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# Diabetes, Palliative and End-of-Life Care

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## Abstract

This chapter provides a brief overview of diabetes prevalence, the associated complications, diabetes-related mortality and management strategies to set the context for discussing palliative and end-of-life care. This chapter highlights: (1) The increasing global focus on palliative and end-of-life care; (2) The relationship among health trajectories, function and palliative and end-of-life care; (3) The imperative to plan care with the individual to achieve personalised care that meets the individual's goals, preferences, values and spiritual needs across the various health trajectories; (4) The need to proactively plan for the transition to palliative and end-of-life care when appropriate and while the individual can make informed decisions. Proactively planning for changing care needs is more likely to achieve care consistent with the individual's goals, values and preferences; (5) The key role of family carers and the effect of caring on carers' health; (6) The importance of having timely, meaningful conversations about palliative and end-of-life care with people with diabetes and their families; and (7) The imperative to ameliorate suffering, optimise quality of life and personalising care.

**Keywords:** diabetes, health trajectories, palliative, end-of-life, communication

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## 1. Introduction

### 1.1. Diabetes: a significant issue also in palliative care setting

Chronic diseases are the leading cause of death globally [1]. Diabetes is the most prevalent chronic disease affecting 422 million people worldwide [2]. Diabetes is linked to 3.7 million deaths per year [2] and is often associated with other chronic diseases, especially hypertension, cardiovascular disease and renal disease, as well as some forms of cancer. Globally, one person with diabetes dies every six seconds [3].

Most chronic disease-related deaths occur in older age and are associated with potentially remediable physical, emotional and spiritual suffering [4]. Relief from suffering is more likely to be achieved if palliative care is initiated early [5]. In addition, early initiation of palliative care leads to cost savings [4]. Significantly, outcomes for people who receive early palliative care are better than those who receive 'usual' care [6]. Consequently, the management of diabetes and its complications is a significant issue to be addressed early in the course of the disease and also in palliative care settings.

People with diabetes are living longer; but diabetes is associated with 8–11% lower 5–10 years survival rates [7]. However, older people with diabetes are a heterogeneous population and there are different types of risks within the population. Several interrelated factors affect survival: duration of diabetes >12 years, poor glycaemic control, multiple comorbidities (comorbid load), especially cardiovascular disease and heart failure, end stage renal failure, advanced foot disease and frailty.

Polypharmacy confers an increased mortality risk for people with diabetes through the interactions among medicines and individual medicine side effects. For example, thiazolidinedione glucose lowering medicines are linked to heart failure and other cardiovascular mortality [8]. Insulin and sulphonylureas are linked to adverse outcomes in older people with diabetes and mortality [9, 10]. Currie et al. [9] described mortality hazard between 10 and 34% for these medicines in combination with metformin and even higher levels when they were used as monotherapy. Glycaemic control is important with good control, HbA1c, <7% (53 mmol/mol) conferring benefits. However, hypoglycaemia is associated with risk of cardiac changes and death, especially in older people and can occur when HbA1c is high as well as low [11].

These risks highlight the importance of identifying and managing the factors that affect mortality as early as possible in the health trajectory, see Section 6. Individually and collectively, they are associated with increased costs, unnecessary interventions, including in the late stages of life, and consequent physical and mental suffering for people with diabetes and families. They also need to be considered and managed in palliative care settings.

## 2. Managing diabetes

Diabetes management requires interdisciplinary team care. Collaborative, respectful interdisciplinary care predicated on effective communication is essential when palliative and end-of-life care is indicated. Diabetes education is regarded as the cornerstone of management and is essential to enable the individual to undertake self-care such as blood glucose monitoring, managing medicines and attending health professional appointments to achieve good outcomes. Education about palliative care options and planning for end-of-life care are not currently regarded as core aspects of diabetes education. However, these issues should be discussed as the person's health and functional status (trajectory) changes.

Eating a healthy diet, regular physical activity/exercise and managing stress (lifestyle factors) are key management strategies for all types of diabetes and for people of all ages, including

when glucose lowering medicines (GLM) and other medicines are required [12]. Healthy active lifestyle also helps protect telomeres and overall health [13].

