Guidelines for Deciding Palliative and End of Life Care with People with Diabetes
Guidelines for deciding Palliative and End of Life Care with People with Diabetes

The Guidelines for Deciding Palliative and End of Life Care with People with Diabetes is a revised version of The Guidelines for Managing Diabetes at the End of Life (2010) and supersedes that publication.

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The recommendations and information in the Guidelines for Deciding Palliative and End of Life Care with People with Diabetes are based on the best available evidence derived from structured literature reviews and expert peer-review. Accepted guideline development processes (NHMRC and GRADE) were used to make the recommendations in these Guidelines. Regular consultation with an interdisciplinary expert advisory group of health professionals and a heterogeneous advisory group of people with diabetes was undertaken to ensure the recommended care is holistic, person-centred and able to meet the needs of the intended target audiences: health professionals, people with diabetes and their families and other carers.

All reasonable steps were taken to ensure the information is accurate and accords with the general policies and recommendations of key bodies and associations such as Palliative Care Australia and the World Palliative Care Association/World Health Organisation. They are aligned with the National Safety and Quality Health Care Standards (2107 2nd edition), Gold Standard Framework (2016) and CareSearch recommendations.

Health professionals are advised to consider the evidence for benefit, safety and risk of any care they recommend and develop care plans with the individual and/or their families and carers when relevant. They should use their knowledge of the individual and individual's values and care preferences, professional judgement, experience and training when making decisions about palliative and end of life care with individuals with diabetes. Refer to specialist palliative care services, at an early stage, when indicated.

Recommendations in the revised Guideline apply to type 1 and type 2 diabetes unless otherwise specified.
I was waiting for the right time—there wasn’t a right time.
But there is always a right time.

(ABC Sunday 2nd August 2015)
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We thank Professor Charles Corke for his ‘wild enthusiasm’ and support of our diabetes palliative and end of life care work and especially for writing the foreword to the Guidelines.
Foreword

It gives me great pleasure to commend this important initiative.

Diabetes is an important chronic disease, arguably the most important. We manage chronic disease - but we don't cure it.

It is the nature of chronic diseases that they persist and progress. Ultimately culminating in death. Without this recognition we ceaselessly ramp up intervention. In the process we can easily make 'endings' very invasive and highly technological—often very different from what the person with diabetes desires.

Without thought we trade dignity, dependence and comfort for a longer, but miserable, existence. We lose sight of humanity.

Of course, some of us DO want 'everything' done as things fall apart, but research tells us that this is a small minority (about 7%).

The remaining 93% want something less than 'everything', and we need to ask them what they do want and what they do not want.

Asking and listening are central to the concept of patient-centred care, driving a logical and compassionate transition to palliative care.

The 2016 'National Strategy for Chronic Conditions' established the national policy platform to 2025. It advocates early detection, [which is very appropriate], and better long term management, [which is admirable]… but that's it … there is no more.

There is 'no end' in the strategy. It seems as if we do better we can live forever. Death is never mentioned.

Unfortunately, these things matter. Strategy drives funding and strategy drives action. In the absence of relevant strategies, this guideline is particularly important.

The authors explained the issues in simple but persuasive terms for patients, families and doctors and other clinicians. I congratulate Diabetes Australia who supported the suite of information for people with diabetes, families and health professionals that accompany these Guidelines, and can be used alone to support shared decisions and Advance Care Planning.

Associate Professor Charles Corke
School of Medicine Deakin University
Intensive Care Specialist Barwon Health
Advocate for Advance Care Planning
Key philosophical principles

The following key philosophical principles underpin these Guidelines

• Death is a normal part of life: the time of death is unknown.
• Most people want ‘a good death.’ The notion of a good death is highly personal.
• Preserving autonomy, independence, personhood and dignity are core care considerations for person-centred care.
• People with diabetes and multimorbidities can benefit from palliative care at any time.
• Palliative care can be used to complement usual diabetes care to reduce treatment and disease burden, manage suffering and improve function and quality of life. Most benefits accrue when palliative care is commenced early.
• Respectful communication and shared decision-making are essential to holistic personalised diabetes care planning.
• Proactive risk assessment to recognise and manage deterioration leads to better decision-making and outcomes.
• Advance care planning and clearly documented values can reduce family and clinician uncertainty when the individual is unable to decide for him/herself.
• Good communication, ethical awareness and shared decision-making are essential health professional skills. Discussing death can help ensure the person receives the benefits of palliative care and make inevitable death easier.
• All health care has ethical implications and can affect outcomes. To be ethical, the aim should be to promote evidence-based care as well as the individual’s dignity, values and care preferences. The following ethical principles should be considered:
  • Autonomy (right to self determination)
  • Beneficence (beneficial care)
  • Maleficence (minimising harm/risks)
  • Justice (fairness, distribution of benefits, burdens and risks)
• Preferences for being involved in shared decision-making depend on the individual and they may change in specific circumstances and over time.

In Australia:

• 54% of people die in hospital and 32% die in residential aged care facilities (RACF).
• Approximately 60–70% would prefer to die at home – only 14% do so.
• 50–90% of Australians could benefit from palliative care – many do not receive it (Swerissen et al 2014).
Framework for implementing diabetes palliative and end of life care to support function and personalised proactive care planning.

### Diabetes trajectory

**Basically well and functionally independent.**
- Consider number of comorbidities.
- Functional assessment, including diabetes-self care.
- Hypoglycemia risk assessment.
- Medicine-related adverse event risk.

**Declining function - one of the following:**
- comorbidities
- polypharmacy
- foot/leg ulcers
- severe hypoglycaemia
- depression, social isolation
- frailty
- falls
- cognitive changes or dementia
- social isolation.
- Carer burden – a predictor of the care recipient admission to a care home.
- Discuss stopping activities such as driving when applicable.

**Significant functional deficits.**
- Sarcopenia, frailty.
- Falls.
- Frequent admission to hospital or Emergency Department.
- Declining will to live.
- Poor self-rated future health.
- Carer not able to cope.

**Terminal Stage**
- End of life and terminal care.
- Decide care according to the individual’s values and goals.
- Simplify medicine regimen and stop most medicines.

### Management focus and care planning

**Usual diabetes management but consider whether HbA1c and blood glucose target ranges are safe.**
- Preventative care: health screening e.g. for cancer, vaccinations and dental checks. Treat reversible inter-current illness including hospital admission if needed.
- Medicine review, diet review and tailor sick day and hypo care plans to individual risk.
- Palliative care could be implemented with usual diabetes care e.g. to manage pain.

**Continue usual diabetes care, complication assessments and consider referring for palliative/geriatric assessment.**
- Treat reversible inter-current illness including hospital admission if needed, but there may be some treatment limitations (LMOT).
- Medicine review.
- Assess frailty status before surgery and before and after hospitalisation and encourage early ambulation.
- Revise HbA1c and other target ranges to avoid hypo and hyperglycaemia.
- Consider discussing values and care goals and use them to inform the care plan. If the person elects to develop their ACD, regularly review it to make sure their preferences have not changed. ACD should be documented before admission to a care home.
- May need protein and other supplements if malnourished and losing weight.

**Palliative care/geriatric assessment and review ACD**
- Medicine review continue insulin in T1DM.
- Consider stopping GLMs and commencing insulin in T2DM if indicated.
- Check that ACD still reflects the individuals care goals.
- Offer dignity therapy if available.

**Provide comfort care e.g. manage pain.**
- Implement the individual’s ACD.
- Pronounce death compassionately.
- Support family carers – e.g. offer bereavement counselling.
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<th>Description</th>
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<tbody>
<tr>
<td>ACC</td>
<td>Annual Cycle of Care (Annual Diabetes Check)</td>
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<td>ACD</td>
<td>Advanced Care Directive</td>
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<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
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<tr>
<td>BGM</td>
<td>Blood glucose monitoring</td>
</tr>
<tr>
<td>CM</td>
<td>Complementary Medicine is an umbrella term that refers to a wide range of traditional, complementary and alternative medicines and other therapies.</td>
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<tr>
<td>CKD</td>
<td>Chronic Kidney Disease</td>
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<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
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<tr>
<td>DE</td>
<td>Diabetes Educator</td>
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<tr>
<td>DKA</td>
<td>Diabetic ketoacidosis</td>
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<tr>
<td>eGFR</td>
<td><em>estimated</em> Glomerular filtration rate</td>
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<tr>
<td>GSF</td>
<td>Gold Standard Framework (The Gold Standard Prognostic Indicator)</td>
</tr>
<tr>
<td>GLM</td>
<td>Glucose lowering medicines (sometimes called Oral Hypoglycaemic Agents (OHA) or antidiabetic medicines)</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HbA1c</td>
<td>Glycated Haemoglobin, a measure the average blood glucose level over the three months preceding the test given as a percentage (%) or mmol/mol</td>
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<tr>
<td>HHS</td>
<td>Hyperosmolar Hyperglycaemic States (formerly known as Hyperosmolar non- ketotic coma or HONK)</td>
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<tr>
<td>Hypo</td>
<td>Hypoglycaemia</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive Care Unit</td>
</tr>
<tr>
<td>IGT</td>
<td>Impaired glucose tolerance/glucose intolerance</td>
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<tr>
<td>IM</td>
<td>Intramuscular</td>
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<tr>
<td>IRS</td>
<td>Insulin resistance syndrome</td>
</tr>
<tr>
<td>IV</td>
<td>Intravenous therapy</td>
</tr>
<tr>
<td>LADA</td>
<td>Latent Autoimmune Diabetes in Adults</td>
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<tr>
<td>LOMT</td>
<td>Limitation of Medical Treatment Orders</td>
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<tr>
<td>MET</td>
<td>Medical Emergency Team</td>
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<tr>
<td>MI</td>
<td>Myocardial infarction</td>
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NHMRC  National Health and Medical Research Council
OGTT  Oral glucose tolerance test
mmol/L  Millimoles/Litre—unit to describe the level of glucose in the blood
PCOC  Palliative Care Outcomes Collaboration
QUM  Quality use of medicines
RACF  Residential Aged Care Facility
RRT  Rapid Response Team
TIA  Transient ischaemic attack
UTI  Urinary tract infection
Doctors have counselled those patients [with diabetes] for many years about the need to control blood sugar [glucose] more tightly. Doing an about face and recommending controlling blood sugar [glucose] less tightly may be uncomfortable for doctors.

(Lee et al. 2016).
Introduction

Palliative care should be seen as complementing usual diabetes care: not as a failure of usual care.

Palliative care improves quality of life and reduces unwanted hospital admissions, including emergency department and intensive care admissions and burdensome, futile end of life care. It is possible to manage symptoms such as pain and delirium to improve comfort and dignity in any care setting (WPCA/WHO 2014, Mannix 2017). Most people require relatively simple clinical approaches, but some require more complex care. Palliative care can be delivered in the individual’s home, a palliative care unit or a hospice, and in hospital.

People with diabetes often have one or more diabetes-related complications such as cardiovascular, renal and hepatic disease, some cancers, neuropathy and sensory deficits that lead to functional decline, especially in older people. In addition, they frequently have other comorbidities such as depression and arthritis; consequently they carry a heavy disease and treatment burden, including polypharmacy. Early introduction of palliative care can reduce some of the burden and improve outcomes, especially, comfort, function and quality of life.

Palliative care can be integrated into ‘usual diabetes care’ including at diagnosis, for example those with significant renal and cardiovascular disease and dementia. That is, a palliative approach to care can be appropriate, even at diagnosis, if it is consistent with the individual’s health status and their values, preferences and goals, and contribute to continuity of care among health services and throughout the disease trajectory (Fjose et al. 2018). However, 80% of people are admitted to hospital in the last year of their life, many spend ≥30 days in hospital, 55% die in hospital, and 12% are admitted to ICU: only 24% receive palliative care (Goldsbury et al. 2015). Palliative care can be cost saving, especially care for people at risk of with dementia (Nguyen et al. 2017).

General goals of palliative care

- Achieve a dignified death in the individual’s place of choice. Consider spiritual, cultural and religious beliefs and needs. People usually appreciate more time at home and less in time in hospital.
- Have honest, open conversations about the individual’s prognosis, concerns, values and goals.
- Provide support for families and other caregivers, including after the individual dies when family are particularly vulnerable.

Other important considerations for people with diabetes include making decisions about how hypo- and hyperglycaemia affect comfort, quality of life and safety. People with diabetes want blood glucose managed to prevent hypo- and hyperglycaemia and describe these conditions as frightening, uncomfortable and affecting their cognition and decision-making capacity (Savage et al. 2012).

Palliative and end of life care and the NSQHS Standards

The revised National Safety and Quality Health Service Standards are due to be fully implemented in 2019 (NSQHS 2017) and could be used in most care settings. The Standards encompass communicating, planning for end of life care, managing medicines and recognising deterioration; all of which are relevant to diabetes palliative and end of life care. Standards 2, 4, 5, 6 and 8 are particularly relevant.

However, it is essential that Standard 1, which concerns clinical governance, encompasses palliative and end of life care to ensure these care options are integrated into organisational policies to enable it to meet the other standards. Shared decision-making, communication, comprehensive care, medicine management and recognising clinical deterioration are important aspects of the Standards and of palliative and end of life care.

The revised Guidelines will help health professionals and organisations incorporate relevant evidence-based diabetes, palliative and end of life strategies into their organisational policies and procedures as well as professional development programs to meet the required standards.

General goals of palliative care

- Consider the ethical and legal aspects of care.
- Improve and maintain dignity, function, independence and quality of life.
- Achieve life goals.
- Ensure the individual is comfortable and that pain and distressing symptoms are adequately managed.
Purpose of the Guidelines

- To support clinicians to provide optimal personalised care to people with diabetes and families when palliative and end of life care is required.
- Provide diabetes-specific guidance that can be used with existing palliative and end of life care guidance.
- Support Advance Care Planning.

Changes made to the revised Diabetes Palliative and end of life care guidelines

The first version of the guidelines published in 2010 only addressed end of life care. The scope was expanded in this second edition to include palliative care and Advance Care Planning. In addition, guidance is provided about communication and shared decision-making, complementary medicine (CM), and evaluating patient reported outcomes and experiences.

Appendix 1, John’s Story, is a case study that links John’s disease trajectory to clinical issues in related sections of the Guidelines.

Appendix 2 explains the terms: life limiting illness, palliative care, end of life care and advance care planning and advance care directives.

Palliative care is for everybody. It affirms life and that death is normal.

Medical Emergency Teams (MET) as well as other clinicians and the public should regard ‘dying’ as a primary diagnosis (Hilton et al. 2013, Jaderling et al. 2017).

The NSQHS standards refer to monitoring vital signs to detect deterioration. Recognising changes in function, health status and the will to live also reflect deterioration and are important guides to decisions about when to implement palliative care and commence advance care planning.

The following palliative and end of life care guideline domains/topics are included in the Guidelines and refer to types 1 and 2 diabetes unless specified:

- Communication.
- Personhood, dignity and spirituality.
- Advance care planning and advance care directives.
- Blood glucose and HbA1c monitoring and target ranges.
- Hyperglycaemia and managing inter-current illnesses – the need for personalised sick day care plans.
- Hypoglycaemia and personalized, hypoglycaemia management plans.
- Nutrition and Hydration.
- Managing medicines: the importance of pharmacovigilance and non-medicine options.
- Diabetes and diabetogenic medicines e.g. corticosteroids.
- Assessing people receiving palliative care for undiagnosed diabetes.
- Diabetes education.
- Supporting caregivers.
- Annual Cycle of Care (ACC).
- Recognising deterioration towards end of life to enable Advanced Care Directives to be initiated.
- Quality indicators to assess and evaluate Palliative and end of life care.

In addition, salient quotes are used throughout the guidelines; their purpose is to highlight key points and could help clinicians reflect on their approach to diabetes and palliative and end of life care and the words they choose.

Key communication strategies clinicians can use to achieve personalised care and core outcomes are included at the end of each guideline.

