



Palliative and End-of-Life Care: Vital Aspects of Holistic Diabetes Care of Older People With Diabetes

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Palliative and end-of-life care and advance care planning are important components of holistic diabetes management, especially for older people with a long duration of diabetes and comorbidities who experience unpleasant symptoms and remediable suffering. Many diabetes clinicians do not have conversations about advance care planning with people with diabetes, often because they are reluctant to discuss these issues and are not familiar with palliative care. This article outlines palliative, terminal, and end-of-life care for older people with type 1 or type 2 diabetes and suggests when to consider changing the focus on tight blood glucose control to a focus on safety and comfort. It proposes strategies to incorporate palliative and end-of-life care into personalized holistic diabetes care, determined with older people with diabetes and their families through shared decision-making.

People with type 1 or type 2 diabetes grow old, but many have a shorter life expectancy than the general population (1). Many older adults with diabetes have long duration of diabetes, diabetes complications, frailty, and cognitive changes or dementia. They are prone to unpleasant symptoms associated with these conditions and to hypoglycemia and hyperglycemia, which cause significant morbidity and mortality (2). Consequently, they often have unmet physical, mental, spiritual, and emotional needs that compound pain and other symptoms. The pain and suffering frequently go unrecognized and untreated.

Diabetes was in the top 10 causes of death globally in 2016; some of the other top 10 causes of death, such as ischemic heart disease (number one), are associated with diabetes (3). Approximately 67% of these deaths occur in people ≥ 60 years of age (3). However, chronological age does not equate to an individual's disease status, functional status, life expectancy, or care needs (4,5), all of which are influenced more by the individual's genetic inheritance and biological age. Many older people with diabetes have three or more comorbidities that reduce life expectancy (e.g., cardiovascular disease, cognitive changes, dementia, renal disease, various degrees of frailty, and cancer [6–8]). Significantly, diabetes complications can be present before type 2 diabetes is diagnosed (4,6).

Several medicines are usually required to manage diabetes and its associated comorbidities. Consequently, polypharmacy

is common, albeit often necessary, and adds to the burden of lifelong self-management. Self-management encompasses eating a healthy diet, undertaking physical activity, monitoring blood glucose, and recognizing and managing hyperglycemia and hypoglycemia.

Hypoglycemia unawareness is common in older people with type 1 diabetes and some people with type 2 diabetes. Thus, many older people on insulin and sulfonylurea glucose-lowering medications are at risk for significant harm from tight blood glucose control (9).

People with diabetes usually follow a chronic disease trajectory in which slow disease progression and unpredictable exacerbations of the underlying disease processes occur and can lead to emergency department presentations or hospital admissions (10–12). The exacerbations become more frequent over time and result in increasing frailty and other geriatric syndromes that cause emotional distress, further functional decline, slow recovery, and eventual death.

Consequently, many older people with diabetes develop significant cumulative burdens related to their disease, treatment, and self-care, which make focusing on tight blood glucose control unrealistic and unsafe as they reach older age (2,5,13). Therefore, the focus of care needs to gradually change to a palliative approach that involves determining a safe blood glucose range to both prevent

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glucose variability and glycemic emergencies and manage the burdens and harms that affect comfort, cause suffering, and reduce quality of life (5,13). That is, the focus shifts to identifying and prioritizing interventions likely to be beneficial and stopping those unlikely to be beneficial in the individual's remaining lifetime. This strategy might include not commencing interventions that delay death but increase suffering (14,15). Such decisions can be challenging for clinicians accustomed to focusing on active and curative care.

We can still learn from Hippocrates, who described the basic philosophy of all care in his *Book of Prognosis*: "First, do no harm, observe all, evaluate honestly, prognosticate when you can, counsel the patient about what to expect in the course of their illness, especially when the prognosis is poor, and when it comes to therapeutics, assist nature" (16). Hippocrates also described prognostic indicators and advocated for effective communication between the patient and the physician (16). The philosophy is still relevant to modern palliative care.

Palliative, Terminal, and End-of Life Care

The three terms, palliative, terminal, and end-of-life care, are defined in Table 1, along with some suggestions for when to implement palliative and end-of-life care and some implementation strategies that may be used.