The broad aim of diabetes management is to keep the blood glucose and HbA1c (an indicator of the average blood glucose level over 3 months) as close to the normal range as possible to prevent or manage long-term diabetes complications. Such complications are associated with reduced life expectancy. However, the blood glucose and HbA1c range must be safe for the individual depending on their functional category, disease trajectory and life expectancy [12, 15].

The risk of severe hypoglycaemia increases, if HbA1c and blood glucose ranges are near or lower than normal in people with multiple comorbidities, longer duration of diabetes and those on insulin/sulphonylureas [11]. Hypoglycaemia is associated with other risks such as falls. Hyperglycaemia can also contribute to falls cognitive changes and delirium. Example HbA1c and blood glucose ranges are as follows:

### 2.1. HbA1c

- In healthy people with short duration of diabetes, no cardiovascular disease, and no severe hypoglycaemia, the HbA1c range is 6.5–7.0% (48–53 mmol/mol). The focus is on preventing complications [3, 14, 15].
- In frail older people with complication's and comorbidities, limited life expectancy and those at the end-of-life, the HbA1c range is 8–8.5% (64–69 mmol/mol). The focus is on managing existing complications to promote safety (palliative approach) [3, 14, 15].

### 2.2. Blood glucose

- Healthy people with type 2 diabetes (T2DM): fasting 6–8, postprandial 6–10 mmol/L [15].
- Frail older people, those with dementia and those with high hypoglycaemia risk on GLMs 6–11 mmol/L [15].

Thus, the management focus and the metabolic parameters used to determine the effectiveness of management strategies often need to change as function and the health trajectory change [16, 17]. Palliative care is a valuable care option, however, many people who would benefit from palliative care to manage symptoms and reduce suffering are not offered such care because health professionals underestimate the problem and are often reluctant to discuss the issue or to give 'bad news' [17]. People with life limiting illnesses should not be excluded from potentially beneficial treatment.

Palliative care can be used for seriously ill surgical patients, and preoperative screening for frailty can reduce 180 days mortality [18]. Likewise, a systematic review of 25 paper involving 8575 patients and 22 different interventions suggests preoperative decision-making concerning palliative care can improve communication, symptom management and reduce use of health care resources and costs [19]. More research is required to substantiate these findings due to methodological flaws and differences and small sample sizes in many of the papers included in the review.

### 3. Glucose lowering medicines

The main types of GLMs are shown in **Table 1**.

Medicines, including GLMs, play a key role in diabetes management in all health trajectories. Medicines confer significant benefits, but they are also associated with adverse events, including in palliative care settings. Ageing and diabetes-related pathophysiological changes and their subsequent risks significantly affect medicine safety and medicine choices and increase the risk of medicine-related adverse events [20]. As people with diabetes grow older, or develop dementia, they have difficulty managing their medicines and rely on other people to help them manage their medicines and other diabetes self-care and activities of daily living. Difficulty managing medicines is one reason for admission to a care home [20].

Key changes that affect medicine action, effectiveness and safety include:

- cardiovascular changes, which affect medicines distribution
- liver changes, which affects medicine metabolism
- renal disease, which affects excretion
- gastrointestinal changes that affect absorption of oral medicines
- changes in the counter-regulatory response to hypoglycaemia due to reduced production of glucagon and autonomic neuropathy, which cause hypoglycaemic unawareness
- cognitive and sensory changes, which affects independence and medicine adherence.

Polypharmacy is common in people with diabetes, especially people with type 2 diabetes who have comorbidities. Polypharmacy might be indicated to manage symptoms and comorbidities, but it is important to use non-medicine options where possible and to ensure polypharmacy is 'thoughtful'. That is, where possible medicines should be stopped before starting another medicine and not commencing medicines whose benefits take longer than the person's life expectancy [20]. The risks and benefits of each medicine must be considered individually, and in the context of the whole medicine regimen, and the individual's goals, preferences and values [21, 22].

Diabetogenic medicines such as corticosteroids, antipsychotics and thiazide diuretics can contribute to hyperglycaemia and induce diabetes in previously undiagnosed older people [3, 15]. High dose corticosteroids are often used in cancer to manage symptoms, cachexia and poor appetite.