The communication strategies relate to the components of the Calgary-Cambridge Framework, and are explained in Appendix 3”” on page 66-69.

Cancer, diabetes, lung and heart disease are the top four killers in the world, accounting for 71% of all deaths globally.

(World Health Organisation June 1 2018).

Palliative care is not only the prerogative of palliative care specialists. All clinicians who care for people with serious conditions need to initiate palliative care in a timely manner. Health service providers need to facilitate palliative care through policies and services.

(National Coalition for Hospice and Palliative Care 2018).
Quality health care includes addressing spiritual needs and maintaining dignity and autonomy as long as possible (Lothian et al. 2001). Spirituality, dignity and autonomy are often undermined in health care settings during personal care, especially when people are cognitively impaired and vulnerable. Providing older people with diabetes and their families with ‘good’ information suited to their capacity to receive the information and using relevant language to encourage decision-making and informed choices are essential aspects of dignity.

Spirituality refers to finding meaning and purpose in life and may or may not include religion (Steinhauser et al. 2009, Parsian & Dunning 2009). People can find meaning and purpose up to the point of death and some religions believe after death. Therefore, spirituality is closely aligned to dignity.

The person’s spirituality and dignity influences their treatment choices and their resilience and coping strategies. People regard a positive end of life experience as part of a good death that helps them be at peace (Steinhauser et al. 2000).

Emotional and spiritual wellbeing are underpinned by ‘the broadly worded construct of being at peace’ (Steinhauser et al. 2009). Clearly documented values and care goals can help people be at peace.

Dignity encompasses maintaining self-respect and being valued by others and is closely aligned with autonomy, having control over one’s life and shared decision-making. Elements of care that help people feel valued, in control, dignified and respected include providing timely adequate information and the quality of their interactions with health professionals (HelpAged 1999).

Stereotypical language, ageism and elderspeak contribute to loss of dignity, depression, hopelessness and make people feel they are a burden to others (Chochinov et al. 2015). Such language can lead to challenging and aggressive behaviour. Thus, good communication and appropriate language have the power to support dignity and heal. Inadequate communication leads to harm and compromises dignity and personhood.

Ascertain the words the person uses and rephrase your words if necessary. Determine what dignity means to the individual.

Ask them questions such as: Are you at Peace? What things give meaning to your life? What does a good death mean to you?

Listen to the person’s word choices, which reveal useful/acceptable language the health professional can use to discuss palliative and end of life care, spirituality and dignity with the individual.

Monitor spiritual health e.g. use The Flourishing Scale (Diener et al. 2010).

Provide relevant information and give the person time to read it, discuss it with important others, and ask questions.

Refer the person for Dignity Therapy programs if they are available, or establish one in your practice setting.

And so it’s listening, honouring and responding to that, [what people say] and maintaining people’s sense of dignity

Lacey, ABC News 2018-09-28
The inability to acknowledge personhood – the insensitivity of not acknowledging personhood – can be psychologically devastating.

(Chochinov 2015).
Communication

Communication is central to personalised care and fostering dignity, autonomy and respect. Effective planning depends on clinicians building a relationship with the person with diabetes and their families to co-share information on which to base care decisions. Clinicians must ask effective questions and then listen to the response.

Various factors affect communication including health literacy of the individual and the clinician.

The Calgary-Cambridge framework (page 10) and Appendix 3 for clinical communication provides a guide to the processes and skills clinicians need to deliver person-centred care. A core aspect of the framework is the requirement to listen and gather information before giving information when clinically possible.

- Consider the communication strategy for each conversation with each individual.
- Use effective listening, for example
  - Look the individual in the eye when you are talking with them to build rapport.
  - Ask about personal issues, not just medical facts.
  - Use probing and clarifying questions.
  - Learn how to interrupt people ‘the right way’; that is in a non-intrusive way that acknowledges the issue such as pain, can build rapport, help the person focus and express support (Starkey D, Niederehe G. (1974) On signalling that its your turn to speak. Journal Experimental Social Psychology 10 (3):234-247).

Many older people with diabetes have sensory and cognitive deficits that influence communication. Likewise, hypo- and hyperglycaemia affect cognition in the short term and can affect problem-solving and decision-making capacity. Important conversations should be undertaken when the blood glucose level is in an acceptable range.

Two pillars: building rapport and maintaining structure to the conversation keeps the person central to the issues being discussed and enables shared decision-making. It is essential to determine the individual’s agenda, see appendix 3.

Four interruption categories are described. Only interrupt if necessary:

1. Interrogative – how long have you had the pain?
2. Elaborative – tell me more about your pain.
3. Recomplete – so, your pain wakes you at night?
4. Refocus – let’s sort out what’s going on.

Each category is appropriate, depending on the individual and the context of the conversation.

Key points

- Clinicians interrupt the individual within 11 seconds of asking a question.
- Individuals share their concerns/agenda within 6 seconds, if they are not interrupted.
- The person’s agenda is not addressed in 80% of conversations (Ospina et al, 2018).
- Do not assume health professionals receiving care know what palliative and end of life care encompasses just because they have a health background.
Figure 1: Calgary–Cambridge Framework
Reproduced with permission.
Advance care planning (ACP) and advance care directive (ACD)

ACP refers to the process patients, family members and health professionals use to discuss, document and communicate values, goals of care and management preferences for a future time when they are not able to make decisions for themselves (Song et al 2015, Victorian Government 2016).

An ACD is a document that describes the person’s values and their care preferences. Values influence people’s care preferences. It is important to understand their values to understand/decide care preferences.

Making ‘in the moment decisions’ can be emotionally confronting (Sudore & Fried 2010), even when the individual has an ACD, especially when there is conflict within the family. Discussing life expectancy and writing an ACD does not have to be done all at once. In fact, ACDs should be reviewed regularly to ensure they still reflect the individual’s preferences and goals, which can change over time.

The discussion can be tailored to the person’s health status and disease trajectory.

In Victoria, the ACD has three sections:
1. Demographic information.
2. Values Directive, which refers to the things that give meaning and purpose to the person’s life.
3. Instructional Directive: The care they want or do not want if they are unable to decide for themselves. (Victorian Government 2016).

The ACD must be witnessed by two people; one of whom must be a medical doctor. It must also be signed and dated. Programs such as Advance Care Planning, formerly Respecting Patient Choices, can help people think through their values and care preferences and document an ACD.
Consider referring the individual for a comprehensive geriatric assessment and/or a palliative care assessment.

Deciding goals of care is an important part of shared decision-making and Advance Care Planning. Discussing and documenting the individual's values and goals of care in an ACD aids clinical and family decisions. Clearly documented values and goals of care are particularly useful in residential aged care facilities (RACF), especially for issues such as CPR/not for CPR, whether to treat reversible illnesses, and comfort/dignity care.

It is becoming increasingly important to encourage people to proactively develop an Advance Care Plan. Often such decisions are left until the person is too unwell to express their own wishes or when an emergency arises. Clearly, emergencies are not the ideal time for people to make complex, emotional decisions. Clinicians should help people with diabetes to make informed decisions by providing them with information about their diabetes and disease trajectory.

Triggers for these discussions include:
- When the person or family asks.
- New diagnosis of diabetes or any medical condition.
- Deterioration in health status.
- Admission to hospital or residential care.
- During the annual Cycle of Care or at the person or caregiver’s request.

It is particularly important that discussions about the Goals of Care occur when a person is admitted to hospital and that they are clearly documented and communicated through usual health services procedures.

Older people with multiple comorbidities are at high risk of dying in hospital, particularly those who experience a deterioration requiring a Rapid Response Team (RRT) or Medical Emergency Team review (ANZICS-CORE annual report 2013).

Clearly, during and just after a MET call is not an ideal time for people to make complex, emotional decisions. Making informed decisions about ACD/LOMT requires a reliable understanding of the individual’s illness trajectory to reduce unwanted and inappropriate treatment, including resuscitation.

Helping each person and their families and caregivers make informed decisions about the care and treatments they want or do not want requires knowledge and careful discussion about the individual’s illness trajectory. It is important that the individual receives treatment that maintains dignity and improves comfort and QOL.

It is important that the individual's values and preferences concerning these issues are documented. Given 20%–35% of RRT/MET calls result in death and 20%–30% of people who die in hospital receive a MET review. Those who are older and have multiple comorbidities are more likely to die in hospital (ANZICS-CORE annual report 2013). However, it is equally important that the individual documents the care they do want to receive.
Key issues to discuss with people with diabetes include their values and care preferences, a resuscitation plan that generally includes information about whether the individual wants to receive or does not want to receive the following life support measures:

- Cardio Pulmonary Resuscitation (CPR)
- Airway support (intubation)
- Non-oral feeding (enteral/parenteral)
- Renal dialysis
- Medical Emergency Treatment (MET) calls when they are in hospital.
- Admission to Intensive Care.
- Medicines e.g. for pain, to treat infections, glucose lowering medicines, including insulin, and when to stop medicines.
- Blood glucose monitoring
- Preferred place of death and who they would like present at their death.

Other important advance care planning issues include:

- Living wills.
- Funeral arrangements.
- Appointing a Medical Treatment Decision-Maker, formerly surrogate decision maker, and other types of powers of attorney.

Dunning et al. 2018 developed three pieces of information to help older people with diabetes, their families and health professionals initiate discussion about palliative and end of life care, Advance Care Planning, and document an Advance Care Directive. All three versions of the information can be downloaded from:

https://www.dropbox.com/s/ubjazzs6z6rsoq4l/Information-for-HPs.pdf?dl=0

https://www.dropbox.com/s/u5absf19uv01kmx/Information-to-help-family.pdf?dl=0


The health professional version can also be accessed from iTunes:


**Key Points**

- Laws and regulations concerning palliative and end of care vary among Australian states.
- Health professionals need to be aware of the laws and regulations in the state they practice in.
- The person should be informed that the laws and regulations can differ in other states and they need to clarify whether their ACD will be honoured in other states and in other countries if they travel.
Advance care directives may be undervalued by the health system, but they will never be forgotten by patients and their families 

(Professor Leanne Rowe 2018)
Blood glucose monitoring (BGM) is still required and is useful when palliative care is implemented. It is especially important in type 1 diabetes (T1DM).

Preventing long term diabetes complications may no longer be a priority; but managing existing complications is important to control the associated uncomfortable symptoms and prevent hypo- or hyperglycaemia and unnecessary admissions to hospital when recovery is unlikely (IDF 2013, Dunning et al. 2010; Savage et al. 2012).

Hypo- and hyperglycaemia affect cognitive function, especially problem-solving and decision-making capacity, and consequently the ability to make autonomous informed decisions.

Monitoring BGM is important to detect hypo- and hyperglycaemia because the associated symptoms are often atypical, and/or are attributed to other causes, and not treated.

People with diabetes and their families want BGM to continue during palliative and end of life care because it is a familiar self-care activity during changing, uncertain times, and importantly, helps them interpret symptoms (Dunning et al 2010, Savage et al. 2012). Some people with diabetes feel staff ‘gave up on them’ if BGM is stopped.

Blood glucose and HbA1c ranges and the frequency of BGM must be personalised to food intake and the action profile of the glucose lowering medicine/s the individual is prescribed or self prescribed (see Appendix 5) and their risk of hypo-hyperglycaemia. A safe general BG target range is 6–11.5 mmol/L and HbA1c 7%–8% (IDF 2013; Dunning et al. 2014). However, there is very little evidence to support these recommendations. The aim is to avoid hypo- and hyperglycaemia and the associated consequences.

Reportable blood glucose ranges are often used in residential aged care facilities (RACF). Many are unsafe. Reporting isolated high BG levels often results in the prescription of ‘top up’ or stat insulin doses, which can cause rebound hypoglycaemia followed by hyperglycaemia and result in a vicious cycle. Stat insulin doses are generally contraindicated and represent outdated practice (American Geriatrics Society 2019, Munshi 2016).

Some complementary medicines (CM) and nutritional supplements can affect blood glucose levels, thus it is important to monitor blood glucose, especially when they begin or cease CM (Yeh et al. 2003). See appendix 4 page 71.
Assess the individual’s:

Care goals, values and preferences.
Self-care capacity including CM use, health literacy, knowledge, manual dexterity, capacity to undertake BGM and vision and hearing.
Support available to help them monitor and interpret the BGM pattern, if they cannot perform BGM themselves.
The carer’s knowledge of diabetes management tasks such as medicine management and BGM and provide education if necessary.

Risk of hypo and hyperglycaemia including the GLM and other medicine risk profiles to determine an appropriate BGM schedule that suits the action profile of the GLM. See hypoglycaemia risk assessment tool on page 24, the medicines management (page 25), managing corticosteroid medicines page 33 and CM interactions (Appendix 4).

BGM pattern to detect consistent hypo- and hyperglycaemia and glucose variability all of which have adverse consequences.

Plan the BGM and HbA1c target ranges with the individual and/or their carers.

Involves carers in discussion, decision-making and education, when relevant.

Ensure the person has personalised hypoglycaemia and hyperglycaemia (sick day) management plans.

Some people could be using an insulin pump and or flash BGM or continuous BGM. These individuals will need specialist advice about their insulin doses and changing insulin needs as their disease progresses e.g. weight loss, commencing diabetogenic medicines. Staff need to respect the individual’s knowledge about the technology, learn the skills to advise how to monitor BGM and interpret the emerging pattern. Provide written personalised information about what the individual should do if their BGM results are outside their target range.

Ensure blood glucose meters are control tested regularly, at least weekly in hospitals and RACFs and between patients/residents (ADA 2019) and BG test strips are in date, and are the correct strips for the blood glucose meter.

Key Communication Strategies

- Person’s perspective of disease - Ideas, Concerns and Expectations (ICE).
- Chunking and checking.
- Aligning agendas if mismatch.

Calgary–Cambridge Section: Shared decision-making (Appendix 3).
Key points

- Recent publications e.g. Malanda et al. (2012), Young et al. (2018) suggest self-BGM is not useful in people with T2DM, who are not using insulin because it only results in 0.3% reduction in HbA1c in six months. However, people with T2DM receiving palliative or end of life care could be eligible to obtain test strips from the National Diabetes Services Scheme (NDSS) because of their comorbidities and health status.

- Decide a blood glucose and HbA1c range that is safe for the individual and that avoids hypo- and hyperglycaemia.

- Isolated top-up/stat doses of insulin to correct hyperglycaemia are not recommended. (ADA 2019, AGS 2019)

- Consider the emerging BG pattern when making care decisions.

- Personalise hypoglycaemia and hyperglycaemia care plans.

- Clean and control test blood glucose meters regularly.

- CM and supplements that can affect blood glucose levels include: zinc, chromium, vitamins D, E and B complex.
Hyperglycaemia

Hyperglycaemia is not benign or acceptable. It is a major contributor to long term complications. In the short term it contributes to dehydration, fluid and electrolyte disturbance and incontinence (Muche 2015) and predisposes the individual to inter-current illnesses such as UTI, foot infections and respiratory diseases. Reduced thirst sensation also contributes to dehydration. Hyperglycaemia affects cognition, especially executive functions, which in turn affects the individual’s problem-solving and decision-making capacity such as when to implement their sick day care plan.

In addition, hyperglycaemia can cause orthostatic hypotension, sensitivity to medicines and increase falls risk (Muche 2015). Osmotic symptoms such as thirst, urinary frequency, lethargy, delirium and confusion are often present. Quality of life is affected and pain can be exacerbated (Savage et al. 2012).

Hyperglycaemia can be present without the usual symptoms; consequently it can be missed and go untreated and progress to diabetic ketoacidosis (DKA) or hyperglycaemic hyperosmolar state (HHS) in people with T2DM.

DKA and HHS are clinical emergencies and are associated with high morbidity and mortality (Dhatariya & Vellanki 2017). About 10% of people with DKA present with euglycaemia. Euglycaemia can also be a feature of HHS, which mostly occurs in older people, develops over days to weeks, commonly presents as an altered mental state and has a higher mortality rate than DKA (Avichal 2019). HHS can occur in people using sodium glucose co-transporter 2 inhibitors (Rittenhouse et al. 2009).