Historically, palliative care was associated with hospice and cancer care at the end of life and did not include curative care. Consequently, many clinicians equate palliative care with terminal care (17) and regard death as a treatment failure. Significantly, though, palliative care can be commenced at any time and can be used with a patient's "usual" care (18,19). Generally, the earlier palliative care is implemented, the greater the benefit (18–20).

Many diabetes clinicians are not familiar with palliative and end-of-life care or comfortable discussing these issues with people with diabetes and their families. The National Coalition for Hospice and Palliative Care has noted that palliative care is the responsibility of all clinicians—not the sole preserve of palliative care specialists (20). The coalition's guidelines recommend that service providers and clinicians integrate palliative care into the care plans of people with serious illnesses, including proactively discussing end-of-life care (20). However, clinicians often wait until a patient or patient's family raises the issue. Likewise, the patient and family often wait until the doctor initiates such conversations. Consequently, nobody raises the issue, and conversations about palliative and end-of-life care do not occur (21).

Optimal palliative care requires many conversations with individuals about their values and care goals as their health status changes. Thus, communication and advance care planning is a continuing process and a key aspect of palliative care. However, many clinicians find it difficult to discuss these issues because of inadequate skills and training, time constraints, fear of conflict (17), and the challenge of prognostication. Clinicians' intuitive prognostication can be inaccurate, and prediction tools are not particularly helpful (21).

Palliative care can be delivered in a person's home, in a hospice, or in the hospital (Table 2). Many people prefer to die at home, but most do not actually do so (18,22).

Managing Diabetes During Transition to End of Life

Two guidelines and one article focus on palliative and end-of-life diabetes care (5,13,23), although the topic is also included within several other general guidelines. Most of the guidance in this area is based on low-level evidence and expert consensus; however, it makes clinical sense, is consistent with palliative care guidelines, and focuses on personalised care. Table 1 defines end-of-life care and outlines care strategies for people with diabetes requiring terminal and end-of-life care.

As previously noted, the care focus must gradually shift from tight blood glucose control to comfort and symptom control for patients with either type 1 or type 2 diabetes (5,8,12,13,23). Preventing hypoglycemia and hyperglycemia and their associated uncomfortable symptoms is essential. Both states are associated with increased risks of death, although hypoglycemia might be a marker, but not a cause, of poor outcomes, at least for people hospitalized after myocardial infarction (24). It might also be important to reduce glucose variability, especially during disease exacerbations (25).

Glucose-lowering medication doses may need to be reduced or different formulations used, while also simplifying the regimen as much as possible. Glucose-lowering medications are used to prevent hyperglycemia and its symptoms and reduce the risk of diabetic ketoacidosis or hyperglycemic hyperosmolar state. That is, they can be used with a palliative intent for symptom control in older people with type 1 or type 2 diabetes rather than to achieve tight blood glucose control. Preventing diabetes complications is largely irrelevant in older people approaching the end of life.

A generally accepted safe blood glucose range is 6–11 mmol/L (108–198 mg/dL) (13,23), although some Australian guidelines recommend 6–15 mmol/L (108–270 mg/dL) (4,5). Sliding-scale insulin (i.e., hyperglycemia correction doses) should not be used alone but may be a useful add-on to a

TABLE 1 Palliative, Terminal, and End-of-Life Care and Suggestions Regarding When and How to Implement Each

