12,41.42].
- Duration of diabetes >10-15 years [43].
- Comorbid load [41].
- Presence of common comorbidities such as cardiovascular disease, renal disease and dementia. [32]
- Polypharmacy [14].
- Frailty and associated weight loss and falls risk and can be present in overweight older people. [13, 44].



What can health professionals do?

Know and regularly assess the older people you care for to identify indicators of changing function and life expectancy such as:

- Declining functional performance e.g. Barthel index, Karnofsky Score, Timed Get up and Go test, Fried Frailty Scale, Rockwood Clinical Frailty Scale [13,45].
- Difficulty undertaking activities of daily living (ADLs) and diabetes self-care.
- Increasing complex symptoms, care burden and advanced disease such as New York Health Association Classification of Heart Failure stages 3 or 4, metastatic cancer, foot ulcers.
- Sentinel event such as a serious fall.
- Severe hyperglycaemia leading to diabetic ketoacidosis (DKA) or hyperosmolar hyperglycaemic state (HHS). These states are often preventable and/or treatable using an appropriate blood glucose, ketone and symptom monitoring program. They are often due to sepsis.
- Several unplanned admissions and readmissions to hospital or ED.
- Progressive weight loss >10% in the past 6 months after assessing for treatable causes such as undiagnosed cancer and thyroid disease [32].
- ≥ 5% weight loss in people with sarcopenia [44].
- Serum albumen < 25g/L [46].
- Increasing polypharmacy [14].
- Self-rated health, will to live and quality of life e.g. Functional Assessment of Chronic Illness Therapy (FACIT) [37, 47].

Discuss the changing health status with the individual, their family and other carers.

- Develop an ACD if the individual does not have one OR check that their existing ACD is still consistent with the individual's goals, values and preferences. Make sure the ACD is signed and witnessed. If a new ACD is made ALL copies of the old ACD must be destroyed.
- Make sure relevant documentation such as the individual's ACD accompanies them during care transitions.
- Consider different dose forms of necessary medicines if the individual has dysphagia.
- Discuss and inform relatives about how to recognise and manage deterioration; even an expected death can be a shock and distressing [48].
- Consider family carer's health. The death of a partner increases the risk of an acute cardiovascular event or infection in the subsequent weeks in surviving partners [49].
- Ensure family members have access to health care advice and counselling and are followed up after a bereavement.

Terminal care

Terminal care refers to care in last few days or hours of life.

What can health professionals do?

Discuss the individual's care with their medical treatment decision maker.

Implement the individual's end of life care plan.

Ensure pain and distressing symptoms are managed according to their ACD.

Support family and relatives.

Arrange for care of the body after death and inform relevant people/organisations considering religious and cultural customs, need for coronial enquiry and write a death certificate.

Care for the family during the palliative process and after death

Family carers make a substantial unpaid contribution to care [48], especially caring for older people with diabetes. Many carers are old themselves and have chronic disease or other health conditions. They often neglect their own health care to care for family and friends.

Caring is often associated with considerable burden and distress and reduced quality of life. Carer age and stress predicts admission of the care recipient to an RACF [47]. Older carers might be particularly vulnerable to myocardial infarction and infections after the death of a family member [40].

Ask the carer about their wellbeing at every opportunity.

As indicated, wellbeing can be assessed using the NAT-C [27]. The NAT-C can be self-completed and discussed with doctors and other health professionals.

However, asking the person in a caring, sensitive manner and observing their mental and physical signs can be just as effective and caring and does not involve 'ticking boxes'.

Refer the individual for bereavement counselling if needed.

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Resources

Advanced Care Planning Australia, www.advancecareplanning.org.au.

Advance Care Planning: Have the conversation. A Strategy for Victorian Health Services 2014-2018 (2014), www.health.vic.gov.au/acp

Cancer Council Australia, www.cancer.org.au

CareSearch, Pallative Care Knowledge Network, www.caresearch.com.au.

CareSearch, Respecting Patient Choices, www.caresearch.com.au/caresearch/tabid/92/Default.aspx. (now referred to as Advance Care Planning)

Clayton J, Hancock K, Butow P, Tattersal M, Currow D. (2007) Clinical Practice Guidelines for Communicating Prognosis and End-of-Life Issues with Adults in the Advanced Stages of Life-limiting Illness and Their Caregivers. Medical Journal of Australia 186 (12) Supplement 16th June.

Death over Dinner Australia www.deathoverdinner.org.au/

Dignity in Care, Dignity Toolkit, http://dignityincare.ca/en/toolkit.html

Heart Foundation, www.heartfoundation.org.au

Kidney Health Australia, www.kidney.org.au

National Prescribing Service (NPS) (2009) Achieving Quality Use of Medicines in the Community for Palliative and End of Life care: a Consultation Report. NPS, Sydney

Office of the Public Advocate, www.publicadvocate.vic.gov.au/

Palliative Care Australia, www.palliativecare.org.au

Royal Australian College of General Practitioners (RACGP), www.racgp.org.au.

WHO Europe (2004) Better Palliative Care for Older People, Copenhagen Denmark.

Worldwide Palliative Care Alliance and World Health Organisation (2014). Global Atlas of Palliative Care at the End of Life, www.THEWPCA.org.

Recommended Reading

Health professionals must be able understand older individuals with diabetes to develop relationships with them and deliver personalised care. Reading literary fiction helps health professionals develop Theory of Mind (TOM). TOM refers to attributes that enable humans to reason about other people's thoughts and actions. TOM encompasses a collection of attributes such as empathy [50].

Health professionals who have a well-developed TOM are better able to manage complex social relationships with a diverse range of people and to identify their own and other people's emotions [51,52]. A well-developed TOM is essential to palliative and end of life care.

These books can help health professionals reflect on the experiences described and help ask them 'good questions'. They are presented in alphabetical order, not the order of the 'best read.'

Abikawa H. (2017), *The Travelling Cat Chronicles,*
Transworld Publishers, London.

Bailey E.T. (2010) *The Sound of a Wild Snail Eating,*
Algonquin Books.

Bauby J.D. (1998) *The Diving Bell and the Butterfly: A Memoir of Life in Death,*
Vintage Books, New York.

Benwell S. (2015) *When the Last Leaf Falls* Definitions, UK.

Cameron, B. (2016) *A Dog's Purpose,* Pan Macmillan Australia, Melbourne.

Chochinov, M. (2011) *Dignity Therapy: Final Words for Final Days,*
Oxford University Press, Oxford.

Corke c. (2018) *Letting Go: How to Plan a good death.* Scribe, Melbourne.

Dosa D. (2010) *Making the Rounds with Oscar*
Headline Publishing Group, London.

Gawande A. (2014) *Being Mortal: Illness, Medicine and What Matters in the End.*
Welcome Collection, London.

Genova L.(2009) *Still Alice* Simon & Schuster, London.

Jong E. (2015) *Fear of Dying.* Cannongate, Edinburgh.

Kalanithi P. (2016) *When Bread Becomes Air* Bodley Head, London.

Kaminsky L. (2015) *The Waiting Room* Vintage Books, Sydney.

Lazarus, J. (2016) *Listen Like a Dog,* HCI Books,

Mannix K. (2017) *With the End in Mind: Dying,*
Death and wisdom in an Age of Denial. Williams Collins, London