Hospital admission and intravenous fluid replacement and insulin may be required to treat DKA and HHS.

T2DM is associated with progressive loss of beta cell function and declining insulin production. Thus, > 50% people with T2DM eventually need insulin (UKPDS 1998), especially in palliative situations when diabetogenic medicines are prescribed. People with T1DM require insulin from diagnosis and may require extra insulin during acute illness and when using diabetogenic medicines.

**DKA diagnostic criteria**

- Glucose > 15 mmol/L
- Blood ketones > 3.0 mmol/L
- pH < 7.3 – use venous pH to diagnosis acidosis.
- Serum bicarbonate < 15 mmol/L

**HHS diagnostic criteria**

- Glucose often very high > 30 mmol/L.
- pH > 7.3
- Plasma osmolality > 320 μOsm/kg
- Bicarbonate > 15 mmol/L
- No blood ketones.
- Hypernatraemia > 50%

**Assess:**

Whether the individual has T1DM or T2DM. There is a danger of not testing for ketones associated with the commonly held ageist attitude that ‘all older people have T2DM.’

Presenting signs and symptoms and the person’s illness story.

Signs of inter-current infection but note these can be atypical.

Self-care capacity, including medicines self-management and adherence, cognitive status, diet and activity and ability to manage or seek help for inter-current illnesses.

BG pattern and HbA1c. However, HbA1c is not a useful diagnostic aid in the short term.

Medicines regimen and ask about self-prescribed medicines, natural health products, supplements, therapies and customary diets or healing practices (see Appendix 4).

Physical assessment: degree of dehydration, thirst, not able to take GLMs and other medicines, inter-current illness.

Vaccination status.

Presence of pain.

Presence of ketones is an indication of ketosis.
People should have a **personalised plan for managing inter-current illnesses** (sick day care). Commonly used sick day care plans may not be appropriate for people receiving palliative care, especially if they are old and/or have swallowing difficulties or are immunocompromised.

The plan must be developed with the individual and/or their family carers.

The plan might include more frequent BGM and blood ketone testing during illnesses, especially in T1DM.

Blood ketone testing must be part of the care plan for people with T1DM who are acutely ill.

Metformin might need to be stopped during acute illnesses in people with T2DM.

The sick day care plan should encompass how to recognise deterioration and when to call a doctor or go to hospital, which might be early to prevent DKA/HHS.

IV fluid replacement and insulin are usually required in hospital.

Discharge planning and education are essential to reduce risk of readmission, which commonly occurs in people age 65 and older, especially those with heart failure, multiple recent hospital admissions and who consult multiple prescribers (Caughey et al. 2017).

Most readmissions occur within 14–30 days but can occur up to 180 days later (Caughey et al. 2017).

Families/caregivers may need support, frequent explanations and education about how to recognise and manage hyperglycaemia and what BG levels and symptoms should trigger them to seek health professional advice (Savage et al. 2012).

Ensure end of life care plans are documented and communicated.

Implement the end of life care plan if relevant. DKA and HHS are remediable but can be fatal.

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**Key points**

Ensure:

- Staff can recognise and intervene early to prevent DKA and HHS.
- Increase BGM frequency and test for ketones. People with T1DM have died unnecessarily in RACFs as a consequence of not testing for ketones and not recognising the severity of the dehydration and metabolic decompensation.
- The individual should have a personalised sick day care plan that could encompass an ACD.
- The individual and family know when and how to seek advice from their clinicians.
- DKA occurred in 4.4% of hospitalised people with T1DM in a recent UK National Diabetes Inpatient Audit (NaDia 2016).
- HHS occurred in 0.2% of people with T2DM.

Many of these episodes are preventable adverse events
Hypoglycaemia is a significant risk for many people on glucose lowering medicines (GLM). Risk factors for hypoglycaemia are listed in the Hypoglycaemia Risk Assessment Tool on page 24 (Dunning et al. 2014).

Hypoglycaemic risk can change over time and in different situations and needs to be assessed regularly e.g. at any change in health status, changes to medicine regimens and during the annual cycle of care (ACC).

Twenty seven percent of hospital inpatients with T1DM had severe hypoglycaemia in a recent UK diabetes hospital inpatient audit (NaDIA 2016). Most severe episodes occurred between 5am and 8.50 am, which suggests they may have had nocturnal hypoglycaemia, which might not be identified by many BGM regimens.

Hypoglycaemia affects delayed and working memory in the short term; thus decision-making and problem-solving (Seaquist et al. 2013, Chopra & Kewal 2012), can trigger myocardial infarction (Bissells et al. 2006), and is associated with dementia in the longer term (Meneilly et al. 2011).

Severe hypoglycaemia results in hospital admission in people > 80 years with T2DM (Greco et al. 2010) and is associated with increased mortality.

Hypoglycaemia contributes to fall and if prolonged can lead to hypothermia in cold weather.

Regular BGM is important to detect hypoglycaemia in people at high risk of hypoglycaemia. Symptoms can differ from ‘text book’ symptoms, especially in older people and those with long duration diabetes.

Adrenergic signs can be missed. Neuрогlycopenic symptoms usually predominate because of the changed counter-regulatory response to falling BG levels.

Over time, glucagon, cortisol and growth hormone production diminishes (Seaquist et al. 2013, McCoubrie et al. 2004). These hormones trigger the adrenergic response. It is important that health professionals learn to recognise the neuрогlycopenic signs and help people with diabetes and their families learn to recognise their new hypoglycaemia cues.

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**Degrees of hypoglycaemia**

- **Mild** <3.9 mmol/L, usually able to self-treat.
- **Autonomic-symptoms** occur about 3 mmol/L.
- **Severe-neuрогlycopenic symptoms** ~ 2.8 mmol/L need assistance to manage the episode (Munshi 2016).
- **Renal disease** affects medicine excretion.
- **Macroalbuminuria** predicts hypoglycaemia (Yun et al. 2013) and end stage renal disease is an indicator of the need for palliative care.
• Proactively undertake a hypoglycaemic risk assessment with the older person and or carers and use the information to decide a safe BG range and develop a personalised hypoglycaemia management plan.
• Undertake a comprehensive medicine review and identify medicines that increase the hypoglycaemia risk.
• Consider whether glucose lowering CM and glucose lowering medicines could be stopped.
• Carefully consider the choice of GLM/s, dose and dose frequency to maintain BG > 4-6 – 11mmol/L to reduce the hypoglycaemia risk (IDF 2013; Diabetes UK 2018, Dunning et al. 2014).
• Ask about complementary medicines, supplements, therapies and customary diets or healing practices and self-prescribed medicine use (see Appendix 5).

**Common risk factors for hypoglycaemia include the following. The more risk factors present the greater the risk:**

• Prescribed glucose lowering medicines (GLM), especially sulphonylureas and insulin.
• Using medicines (both pharmaceutical or CM), natural health products and supplements that interact with GLMs.
  - Medicines that affect appetite. Many self-prescribed medicines can affect appetite, e.g. diet/weight loss some are considered natural or complementary medicines.
  - Weight loss, malnourishment and cachexia affect glucose stores and inhibit the ability to mount a counter-regulatory response.
  - Cachexia occurs in 40-90% of people with cancer (Sequist et al. 2013).
  - Hypoglycaemia.
• Liver disease affects medicine metabolism.
• Autonomic neuropathy that affects the gastrointestinal tract can reduce food absorption.
• Hypoglycaemia unawareness is common, especially in people with long duration of diabetes and autonomic neuropathy, and affects their ability to mount a counter-regulatory response because of inadequate secretion of key counter regulatory hormones such as glucagon (Sequist et al. 2013, McCoubrie et al. 2004)
• Cognitive impairment and delirium, which could be due to chronic hypoglycaemia, hyperglycaemia, medicines, renal disease, depression, dementia, delerium, other causes or a combination of all of these factors.
• Unmanaged pain affects appetite and glucose stores. Adequate pain management is essential.
• Fasting for procedures, surgical interventions or for religious reasons.
• Health professionals and family carers mistakenly attributing hypo-hyperglycaemic coma to other causes such as the dying process.
• Set safe BG and HbA1c target ranges for the individual.
• Develop personalised hypoglycaemia care plan.
• Select the safest class of medicine and individual medicine in the class. Newer SGLT-2 medicines and insulin analogues have lower risk of hypoglycaemia (Wu 2017).
• Treating hypoglycaemia is difficult when people have anorexia and nausea and/or vomiting because of the low glucose stores in muscle and liver and the changed counter-regulatory response to falling blood glucose levels that often occurs in older people and those with long duration of diabetes (Smythe & Smythe 2005). Small frequent snacks, rather than ‘three meals per day’ might be easier for people to consume and digest.
• Help the person develop a personalised hypoglycaemia management plan which might include teaching the family how and when to use Glucagon and what to include in a hypo management kit e.g. BG monitoring equipment, fast acting glucose.
• GLMs are often stopped when people have frequent severe hypoglycaemic episodes. However, stopping GLMs might not be appropriate, except in the deteriorating and terminal stages, because of the likelihood of hyperglycaemia and its adverse effects, especially people with T1DM and insulin requiring T2DM.
• Educate the individual, family/carers and health professionals about how to recognise hypoglycaemia e.g. consider Blood Glucose Awareness training (BGAT).
• Educate the individual and family carers about every change to the medicine regimen.
• Dietetic advice can help health professionals and family/carers plan an acceptable diet and provide supplements if necessary to reduce the effects of malnutrition and minimise weight loss. Cachexia and sarcopenia lead to loss of muscle mass, which contributes to weakness, reduced capacity to mount a counter-regulatory response to hypoglycaemia and increases falls risk.
• Discuss risk of hypoglycaemia when driving. BG must be ‘above 5 to drive’ (Diabetes Australia 2018).
• Treat episodes according to relevant guidelines and the severity of the episode. Refer to the person’s Advance Care Directive if relevant.

Key Communication Strategies
• Safety netting (what to do in case it happens).
• Patient Summary or “Teach back” technique (checking they understand what to do).
• Explore concerns (without premature reassurance).

Calgary-Cambridge Section: Explanation and planning (Appendix 3).
Key points

- Some experts suggest severe hypoglycaemia should be a ‘red flag’ event.
- ‘Tight control’ is generally not safe for older people and those receiving palliative and end of life care. The aim is to avoid unpleasant symptoms of hypo- and hyperglycaemia.
- Hypoglycaemia is often unrecognised and asymptomatic.
- Assess the individual’s hypoglycaemia risk.
- Personalise the hypoglycaemia care plan based on the individual’s risk with the individual and family, if relevant.
- Suggest strategies to help the individual, family and health professionals recognise atypical signs of hypoglycaemia, ‘hypo cues’.
- Plan care to minimise the risk.
- People with T1DM are particularly at risk of nocturnal hypoglycaemia.
- Recommend/provide bedtime snacks to people at risk of nocturnal hypoglycaemia, including in hospital and RACF.
- Advise people to monitor their BG before driving.
- Ask about CM, natural health products and supplement use.
Hypoglycaemia risk assessment tool

Why complete the tool?
- To determine the person’s risk of hypoglycaemia.
- Use the outcome of the risk assessment to proactively manage the risk.

How to complete
- Complete with the person/family where possible and consult the medical record.
- Place a cross in all the boxes that apply to the person.
- At risk – one or more risk factors identified. Plan care to reduce/manage the risk.
- If no boxes were crossed complete the risk assessment at regular intervals.

When to complete
- Complete when the person first presents for care as part of a comprehensive assessment.
- Review risk at any change in health status, before commencing or changing medicines and following a hypoglycaemic episode.

Hypoglycaemia unawareness
☐ The person does not recognise hypoglycaemia signs or symptoms (hypoglycaemic unawareness). Ask the person whether he/she knows when they are having a hypoglycaemic episode.
☐ The person has dementia/cognitive impairment.

Individual factors
☐ Long duration of diabetes.
☐ Consistently low HbA1c (≤ 7%, 53 mmol/mol).
☐ Recent hypoglycaemia episode.
☐ Incorrect insulin and other injectable GLM injection technique or oral GLM management.
☐ Fasting ketones before breakfast can indicate nocturnal hypoglycaemia.
☐ Pacing/wandering behaviour.
☐ Fasting for a procedure or religious customs.
☐ Alcohol use.

Medicine-related factors
☐ On insulin.
☐ On sulphonylureas (SU) such as gliclazide, glibenclamide, glimepiride, glipizide.
☐ On SGLT-2 inhibitor with insulin or SU.
☐ On insulin and sulphonylureas.
☐ On sedative medicines.
☐ CM such as Panax ginseng, Mormordica charantia.

Comorbidities
☐ Renal disease.
☐ Liver disease.
☐ Cardiovascular disease.
☐ Gastrointestinal problems e.g. malabsorption conditions such as coeliac disease, gastrointestinal autonomic neuropathy.
☐ Frailty.
☐ Cachexia related to cancer.
☐ Depression.

Food-related factors
☐ Eating disorder.
☐ Low carbohydrate content in meals.
☐ Swallowing difficulties.
☐ Diarrhoea, vomiting or nausea.
☐ Erratic appetite.

Clinician-related factors
☐ Meal times do not match the action profile of the GLMs prescribed.
☐ Inappropriate prescribing: e.g. medicine choice, dose, dose frequency.
☐ Incorrect insulin injection technique.
☐ BGM regimens in hospital and RACF that do not reflect the action profile of prescribed GLMs.
☐ Over correcting hyperglycaemic episodes using stat/top-up insulin doses, often used in aged care facilities.

Abbreviations:
GLM – Glucose lowering medicine
CM – Complementary medicine
RACF – Residential aged care facility
BGM – Blood glucose monitoring
SU – Sulphonylureas
Polypharmacy is common in older people, especially people with diabetes, and increases the risk of medicine-related adverse events (Payne & Avery 2004).

Quality use of medicines (Rowett et al. 2012) and regular medicine reviews are essential to reduce polypharmacy or ensure thoughtful polypharmacy, achieve acceptable glycaemic control and minimise hypoglycaemia and other medicine-related risks.

QUM encompasses deciding whether a medicine is needed, selecting appropriate medicine/s if a medicine is required, proactively monitoring medicine effectiveness and stopping medicines (deprescribing) where possible (Rowett et al. 2012; Johns Hopkins Medical Centre 2014).

Medicine choices are influenced by their availability and cost, the person’s prognosis, health status, oral intake, medicine risk profile, comorbidities, health literacy, life expectancy and other personal, social, systems, resource and disease-related factors (Boitshoko et al. 2017) and whether they have T1DM or T2DM.

GLMs are usually needed lifelong to manage symptoms and prevent disease progression.

Taking medicines is a complex, highly individual self-care activity. Medicine non-adherence is common: 30-50% of prescribed medicines are not taken as recommended (Felzmann et al. 2012). Inadequate adherence can lead to symptom recurrence, deterioration and suboptimal outcomes.

People with diabetes may also be using natural therapies, complementary medicine (CM) and healing practices (Canaway & Manderson 2013). They use CM for various personal reasons including experience, preferences, values, ethnicity, affordability and availability. The therapeutic alliance/HP-patient relationship is another important influence on medicine choices and adherence.

Social context – opinions and attitudes of friends, family and caregivers also play a role.

Appendix 4 outlines key issues concerning CM use in Australia, some key tips for discussing sources of evidence based CM information and potential benefits of CM on page 71-75.