Definition	When to Implement	Implementation Strategies
<p>Palliative care focuses on relieving suffering and maintaining function, independence, and quality of life and can be started at any time in the diabetes disease trajectory and at any age (15,18,19). For people with diabetes, its aims include managing pain and enhancing quality of life by assessing and treating physical and emotional suffering and preparing patients and families for eventual death (40).</p>	<p>Early implementation reduces pain and suffering, improves function and quality of life, and may increase longevity (3). This can be achieved by diabetes clinicians, or they can refer patients to specialty palliative care services where they exist. Consider starting or referring for palliative care for people with diabetes at every consultation, with significant change in health status, during annual complication screening, and especially for people with the following conditions, which are associated with increased risk of further morbidity and mortality:</p> <ul style="list-style-type: none"> • Long duration of diabetes with consistently high A1C and blood glucose (4) • Multiple comorbidities (e.g., renal, liver, cardiovascular, and gastrointestinal problems) (41,42) • Cancer associated with diabetes (43) • Polypharmacy and unnecessary medications with questionable benefits in palliative and end-of-life situations (44,45) • Low A1C or hypoglycemia (46) • Failure to thrive, with nutrition deficits, weight loss, fatigue, and mental and social consequences (5) • Sarcopenia or frailty; slow timed up-and-go test and slow gait speed (45,47) • Cognitive changes or dementia • Depression • Falls (45) • Frequent admissions to the hospital or ED • Loneliness and isolation (48,49) • Admission to an aged care home 	<ul style="list-style-type: none"> • Consider holding a case conference to discuss the patient's health status with the patient and relevant care providers and family members to introduce the benefits of palliative care. Prepare for the consultation by having all relevant information available, preparing the patient and family for the case conference, and creating a quiet, respectful, private environment. Consider any sensory deficits such as low vision or hearing issues that can affect the patient's capacity to participate in the discussion or read written information. • Undertake a comprehensive assessment (8), including a medication review and reconciliation and/or referral for a comprehensive geriatric and/or palliative care assessment. Stop any unnecessary medications and those that are contraindicated or no longer confer benefit. Do not start medications or interventions unlikely to benefit the patient in his or her lifetime. Simplify the regimen for remaining medications. Avoid using sliding-scale insulin; it may be safer to establish a basal-bolus insulin regimen (5,13). Ask about the use of complementary medicines and therapies; some can interact with conventional medicines. • Comprehensive geriatric assessments and appropriate care strategies, including rehabilitation, can enable the patient to return home after a hospital admission (45). Undertake relevant risk assessments to help determine care needs (e.g., risk of falls, hypoglycemia, pain, medicine-related adverse events, or functional and self-care capacity) (5). • Decide on metabolic (i.e., blood glucose and A1C) target ranges and other care goals considering the patient's safety, values, goals, care preferences, and life expectancy. A generally safe blood glucose ranges is 6–11 mmol/L (108–198 mg/dL) and A1C up to 8%, but A1C may not be particularly useful toward the end of life (4,5,13,23). • Develop a personalized sick day recognition and care plan and a personalized hypoglycemia recognition and management plan with the patient and family. • Undertake regular general health assessments that encompass height and weight, diet, activity, oral/dental health, mental health, smoking, alcohol intake, and vaccination status and screenings for cancer (e.g., prostate and breast cancer). Consider mental health and risk of loneliness and depression. • Encourage healthy eating and consider erratic eating and nutritional deficiencies and how they affect other care decisions, including the glucose-lowering medication regimen. • Encourage activity such as tai chi, smoking cessation, and limiting alcohol intake. Calcium and vitamins D, B12, and folate might be required. • Educate the patient's family and other carers to recognize and act on signs of deterioration, bearing in mind that symptoms of heart attack, hypoglycemia, and infection are often atypical. • Encourage the patient to prepare an ACP, a will, power of attorney, and other relevant documents or revise current plans if necessary. • Document the discussion and communicate it to other relevant care providers and the patient and family.

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TABLE 1 Palliative, Terminal, and End-of-Life Care and Suggestions Regarding When and How to Implement Each

