

Palliative and end of life care: information for older people with diabetes



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

Orledge, R. (1979) *Gabriel Faure*, London, Eulenburg Books.

Disclaimer

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

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

The Information was designed to be used with other relevant guidelines and policies for managing older people with diabetes receiving palliative and end of life care of older people with diabetes. The authors and Advisory Groups who developed the information are not responsible for any actual care provided on the basis of the suite of information and disclaim liability and responsibility to any person for the consequences of anything done or omitted by any person relying wholly or partially on the whole or part of the content or any part of the suite of information.

Conflict of interest

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

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Introduction

The information in this book was developed to help older people with diabetes understand palliative and end of life care and discuss their future care with family members and health professionals.

It explains what happens as people approach their end of life and what happens when they are dying.

Older people with diabetes, their families, doctors and other health professionals share the responsibility for making decisions about care.

Making decisions becomes more difficult and stressful in life-threatening situations and emergencies. Planning ahead of time can help reduce stress for you, your family and your health professionals.

Sometimes a lot of treatment might not be beneficial. It might prolong your life, but not give you the sort of life you want. Programs such as dignity therapy, writing lifestories and music can help manage physical and emotional pain.

Some people find it hard or upsetting to talk about end of life but talking to your family and doctors about your values, preferences and goals is very important when you make decisions about your care.

You are the only person who really knows what makes your life worth living and how you want to spend the rest of your life. Help your family and health professionals understand your needs by talking with them.

Knowing when to start palliative care to keep you comfortable and help you have acceptable quality of life, depends on the benefits and risks of any treatment, how much pain and suffering you feel and how long you have left to live.

Deciding how long you have to live is called prognosis. It is very hard to know exactly how much time a person has left. Having some idea about 'how much time you have left' can help you complete unfinished business and say goodbye to the people and pets who are important to you.

Dying is a very emotional, social, cultural and spiritual time. It is also a very personal experience. Dignity therapy is a program that can be used with palliative care and your Advance Care Directive to help you and your family manage emotional pain and suffering and come to terms with dying.



What is Palliative Care?

Palliative care is a type of care used to improve comfort and quality of life by treating pain and other distressing symptoms so you can live as comfortably and as actively as possible for as long as possible.

Palliative care can be used at any time. It can be used with your usual diabetes care.

People who start palliative care early often find they have less pain and suffering, can function better and have more control over their life.

How will I know whether palliative care could help me?

The following is a list of some signs you might feel or notice that could mean palliative care could help you:

- Pain and suffering - mental and/or physical.
- Falling.
- A lot of low blood glucose levels (hypoglycaemia or hypo).
- Foot infections or ulcers that are not healing.
- Heart problems.
- Stroke.
- Kidney problems, especially if you need dialysis.
- Dementia.
- Depression.
- Having trouble walking.
- Losing the will to live.
- Needing to go into hospital more often than usual.

You might have more than one sign. The more signs you have the more benefit you could have from starting palliative care.

Starting palliative care early can help reduce pain and suffering. It does not mean the doctors and nurses are 'giving up on you.'

You do not have to be old to develop an Advance Care Directive. Your family could develop their Advance Care Directives too.

What can I do?

- Ask your doctors, diabetes educator or other health professionals when palliative care could help you. Your family could be part of the discussion.
- Decide who you want to be make decisions for you if you are unable to make decisions for yourself. This person is called your medical treatment decision-maker. Make sure they are willing to make decisions for you if you are not able to decide for yourself.
- Find out about dignity therapy, or life story programs that are designed to help people maintain dignity and hope and feel they are in control of their remaining life. They help people to live in and enjoy the moment.
- Develop an Advance Care Directive and tell your family, doctors and other health professionals where it is kept and what it says.

What is an Advance Care Directive?