- Ask the individual about their medicine-related beliefs, attitudes and explanatory models for health issues. These factors influence medicine adherence.
- Determine risk of medicine-related adverse events. Consider the risk associated with individual medicines and the combination of medicines.
- Undertake/refer for a comprehensive medicine review including use of self – prescribed medicines and CM
- Table 1 outlines some commonly prescribed GLM classes and some issues to consider when prescribing and monitoring GLMs in palliative and end of life care.
- Check the individual takes the medicine appropriately e.g. correct dose, dose interval, time in relation to food.
- Check whether the individual has swallowing difficulties that might mean a change of dose form is warranted.
- Check whether insulin-using individuals rotate insulin injection sites and assess injection sites for lipodystrophy
- Commonly used GLM and some issues to consider are shown in table 1 page 27.
• Consider the factors described in tables 1 and 2 to reduce unnecessary polypharmacy.
• Undertake regular medicine reviews to ensure the medicine regimen remains relevant and safe.
• Ask about CM use and document CM use on the medicines record.
• Achieve acceptable glycaemic control and minimise hypoglycaemia and hyperglycaemia and other medicine-related risks.

Key Communication Strategies
• Establish goals, preferences, beliefs and values.
• Share all the options, including doing nothing.
• Assess motivation for change.

Calgary-Cambridge Section: Shared decision-making (Appendix 3)
Table 1: Commonly used glucose lowering medicines and issues to consider when prescribing them and reviewing the medicine regimen in palliative and end of life care. Read the prescribing information before prescribing because individual medicines within a class can differ.

<table>
<thead>
<tr>
<th>Medicine class</th>
<th>Issues to consider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biguanides</td>
<td>Monitor renal function and adjust or cease medicines such as Metformin if renal function declines e.g. creatinine &gt; 150 mmol/L or eGFR &lt; 30 ml/min/1.73 metres squared. Metformin may also be contraindicated if the person has risk factors for lactic acidosis (rare), experiences gastrointestinal symptoms such as nausea and flatulence and significant weight loss. Metformin is associated with impaired absorption of vitamin B and contributes to tiredness; deficiency of B12 may exacerbate neuropathic pain including peripheral neuropathy. Supplements may be required. Metformin alters the gut microbiota in treatment naive people with T2DM and contributes to the BG lowering effect of Metformin (Wu et al. 2017). Reduce the dose or stop during acute illnesses and surgery.</td>
</tr>
<tr>
<td>Sulphonylureas</td>
<td>Sulphonylureas may be contraindicated if the person eats erratically and/or has renal or liver disease or acute weight loss because of the increased hypoglycaemia risk. Long acting sulphonylureas are contraindicated in older people. They are a Red Flag hypoglycaemia risk</td>
</tr>
<tr>
<td>Thiazolididiones (TZD)</td>
<td>TZDs can be useful if the person has significant insulin resistance. They should not be used if the individual has liver and/or congestive heart failure. TZD can cause oedema, which can cause discomfort and uncomfortable symptoms and limit function. Pioglitazone is associated with risk of bladder cancer and should not be prescribed for people diagnosed with bladder cancer. Risk of atypical fractures in extremities especially in women.</td>
</tr>
<tr>
<td>Incretins</td>
<td>Some GLP-1 and DPP-4 inhibitors are oral and some are injectable. Some are given once a week e.g. Bydureon. Follow GLP-1 analogues and DPP-4 inhibitor prescribing indications. Some reduce infarct volume and increase functional outcomes after ischaemic stroke (Baker IDI 2019). Reduce the dose or stop if renal function declines. Stop GLP-1 if eGFR &lt; 30. Combining GLP-1 analogues and a sulphonylurea increases the risk of hypoglycaemia. GLP-1 often causes nausea and weight loss and may be contraindicated in people at risk of weight loss, loss of muscle mass and frailty. Both GLP-1 and DPP-4 inhibitors have been associated with pancreatitis and may not be the best choice in people with pancreatic disease and should be stopped if they cause abdominal pain.</td>
</tr>
<tr>
<td>Medicine class</td>
<td>Issues to consider</td>
</tr>
<tr>
<td>----------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Sodium-glucose cotransporter-2 inhibitors (SGLT-2)</td>
<td>Significant cardiovascular benefits (Zinman 2015). May cause weight loss – monitor weight. There is not enough clinical experience with the SGLT-2 medicines to recommend their use in palliative care situations. Some are associated with urinary tract and genital infections, polyuria and hypovolaemia. Many are contraindicated in people age 75 years and older. Euglycaemic DKA can occur during medical and surgical procedures with dapagliflozin and empagliflozin, including when the BG is not significantly high.</td>
</tr>
<tr>
<td>Insulin</td>
<td>A range of insulins are available. People with T1DM require insulin to replace absent endogenous insulin. Most people with T2DM eventually require insulin and may already be on insulin when they commence palliative care. Insulin doses are easier to adjust than oral GLMs. Initiating insulin can reduce the medicine burden and simplify the medicine regimen but some insulins increase the hypoglycaemia risk. The newer long acting insulin analogues have a lower risk profile. A safe strategy is to use a daily dose of basal insulin and inject rapid acting insulin when people eat rather than at fixed times to reduce hypoglycaemia risk in palliative situations and individuals with dementia. Premixed insulin is associated with higher hypoglycaemia risk. Insulin could be a ‘palliative medicine’: by managing hyperglycaemia to avoid distressing symptoms e.g. thirst, fatigue.</td>
</tr>
</tbody>
</table>

The information is based on relevant prescribing information e.g. TG Endocrinology, Australian Medicines Handbook, Deed 2018, RACGP 2016 – 2018.

**Key points**

- Stop SGLT-2 3 days before surgery. Recomence when the person is well hydrated or use another GLM/insulin (ADA 2019).
- It is often important to continue to manage cardiovascular risk (lipids, blood pressure and weight) and renal disease. Therefore, diuretics, antihypertensive and other medicines may still be needed during palliative care, depending on risk and likely benefit within the persons life expectancy.
- Analgesia is also often required.
Table 2: Factors to consider when determining the need for diabetes medicines, other than glucose lowering medicines, for people with diabetes receiving palliative care – if medicines are indicated.

<table>
<thead>
<tr>
<th>Medicine Type</th>
<th>Consideration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diuretics</td>
<td>Can exacerbate dehydration and increase blood glucose levels.</td>
</tr>
<tr>
<td>Corticosteroids</td>
<td>Atypical antipsychotics are frequently used in palliative care and other disease processes and increase blood glucose levels.</td>
</tr>
<tr>
<td>Opioids</td>
<td>Can mask hypoglycaemia.</td>
</tr>
<tr>
<td>Glucagon</td>
<td>Used to treat severe hypoglycaemia, usually increases blood glucose quickly. A second dose can induce nausea but may be ineffective in emaciated people with reduced glycogen stores. This means if oral glucose treatment of hypoglycaemia and IM glucagon are ineffective or contraindicated, IV dextrose may be required.</td>
</tr>
<tr>
<td>Oral Nutrition</td>
<td>Supplements such as Sustagen affect blood glucose levels, often leading to hyperglycaemia.</td>
</tr>
<tr>
<td>Complementary Medicine</td>
<td>Always ask about use. People with diabetes commonly use CM therapies for general health and wellbeing, or to manage diabetes and comorbidities.</td>
</tr>
<tr>
<td>Exploring Understanding</td>
<td>Discuss any concerns. Provide evidence-based advice that balances the potential benefits and risks of CM use, whilst respecting the person’s beliefs, values and preferences. (Appendix 4).</td>
</tr>
<tr>
<td>Support</td>
<td>and educate family carers to help the individual manage their medicines and ask them about any problems they encounter.</td>
</tr>
</tbody>
</table>

Deprescribing towards the end of life

Physiological and functional changes towards the end of life mean the goals of care usually change from cure and prevention to ensuring comfort and quality of life. This includes deprescribing.

Deprescribing refers to ‘the planned, supervised dose reduction or stopping of a medication’ (Reeve et al. 2015). It encompasses reducing medicine doses, and/or dose frequency and stopping medicines.

Deprescribing is an important aspect of the quality use of medicines. It is especially important towards the end of life. The following tools can help clinicians make decisions about deprescribing in palliative/end of life situations.

- American Geriatric Society BEERS criteria (AGS 2019).
- Guide to deprescribing, a general tool (Holmes et al. 2006).
- Geriatric-Palliative Algorithm (Garfinkle et al. 2007).
- List of Evidence-Based Deprescribing for Chronic Patients (LESS-CHRON) (Rodriguez-Perez et al. 2017).
- Palliative and Therapeutic Harmonisation Program (PATH) https://pathclinic.ca/education/clinical-practice-guidelines/
- Screening Tool of Older Persons Prescriptions in Frail adults with limited life expectancy (STOPPFrail) (Lavan et al. 2016).
Diabetogenic medicines

Some medicines affect glucose homeostasis and cause/exacerbate hyperglycaemia in people with diagnosed diabetes and predispose people at risk of diabetes to corticosteroid-induced diabetes (Guilford et al. 2006. Mitra 2011). The degree of hyperglycaemia is proportional to the dose, dose formulation, dose regimen and duration of treatment. Short courses may not cause significant hyperglycaemia or only have a short term effect on the blood glucose.

Commonly prescribed diabetogenic medicines include antipsychotic medicines, thiazide diuretics and corticosteroids e.g. dexamethasone or prednisolone.

Corticosteroids are commonly used to manage conditions such as haematological malignancies, inflammatory diseases, cachexia in people with cancer, chronic constructive pulmonary disease (COPD), allergies, shock and symptoms in palliative care.

Corticosteroids can mask the signs and symptoms of infections, which are often atypical in people with diabetes, especially those with long duration of diabetes. The skin can become thin and fragile and prone to tears, especially in older people, and cause considerable discomfort and distress. Corticosteroids also have variable effects on bone formation and reduce calcium absorption, which increases the risk of osteoporotic fractures and pain (Brown & Beard 2006). Mental changes range from mild psychosis to significant psychiatric pathology and might be difficult to distinguish from delirium and other cognitive changes (Australian Diabetes Society (ADS) 2012).

Screen for diabetes risk factors before commencing corticosteroids to identify the likelihood the individual will develop corticosteroid-induced hyperglycaemia and the psychological effects associated with corticosteroids e.g. use the AUSD Risk tool.

Determine whether BGM will be required and the individual's capacity to undertake BGM, or evaluate support to do so.

See pages page 32 and page 33 for specific information about T1DM and T2DM.

Aim to balance the benefits of using corticosteroids and the effects on glucose homeostasis.

Educate people with diabetes about the effect on their BG and possible symptoms e.g. hyperglycaemia, typically in the afternoon.

Suggest an appropriate BG monitoring regimen that identifies hyperglycaemia to enable early initiation of treatment.

Monitor BG more frequently if insulin is prescribed and proactively adjust insulin doses to reduce hyperglycaemia.

People managed using diet are likely to require GLMs when they are prescribed corticosteroids. The choice of GLM depends on health status, corticosteroid regimen and relevant medicine precautions and contraindications (Fowler 2000).

Target BG range is fasting ~ 6 mmol/L and postprandial < 11 mmol/L (Mills & Devendra 2105) to prevent DKA and HHS.

Monitor adrenal function if large doses of corticosteroids are used for more than two weeks. Large corticosteroid doses can induce adrenal insufficiency, and dramatically reduce insulin requirements. The signs of adrenal insufficiency include fatigue, weight loss, nausea and diarrhoea (Fowler 2000).

Decide whether the corticosteroid dose schedule will be intermittent or continuous and choose the least diabetogenic corticosteroid and use it for the shortest time to limit the effects on glucose homeostasis.

When ceasing the corticosteroid; slowly reduce doses and adjust insulin and other GLM doses to prevent hypoglycaemia (Mpofu et al. 2004).
**Key Communication Strategies**

- Establish goals, preferences, beliefs and values.
- Share all the options including doing nothing.
- Assess motivation for change.

Calgary-Cambridge Section: Shared decision-making (Appendix 3).

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**Key points**

- Use lowest effective corticosteroids and doses for the shortest time.
- Monitor BG to help decide GLM requirements.
- BG often increases in the afternoon. Therefore BGM should be tailored to detect the rise in BG.
- Consider new diagnosis of diabetes in people with diabetes risk factors.
Managing corticosteroids and other diabetogenic medicines in people with type 1 diabetes receiving palliative care

**Diabetes Approach**

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

**Assessment**

- Revise medicine regimen: if possible avoid other diabetogenic medicines or use lowest possible dose.
- Conduct a collaborative team meeting with the GP, specialists – palliative, diabetes educator, endocrinologist, and patient and family/carers.
- Ascertain patient/carer education requirements.
- Appropriate medicine self-management (when, how, why, interactions, side effects).
  - BGM regimen to suit the corticosteroid onset and peak action times.

- Increased risk of hypoglycaemia if hypo unawareness is present, especially when weaning or ceasing steroids when insulin doses were increased.

Commence BGM – consider increasing frequency while on diabetogenic medicines (e.g. 3-4/day)

- Revise diet and exercise routines but food choices should not be limited if the person is cachectic or anorexic.

**Care planning**

- Increase insulin dose if BG > 10 mmol/L especially if ketones are present.
- Patients in ICU or fasting may require an IV insulin infusion.
- Use subcutaneous insulin if eating.
- Adjust prandial insulin doses because the post prandial BG tends to increase.
- Consider the effect of the carbohydrate meal content on BG and the need to provide energy if patient is on enteral feeds.
- Monitor and record BG before meals and before bed and determine the emerging pattern.

- Monitor blood ketones if BG >15 mmol/L or symptoms present.
- Manage hyperglycaemia and hypoglycaemia.
- An AM insulin dose may be needed because BG often peaks in the early afternoon and tends to fall overnight.
- Revise patient and carer knowledge and provide education, especially about managing hyperglycaemia if managed at home.
- Consider need for access to ‘on call/after hours’ support.

Long term steroid use can:

- cause hypercalcaemia
- suppress the hypothalamic-pituitary-adrenal axis.

Both states can complicate management but may not be relevant, depending on the prognosis.
Managing corticosteroids and other diabetogenic medicines in people with type 2 diabetes or new diagnosis of diabetes receiving palliative care

**Diabetes Approach**

Short courses not causing symptoms or hyperglycaemic hyperosmolar state may not require regimen changes but effects on BG often occur after 1-2 doses.

- People with type 2 can develop HHS or ketoacidosis during significant illnesses.
- Courses > three days usually require regimen changes.

Long term corticosteroid use can suppress the hypothalamic-pituitary-adrenal axis.

This can complicate management but may not be relevant depending on the prognosis.

**Assessment**

Revise medicine regimen: if possible avoid other diabetogenic medicines or use lowest possible dose for the shortest possible time.

- Conduct a collaborative team meeting with the GP, specialists – palliative, diabetes educator, endocrinologist and oncologist, and patient and family/caregivers.
- Glucose lowering medicine doses may need to be adjusted OR

**Care Planning**

Consider insulin preparations

- Prebreakfast long acting analogue such as lantus or protaphane OR
- Premixed insulin before lunch e.g. Mixtard 30/70

- Note: Patients in ICU or fasting may require an insulin infusion.
- Consider the effect of the carbohydrate meal content on BG and the need to provide energy if patient is on enteral feeds.

- Consider commencing insulin if BG is consistently > 11 mmol/L.
  - Ascertain patient/carer education requirements – appropriate medicine self-management (when, how, why, interactions, side effects); hypoglycaemia management
  - BG testing.

- Revise diet and exercise routines but food choices should not be limited if the person is cachectic or anorexic.
- Commence BG monitoring – consider increasing frequency while on diabetogenic medicines (e.g. 3-4/day or fasting and pre-evening meal).

- Monitor and record BG before meals and before bed.
- Manage hyperglycaemia and hypoglycaemia.
- Revise patient and carer knowledge especially managing hyperglycaemia if managed at home.
- Consider need for access to ‘on call/after hours’ support.
Assessing people receiving palliative care for undiagnosed diabetes

Diabetes can be first diagnosed when the person enters palliative care. The presence of diabetes influences care and outcomes. T2DM can present with a complication and some medicines are diabetogenic and cause hyperglycaemia, e.g. corticosteroids, which are often used in cancer and palliative care.