Definition	When to Implement	Implementation Strategies
<p>End-of-life care is provided to people who are likely to die in the next 12 months (12,15,18). For these patients, preventing complications is no longer relevant, but managing the symptoms associated with existing complications is still relevant. End-of-life care can be delivered in a person's home, a hospice, or a hospital. It often spans four related but nonsequential stages: stable, unstable, deteriorating, and terminal, when death is imminent (15,37).</p> <p>The GSF (37) recommends three main steps:</p> <ol style="list-style-type: none"> 1. Identify people who need palliative/end-of-life care. 2. Assess and document their needs. 3. Plan and deliver their care, including deciding where the person wants to die. 	<p>It is difficult to predict when a person will die. People often seem to know when they are approaching the end of life. Some signs that a person could be entering the last stage of life include answering "no" to the surprise question (i.e., "Would I be surprised if this man/woman died in the next few months?") Answering in the negative indicates that it is time to plan for the end of life (37).</p> <p>Regularly assess the individual for indicators of decline such as:</p> <ul style="list-style-type: none"> • Declining function (e.g., Comorbidity Index, Barthel Index, Karnofsky Score, Fried Frailty Scale), which leads to difficulty undertaking activities of daily living and diabetes self-care • Increasingly complex symptom and care burden and advanced disease such as stage 3 or 4 heart disease, end-stage renal failure, metastatic cancer, or leg or foot ulcers • A sentinel event such as a serious fall, severe hypoglycemia, or hyperglycemia leading to diabetic ketoacidosis or hyperglycemic hyperosmolar state • Several unplanned admissions to the hospital or ED • Progressive weight loss >10% in the past 6 months after assessing for treatable causes such as undiagnosed cancer and thyroid disease, or weight loss >5% if the person has sarcopenia (50) • Serum albumin <25 g/L • Self-reported poor health especially when asking about future rather than current health 	<ul style="list-style-type: none"> • Discuss the patient's changing health status with the patient, family, and other carers if the patient agrees. • Develop an ACP if the patient does not have one or review the existing plan to ensure that it is still consistent with the patient's values, goals, and preferences. Ensure that it is available in the medical record and communicated to relevant people. Values rarely change over time, but care preferences can and do. • Make sure the ACP accompanies the patient during important care transitions within and among health services. If the person elects to die at home, ensure that integrated team care is provided and the patient's primary care provider and palliative care nurses are involved. • Proactively plan for necessary care transitions but avoid unnecessary admissions to the hospital, ED, or intensive care according to the patient's ACP and GSF (37) status. • Consider different formulations of necessary medicines if the patient has dysphagia. Dental problems can contribute to swallowing problems, but medicines may not need to be crushed for these people (50). Extended-release medicines and some other formulations should not be crushed. • Inform relatives about the patient's condition; even an expected death can be shocking and distressing. The death of a partner increases the risk of an acute cardiovascular event and infection in the subsequent weeks in the surviving partner (51). Carer stress predicts admission to an aged care home (52).
<p>Terminal care is provided in the last few days or hours of life and can be delivered at home, in a hospice, or in a hospital (15,18,19).</p>	<p>When the person is actively dying</p>	<ul style="list-style-type: none"> • Enact the patient's ACP. If there is no plan, consult with relatives and make decisions likely to match the patient's values. • Ensure that pain and distressing symptoms are managed. Withdraw diabetes treatment such as medications and blood glucose monitoring when there are more risks than benefits. • Institute bereavement therapy where it is available and/or counsel and support family and relatives. • After death, clinician debriefing might be indicated in some cases. Provide bereavement care for the family. Complete relevant documentation such as a death certificate and arrange for the care of the body, considering religious and cultural needs.

ACP, advance care plan; ED, emergency department; GSF, Gold Standard Framework. Adapted from ref. 38.

TABLE 2 Palliative and End-of-Life Care Settings and Issues to Be Considered in Each