#### 3.1. Hypoglycaemia

Changes in pancreatic alpha cells with increasing duration of diabetes and advancing age affects glucagon production, which reduces the individual's ability to mount an effective counter-regulatory response to hypoglycaemia [22–24]. In addition, autonomic and sensory changes affect the individual's ability to recognise the usual hypoglycaemic autonomic

Type of medicine	Main mode of action	Main side effects
<b>Oral GLMs</b>		
Metformin	Reduces hepatic glucose output.	Gastrointestinal (GIT) problems such as bloating and flatulence in the early days. GIT problems less likely with slow release dose forms (these should not be crushed). Rarely lactic acidosis—contraindicated in significant renal failure. Long-term use might lead to vitamin B <sub>12</sub> deficiency and lead to anaemia and its consequences.
Sulphonylureas	Binds to the beta cell receptor and triggers insulin release independent of glucose.	Hypoglycaemia. Weight gain.
DPP-4 inhibitors	Improve beta cell function and insulin secretion. Reduces gastric emptying and postprandial blood glucose.	GIT problems. Nasopharyngitis. Heart failure in people with or at risk of cardiovascular disease.
Thiazolidinediones (TZD)	Sensitise tissues to insulin.	Weight gain. Fluid retention. Heart failure. Risk of non-axial fracture in women
Alpha-glucosidase inhibitor	Slows carbohydrate absorption from the intestines and reduces postprandial blood glucose.	GIT problems especially bloating and flatulence.
Sodium-glucose cotransporter-2 (SGLT-2)	Inhibit the SGLT-2 transporter exchange sodium and glucose in the kidney and glucose is excreted in the urine. Reduces systolic blood pressure and cardiovascular risk.	Dehydration. Dizziness. Risk of genitourinary infections. Older people risk of electrolyte changes and hyperosmolar states. Not use with loop diuretics.
<b>Injectable GLMs</b>		
GLP-1		Weight loss GIT problems especially nausea and vomiting
Insulin* Short, rapid, intermediate and long acting analogues Premixed	Lower blood glucose	Hypoglycaemia

**Notes:** \*Injecting repeatedly into the same site can cause lipodystrophy and lipoatrophy. Injecting in lipodystrophy/atrophy tissue or using incorrect injection technique or needle size can affect insulin action and effectiveness and lead to glucose variability [51].

Combinations of some types of oral GLMs and of the different types of insulin are available.

**Table 1.** Classes of glucose lowering medicines, main mode of action and main side effects.

warning symptoms (sweating, trembling and palpitations) and put them at significant risk of severe hypoglycaemia requiring hospital admission, and cardiovascular complications [25].

A severe hypoglycaemia is associated with poor prognosis, leads to cognitive changes, coma, falls and injuries such as fractures, cognitive changes, acute coronary syndrome, recurrent hypoglycaemia, admission to hospital and sudden death [22, 23]. Hypoglycaemia affects age-related cognitive function due to changes in the counter-regulatory response to hypoglycaemia and the delivery of 'fuel' to the brain. Executive function is affected and reduces the individual's ability to recognise, problem-solve, make decisions, including about treating their hypoglycaemia [26] and is associated with dementia in the long term [27]. In addition, hypoglycaemia engenders fear, reduces quality of life (QOL) of the individual and family caregivers [28].

### 3.2. Hyperglycaemia

Hyperglycaemia is not a benign condition. It is an underlying cause of complications that affect functional status and life expectancy [3, 15]. It causes unpleasant symptoms and other metabolic changes such as incontinence, dehydration, triggers inflammatory processes, increases risk of intercurrent infections, weight loss and affects cognitive function. Some of these processes can lead to ketoacidosis (DKA) in type 1 diabetes (T1DM) and hyperglycaemia hyperosmolar states (HHS) in T2DM [3, 14, 15].

## 4. Palliative care

Palliative care was traditionally used to refer to care of people at the end-of-life. Definitions of palliative, end-of-life and terminal care are shown in **Table 2**. It is important to note that the definition of palliative care changed over 6 years ago to encompass chronic diseases that have a longer trajectory to end-of-life [29]. The definition was changed to reflect the association among chronic disease, suffering and life expectancy, and the fact that the chronic disease and frailty trajectories to death are less predictable than and different from the cancer trajectory. Health trajectories are described in Section 6.

As indicated, palliative care improves function and QOL and reduces unwanted hospital admissions and aggressive end-of-life care. It can be delivered in various settings such as in individual's homes, hospital, aged care homes and hospices. Palliative care can be integrated with usual diabetes care including at diagnosis, or can replace usual care.