Your Advance Care Directive is a legal document and must be signed and witnessed. An Advance Care Directive has three parts:

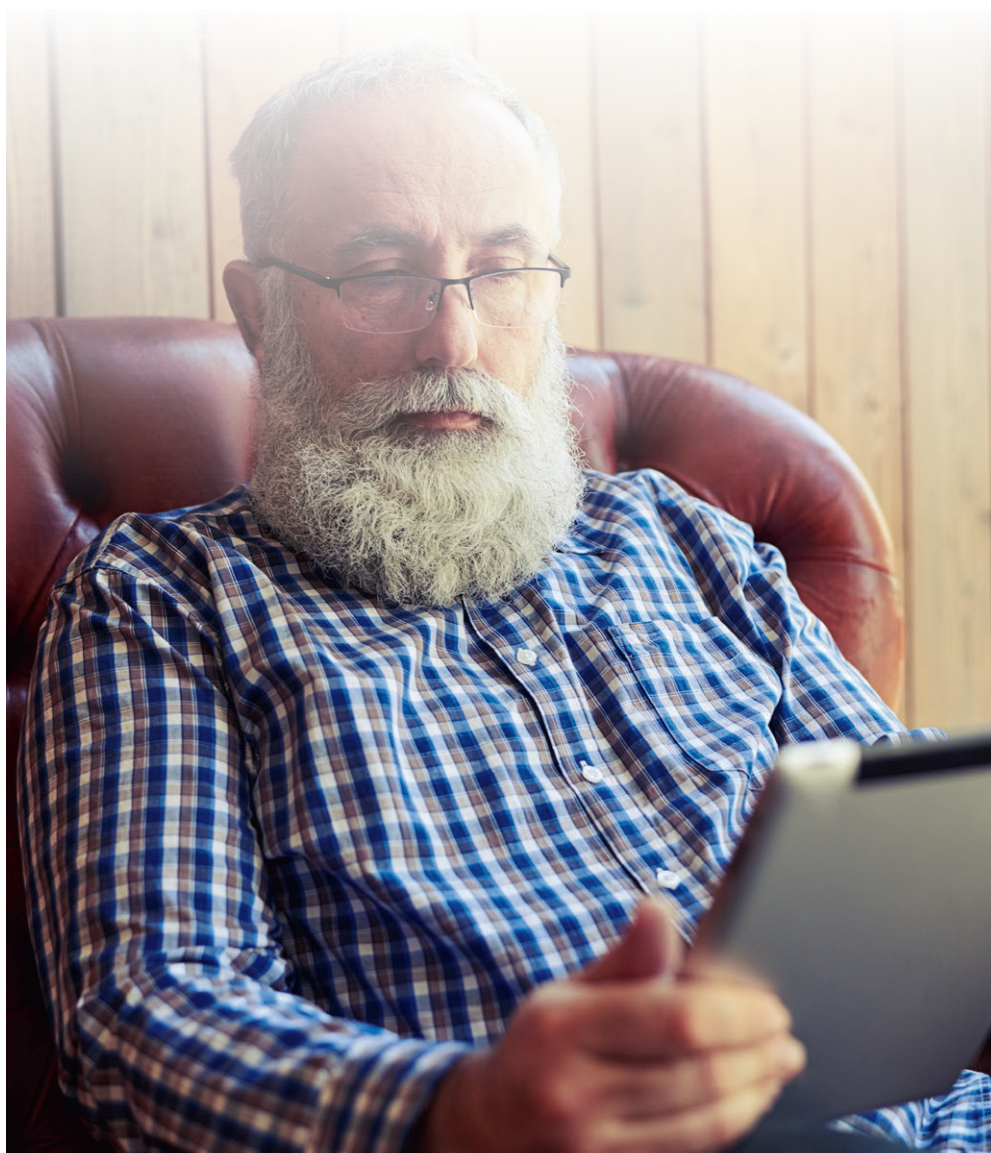
1. Your personal details.
2. A part where you write your values, care preferences and goals to help families make decisions for you if you are unable to decide for yourself.
3. A part where you write down what treatment you want or do not want so your health professionals understand your preferences.

What if I need help to write an Advance Care Directive?

You can find more information about Advance Care Directives on the Victoria State Government website: <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning>

If you find the information hard to read or you do not understand it, you can ask your health professionals for help to write your Advance Care Directive.