Home	<ul style="list-style-type: none"> • Clear policies and protocols to support clinical and other care for people with type 1 or type 2 diabetes should be in place. These protocols should outline clear, bidirectional processes and documentation for care transitions such as to and from a hospital. • The complexity of home care can be similar to that provided in a hospital. Thus, the family must be able to cope with complex care regimens. Caregiving is hard work, particularly managing medications when people are dying. Therefore, caregivers' health and well-being should be assessed when relevant. • Many people with diabetes are accustomed to managing their diabetes and should be encouraged to continue to do so for as long as possible. Families require support, education, and resources when they undertake diabetes self-care and other care for their relative with diabetes. They need access to advice when needed, including access to the primary care provider and diabetes and palliative care experts. They also need a plan for when to call the doctor or an ambulance or to take their relative to the hospital. This information can be included in sick day and hypoglycemia management plans. Caregivers must be able to recognize and manage atypical presentations of hypoglycemia, hyperglycemia, and cardiac events. • Most people prefer to stay at home for as long as possible, and many want to die at home, but that is not always possible. The individual's ACP should be respected and used to guide care. Conflict can arise in some situations such as when an individual becomes ill and refuses to go to the hospital when the family thinks such a transfer is needed. • Family members may have concerns about caring for their relative when they die at home. They worry about watching their relative die in pain and suffering or over-medicating them. • The social aspects of care need to be considered and addressed (e.g., when a patient should stop driving). All written information should be in plain language considering the health literacy of the patient and family.
Hospice	<ul style="list-style-type: none"> • Hospices specialize in caring for people who are dying and provide various supportive treatment options not usually available in hospitals (e.g., music therapy, aromatherapy, massage, or pet therapy). • Hospices should have clear policies and protocols, resources, and access to diabetes clinicians for advice, if needed, to support the care of patients with diabetes. Staff must have the skills and knowledge to care for older people with diabetes when they are dying and must know when to stop glucose-lowering medications and blood glucose monitoring. If patients elect to continue their diabetes self-care, they should be supported in doing so. • The individual's ACP should be respected and used to guide care.
Hospital	<ul style="list-style-type: none"> • Hypoglycemia, hyperglycemia, illness, cardiovascular events, foot infections, falls, and acopia are some common reasons older people present to the hospital. • Patients' ACP should accompany them during care transitions and be respected and used to guide care. • Patients can spend considerable time waiting for services, and an ED is not a nice place to die. Patients may present to an ED and then be transferred to various other places such as a geriatric evaluation unit, a medical ward, or an intensive care unit. • Diabetes can be diagnosed in an ED. For those with existing diabetes, the medical record should clearly state whether the patient has type 1 or type 2 diabetes. • Up-to-date policies and protocols to support the care for people with diabetes should be in place. • Bidirectional processes for managing care transitions must be in place and include clear communication among the various wards within the hospital, as well as communication from the hospital to the primary care provider and diabetes and palliative care experts, as relevant, at discharge or other transitions. Information such as the results of investigations and adjustments to the medication regimen should be communicated. • Discharge education is important and should include patients' family, when relevant. Allow time, and use teach-back techniques rather than didactic teaching styles to enhance understanding and recall. Written information should be provided in plain language considering the health literacy of the patient and family. • Integrated care pathways are used in some places for end-of-life care transitions.

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TABLE 2 Palliative and End-of-Life Care Settings and Issues to Be Considered in Each

Aged Care Homes and LTC Facilities	<ul style="list-style-type: none"> • Older people can be admitted to an aged care home or LTC facility for respite care, rehabilitation, and palliative care or to live permanently. The reason for and duration of the admission influences their care. The care plan must state whether the person has type 1 or type 2 diabetes. • Monitor patients for depression and loneliness. Permanent admission often triggers grief and loss of dignity, independence, and beloved pets; thus, patients need to be supported and given time to adapt to their new situation. • Ideally, people with diabetes have an ACP before they are admitted to an aged care home or LTC permanently. If they do not have such a plan, one should be drawn up as soon as possible. • Up-to-date clear policies, protocols, and guidelines must be in place and used to support diabetes care and palliative and end-of-life care, as well as care of the body after death, which should be consistent with religious and cultural customs. • Staff must have the skills and knowledge to care for older people with diabetes. Many facilities are understaffed or employ non-health professional staff who do not have the education and training to care for people with complex care needs. • Relevant equipment should be available (e.g., supplies to treat hypoglycemia, glucagon, and ketone strips to test for ketoacidosis). • All people taking glucose-lowering medicines should have a hypoglycemia risk assessment and an individualized hypoglycemia care plan based on their risk. This plan should include when to call the doctor and the information to provide to the doctor to facilitate care decisions. • Every person with diabetes should have a personalized sick day care plan that includes a plan for blood glucose monitoring and ketone testing, especially for older people. • Food plans need to be flexible and consider the individual's medication regimen, food intake, and activity levels. Many older people eat erratically, which means they are at risk for hypoglycemia. • Sliding-scale insulin should not be used. Basal insulin with a small dose of rapid-acting insulin when the individual eats is safer but more labor-intensive (5,13). • Some people will be on enteral feeding. Products with less impact on blood glucose, such as Glucerna, are preferred. • LTC facility staff need support when a resident dies. They often suffer unresolved grief or stress at such times.
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ACP, advance care plan; LTC, long-term care.