Palliative care is associated with improved outcomes if it is implemented early; but most people are not referred to palliative care services until last few weeks of life [29, 30] and are often admitted to and die in intensive care units, despite meeting Gold Standards Framework (GSF) criteria [31]. Significantly, older people often meet medical emergency team (MET) criteria before they are discharged from hospital and often represent 30 days of discharge or sooner [32].

MET criteria refer to vital signs such as blood pressure, respiration and heart rate and rhythm that are monitored to detect change to enable treatment to be implemented to prevent a medical

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<b>Palliative care</b>	Palliative care is predicated on the fact that dying is a normal process. It focuses on improving quality of life by relieving suffering, promoting comfort and managing symptoms through comprehensive assessments and personalising care by engaging with the individual and family carers. Palliative care can be integrated with usual diabetes care at any stage in the disease trajectory. Most benefits accrue when palliative care is introduced early. It emphasises the importance of counselling patients and families, supporting patients to understand the change in the focus of care and helping them make decisions about their treatment and goals of care, documenting their end-of-life care preferences and care coordination.
<b>Advance care planning</b>	The process patients, family members or surrogate decision-makers and health professionals anticipate, discuss, document and communicate treatment options as the health status changes. Advance care plans help health professionals make 'in the moment decisions', which can be emotionally confronting, especially when there is conflict within the family.
<b>End-of-life care</b>	End-of-life care refers care for likely to die in the following 12 months. It includes imminent death in a few hours or days and progressive incurable life-threatening illnesses such as diabetes.
<b>Terminal care</b>	Last few days or hours of life.

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**Table 2.** Definitions of palliative care, advance care planning and end-of-life care and terminal care [29, 35, 36].

emergency. Worryingly, 25% of people are discharged *on the same day they have a MET call* [33], and 30% of people aged 70 and 50% of those aged 80 and older leave hospital more disabled than when they were admitted. Recognising and responding to deterioration is essential [34] to treat remedial deterioration as soon as possible. Blood glucose monitoring can be a useful tool to detect deterioration associated with hypo- and hyperglycaemia and implement treatment before preventable conditions such as DKA and HHS. That is, the health trajectory and life expectancy can change during and after a hospital admission.

#### 4.1. Goals of palliative care

The main goals of palliative care are to:

- Improve and maintain function to support independence and QOL.
- Achieve their life goals.
- Remain comfortable and free of pain and distressing symptoms.
- Achieve a dignified death in their place of choice.
- Address their spiritual, cultural and religious needs.

These goals also apply to individuals with diabetes [3, 35, 36]. They highlight the importance of discussing life and care goals, values and preferences with people with diabetes and ensuring

they are documented and communicated to the family and the individual's other clinicians. Clinicians need to accept that the individual may have different views from their own, and often from their family. In addition, people can change their care preferences over time; therefore, clinicians should ask about any changes for time-to-time such as during annual health reviews, preoperative assessments and changes in health status.

It is also important to provide support for families and other caregivers, including after the death of a loved one when they are particularly vulnerable to acute cardiovascular events, infection and depression [3, 38, 39].

#### 4.2. Health trajectories

The complex changing nature of diabetes and prognostic uncertainty makes it difficult to predict when an individual with diabetes would benefit from palliative care. Understanding their functional status and health trajectory can enable health professionals to discuss future care including the option of palliative care and to commence planning for the end-of-life. The following health trajectories are a useful framework for monitoring current and changing health status and care needs and to plan care with people with diabetes to meet changing needs [40, 41].

Unintentional injuries in older people, especially falls, often lead to death and can occur in any health trajectory.