* Palliative Care Outcomes Collaborative 2017
Nutrition and hydration

Anorexia, cachexia and dysphagia are common in people receiving palliative care (Middleton et al. 2001). People with diabetes are often deficient in essential nutrients or are anaemic and may require supplementary nutrients including protein in palliative and end of life care (Fowler 2000). Enteral feeds may be required to provide energy, essential nutrition and fluids when people cannot consume adequate food and fluids orally. Ensure nutritional replacement aligns with the person’s physiological as well as philosophical or religious beliefs and their ACD.

The risks and benefits of enteral feeding, including the risk of accelerating death, must be considered before commencing enteral feeds.

Vitamin B₁₂ deficiency is associated with Metformin use (Liu et al. 2014), cognitive decline and neuropathy. The risk appears to be associated with high serum folate levels (Moore et al. 2014).

Assess serum protein, ferritin, folate and vitamin B₁₂.

Assess the person’s ability to consume food orally.

Assess the blood glucose pattern.

Determine sarcopenia and/or frailty status.

Enquire about food preferences – tastes, texture, culture and availability. Enquire about digestive symptoms and potential co-morbidities such as periodontal disease, autonomic neuropathies and medication side effects that may affect the person’s ability to taste and consume food orally.

and evidence based CM therapies such as acupressure/acupuncture, ginger, peppermint oil, caraway oil and Cinnamon; appendix 4.

It may be more cost-effective to routinely prescribe oral B₁₂ for people with fatigue, especially if they are taking Metformin for >3mths than to first test for deficiency.

Revise BG and other metabolic targets to suit the person’s stage of illness and safety.

Key Communication Strategies

• Establish goals, preferences, beliefs and values.
• Share all the options including doing nothing.
• Assess motivation for change.

Calgary-Cambridge Section: Shared decision-making (Appendix 3).
**Key points**

- Regular nutrition assessments are essential.
- Overweight individuals can be sarcopenic and at risk of frailty. Weight loss may be unsafe in these people.
- Consider using a low dose, long acting insulin analogue basal insulin and inject a low dose of rapid acting insulin when the person eats, if needed. The focus is on preventing hyperglycaemia and its effects on comfort, not achieving ‘good control’.
Managing Pain

Pain is a personal experience. It has many general and diabetes-specific causes. The latter include neuropathic pain. Pain can be exacerbated by hyperglycaemia. Pain compromises comfort and quality of life and is often under-recognised and under-treated.

Significantly, pain is often atypical in people with diabetes and not recognised. Atypical pain includes cardiac pain and pain associated with foot ulcers.

Pain management is often suboptimal.

Assessment

Undertake pain assessment: ask about pain intensity, pain pattern, location, what effects it has on function and quality of life, what things exacerbate the pain and what things relieve it.

Consider emotional and spiritual pain and distress as well as physical pain.

Use relevant pain assessment tools such as:

- The Abbey Pain Scale
- FLACC Scale

Care planning

Plan pain care with the individual and/or their families.

Use simple analgesia first if effective.

Prescribe analgesics suited to the pain level and safety: refer to The Pain Management and Palliative Care Therapeutic Guidelines.

- Numeric Pain Intensity Scale
- palliAged app
- Diabetes Distress scale, which indicates diabetes distress is present. Pain can contribute to such distress.

Choose language carefully e.g. people may not use the word ‘pain’ but might use hurts, burns or sore.

Ask what activities are affected by pain e.g. walking, sitting.

Consider non-pharmaceutical and CM pain management strategies such as gentle massage and meditation. (Appendix 4)

Opioids may be the medicine of choice in the terminal stage.

Key Communication Strategies

- Sharing all the options including doing nothing.
- Safety netting (what to do if the plan does not control the pain).
- Patient Summary/ “Teach back” (being clear what the plan is, including regular and as needed pain relief and self-managed dosing).

Calgary-Cambridge Section: Explanation and planning (Appendix 3).

Key points

- Refer to TG palliative care and TG pain guidelines and/or refer the person to a palliative care specialist and/or pain specialist.
- Pain is a subjective personal experience.
- It is what the person says it is.
Recognising and managing clinical deterioration

Deterioration can be gradual in the chronic disease and frailty trajectories. See page 42

Periods of deterioration or ‘unstable diabetes’ are common throughout the person with diabetes’ life. A key consideration is whether the cause of the deterioration is remedial or indicates a transition towards the end of life.

Deterioration can be rapid in acute conditions e.g. DKA or occur more slowly in HHS, from sepsis due to pressure ulcers, and in dementia.

Significantly, signs of deterioration can be present before changes in vital signs are detected using technology. Nurses rely on technology rather than clinical observation and assessment and can miss the early signs of deterioration (Chua et al. 2013).

Review/document diabetes management plan including medicines: insulin, other glucose lowering medicines, and natural and complementary health products.
• Consult with GP diabetes educator, endocrinologist.

• Check the need for continuing and planned treatments e.g. dialysis, chemotherapy, radiotherapy, surgery.
• Revise or commence the person’s Advance Care Directive and include diabetes management.
• Provide information/discuss management with the individual and family members/caregivers.

Ideally, the two methods complement each other.

It can be difficult for people with diabetes and family carers to recognise changes in health status and decide what to do.

Underlying causes of deterioration in people with diabetes include hypoglycaemia, heart failure, stroke, infections such as foot infections and respiratory disease. These are common causes of hospital admission.

Deterioration can occur when the individual transitions between care settings. People who require emergency interhospital transfer from subacute care often have high admission rates and in-hospital mortality and many meet MET call criteria before they are transferred (Considine et al. 2016).

General and diabetes related indicators of deterioration. Consider in particular:
• Anorexia
• Cachexia
• Changing functional status
• Malignancies

Assess symptoms:
• Pain
• Nausea/vomiting
• Oral intake
• Oral pathology
• Delirium
• Infection – occult or overt sepsis
• Depression/anxiety
• Acute dyspnoea
• Polyuria, oliguria, thirst
• Medicines including CM

Consider diabetes as a cause of the symptoms and the impact of the symptoms on blood glucose.

Decide whether symptoms represent a diabetes, oncology or other emergency and treat or refer accordingly.

Factors and situations that could precipitate deterioration include:
• Significant life change
• Death of a spouse or beloved pet.
• Reducing self-care capacity to manage intercurrent illnesses.
• Non-adherence to medicines or changes in prescribed/self-prescribed medicine regimen.

Screen people for frailty before surgical procedures (Garcia et al. 2016); but surgical interventions can improve symptoms, function and life expectancy.

Each episode of deterioration reduces functional reserve.

Check whether the person has an ACD documented, when it should be activated and whether they have appointed a Medical Treatment Decision Maker. If not, discuss these issues with the individual or family or refer them to an Advance Care Planning expert (in Victoria, formerly called Respecting Patient Choices).
Develop sick day care plans with the individual and families and ensure plans include information about recognising and managing deterioration and activating their ACD.

Educate the individual and family to understand and recognise deterioration and what to do.

Review The ACD and encourage the person to appoint a Medical Treatment Decision Maker (formerly surrogate decision maker) if they have not done so.

Consider whether personal alarms and other assistive technology could help the individual.

Re-evaluate diabetes management strategies:
- BG and ketone monitoring is still useful to determine whether ketosis exists but may be less frequent (1-2/day).
- New blood glucose targets < 10 mmol/L fasting.
- Ensure all pharmaceutical and CM medicines are optimal for the deterioration phase – cease medicines where possible to promote comfort

Consider commencing/continuing insulin to promote comfort in people with T2DM on other GLMs

If an emergency:
- Treat the underlying cause
- Decide whether admission to hospital is necessary/likely to be beneficial
- Consider referring to an endocrinologist or palliative care
- Manage comfort
- Monitor response

If not an emergency:
- Manage comfort
- Consider initiating management strategies (see left)
- Implement additional support/education for family/carers
- Review the ACD.

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**Key Communication Strategies**

- Check the persons baseline understanding.
- Breaking Bad News (SPIKES).
- Recognising and responding to emotional cues (Clinician).

Calgary-Cambridge Section: Explanation and planning (Appendix 3).

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**Key points**

- Deterioration in health status does not necessarily mean acute deterioration in vital signs as monitored in acute care. It also refers to changes in the chronic disease trajectory on page page 42.
- Decide whether the change is remediable, if so offer treatment.
- Educate people with diabetes and families to recognise changes such as ‘slowing down’, ‘not wanting to be bothered’ and inability to perform self-care and ADLs.
- The MET team can activate the individual’s ACD, including implementing their end of life care plan, if indicated.
Overview of the main health trajectories with some explanatory notes. The information was adapted from Lynn 2003 and Dunning 2018. The trajectories often overlap and people could have features of more than one trajectory. Death can be sudden in any trajectory and can occur at any time from the underlying disease, trauma, accidents and suicide.

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Explanatory notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
<td>Genetic inheritance and epigenetic factors predispose people to T2DM and other disease processes and affect life expectancy. Dysglycaemia and complications can be present &gt; 7 years before T2DM is diagnosed. Thus, it is important to maintain health, preserve function, prevent diabetes and its complications, from (before) birth by: Early diagnosis and appropriate management if diabetes is diagnosed because the children of women with gestational diabetes are at increased risk T2DM, hypertension and cardiovascular disease. Older age is associated with increased risk of diabetes due to insulin resistance, reduced insulin secretion and obesity. Eating a healthy diet, being active and managing stress are important to reduce the negative genetic influence and reduce the risk of sarcopenia, frailty and gestational diabetes (GDM) and T2DM in the children of women with GDM. Adequate sleep is important to neuroplasticity and memory. General health care in addition to diabetes care is important at every age and includes relevant risk screening, immunisation programs, regular dental care, cancer screening such as breast, bowel and prostate cancers. Most cancer occurs after age 65. Planning for expected life transitions.</td>
</tr>
<tr>
<td>Steady progression to the end of life</td>
<td>Often called the cancer trajectory. The aim is to diagnose cancer early through population based-screening and awareness programs. Manage the cancer effectively to preserve function and quality of life and plan for palliative and end of life care when relevant. Some forms of cancer are linked to diabetes. Some experts suggest chronic disease is an overlooked risk factor for cancer. Care includes screening people with diabetes for cancer and screening for diabetes in people diagnosed with cancer, especially people with cancer treated with diabetogenic medicines e.g. glucocorticoid medicines.</td>
</tr>
<tr>
<td>Trajectory</td>
<td>Explanatory notes</td>
</tr>
<tr>
<td>--------------------------------</td>
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</tr>
<tr>
<td>The chronic disease trajectory</td>
<td><strong>Diabetes</strong> is the most prevalent chronic disease.</td>
</tr>
<tr>
<td></td>
<td>The chronic disease trajectory typically involves episodes of stability and episodes of deterioration and recovery, many times before the progression to end of life.</td>
</tr>
<tr>
<td></td>
<td>The blood glucose and HbA1c ranges must be personalised to balance the risk of hyperglycaemia and its consequences against the risk of hypoglycaemia.</td>
</tr>
<tr>
<td></td>
<td>Lipids and blood pressure need to be managed as per trajectory 1 to prevent complications or detect them early and maintain function and quality of life.</td>
</tr>
<tr>
<td></td>
<td>Proactively screening for diabetes complications to detect and manage them early is important to preserve function and autonomy.</td>
</tr>
<tr>
<td></td>
<td>General health care and regular complication screening (annual cycle of care) should continue. Changes could trigger a review of the care plan and ACD.</td>
</tr>
<tr>
<td></td>
<td>Timely discussions about changing function and life expectancy and advance care planning are important considerations as function changes.</td>
</tr>
<tr>
<td></td>
<td>Unstable diabetes can be due to remediable intercurrent illness, ‘acopia’ and physical and psychological stressors.</td>
</tr>
<tr>
<td></td>
<td>Document and communicate the plan for life transitions and an ACD among care services and all relevant care providers, including emergency services.</td>
</tr>
<tr>
<td>The frailty trajectory</td>
<td>People who do not have cancer or chronic diseases that lead to organ damage/failure usually die in older age from dementia or generalised frailty.</td>
</tr>
<tr>
<td></td>
<td>Frailty is often preceded by sarcopenia and reduces the person’s ability to recover from illnesses and stress. It compromises autonomy and life expectancy.</td>
</tr>
<tr>
<td></td>
<td>A range of tools is available to monitor frailty status e.g. Frail non-Disabled questionnaire (FinND), Fried Frailty criteria (frailty phenotype), Frailty Index.</td>
</tr>
<tr>
<td></td>
<td>Recent research suggests the FRAX is useful to screen for frailty as well as fracture risk (Tembo et al. 2018).</td>
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<tr>
<td></td>
<td>And</td>
</tr>
<tr>
<td></td>
<td>Functional decline and changing life expectancy e.g. the GSF, PCOC stages, Karnovsky and/or Charlson Scales, and absolute risk e.g. for cardiovascular disease.</td>
</tr>
</tbody>
</table>
Indications that the person is entering the terminal stage are described in the Gold Standard Proactive Guidance (2016)

- Review/document diabetes management including medicines: insulin, glucose lowering medicines, natural health products and complementary medicines with a view to ceasing if at the end of life. Insulin may be continued in T1DM to manage distressing hyperglycaemia symptoms.

- Caregiver involvement may increase, and they need to be informed, supported and involved at their desired level.
- Communicate with the GP, the palliative care specialist team and other relevant clinicians.
- Implement Advance Care Directive in a timely manner.
- Provide information/discuss management with the individual and family members/caregivers.

• Assess whether short term diabetes complications need to be treated to achieve comfort.
• Refer to the Advance Care Directive
• Identify caregivers/family bereavement risks.
• Assess and manage conditions to alleviate symptoms e.g.
  - Pain
  - Nausea/vomiting

Focus of diabetes management is on comfort, and a peaceful death free from pain.

Re-evaluate diabetes management strategies:

- Consider the individual’s and caregiver’s preferences for GLM and stop any that are unnecessary.
- Consider ceasing BG monitoring – check Advance Care Directive and/or discuss with caregiver if the person has not given instructions to ensure monitoring is consistent with the person’s wishes

• Decide whether care is provided in home, hospital or hospice.

Note: Medicines may not be appropriate except to achieve comfort. Rationalise pharmaceutical and CM management.

Terminal stage refers to the last 12 months of life.

Death does not represent treatment failure in most cases. It is a normal part of life.

End of life refers to the last week or days. (Prognostication is difficult).

- A range of indicators can be used but do not predict death; they can guide likely life expectancy.
- The person’s declining will to live is a good indication they will die soon (Karppinen et al. 2012).
- A lot of people know they will not recover, some want affirmation from their treating clinicians - but clinicians are often reluctant to discuss declining health and death.
- Family members often know their relative is dying but find it difficult to discuss.
Withdrawal

Decisions about withdrawing treatment raise ethical questions. These decisions are more difficult when people’s values and desired end of life care is not documented and/or not communicated.

Proactively discussing end of life care with people with diabetes and their families when palliative care is initiated, before they are admitted to an RACF in the stable end of life stage and clearly documenting and communicating the information to the care team is essential and can mitigate difficult clinical decisions and avoid unnecessary admission to hospital and/or ICU during episodes of deterioration.

However, decisions people make when they are relatively well may change at a later date, consequently the ACD plan should be reassessed, for example during the annual health check and during periods of unstable disease.


The deteriorating and terminal end of life phases are often key decision points for withdrawing treatment. Knowing the prognosis helps health professionals, people with diabetes and their caregivers make decisions about withdrawing treatment, but it is difficult to predict prognosis.

The Gold Standard Proactive Guidance (2016) and the Palliative Care Outcomes Collaborative (PCOC 2017) end of life stages are useful guides to likely prognosis.

Spirituality is important to many people. Spirituality refers to finding meaning and purpose in life and ongoing personal growth. It does not necessarily involve religion (Persian & Dunning 2009, Puchalski 2011). Personal growth can occur up to the moment of death.