They might suggest you make an appointment with the staff of a program called Advance Care Planning, who are experts in helping people write their Advance Care Directive.



You need to sign your Advance Care Directive in front of two witnesses. One must be a medical doctor. Your family and medical treatment decision- maker will need a copy of your Advance Care Directive

You can put an expiry date on your Advance Care Directive but if you do, you will need to make a new Advance Care Directive after the expiry date whether you change your mind about the care you want or your goals and preferences stay the same.

Make sure you put the date on the new one, that it is witnessed by a medical doctor and another person and destroy ALL copies of the expired Advance Care Directive.



.What should I write in my Advance Care Directive?

Your Advance Care Directive should tell health professionals and your family members the type of care you want or do not want if you are very ill or can no longer decide for yourself. Some of the things you might want to include are whether you want:

- Resuscitation, often known as cardiopulmonary resuscitation or CPR, if your heart stops beating.
- To be put on a breathing machine (ventilator) to help you breathe.
- To be fed through a tube into your stomach or vein if you have trouble eating and/or drinking.
- To start new medicines such as antibiotics to treat infections, to continue your usual medicines or want pain relieving medicines.
- Your blood glucose to be monitored. Monitoring blood glucose can help you tell if it is high or low. Both high and low blood glucose can cause unpleasant symptoms and make it difficult to think straight.
- Staff to call the Medical Emergency Team (MET) if you are in hospital. The MET team can manage the problem and/or provide palliative care to make you comfortable and relieve pain.

Other things to think about

- Where you want to spend the last days of your life, for example at home, in a hospital or in an aged care home. You need to discuss these options with your family. It could be hard for them to watch you suffer at home.
- You and your family can be supported by the community palliative care team and your GP if you prefer to die at home.
- Who you want to make decisions for you if you cannot decide for yourself. This person is called your medical treatment decision-maker.
- Any religious or cultural customs or practices that are important to you that your health professionals need to know about.

You do not need to write your Advance Care Directive all at once.

Find out what you need to do and take time to think about your values and what care you want. Talk about it with the people important to you.

What should I do with my Advance Care Directive

- Keep a copy of your signed, dated and witnessed Advance Care Directive.
- Tell important people where to find it.
- Give a copy of your Advance Care Directive to your medical treatment decision-maker and family.
- Upload the Advance Care Directive into your electronic health record if you want other doctors and nurses to know your wishes, especially when you are travelling.
- Ask for help to upload your Advance Care Directive to your electronic health record if you can't do it yourself.





What is end of life care?

End of life care is care given in the last six to 12 months of life.

Sometimes people die suddenly and unexpectedly, but it is hard to know when a person will die.

There are some signs that suggest you might be entering the last stage of your life. The last stage of life is sometimes called the terminal stage but terminal usually means the last few days or hours of life.

Many people 'know' when they are entering the last stages of their life.

Knowing the signs that mean you are coming to the end of your life can help you, your family and your doctor and other health professionals use your Advance Care Directive to keep you comfortable so you have a dignified death when that time comes.



Signs that might mean you are nearing your end of life

- Many people become weaker (frailer) towards the end of their life and find it harder to do things.
- You might sleep more and for longer.
- Falling.

You:

- Have more than three health problems. For example, foot infections, kidney problems and heart problems.
- Are losing weight without trying.
- Have infected foot ulcers.
- Have low blood glucose levels you do not recognise or cannot treat yourself (hypoglycaemia).
- Need to go to the emergency department or be admitted to hospital more often than usual.



Many people seem know they are getting close to the last stage of their life.

What can I do?