1. **Trajectory 1:** Health trajectory where the person is independent, and has none or few complications when the focus is on maintaining health and preventing complications by striving for normoglycaemia (tight glycaemic control). However, death can be sudden in diabetes due to hypoglycaemia or silent myocardial infarction.
2. **Trajectory 2:** Sometimes called the cancer trajectory. There is a steady reasonably predictable decline in physical health over time (weeks, months or years). However, some cancers are curable and people may survive for many years and are referred to as cancer survivors. That is, they enter another health trajectory.
3. **Trajectory 3:** It is associated with long-term functional decline and intermittent periods of deterioration (unstable diabetes, e.g., due to intercurrent illness) that can be serious and require admission to hospital and/or intensive care unit (ICU). The individual usually recovers, but each deterioration results in further decline and can result in death. The time of death is unpredictable. Older people admitted to ICU are likely to die and may derive more benefit from palliative care, which avoids unnecessary life-prolonging treatment. Generally, QOL and pain management are more important to people with limited life expectancy than prolonging life.
4. **Trajectory 4:** People who do not have cancer or chronic diseases that cause organ damage/failure are likely to die at an older age from dementia or generalised frailty that involves multiple body systems after 'prolonged dwindling'.

Physical, psychological and spiritual needs differ among people with diabetes and their families and among and within the trajectories. Therefore, palliative and end-of-life care plans

should be developed sensitively and reviewed regularly to ensure they reflect the preferences of the individual [35, 40, 42]. Cultural and religious beliefs and traditions about health/ill health, death and dying must be considered and respected, including care of the body after death. **Table 3** shows some assessment and screening tools that can be used to monitor the individual's trajectory.

Malnutrition, deficient calorie, vitamin, mineral, protein, water intake, contributes to frailty and 'failure to thrive' in older people described in trajectory 4 [43]. Failure to thrive is associated with weight loss, often dehydration, skin fragility, osteoporosis, depression, immune system dysfunction, low cholesterol and functional decline [43]. Diabetes complications affect the individual's ability to thrive, as do some medicines. It is present in 5–35% of community dwelling older Americans, 25–40% of older people in aged care homes and increases the risk of morbidity and mortality. Palliative can be very valuable in such people.

It is generally difficult to precisely predict when an individual will die. Prognosis prediction models and their clinical utility in palliative care are addressed in a dedicated chapter of this book.

Some general indicators of poor prognosis are described in the Gold Standards Framework (GSF) [31] and can also inform care decisions, for example:

- Sarcopenia and frailty.
- Hospital admissions—increased risk of death in people >65 years with mulitmorbidities and heart failure.
- Sentinel events such as a fall, bereavement, and admission to and aged care home.
- Serum albumin <2.5 g/dL.
- Weight loss >10% in the preceding 6 months, although some experts indicate weight loss >5% over 6 months should be investigated.

Another useful prognostic indicator is the 'surprise question': would I be surprised if this person died in the next 12 months? If the answer is 'no, I would not be surprised', it is time to discuss and document palliative and end-of-life care, if that has not already been done [31, 41]. Documented palliative/end-of-life care plans should be reviewed. If the answer is 'yes' it could be time to begin initiating health professional and family case conferences.

Physical, psychological and spiritual needs differ among people with diabetes and their families and among and within the trajectories. As indicated, palliative and end-of-life care plans should be reviewed regularly to ensure they reflect the preferences of the individual. Cultural and religious beliefs and traditions about health/ill health, death and dying must be considered and respected including care of the body after death. The risk of developing many diseases increase with age, including diabetes, dementia and some forms of cancer; 80% of cancers occur after age 60 [44]. Some cancers and type 2 diabetes are associated with obesity [45]. Thus, it is reasonable to expect the health trajectory to change over time.