Assess the following general indicators from the GSF that suggest the individual has a short prognosis consistent with the individuals values and ACD:

• Consider the surprise question; would I be surprised if this person died soon?
• Presence of multiple comorbidities.
• Weight loss > 10% in a short period of time.
• ‘Failure to thrive’ and/or general decline.
• Serum albumin < 25 g/L.
• Declining performance such as a Karnofsky Performance Status scale < 50%.
• Decreasing response to treatment.

• Difficulty reversing intercurrent illnesses.
• Sentinel event such as a fall.
• Admission to RACF.
• Needing significant help to perform usual activities of daily living and diabetes self-care tasks.

The individual’s will to live. The will to live is a strong predictor of survival in older people regardless of age, gender and comorbidities (Karppinen et al. 2012) Social factors such as satisfaction, support from family, friends and health professionals are important to the will to live.
Liaise with the family and keep them informed. Follow the individual’s documented values, goals and preferences in their ACD. If they are not documented, discuss, document and communicate them if possible.

Document LOMT based on the ACD.

Stop GLMs when the risks of continuing them outweigh the benefits: e.g. frequent severe hypoglycaemia and other associated risks such as falls, especially in the deteriorating and terminal phases.

Consider the discomfort and risks associated with hyperglycaemia if GLMs are stopped in light of the likely prognosis.

Decide whether there are any safe CM non-medicine options. Some herbal medicines can interact with conventional medicines. If CM medicines are used they should be monitored as part of the overall care plan.

Massage, with and without essential oils. Music therapy and/or art therapies.

Guided imagery.

Essential oils administered in vapourisers, baths or massage, reflexology or music.

Acupuncture.

Pet therapy, the book, Making the Rounds with Oscar (Dosa 2010) demonstrates the power of pets at the end of life.

Meditation.

Ensure spiritual needs are considered by assisting the individual and their families find meaning and purpose in dying and having a peaceful, dignified death.

Document any religious and cultural care of the body after death in the care plan when relevant.

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**Key Communication Strategies**

- Explore hopes and fears related to illness.
- Establish goals, preferences, beliefs and values.
- Respond to emotional cues. Use simple sincere and explicit empathetic statements followed by silence.

Calgary-Cambridge Section: Shared decision-making (Appendix 3).

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**PCOC Phases**

These phases can help clinicians and people with diabetes/families understand the person’s palliative/end of life journey and the person and family’s changing care needs. The phases are:

- Stable
- Unstable
- Deteriorating
- Terminal
- Bereavement after death

The phases have a beginning and an end but are not chronological and often overlap. Care needs to be assessed and reassessed in the beginning and end of each phase (PCOC 2018).
Supporting family/carers

Diabetes Approach

Family and carers have an important role helping relatives with diabetes cope in palliative situations. Caring represents a significant burden for carers often causing stress that affects sleep, wellbeing and causes inflammatory processes that compromise immunity and cause haemodynamic changes that increase their own risk of death (Carey et al. 2014) and Broken Heart Syndrome, which results in permanent damage and increased mortality risk, especially those with cardiovascular risk factors (Health Ed 2018).

Ideally family and carers are informed about the care plan developed for/with individual they care for. Often they should be involved in developing a care plan.

Some family and care givers require education about diabetes self-care tasks such as BGM and administering insulin to enable them to safely provide care for the person with diabetes (Savage et al. 2012).

Assessment

Regularly ask family and caregivers about their physical and mental health and the types of care they provide.

Monitor them for stress e.g. use Caregiver Strain Index.

Ensure their general health care needs are met e.g. immunisation and cancer screening, managing diseases such as diabetes.

Assess family ‘dynamics’ if possible.

Care planning

Involve family/carers in planning palliative care for their loved one. They can have a role in physical care, psychological and emotional care, advocate and make surrogate decisions for their relative and informing staff about key information e.g. recognising when he is not quite right.

Inform them their relative is dying so they can plan for the loss and have time to say goodbye.

Enable them to help with feeds, administer CM and other treatment when their loved one is in hospital or RACF.

Schedule ward rounds to coincide with family/carer visits if possible.

Hold case conferences that include family members and the individual with diabetes.

Provide bereavement care after the relative dies and monitor for family ICU syndrome i.e. family may become the ‘patient’.

Key Communication Strategies

- Ask-tell-ask.
- Shared agendas.
- Recognising and responding to cues.

Calgary-Cambridge Section: Gathering information. (Appendix 3).

There are many false assumptions about what families already know.
Key points

- Family often know the person better than the staff- ‘they know his problems, I know him’ (person with diabetes).
- Monitor caregivers’ health.
- They are at risk of illness or death in the 12 months after a relative dies.
- While family provide vital support and care for people who cannot self-care, they can also take advantage of them and be responsible for physical, emotional and financial bullying.
- Family can also disagree with each other and the person with diabetes and their ACP.
- Clinicians need to think about these possibilities and develop strategies to manage them if they arise e.g. refer to a Clinical Ethics Committee.
Evaluating diabetes palliative and end of life care

A key aim of these guidelines is for people with diabetes to receive quality care and be safe. Therefore, every person with diabetes and their families should have access to interdisciplinary palliative and end of life care in a timely manner. This requires strong leadership, clear guidance and regular evaluation. Significantly, care should be provided by competent informed staff. Evaluation is a key aspect of quality care.

It is important to determine the value of the care provided from an economic and clinical outcome basis. However, it is equally important to consider the diverse needs of each individual.

Key concerns for people with diabetes are having their goals and preferences addressed as well as addressing their emotional and spiritual needs, preserving their dignity and the factors that cause physical and emotional suffering (Teno 2005).

Evaluation consists of three key aspects to assess benefits for:

1. Patient/caregivers e.g. self-appraisal and monitoring progress.
2. Clinical care e.g. identify/screen for problems, assess patient’s progress to inform clinical decisions, clinical audits.
3. Health services e.g. inform service provision, clinical care guidelines, policy, funding (Paterson 1996; Paterson et al. 2000, Paterson et al. 2007).

Although a range of tools are available to monitor patient outcomes (PROMS), it might be more appropriate, and more personalised to decide what to monitor with the individual by asking them to name the issues that are important to them and constructing a simple measurement scale to monitor changes over time. This is consistent with person-centred care but may not enable comparisons among individuals.

Alternatively consider using MYMOP/MYCAW, an individualised PROM that quantitatively assesses problems/outcomes that the patient identified as being the most important to them early in the care plan and monitor over time.

PROMs can be useful to compare services but they might not reflect issues important to the individual.

They may not assess individual health professional performance or communication efficacy or organisational factors (process indicators).

**General tools**

Wellbeing Index.
Patient Dignity Inventory.
Quality of Communication Questionnaire.
AHCQs standards, especially standard complex care.

**Diabetes-related tools**

Diabetes-related Distress (DDS).

Undertaking clinical audits to determine documented care is consistent with these and other relevant guidelines.

**Palliative and end of life tools**

Choose tools from Teno’s toolkit.

Problems and Needs in Palliative Care Questionnaire.
Quality Care Questionnaire End of life.

Use the Palliative Care Australia Standards (2018) to develop clinical care and organisational policies/procedures.

Key issues concerning health professional competence to address diabetes palliative and end of life care are shown on the next page.

The information can be used to guide health professional education at all levels, as well as to assess care.
Health professional competence to address diabetes palliative and end of life care

**Rationale**

Diabetes is a chronic disease associated with significant long-term complications and reduced life expectancy compared to people who do not have diabetes.

The Australian population is ageing. Increasing age is a risk factor for diabetes. Diabetes reduces life expectancy through a range of complications and associated comorbidities such as frailty. Approximately 24% of older people in residential aged care facilities have diabetes and a further 20% at risk of diabetes but undiagnosed.

Diabetes and its complications represent a significant individual and combined burden of disease, treatment, medicines and self-care for the individual and families. Some of the burden is remediable using palliative care with usual diabetes care.

The recent *Medical Treatment Planning and Decisions Act*, the release of the revised Australian Health Care Standards (ACHQS 2017) and Palliative Care Standards (Palliative Care Australia 2018) mean all health professionals have a role in initiating conversations with people, including people with diabetes, about these important life transitions and should acquire the social, emotional and communication skills that are core knowledge and competence to do so.

<table>
<thead>
<tr>
<th>Required knowledge and attributes</th>
<th>Performance criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understand basic glucose homeostasis and the difference between type 1 and type 2 diabetes.</td>
<td>Describe the basic difference between Type 1 and Type 2 diabetes.</td>
</tr>
<tr>
<td>Ability to undertake an assessment to recognise signs of deterioration and indicators that palliative or end of life care could be beneficial.</td>
<td>Know the diabetes-related factors associated with reduced life expectancy.</td>
</tr>
<tr>
<td>Emotional intelligence and communication skills, including active listening and ability to ask relevant questions.</td>
<td>Understand the core elements of the <em>Medical Treatment Planning and Decisions Act</em> and the ACHQS standards, particularly the Comprehensive Care and Communication Standards.</td>
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<tr>
<td></td>
<td>Understand the importance of helping the individual document their values and wishes.</td>
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<td></td>
<td>Identify and act on cues that an individual is ready to start a conversation about palliative and end of life care.</td>
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<tr>
<td></td>
<td>Demonstrate the relevant knowledge and skills to conduct conversations e.g. set an agenda, use open questions and actively listen and use appropriate probing and clarifying questions, when indicated.</td>
</tr>
<tr>
<td></td>
<td>Identify the health and other needs of family carers.</td>
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<tr>
<td></td>
<td>Know when and how to refer to relevant services.</td>
</tr>
<tr>
<td>Required knowledge and attributes</td>
<td>Performance criteria</td>
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<tr>
<td>---------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Ability to provide personalised holistic care according to relevant guidelines, legislation and</td>
<td>Perform care according to their role and scope of practice.</td>
</tr>
<tr>
<td>policies to address key care issues such as:</td>
<td>Ability to work in a multidisciplinary team.</td>
</tr>
<tr>
<td>Hyperglycaemia and resultant effects on function and cognition and the associated risks of</td>
<td>Use shared decision-making to develop a personalised care plan with the individual and/or</td>
</tr>
<tr>
<td>ketoacidosis or hyperosmolar states and their prevention and management.</td>
<td>their family.</td>
</tr>
<tr>
<td>Hypoglycaemia and effects on cognition and safety.</td>
<td>Know the effects of hypo- and hyperglycaemia on comfort, quality of life and cognition.</td>
</tr>
<tr>
<td>Pharmacovigilance: medicine management, reviews, using non-medicine options where safe and</td>
<td>Determine a safe blood glucose and HbA1c range for the individual to balance the risk of</td>
</tr>
<tr>
<td>relevant and deprescribing.</td>
<td>hyper- and hypoglycaemia and safety.</td>
</tr>
<tr>
<td>Pain identification and management.</td>
<td>Understand the risks associated with medicines and uses an appropriate blood glucose and</td>
</tr>
<tr>
<td>Hydration and nutrition.</td>
<td>blood ketone monitoring regimen to identify and act on changes.</td>
</tr>
<tr>
<td>Cognition.</td>
<td>Risks include hyperglycaemia associated with diabetogenic medicines, hypoglycaemia</td>
</tr>
<tr>
<td>Diabetes education to support self-care.</td>
<td>associated with medicines and medicine interactions including complementary medicines.</td>
</tr>
<tr>
<td>Supporting families to care for their relative and for themselves.</td>
<td>Ability to undertake general and specific risk assessment to identify changes in physical</td>
</tr>
<tr>
<td>Ability to identify signs of deterioration, (GSF and Diabetes-specific factors), as well as the</td>
<td>and psychological function that could indicate slow deterioration.</td>
</tr>
<tr>
<td>usual changes in vital signs and to respond appropriately.</td>
<td>Recognise and manage acute deterioration such as DKA and hypoglycaemia.</td>
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<tr>
<td></td>
<td>Link these changes to the individual’s values and instructional ACD. OR start a</td>
</tr>
<tr>
<td></td>
<td>conversation to help the individual and their family develop an ACD.</td>
</tr>
<tr>
<td></td>
<td>Know signs and symptoms can be atypical in people with long standing diabetes.</td>
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<tr>
<td>Required knowledge and attributes</td>
<td>Performance criteria</td>
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</tr>
<tr>
<td>Ethical awareness.</td>
<td>Ability to recognise the ethical implications of their actions/decisions and/or inaction.</td>
</tr>
<tr>
<td>All care has ethical implications, especially palliative and end of life care (Milliken 2018).</td>
<td>Develop care with individual and family that promotes the person’s values and care goals and the four key ethical principles.</td>
</tr>
<tr>
<td>Provide care for the person’s body after death.</td>
<td>Autonomy – right to self determination.</td>
</tr>
<tr>
<td>Support family bereavement.</td>
<td>Beneficence – benefit outweighs the risk.</td>
</tr>
<tr>
<td></td>
<td>Maleficence – avoid causing harm.</td>
</tr>
<tr>
<td></td>
<td>Justice – fair distribution of benefit and risk.</td>
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<tr>
<td></td>
<td>Treat the person’s body with dignity and respect relevant to the culture, religion and customs.</td>
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<tr>
<td></td>
<td>Inform relatives about the death and certifies the death in a caring and compassionate manner.</td>
</tr>
</tbody>
</table>
Resources


Evaluation and Quality Assessment of End-of-Life Care - CareSearch: https://www.caresearch.com.au


National Dignity Council - About - Dignity in Care www.nationaldignitycouncil.org.uk/


Recommended reading

The following list consists of books written by people, their families and clinicians dealing with life limiting illnesses and coming to terms with death. They are included because they might help clinicians understand some of the issues people think about and confront as they live with a life limiting illness. They are presented in alphabetical order, not the order of the ‘best read.’


References


Palliative and end of life care: information for older people with diabetes
Palliative and end of life care: information for families caring for older relatives with diabetes
Planning palliative and end of life care with older people with diabetes: Information for health professionals


Hartford Institute for Geriatric Nursing. www.hartfordin.org/publications/trythis/issue14


HelpAge International: Helping older people live full and secure lives
www.helpage.org/


Johns Hopkins Medicine (2014) www.hopkinsmedicine.org/gastroenterology...stomach/


### Appendix 1

John’s story - a case study linking John’s diabetes trajectory and related clinical issues to relevant sections of the Guidelines.