- Write down your values, preferences and goals so you do not forget important things when you talk with your family, doctor and other health professionals about your life and other goals, the things you value, and the way you want to be cared for in your Advance Care Directive.
- The Advance Care Directive has a section where you can write down your values, called a Values Directive, and a section where you write the care you want or do not want, called an Instructional Directive. It tells your family, health professionals what you want to happen if you cannot tell them yourself at the time.
- Ask somebody you trust to make treatment decisions if you are unable to decide for yourself. These people are called medical treatment decision makers.
- Make sure your medical treatment decision maker, your family and health professionals have a signed, dated and witnessed original copy of your Advance Care Directive.
- If you already have an Advance Care Directive, make sure it still reflects your wishes.
- If you decide to change your Advance Care Directive, make sure your new one has a date on it, is witnessed by a doctor and another person and destroy ALL copies of the old one.
- If it is difficult for you to swallow your medicines by mouth ask your doctor whether there are other forms of medicines you can use such as patches, gels, liquid medicines or injections.

What is the terminal stage?

The terminal stage usually means the last few days or hours of life.

Even when death is expected it can be a shock and distressing for your family and friends.

However, it might be relief for your family to know you are no longer suffering or in pain.

It can be important for family, including children and pets, to be with you at your end of life, just as it was for them to be with you during your life.

It might be relief for your family to know you are no longer suffering or in pain.





Signs the end is near

The following signs mean your body is gradually slowing down. Not everybody will have all of these signs and they do not occur in any particular order.

Sometimes the signs occur a few hours before death, sometimes they occur a few days before.

Your family or health professionals might be more aware of the signs than you are.

- Not wanting to eat or drink. This might be a good thing, because it helps reduce fluid in your chest, bed wetting and vomiting, which can be exhausting and distressing and undignified for you.
- Drowsiness, sleeping a lot and not being able to 'think straight.'
- Changes in body temperature. Sometimes you might feel hot and sometimes you might feel cold.
- You may produce less urine and your urine may be a dark colour if you are not drinking much fluid.
- You may lose control of your bladder and bowels as your muscles relax.
- Coughing and swallowing slow down, so saliva and mucous can collect in your throat and make a gurgling or bubbling sound. This can be distressing for your family to see and hear, but it is not usually painful. Sometimes treatments can be used to help dry up the saliva.
- Your breathing may change. It may become noisy or shallow. Sometimes it is fast and sometimes there are long gaps between breaths.
- You may become anxious, restless or agitated. These symptoms can be treated to keep you comfortable.
- Some people have end of life dreams. If you do, you might want to share your dreams with your family.
- You will probably slip into a coma but you may not notice when that happens. Your family will notice the change.

The time just before death is often peaceful.



What can you do?

- Say your final goodbyes to family members, friends and special pets.
- Make sure your family, carers, doctors and other health professionals know about any religious and cultural customs important to you and what your Advance Care Directive says and ask them to follow it.
- Ask your doctor and other health professionals about anything that is worrying you.
- Ask for pain relief if you need it.
- Ask your family for any support you need and make sure they know what you want and what you do not want.



Where can I get more information?

Advance Care Planning Australia,

www.advancecareplanning.org.au

Better Health Channel,

www.betterhealth.vic.gov.au

Cancer Council Australia,

www.cancer.org.au

Care Search Palliative Care Knowledge Network

<https://www.caresearch.com.au/caresearch/tabid/64/Default.aspx>

Diabetes Australia,

www.diabetesaustralia.com.au

Diabetes Victoria,

www.diabetesvic.org.au

Dignity in Care (Dignity Toolkit),

<http://dignityincare.ca/en/toolkit.html>

Heart Foundation,

www.heartfoundation.org.au

Kidney Health Australia,

kidney.org.au

Advance Care Planning,

www.advancecareplanning.org.au

Palliative Care Australia,

www.palliativecare.org.au

Victoria State Government website, 'Advance Care

Planning', <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning>

Interesting books you might like to read

These books were written by or about people living with life limiting illnesses. They are included because you or your family might find comfort from reading other people's stories.

The books are presented in alphabetical order, not the order of the 'best read.'

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

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

Bain G (2017) *The Book Museum* Scribe, Sydney.

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

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

Corke C. (2018) *How to Plan Good Death* Scribe Melbourne.

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

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

Williams M. (1922) *The Velveteen Rabbit* Doubleday, New York.