Tool	Comments
The surprise question <i>Would I be surprised if this person died within 12 months?</i>	Ask any time health changes.
Gold Standard Framework (GSF) prognostic indicator guidance	General indicators of decline/deterioration and the increasing need or choice for no further active care. Includes the surprise question.
Cognitive assessment toolkit Mini-mental examination	Assess cognitive function.
Supportive and palliative care indicators tool (SPICT)	Identify people at risk of deteriorating and dying.
Palliative care necessities CCOMS-ICO (NECPAL)	Identify people in need of palliative care.
RADboud indicators for palliative care needs (RADPAC)	Identify indicators of palliative care needs.
Charlson comorbidity index (CCI)	Designed to estimate 1–10 years mortality in longitudinal studies but is not a valid prognostic indicator for short term outcomes.
Clinical frailty scale	Determine frailty and function.
Karnofsky performance status scale	Quality of life across the spectrum of health from well to terminal.
Barthel index	Assesses capacity to perform basic activities of daily living.
Confusion assessment method (CAM)	Determine presence of confusion.
Weight, body mass index, food records, and nutrition assessment tools	Monitor nutrition status and related risk of malnutrition.
Hypoglycaemia risk assessment tool	Determine risk of hypoglycaemia. Available in the McKellar Guidelines <a href="http://www.adma.org.au/.../133-the-mckellar-guidelines-for-managing-older-people-with-diabetes-in-residential-and-other-care-settings_9dec2013">www.adma.org.au/.../133-the-mckellar-guidelines-for-managing-older-people-with-diabetes-in-residential-and-other-care-settings_9dec2013</a>
Diabetes-specific medicine-related adverse risk assessment tool	Determine risk of medicine-related adverse events. Available in the McKellar Guidelines
Medicine-related tools, e.g., Beers and STOPP/START	Used when prescribing medicines, when new symptoms develop and to undertake regular medicine reviews. When any new medicines is commenced and new symptoms develop especially in older people.
Absolute cardiovascular risk benefit calculator	Estimate cardiovascular risk including when prescribing medicines.
Fracture risk assessment tool (FRAX)	Estimate risk of fracture including when frail and when prescribing medicines.
Acute physiology and chronic disease evaluation (APACHE) and its variants	Designed to measure severity of disease in adults and used to predict in-hospital death and risk-adjusted length of stay in ICU. Indicate risk of death in patient groups rather than specific individuals and depend on laboratory data.

**Table 3.** Some useful assessment/screening tools can be used in any health trajectory.

## 5. Personalised palliative, end-of-life care and advance care planning

It is essential to actively involve people in decisions about their care goals, targets and plan including commencing and stopping medicines and other treatments. Involving people in care decisions can be challenging for many health professionals, especially when it concerns emotive issues such as palliative and end-of-life care. Well-designed training courses can improve health professional communication skills [32]. Health professionals find it difficult to resolve the dilemma among 'truth telling', instilling hope, and respecting people's autonomy. Truth telling often means delivering 'bad news' and is stressful. Thus, despite the global trend towards 'truth telling', non-disclosure is still an issue [29, 45].

People with a life-threatening illness (and their families) often ask 'how long have I got?' Inherent in that question is recognition that they have a life-threatening illness and need some guidance about the likely health trajectory (what will happen?), so they can complete 'unfinished business and get their house in order'. They may not initiate discussion about the issue, often because they do not want to upset family, friends or their health professionals. In most cases, people are not concerned so much about dying, as they are of suffering, and having loved ones witness their suffering [38, 46].

Most people want to die at home and die with dignity [29, 30]. Several resources and decision aids are available to help people with diabetes and health professionals make care decision by helping them decide an individual's personal risks and leads to the appropriate use of elective procedures [47]. Some useful resources are listed after the reference list.

### 5.1. Advance care planning

Various countries have different legislative and other procedures guiding advance care planning. Such planning involves shared responsibility among health professionals, the individual and their families. The aim is to identify the individual's values, preferences and goals and communicate them to relevant services and relevant others so the plan can be implemented when indicated.

Research shows people with cancer and dementia have a better end-of-life quality than those with end stage renal disease, cardiopulmonary failure and frailty [29, 30]. Some possible reasons include early initiation of palliative care, documented advance care plans, 'not for resuscitation orders', and fewer admissions to ICU [32, 47]. These findings suggest it is imperative that other disease processes ensure palliative and end-of-life care planning are included in clinical management guidelines.

Key information to discuss and document includes preferences concerning:

- Resuscitation
- Airway support
- Enteral nutrition and fluids

- MET calls if they are admitted to hospital
- Pain management
- Diabetes self-care such as blood glucose monitoring and GLMs
- Other important end-of-life planning includes religious, spiritual and cultural issues surrounding end-of-life care, making a will, funeral planning and designating surrogate decision-makers/power of attorney.

## 6. Good communication

Communication is central to effective palliative care planning. Listening, effective use of silence and using appropriate probing and clarifying questions are key clinician skills [46]. A variety of communication strategies have been designed to enhance health professional and people with diabetes capacity to discuss these emotive issues in a timely and sensitive manner and help reduce uncertainty. However, decisions about treatment options are increasingly complex in an age where advanced technology and treatments promise the hope of extending life.