basal-bolus insulin regimen. Sliding-scale insulin is more likely to cause glucose variability and hypoglycemia that can lead to a hospital admission (5,13,25) and is a predictor of death in critical illness (25). Transitioning to a basal-bolus insulin regimen can help avoid hypoglycemia and reduce the care burden on the patient, family, and care staff (5,13).

Usual prescribing guidelines and algorithms should be used to manage all classes of medications and individual drugs within each class. However, the following cautions apply with regard to glucose-lowering medicines (5,13,23).

- Metformin is generally safe but may be contraindicated in people with gastrointestinal cancers and other gastrointestinal problems.
- Sulfonylureas increase the risk of hypoglycemia, especially in people with low oral intake and/or liver disease. This risk is further increased if insulin is used with a sulfonylurea.
- Pioglitazone may be contraindicated in people with or at risk for bladder cancer.
- Dipeptidyl peptidase-4 (DPP-4) inhibitors have low hypoglycemia risk alone but can increase the risk of hypoglycemia if used with sulfonylureas. Some DPP-4

inhibitors should be used with caution or stopped in people with renal disease.

- Glucagon-like peptide 1 receptor agonists have low or no hypoglycemia risk but should be stopped in patients who develop pancreatitis or abdominal pain.
- Sodium-glucose cotransporter 2 inhibitors have a low hypoglycemia risk. They should be stopped when patients develop an intercurrent illness or require surgery because of the risk of dehydration and associated hyperosmolar or ketoacidotic states. Ketone testing should be started if it is not already used.

Blood glucose monitoring can be a useful guide to the underlying cause of symptoms such as nausea, headache, and urinary frequency in people with type 1 and type 2 diabetes (26). Our research shows that people in the last stages of life value blood glucose monitoring because it enables the identification and treatment of the causes of some symptoms (27). It is also useful when corticosteroids are used (5,13,23). Monitoring frequency should be tailored to the action profile of the glucose-lowering medications and the individual's food intake and activity levels. Food intake can be erratic for a range of reasons, including dementia, dysphagia, changed taste sensation resulting from aging or chemotherapy, and dissatisfaction with the food served in hospitals, aged care homes, or long-term care facilities.

Advance Care Planning

The terms and processes used for advance care planning vary around the world to accommodate legislation, language, and religious and cultural imperatives. However, the purpose remains constant: to ensure that the individual has a good death. Diabetes clinicians are ideally placed to help older people with diabetes clarify their values, preferences, and care goals and to document them in an advance care plan because diabetes care requires regular follow-up appointments and screenings for complications.

Advance care planning involves people with diabetes discussing their preferred future care with clinicians and family members while they can make autonomous decisions (informed consent). Documenting the person's values—the things that give meaning and purpose to the person's life—is extremely important. Values are a useful guide later on to the type of care a person would choose to achieve quality of life.

People value having some control over the way they die, being free from pain, and having time to complete important business and to say goodbye to family and friends (5,22,27). For example, achieving personal goals such as attending a grandchild's wedding may be more important than living a longer life (28). Thus, care should support people in achieving their goals, when possible. Significantly, people who document their values and goals and instructions about the care they want or do not want are more likely to receive care consistent with their preferences. Discrepancies between the values of patients and clinicians are well documented (29). For example, clinicians underestimate the burden of symptom severity compared with patient ratings, and many tools that measure such outcomes do not adequately capture the patients' perspective (28,29).

Advance care plans are guides to and decision aids for determining an individual's values and care goals. They can help clinicians and patient surrogates or caregivers make difficult treatment decisions when patients cannot decide for themselves, provided they meet legal requirements (e.g., they are signed and witnessed) (21,30). As previously noted, clinicians often miss opportunities to initiate conversations to help people make such plans (31). Indeed, some such conversations occur during rapid response or medical emergency interventions (32), which is clearly not an appropriate time to make decisions about emotion-laden issues.