<table>
<thead>
<tr>
<th>John’s Story</th>
<th>Phase/Timepoint</th>
<th>Clinical Issues and Related Section of the Guideline</th>
</tr>
</thead>
<tbody>
<tr>
<td>John was diagnosed with T2DM when he was 58 years old. He didn’t worry too much about it until he had a stroke at age 64. By that time, he also had diabetic nephropathy, and mild peripheral neuropathy. After the stroke he was commenced on glucose lowering medicines that included Metformin and vitamin B₁₂.</td>
<td>Diagnosis Stable</td>
<td>End of Life Guidelines not relevant at this point, but discuss ACD with John and his family (page 11) Nutrition and hydration (page 36) Determine John’s perception of his disease and the positive life course.</td>
</tr>
<tr>
<td>At age 67 he was diagnosed with a combination of Alzheimer’s Dementia and vascular dementia. To reduce the risk of further central and peripheral neurological damage, it was recommended that John’s diabetes control be optimized and to continue taking a self-prescribed multi-B vitamin/zinc supplement. His wife Judy took over monitoring his blood glucose levels and administering his medications.</td>
<td>Life limiting illness Stable</td>
<td>Identify John’s values, goals and preferences to aid decisions when he deteriorates. This might involve giving ‘bad news’ (SPIKES page 69) Hyperglycaemia (page 18) Glycaemic Targets and monitoring (page 15) Medication management (page 25) Nutrition and hydration (page 36) Appendix Complementary Medicine (page 71)</td>
</tr>
<tr>
<td>John's Story</td>
<td>Phase/Timepoint</td>
<td>Clinical Issues and Related Section of the Guideline</td>
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<tr>
<td>At age 69 John's renal physician discussed with him and his wife dialysis because he had stage 3 chronic kidney disease and they wanted to have a plan if he developed end stage renal failure. John and his wife discussed this with their family. Ultimately they felt that dialysis would be too much for John, and his wife Judy who was now assisting him with most of his care, John created an Advance Care Plan.</td>
<td>Additional Life Limiting Illnesses Stable with unstable episodes</td>
<td>Managing hypoglycaemia (page 20) Recognising and managing clinical deterioration (page 39) Supporting family/carers (page 47) Support recall of information using 'teach-back' technique (page 67) Review ACD</td>
</tr>
<tr>
<td>A few months later John was admitted to hospital with severe shoulder pain and diagnosed with polymyalgia rheumatica. He was commenced on high dose prednisolone. Consequently, he had hyperglycaemia and in hospital was commenced on insulin using a basal bolus regimen. On discharge both John and Judy found it difficult to manage the insulin regimen. John was having frequent hypoglycaemic episodes when he returned home, which led to falls and the need to call the ambulance twice to pick him up from the ground. His GP changed him to a more manageable twice daily insulin regimen and discussed with John and his family that avoiding hypos was now the main goal rather than tight blood glucose control.</td>
<td></td>
<td>Diabetogenic medications Managing pain Hyperglycaemia (page 18) Hypoglycaemia (page 20) Supporting family/carers (page 47) Recognising and managing clinical deterioration (page 39) Caring for family (page 47) Review ACD</td>
</tr>
<tr>
<td>A few months later John's dementia and care needs had progressed and he moved into residential care because he needed more and more assistance with his mobility. In the RACF the nurses noticed John didn't like having the insulin injections. His GP tried stopping insulin and oral GLMs but his blood glucose levels fluctuated dramatically and he was quite symptomatic of hypoglycaemia and hyperglycaemia. Consequently John, Judy and the clinicians decided it was beneficial to continue insulin and blood glucose monitoring. Symptoms, it was decided that it was beneficial to continue the insulin and blood glucose monitoring.</td>
<td>End of life deteriorating</td>
<td>Recognising and managing clinical deterioration (page 39) Hyperglycaemia (page 18) Hypoglycaemia (page 20) Review ACD Explain and plan with family and respond to emotional and other cues (page 67)</td>
</tr>
</tbody>
</table>
### John’s Story

John’s dementia continued to progress and one morning he was found with a significantly altered conscious state and diagnosed with pneumonia. He was given subcutaneous fluids and intramuscular antibiotics in the RACF because his Advance Care Plan indicated he preferred care in the RACF. His insulin and oral medication were withheld because he was unable to eat or drink. John’s condition continued to deteriorate over the next few days and blood glucose monitoring, his insulin and other medications were stopped. His symptoms were managed with analgesia and sedative medications. He died 3 days after he was diagnosed with pneumonia.

### Phase/Timepoint

End of life
Terminal

### Clinical Issues and Related Section of the Guideline

- Recognising and managing clinical deterioration (page 39)
- Terminal Care (page 44)
- Hypoglycaemia (page 20)
- Withdrawing Treatment (page 45)
- Advance Care Directive (page 11)
- Support shared decision-making to uphold John’s values and goals (page 44)
- Supporting family (page 47)

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*Dadirri is inner, deep listening and quiet, still awareness. Dadirri recognises the deep spring that is inside us.*

*(Senior elder Miriam-Rose Ungunmerr-Baumann)*
## Appendix 2

Explanation of the terms life limiting illness, palliative care, end of life care and Advance Care Directives.

<table>
<thead>
<tr>
<th>Term</th>
<th>Explanation</th>
<th>Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life limiting illness</td>
<td>The term Life limiting illness describes people at high risk of dying in the subsequent 12-months. Many people admitted to hospitals and ICUs have a life limiting illness. The Gold Standards Framework Prognostic Indicator (GSF) (2016) outlines indicators of life limiting illnesses for cancer, chronic obstructive pulmonary disease, heart failure, renal disease, neurological diseases, frailty, dementia, and stroke. Diabetes is not mentioned in the GSF even though it is the main underlying cause of renal disease, cardiovascular disease and is associated with some forms of cancer, frailty and dementia. Therefore, it is often unclear what ‘initial’ disease commenced the underlying disease, which could be a common underlying inflammatory process, related to obesity.</td>
<td>Guidelines recommend people document their end of life preferences while they are able to make informed, autonomous decisions. Fewer than 50% of people with life limiting illnesses actually have documented goals of care and &lt; 24% has documented care goals. Diabetes-related indicators in addition to duration of diabetes and multimorbidity include: Glucose variability (high and low blood glucose levels) and rapid reduction in HbA1c (Barnett et al. 2006, Huang et al. 2011, Iglay 2016) severe hypoglycaemia (Ito 2012) especially people on sulphonylureas and insulin with hypoglycaemic unawareness. Lower limb and foot disease (Ndosi 2017). Polypharmacy (Jrykka et al. 2009). Comorbid depression (ADA 2018) Recognise and explore suicide ideation. Suicide is twice as common in older people and depressive symptoms are present in 80% of people &gt; age 74 who commit suicide. The severity of depression is a determinate of suicidal ideation. Frailty (Castro-Rodriguez et al. 2016). The FRAX scale is simple to administer and indicate fracture risk and risk of frailty. Other GSF indicators that palliative care could be beneficial include: Decline in health and function Unplanned hospital admissions Symptoms that are difficult to manage and the person becomes less responsive to treatment Person chooses not to accept active treatment &gt; 10 Kg progressive weight loss in the preceding six months Serum albumin &lt; 25g/l (Corti et al. 1994 GSF 2016) Relying on carers for support to undertake diabetes self-care and activities of daily living.</td>
</tr>
<tr>
<td>Term</td>
<td>Explanation</td>
<td>Considerations</td>
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</tr>
<tr>
<td>Palliative care</td>
<td>The aim of palliative care is to improve quality of life, relieve suffering and manage distressing symptoms. Palliative care can be used at any time and can complement usual diabetes care. Palliative care should be commenced early for maximum benefit to archive these aims. Early palliative care also increases satisfaction with care.</td>
<td>Many older people with diabetes could benefit from combining palliative care into their usual diabetes care. They also benefit from support to document advance care directives much earlier than currently occurs. Good communication is essential to support older people to make informed decisions and to document their values and care preferences and goals.</td>
</tr>
<tr>
<td>End of life care</td>
<td>The last 12 months of life and includes imminent death in a few hours or days (GSF 2016, WHO 2014).</td>
<td>Health professionals need to become ‘death literate’. Many people want to die at home but most older people with multiple comorbidities die in hospital.</td>
</tr>
<tr>
<td>Advance Care Plan (ACP) and Advance Care Directive (ACD)</td>
<td>ACP refers to the process used to develop an ACP. ACP can occur over time, it does not have to be done all at once. ACD is a document that clearly describes an individual’s values and the type of treatment they want if they are not capable of deciding for themselves and guides their medical treatment decision-maker and clinicians to make decision on their behalf that accord with their values and care preference. ACDs are often first documented when the individual has MET call to assess sudden deterioration. It is important to consider cultural and religious needs when discussing ACDs. These differ among cultures and within cultures and influence the way individuals view end of life and ACDs.</td>
<td>Start a conversation about values, goals and preferences and give the person time to think about what is important to them and discuss with family and relevant other and/or refer them to an ACP expert in the area. Important information for older people with diabetes to document in their ACD is the things they value and give meaning and purpose to their life (values directive) and the care they want to receive and the care they do not want to receive (Instructional Directive). The ACD does not have to be completed all at once. Older people need time to think about the issue and discuss them with relevant people. So, start the conversation and follow up at a later time. It is important to check the persons’ values and care preferences as part of ongoing care. Values remain relatively constant but care preferences can change over time.</td>
</tr>
</tbody>
</table>
• Start a conversation.
• Listen.
• Establish the person’s values, beliefs and preferences.
• Respond to emotional and verbal cues.
(Appendix 3).

“I am not sure if it is worth it at this stage, I will die soon anyway.”

(Liossi and While, 2001)
Appendix 3
Core Communication Skills
Calgary - Cambridge Framework Sections

The following information relates to the communication care plan described on page 17.

1. Establish rapport and initiating consultation:
   - Know the person’s patient name and the names of significant others.
   - Introduce yourself, your role and outline the context and nature of the consultation.
   - Ask permission, demonstrate respect for the individual’s personhood and dignity.
   - Attend to their comfort.

2. Maintain rapport/build relationship:
   - Use appropriate non-verbal behaviour.
   - If you need to use notes or a computer make sure they do not distract you from establishing and maintaining rapport and attending to verbal and non-verbal cues and dialogue.
   - Identify and respond to the individual/carer’s verbal and non-verbal cues.
   - Be aware of non-verbal behaviour such as eye contact, facial expressions, posture, position, movement, vocal rate/volume/intonation and thinking silences.
   - Acknowledge the individual’s views/feelings and maintain a respectful non-judgemental approach.
   - Convey explicit empathy non-verbally and verbally.
   - Respond to emotions as they arise.
   - Provide support as required.

3. Provide structure to the consultation
   - Clarify/negotiate a shared agenda early in the consultation.
   - Proceed in a logical sequence
   - Explain the structure of the consultation to the individual.
   - Consider using reliable decision aids before, during or after the consultation.
   - Negotiate the order problems/issues will be addressed in if there is more than one (shared decision-making).
   - Periodically summarise the conversation to date to keep the discussion focused on the individual’s agenda.
   - Agree immediate next steps at the end of the discussion and check the individual understands them at the conclusion of the consultation. Ask the individual to summarise them to check for understanding.

4. General
   - Take time to establish rapport especially when discussing sensitive topics.
   - Identify the individual’s key problem/issues in the opening question, then listen and allow them time to answer.
   - Establish what the person already knows about the issue (especially in breaking bad news)
   - Explore the person with diabetes’ and the clinician’s agendas, negotiate and agree what needs to be prioritised in the consultation and what can be addressed at another time.
   - Listen attentively—active listening, avoid interrupting and use silence/pauses.
   - Identify, explore and address cues.
   - Use screening (probing and clarifying) questions until all the main problems are identified to support clinical reasoning.
   - Be aware of the part of the CC framework you are using and whether you need to provide structure or build rapport and the relationship.
5. Information Gathering
   • Ask one question at a time.
   • Usually begin with open questions and then use probing/clarifying/checking questions before using closed questions.
   • Listen attentively: the person will provide most of the information needed in the first 2-4 minutes if they are not interrupted. Interruptions can change the focus and direction of the conversation — usually to where the clinician wants to go and the person's agenda might not be addressed.
   • Use paraphrasing to demonstrate you are listening
   • Gather information in small chunks and then check your understanding.
   • Periodically summarise the discussion.
   • Use easy to understand language — reflect the language the individual uses.
   • Be concise — use as few words as possible to convey your meaning.
   • Gather information about biomedical data and illness data appropriate to the individual and the issue/s under discussion.

6. Ensure the individual's perspective is included (person-centred shared decision-making)
   • Ensure the same core skills are used to gather information about the individual's explanatory models for and perspectives about their illness, including their perspectives about their:
     • problems/issues and any possible solutions
     • concerns, feelings, worries
     • the impact on their life
     • expectations of the consultation
     • values, goals and belief systems (general, cultural, religious, spiritual) that are important to them.

7. Explanation and planning
   • Gauge the type and amount of information to give the individual.
   • Provide information in a way they can understand and that support recall.
   • Relate explanations and information to their perspective, values and goals
   • Assess their understanding of the discussion and the information using an interactive approach.
   • Involve the person in planning and decision-making to achieve collaborative decisions likely to increase the person's commitment and adherence to the plan.
   • Include information about diagnosis, prognosis and causation, when relevant.
   • Regularly check the person understands the information.
   • Use a variety of information methods to explain issues, especially visual methods to convey information.

8. Aid recall and understanding
   • Explain the rationale and share your thinking about the issues under discussion.
   • Shared/collaborative decision-making is more likely to result in a management plan the person can adhere to and be satisfied with.
   • Identify the person's information needs and information format/style preferences.
   • Once the person's baseline understanding is clear decide what additional information they require.
   • Offer a variety of information formats e.g. verbal, visual, audio, comics but ensure they meet usability, readability and design criteria.
   • Use 'teach back' strategies to clarify what the person understood from the discussion and what they intend to do to enable misinformation/misunderstanding to be clarified.
9. Providing complex information
   • Assess the person’s starting point.
   • Determine their information preferences (what, how, when, format).
   • Provide the information into understandable chunks.
   • Check for understanding frequently.
   • Consider using valid well-designed decision aids to help make particularly difficult or complex decisions.

10. Shared decision-making
    • Share your thinking as appropriate.
    • Involve the individual and offer choices and suggestions rather than directives, and encourage the individual to offer ideas and suggestions. People with diabetes usually have long experience self-managing their diabetes, solving problems and making decisions that need to be valued and respected.
    • Relate explanations and recommendations to individual’s ideas, concerns and understanding about how the disease/problem affects their lifestyle and quality of life.
    • Use silence and go slow allow the person time to consider and respond. It can take time to retrieve information from memory stores, especially in stressful situations.
    • Negotiate a mutually acceptable plan.
    • Determine Individual’s preferences.
    • State your preference or position about the available options.
    • Collaboratively decide the best option/s to achieve the individual’s values, goals, lifestyle and quality of life.
    • Check the agreed plan is acceptable to the individual and that their concerns were addressed.

11. Microskills: skills the clinician needs to be an effective communicator (emotional and social intelligence)
    • Ask-tell-ask
      • Start with an open question, respond, and check.
    • Chunk and check
      • Provide a small amount of information then check the individual understood it.
    • Tell me more
      • Encourage the person to share more information, narrow/focus the topic and check assumptions.
    • Signposting
    • Periodically summarise (more than a simple check)
    • Clinician Summary (a more structured summative summary)
    • Check the person’s baseline understanding of current problem/illness
    • Share thinking and agendas
    • Make recommendations
    • Explore the person’s hopes and fears related to their illness/issues under discussion
    • Establish values, goals, preferences, beliefs and attitudes
    • Assess the person’s motivation and capability to change/undertake the management plan
    • Share all the options, including doing nothing
    • Ask the individual to summarise ‘Teach Back’ - the individual summarises their understanding of the discussion, the decisions and the ext. steps.
    • Safety netting (explaining risks and benefits)
      • Describe the benefits and adverse effects (risks) from the various management options and what to do if an adverse event occurs. Relate the information to the individual rather than ‘this only happens to 1 person in every 100’.
12. Responding to the person’s emotion - NURSE
   • Name the emotion (validate and acknowledge the emotion)
   • Understand (what is driving the emotion)
   • Respect and Praise
   • Support and Silence (listen)
   • Empathy and Explore. Help the person understand that we do not need to ‘fix’ the issues that arise in
   the discussion but it is important to hear them, validate them and guide the individual, if possible.

13. Discussing sensitive issues
   • Ask permission to address sensitive issues
   • Be alert to the person’s non-verbal and verbal responses which may be clearly affirmative, ambivalent or
     not wish to discuss it
   • Normalise for the population that the person comes from.
     • For example ‘A lot of men with diabetes are concerned about sexual activity. Do you have concerns
       about that?”
   • Provide opportunities for the individual to shape the content and direction of the consultation

14. Breaking bad news – use SPIKES
   • Set up
   • Perception (what do you understood about...?, use the ICE framework)
   • Invitation (sign post that bad news is coming and determine whether the person would like a relative/
     advocate to be present)
   • Knowledge (give a simple explanation then wait for response),
   • Emotion and empathy (recognise and respond to emotions that arise),
   • Summarise and support (what was discussed and immediate next steps).

15. Prognostic discussions
   • Use a hypothetical – ‘If your condition gets worse quite quickly, would you want …?’

16. Mismatched agendas (clinician and individual have different views).
   • Be open to alternate points of view.
   • Use collaborative discussion to align agendas and strive for common ground/goals.
   • Focus on what the person hopes their alternative will offer that is different from your point of view.
“You never ask how important it is to me to receive this service . . .
I so much look forward to it . . . I’m amazed you don’t ask me this question. It should be the featured question.”