Initiating discussion about end-of-life care earlier and in a planned manner enables people to make more informed choices when they are not under physical or mental stress and achieve better outcomes. People who discuss their palliative and end-of-life care needs are more likely to receive care consistent with those preferences [6, 29, 30]. Such discussion includes clarifying the individual's goals and their concept of what a 'good death' means to them. Health professionals need to have the relevant skills to communicate about these issues.

## 7. Family carers

Family carers, often a spouse, play a significant role supporting and caring for people with diabetes. They often have health problems themselves and are at high risk of unexpected morbidity and mortality after the death of a loved one, especially if the death is unexpected and not planned for [37, 38]. Caring is hard work and often causes stress that affects sleep, immunity and wellbeing and mobilises inflammatory processes and haemodynamic changes that predispose them to dying [37]. The family carer can neglect their own health care such as taking medicines to perform the caring role. Therefore, carers also need a care plan and their health needs to be monitored. Keeping carers informed and included in case conferences and care decision can reduce stress.

A significant cause of family stress the uncertainties associated with dying. These include undertaking diabetes management tasks such as blood glucose monitoring and injecting insulin and understanding when their loved one is actively dying [46]. Family are often reluctant to support loved ones die at home because of these uncertainties and the responsibility involved. Ensuring these issues are included in family discussions can help relieve stress. Significantly, carer wellbeing affects the experiences of the person they provide care for. The latter are likely to report poor quality of life if their carer has depression [47]. Thus, carers can be 'invisible' or 'hidden' patients.

## 8. What do people with diabetes think?

People with diabetes and their health professionals face many complex decisions where there is no right or wrong answer when considering palliative and end-of-life care. Prognostic uncertainty, competing priorities and weighing benefits and risks overall and the positive and negative outcomes of treatment complicate decision-making [30]. Such decisions can be particularly challenging with respect to managing diabetes when the focus on tight blood glucose control no longer confers benefit and changes to focusing on safety comfort and quality of life, especially given there are no large observational or randomised controlled trials to support many care recommendations [40].

We interviewed people with diabetes receiving palliative care for a range of diagnoses, their family carers (mostly spouses) and palliative care health professionals when we developed Guidelines for Managing Diabetes at the End of Life [35]. Our research suggests people with diabetes and families regard blood glucose testing as an important guide to detecting hypo- and hyperglycaemia, both of which compromise comfort [47, 48]. It is also a reassuringly familiar routine in a sometimes rapidly changing world.

People with diabetes indicated health professionals do not pay enough attention to their diabetes, do not understand the physical and psychological impact of hypo- and hyperglycaemia and the relentless self-care required to manage diabetes and do not respect their lifetime of accumulating diabetes knowledge and solving diabetes care problems. Generally, they wanted blood glucose monitoring continued until the final stages of dying because 'it helps sort out the causes of things like confusion and pain' [47]. They also wanted to continue taking their GLMs until the terminal stage to manage hyperglycaemia, which they stated caused confusion, frequency and tiredness, what affected their comfort and quality of life.

Carers were interviewed separately and reported similar views. They also reported they worried about having to undertake diabetes tasks such as blood glucose testing and administering insulin because they had not received education about these tasks and worried that they might accidentally give the wrong insulin dose and hasten death [47, 48].

Our earlier research indicated health professionals reported dilemmas deciding when 'is the right time, to stop blood glucose monitoring and felt finger pricking caused discomfort. They felt 'there was a tension between avoiding discomfort and performing useful investigations' [49]. This study was the impetus for developing the Guidelines for Managing Diabetes at the End of Life [35], which is currently under review.

## 9. Summary

Proactively planning for palliative and end-of-life care can improve comfort and other outcomes for people with diabetes, especially in older age, and their families. Planning for the end-of-life is a shared responsibility between health professionals, people with diabetes and often family carers and reduces decisional conflict when health deteriorates. It is essential to understand people's goals, values and preferences and to personalise care. It is important to consider culture and religion and proactively monitor the individual's and their families'

health status. Palliative care aims to promote comfort and alleviate suffering (see **Table 2**) It can be initiated at any time in the diabetes trajectory: early initiation results in better outcomes. General palliative and end-of-life care/guidelines discussed in other chapters in the book apply to people with diabetes. This chapter addressed key diabetes-related care issues that need to be considered.

Significantly: *The way people dies remains in the memory of those who live on.* [Dame Cecily Saunders] [50].

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## Some useful resources

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