Some clinicians believe that people do not want to discuss dying and advance care planning, and in some cases, this is

true. Generally, however, people are more open to such discussions when they have disabilities and illnesses (33). Our research shows that people with diabetes want to discuss their end-of-life care in their last months of life, but they are often reluctant to initiate discussions because they worry about upsetting their clinicians and because clinicians do not ask them (27,34).

Most patients, caregivers, and clinicians want some idea of prognosis when a patient's condition deteriorates, and not considering prognosis could result in lower-quality care (35). Prognostication, like deciding benefits and harms, is challenging, however. As Hippocrates said, "It appears to be a most excellent thing for the physician to cultivate prognosis" (16).

Palliative and diabetes prognostic tools that can help clinicians "cultivate prognosis" include the Supportive and Palliative Care Indicators Tool (36) and The Gold Standards Framework Prognostic Indicator (37). These tools can help clinicians identify people who would benefit from palliative care. Clinicians can then provide palliative care themselves or refer patients to specialist palliative care services (5), as well as help the identified patients develop or update their advance care plans, if necessary.

What Do People With Diabetes and Their Families Think?

People with diabetes and their families need to make many complex decisions about their diabetes self-care on a daily basis and when considering palliative and end-of-life care. We interviewed older people with type 1 or type 2 diabetes receiving palliative care, their family carers, and palliative care clinicians when we developed the Guidelines for Managing Diabetes at the End of Life (38). Our findings suggest that people with diabetes and their families consider blood glucose testing to be a useful guide to identifying hypoglycemia and hyperglycemia and enables early recognition and treatment of their associated unpleasant symptoms (27). Blood glucose monitoring is also a familiar routine for many people with type 1 diabetes during a time of change.

We also found that most people wanted to continue taking their glucose-lowering medications until the terminal stage to manage hyperglycemia, which can cause confusion, frequent urination, and tiredness and compound other symptoms such as delirium, all of which cause discomfort and reduce quality of life. They also wanted to avoid hypoglycemia because of its associated loss of control and symptom burden (27,34).

Patients' family members, mostly spouses, were concerned about having to undertake diabetes tasks such as blood glucose monitoring and insulin administration when their relative could no longer manage (27). They said they had not received education about how to do these tasks and worried they could accidentally give the wrong insulin dose and hasten death. Underlying this concern was the risk of unintentionally causing death and being accused of murdering their relative.

Documenting an advance care plan is time-consuming and distressing for individuals, their family members, and clinicians. However, advance care planning specialists, when available, can help reduce the stress. Helping people create a life narrative enables them to find meaning and purpose, develop a sense of coherence, and maintain their identity (personhood), self-esteem, and coping capacity as they prepare for their end of life (39).

Summary

It is important to understand individuals' journey with diabetes and changing care needs as they transition through older age and toward the end of life. Helping people with diabetes cope with a life-limiting illness is a privilege. It is also an ethical responsibility, given the current focus on autonomy, patient engagement, and personalized care. Generally, a more flexible approach to food choices, blood glucose monitoring, and the blood glucose target range is preferable to achieving tight glycemic control. The specifics of care must be decided with individuals and their families. Prognostication is challenging and contributes to moral distress. Thus, clinicians and people with diabetes need to know how to or get help to manage uncertainty and cope with such distress.

Documented values, care goals, and preferences can help reduce uncertainty and aid decision-making when older people cannot decide for themselves and can be used in conjunction with guidelines such as the Gold Standards Framework (37). Such plans do not need to be completed all at once; starting early allows people time to think through the issues involved. Once a plan is documented, it should be reviewed regularly because peoples' goals of care can change, although their values tend to remain relatively constant. Significantly, living as long as possible is not always the most important goal. For many people, avoiding pain and suffering and having a good death are more important (28).

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No potential conflicts of interest relevant to this article were reported.

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T.L.D. is the sole author and guarantor of this work and takes responsibility for the integrity of the information presented.

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