(Downey et al., 2009)
Appendix 4
Complementary Medicine

Complementary medicine (CM) use in Australia

In Australia, an estimated 37% of all adults with diabetes and 25% of adults at the end of life with any disease have used CM in the last 12 months (Canaway and Manderson, 2013, Correa-Velez et al., 2005). These therapies are mostly used alongside conventional care to support general health, symptom relief, to improve functioning and quality of life, to enhance psycho-spiritual wellbeing and self-efficacy.

Adults with diabetes commonly use ingestible therapies such as nutritional supplements (31%), Western herbal medicine (10%) and Chinese herbal medicine (3%) (Canaway and Manderson, 2013, Correa-Velez et al., 2005, Tilden et al., 2004). Often these are self-prescribed, which increases the risk of CM-drug interactions. Less than 10% consult a naturopath or herbalist (Canaway and Manderson, 2013).

Commonly used non-ingestible therapies are massage +/- aromatherapy (38%) and chiropractic or osteopathic care (27%). Less common are movement therapies such as yoga or tai chi (10%), creative therapies such as art or music (8%); touch therapy such as reiki, therapeutic touch or kinesiology (8%), acupuncture (8%), or meditation, spiritual healing or prayer (5%) (Canaway and Manderson, 2013).

Increasing disease severity and declining overall health status are important predictors of use (Nahin et al., 2012). Patient experiences (e.g. dissatisfaction with conventional healthcare services), preferences and values (e.g. more natural, less invasive approach), health behaviour characteristics (e.g. proactive engagement in diabetes care), ethnicity and culture, and affordability and availability influence the decision to use (or try) CM, the types of interventions used and the amount that is used (Dunning, 2003, Canaway et al., 2014, Arcury et al., 2006, Bell et al., 2006, Nahin et al., 2012).

Although the importance of receiving psycho-spiritual care increases near the end-of-life, the use of CM therapies designed to meet these needs appears to decline (Correa-Velez et al., 2005). This observation may in part reflect increasing difficulties with access, particularly as an inpatient or when in residential care.

Discussing Complementary Medicine

Don’t ask – Don’t tell

Whilst polypharmacy and concurrent use of ingestible therapies are very common, healthcare practitioners often do not discuss CM use with their patients and their carers despite the potential for both positive and negative interactions (Chang et al., 2007).

When discussing CM use

1. Remain open and non-judgemental
2. Use a broad range of non-technical terms
   e.g. “People often use natural therapies, vitamins, herbs, teas, foods or traditional remedies…”
3. Explore and understand the reasons for use
4. Actively listen and respond to the person’s and their carers’ emotional status, attitudes and values
5. Provide evidence-based advice about potential benefits and risks (COSA, 2016).

Providing evidence-based advice

There is a paucity of high-quality evidence for both conventional and CM interventions to inform clinical decisions about diabetes management for palliative and end of life care. Evidence-based practice is often informed by translating research from other clinical settings, along with the clinical experience of the practitioner and the preferences of the person and their carers. The overarching goal is to improve the quality of life of the person and their carers.
Evidence-based information sources for healthcare practitioners

- ReviewCollectionComplementaryTherapies/tabid/705/Default.aspx#CTMedRel
- Natural Medicines Comprehensive Database (recommended by COSA with free access for members) http://naturaldatabase.therapeuticresearch.com/
- Integrative Medicine IM Gateway (also available through eMIMS) http://www.imgateway.net
- trc*Natural Medicines https://naturalmedicines.therapeuticresearch.com/

Note: some of these sources require subscription to access all the data

Reliable, user-friendly information sources for lay persons and carers about end of life care


Starting or Stopping Complementary Medicine

Given the paucity of evidence about safety and effectiveness of the use of CM therapies for people with diabetes receiving palliative care, the decision to either continue or discontinue most CM therapies will be strongly influenced by the preferences of the person and/or their carers. There are some instances however, when healthcare practitioners could make a clear recommendation to either start or stop a CM therapy (Cohen and Hunter, 2017).

Healthcare practitioners could recommend starting a CM intervention or referring to a practitioner with appropriate CM training when:

There is at least a moderate certainty about safety/interactions and effectiveness, AND there are minimal opportunity costs; AND either

1. The intervention can potentially alleviate multiple symptoms or improve function and does not add to polypharmacy (e.g. acupuncture for pain, fatigue, mental health and quality of life (Lau et al., 2016, Bonakdar, 2017, Zhou et al., 2017); tai chi for prevention of falls, sarcopenia, cognitive performance, mental health, osteoarthritis and pain (Solloway et al., 2016); massage +/- aromatherapy for pain and mental health (Boyd et al., 2016b, Boyd et al., 2016a, Crawford et al., 2016, Shin et al., 2016)); OR
2. There is a strong preference by the person or their carers to first try natural therapies for symptom relief before trying other equally or more effective interventions (e.g. acupressure wrist band for nausea (Lee et al., 2015, Wu et al., 2015); meditation or mindfulness-based interventions for mental health and spiritual wellbeing (Chan and Larson, 2015, Gu et al., 2015)); OR
3. The intervention is logistically feasible to provide AND affordable to the patient or health service (e.g. additional oral, sublingual or intramuscular vitamin B12 for symptomatic relief of diabetic peripheral neuropathy (Sun et al., 2005), particularly if there is concurrent or recent use of metformin (Chapman et al., 2016)).

Healthcare practitioners should strongly advise stopping a CM intervention when either:

1. There is high certainty in the evidence of no benefit (as opposed to uncertainty due to a lack of clinical trials, low-quality evidence or conflicting results); OR
2. There is at least moderate certainty in the evidence of a more effective, better tolerated and more affordable therapy that is equally as acceptable to the person and their carers; OR
3. The person wants to reduce the number of interventions they are using, or reduce their out-of-pocket health care costs AND there is minimal evidence to justify ongoing use; OR
4. There are probable side-effects, interactions or other risks, the consequences of which are unacceptable to the person and their carers.

**Unproven safety concerns and theoretical risks are insufficient on their own to justify making a strong recommendation to stop a CM therapy**, particularly if there are no observed adverse events, there is scientific evidence of other potential benefits, or the person or their carers claim subjective benefit. Further, Australian hospitals and hospices do not have the legal authority to ban self-prescribed or self-administered CM products (CATAG, 2015). **Weighing up the benefits and risks**

Whilst CM products are most commonly used in Australia for reasons other than glycaemic control (Nahin et al., 2012), both positive and negative interactions with diabetes and pharmaceuticals should be considered.

**Potential additive effects of herbal medicine combined with diabetes medication**

<table>
<thead>
<tr>
<th>Herbal Medicine</th>
<th>Pharmaceutical Interactions</th>
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<tbody>
<tr>
<td>Aloe Vera – <em>Aloe barbadensis</em></td>
<td>Glibenclamide, Pioglitazone,</td>
</tr>
<tr>
<td>Cassia – <em>Cassia fistula, Cassia occidentalis</em></td>
<td>Glibenclamide*, Glimepiride*, Glipizide*, Pioglitazone*, Rosiglitazone*</td>
</tr>
<tr>
<td>Fenugreek – <em>Trigonellafoenum-graecum</em></td>
<td>Glibenclamide, Metformin</td>
</tr>
<tr>
<td>Garlic – <em>Allium sativum</em></td>
<td>Metformin</td>
</tr>
<tr>
<td>Ginger – <em>Zingiber officinale</em></td>
<td>Glibenclamide*</td>
</tr>
<tr>
<td>Ginseng – <em>Panax ginseng, Panax quinquefolium</em></td>
<td>Metformin</td>
</tr>
<tr>
<td>Gymnema – <em>Gymnema sylvestre</em></td>
<td>Metformin*</td>
</tr>
<tr>
<td>Karela / Bitter Melon – <em>Momordica charantia</em></td>
<td>Glibenclamide, Metformin</td>
</tr>
<tr>
<td>Olive Leaf Extract – <em>Olea europaea L.</em></td>
<td>Oral diabetes medication (not specified)</td>
</tr>
<tr>
<td>Prickly pear cactus / Nopal – <em>Opuntiaac iculata</em></td>
<td>Glipizide, Metformin</td>
</tr>
<tr>
<td>Scutellaria – <em>Scutellaria baicalensis</em></td>
<td>Metformin*</td>
</tr>
<tr>
<td>Sesame Oil</td>
<td>Glibenclamide</td>
</tr>
<tr>
<td>St John’s wort – <em>Hypericum perforatum</em></td>
<td>Metformin</td>
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</table>

(Gupta et al., 2017) *animal models only*

**Before ceasing a CM product, have you considered the potential benefits?**

For example, meta-analyses of zinc supplementation of >20-30mg daily consistently demonstrate a “significant albeit modest reduction in glucose concentrations and tendency for a decrease in HbA1c” (Jayawardena et al., 2012, Capdor et al., 2013). However, the potential risk of hypoglycaemia might be outweighed by the potential benefits of prescribing zinc in a population group that has a high risk of suboptimal zinc intake/absorption and may have other co-morbidities such as acute/chronic infections or diabetes related neuropathy or retinopathy that may be assisted by zinc supplementation (Hemila, 2017, Science et al., 2012, Jayawardena et al., 2012, Pushparani, 2014).

Rather than ceasing zinc, consider whether reducing the dose of insulin or a sulphonylurea is more appropriate.
## Risk benefit analysis of some CM products commonly used by adults with diabetes

<table>
<thead>
<tr>
<th></th>
<th>Hyperglycaemic risk</th>
<th>Other potential benefits &amp; risks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glucosamine</td>
<td>Theoretical risk, mostly unsupported by human studies (Salazar et al., 2014).</td>
<td>High certainty of benefit for knee osteoarthritis with patented crystalline glucosamine sulfate (DONA”); low to moderate certainty for other formulations and other joints (Bruyere et al., 2016a, Bruyere et al., 2016b).</td>
</tr>
<tr>
<td>Omega 3 fish oils</td>
<td>Statistically significant risk, however, clinical significance is uncertain (Chang et al., 2018).</td>
<td>Moderate certainty of benefit for all adults with depression (Pouwer et al., 2005), and for reducing chronic kidney disease progression in adults with Type 2 diabetes of (Elajami et al., 2017, Miller et al., 2013) and inflammation (CRP) (Lin et al., 2016). Adverse effects: decreased haemoglobin/haematocrit, belching/nausea (Chang et al., 2018). Theoretical anti-coagulant activity risk (Chang et al., 2018). Moderate certainty of safety peri-operatively and for concurrent anticoagulant use (Jeansen et al., 2018).</td>
</tr>
</tbody>
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</thead>
<tbody>
<tr>
<td>Aloe vera</td>
<td>Additive risk with glibenclamide, pioglitazone (Gupta et al., 2017).</td>
<td>Low certainty of benefit for topical applications to prevent or treat infusion phlebitis (Zheng et al., 2014). Adverse events from ingestion: diarrhea, hypokalemia, pseudomelanosis colic, kidney failure (Guo and Mei, 2016).</td>
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<tr>
<td>Aloe barbadensis</td>
<td></td>
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<tr>
<td>Andrographis</td>
<td>Theoretical additive risk with oral diabetes medication from CYP2C9 and CYP3A4 inhibition (Gupta et al., 2017).</td>
<td>Low certainty of benefit for reducing symptoms and duration of respiratory tract infections (Hu et al., 2017)</td>
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<tr>
<td>Andrographis paniculata</td>
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<tr>
<td>Chromium</td>
<td>Chromium picolinate &gt;200mcg daily may reduce fasting blood glucose levels (Suksomboon et al., 2014).</td>
<td>May reduce absorption of levothyroxine(John-Kalarickal et al., 2007). Accumulates in kidneys, risk is uncertain (Lamson and Plaza, 2002)</td>
</tr>
<tr>
<td>Cinnamon bark and quills (capsules) Cinnamomum sp.</td>
<td>May reduce fasting blood glucose levels (Allen, 2013).</td>
<td>Low certainty that olfactory cortex is activated and for management of oral candidiasis (people with HIV infection at the end of life) (Dugoua et al., 2007).</td>
</tr>
<tr>
<td><strong>Risk benefit analysis of some CM products commonly used by adults with diabetes</strong></td>
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<tr>
<td><strong>Hyperglycaemic risk</strong></td>
<td><strong>Other potential benefits &amp; risks</strong></td>
<td></td>
</tr>
<tr>
<td>Garlic <em>(capsules or juice)</em></td>
<td>Additive risk with metformin (Gupta et al., 2017).</td>
<td>Moderate certainty for improved immunity <em>(e.g. reduce the number, duration, and severity upper respiratory tract infections)</em> (Ried, 2016).</td>
</tr>
<tr>
<td><em>Allium sativum</em></td>
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</tbody>
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| **Hypoglycaemic risk**                           | **Other potential benefits & risks**             |
|-------------------------------------------------|-------------------------------------------------|-------------------------------------------------|
| Ginger *(Zingiber officinale)*                   | May reduce fasting blood glucose levels *(Zhu et al., 2018)*. Theoretical risk of interaction with Glibenclamide (Gupta et al., 2017). | Low-moderate certainty of benefit for nausea and vomiting *(Ernst and Pirtler, 2000, Marx et al., 2013, McPadin et al., 2016)*. Low certainty for muscle or arthritic pain relief *(Lakhan et al., 2015)*, renoprotection for diabetic nephropathy *(Rafeian-Kopaei and Nasti, 2014)*. |
| *Panax ginseng or quinquefolium*                 | Additive risk with Metformin (Gupta et al., 2017). May reduce fasting blood glucose (Gui et al., 2016). | Low-moderate certainty of benefit for fatigue associate with chronic disease *(Arring et al., 2018)*. |
| Olive leaf extract *(Olea europaea L)*           | May reduce fasting blood glucose *(de Bock et al., 2013, Wainstein et al., 2012)*. | Low certainty of benefit for reducing cardiovascular risks *(Lockyer et al., 2015)* including systolic and diastolic blood pressure in people with stage 1 hypertension *(Perrinjaquet-Moccetti et al., 2008)* demonstrated equivalence with Captopril *(Susalit et al., 2011)*. |
| St John’s wort *(Hypericum perforatum)*         | May decrease renal clearance of metformin, no other pharmacodynamic effects on metformin or repaglinide (Gupta et al., 2017). | Moderate to high certainty of benefit for mild-moderate depression; moderate certainty of less side effects than SSRIs *(Apaydin et al., 2016)*. |
| Zinc                                            | May reduced fasting blood glucose levels >20-30mg daily *(Jayawardena et al., 2012, Capdor et al., 2013)*. | Low-moderate certainty of benefit for acute infections *(Hemila, 2017, Science et al., 2012)*, periodontal disease *(Pushparani, 2014)* and with combination vitamin/mineral products for symptoms of diabetic neuropathy or retinopathy *(Jayawardena et al., 2012)*. No effect on kidney or liver function *(Jayawardena et al., 2012)*. |

**NOTE**: whilst numerous other CM therapies have demonstrated improvements in glycaemic control and may therefore increase the risk of hypoglycaemia, only those that also have potential benefits relevant to palliative care and end of life problems have been listed.
References


Cosa 2016. Guideline for discussing complementary and alternative medicine (CAM) with patients, Sydney: Clinical Oncology Society of Australia - Complementary and Integrative Therapies Group.


Lin, N., Shi, J.-J., Li, Y.-M., Zhang, X.-Y., Chen, Y., Calder, P. C. & Tang, L.-J. 2016. What is the impact of n-3 PUFA's on inflammation markers in Type 2 diabetic mellitus populations?: a systematic review and meta-analysis of randomized controlled trials. Lipids In Health And Disease, 15, 133-133.


Gone are my familiar friends,  
The men I used to know;  
Yet still on Taksago beach  
The same old pine trees grow,  
That I knew long ago.

(Okikaze Fujiwara)