

Palliative and end of life care: information for families caring for older relatives 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

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Introduction

The information in this book was developed to help families caring for an older relative with diabetes understand palliative and end of life care and the importance of talking with them about their values, preferences and goals for their future care. You might also like to talk with the health professionals caring for your relative.

The information explains what happens as people approach the 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 everybody in emergencies.

Sometimes a lot of treatment might not be beneficial and might not improve your relative's quality of life. It might prolong their life, but not give them the life they want.

Some people find it upsetting to talk about end of life; but knowing your relative's values, preferences and care goals is very important if you have to make decisions about their care when they cannot make decisions for themselves.

Sometimes a lot of treatment or going to the intensive care unit might not improve your relative's quality of life. It might prolong their life but not give them the life they want.

Knowing when to start palliative care to keep your relative comfortable so they continue to have quality of life depends on the benefits and risks of any treatment, how much pain and suffering they experience, their illness and how long they have left to live.

Deciding how long your relative has 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 your relative has left' can help you and them complete unfinished business and say goodbye to the people and pets who are important to them.

Dying is a very emotional, social, cultural and spiritual time. It is also a very personal experience for you, other family, friends and your relative.

Programs such as dignity therapy and life narratives/stories can be used with palliative care and Advance Care Directives, and could help your relative manage their physical and emotional pain and suffering and help them cope and find meaning in their remaining life.



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 to help people 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 relative's usual diabetes care. So starting palliative care does not mean the doctors and nurses are 'giving up on your relative'.

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

Starting palliative care does not mean the doctors and nurses are 'giving up on your relative'.



How will I know whether palliative care could help my relative?

Following is a list of some signs your relative might tell you about, or you might notice, that could mean palliative care could help make your relative comfortable:

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



What can families do?

- Discuss palliative care with your relative, their doctors, diabetes educators, other health professionals and other family members.
- Find out about programs such as dignity therapy and life narratives that are designed to help people maintain dignity and hope, help them have sense of control over the rest of their life and to 'live in the moment.'
- Ask your relative whether they developed an Advance Care Directive and appointed a person to make decisions for them, if they are not able to decide for themselves. This person is called a medical treatment decision-maker.
- Make sure they tell their family, doctors and other health professionals where their Advance Care Directive is kept and what it says.

What is an Advance Care Directive?

An Advance Care Directive has three parts:

1. A part where your relative writes their personal details.
2. A part where your relative writes their values, care preferences and goals to help their family make decisions for them if they are unable to decide for themselves.
3. A part where your relative writes down what treatment they want or do not want so their health professionals understand what they want.

Your relative's Advance Care Directive is a legal document and they must sign it in front of two witnesses.

One witness must be a medical doctor.

Your relative must give a copy to their family and their medical treatment decision maker.

If your relative decides to put an expiry date on their Advance Care Directive they will need to make a new Advanced Care Directive when it expires. It is important the new Advance Care Directive is dated, signed and witnessed and ALL copies of the old Advance Care Directive are destroyed.

You do not have to be old to develop an Advance Care Directive. Everybody can develop an Advance Care Directive.

You could consider writing yours.



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

You can find more information about Advance Care Directives at 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 need help to understand the information you can ask your relative's health professionals for help.

You can also seek help from the staff who offer programs such as Advance Care Planning in your area.



What should my relative write in their Advance Care Directive?

Your relative's Advance Care Directive should clearly tell health professionals and their families the type of care they want and the care they do not want if they are too ill or no longer able to decide for themselves.

For example, whether they want to be:

- Resuscitated, often known as cardiopulmonary resuscitation or CPR, if their heart stops beating.
- Put on a breathing machine (ventilator) to help them breathe.
- Fed through a tube into their stomach or into a vein if they have trouble eating and/or drinking.
- Treated with medicines, including continuing their usual medicines to manage blood glucose and be given pain medicines or medicines to treat infections (antibiotics).
- Their blood glucose to be tested. Testing blood glucose can help decide whether high or low blood glucose is causing problems such as confusion that can be treated to keep them comfortable. Insulin can be used as a 'palliative' care medicine to treat high blood glucose and help make your relative comfortable.
- Staff to call the Medical Emergency Team (MET) if they become very unwell when they are in hospital. The MET team can use your relative's Advance Care Directive to make them comfortable and relieve pain.

Other things for you and the person to think about are:

- Their preferred place for their end of life care, for example at home, in a hospital or in an aged care home. You need to discuss these options with your relative. It could be hard for you to watch your relative suffer and providing care can be difficult.
- There may be religious and cultural customs that need to be considered and that health professionals need to know about.
- However, dying peacefully at home with family and beloved pets and support from the community palliative care team can be a very special time for everybody.
- A medical treatment decision-maker to make decisions for them if they cannot decide for themselves.

You and your relative can be supported by the community palliative care team and/or their GP if they decide to stay at home for their end of life care.

Your relative does not need to do everything at once. Start by talking about what they want. Give them time to think about it and when they are ready they can write their Advance Care Directive.



What should I do with my relative's Advance Care Directive?

- Keep a copy of your relative's signed Advance Care Directive in a safe place.
- Make sure your relative asked to make decisions for them if they cannot decide for themselves, has a copy of the Advance Care Directive. This person is called a medical treatment decision-maker.
- Help your relative upload the Advance Care Directive into their electronic health record, especially if they travel interstate or overseas.
- Try to make sure your relative's GP, other doctors and emergency services (paramedics) have access to their electronic medical record.



What is end of life care?

End of life care is care given in the last six to 12 months of life. It is sometimes called the terminal stage, but terminal usually means the last few days or hours of life.

Sometimes people die suddenly and unexpectedly. It is hard to know when a person will die, but there are some signs that suggest your relative might be entering the last stage of their life.

Many people seem to 'know' when they are entering the last stage of their life.

Knowing the signs your relative is nearing the end of their life can help you, other family, and their doctor and other health professionals follow their Advance Care Directive and help them have a comfortable and dignified death, when that time comes.



Signs that might mean your relative is nearing the end of their life:

Ask yourself, 'would I be surprised if my relative died in the next few months'?

If the answer is 'no, I would not be surprised' and they do not have an Advance Care Directive, it is time to help them think about their values, preferences and goals and write down the type of care they want or do not want.

People who plan for their end of life have better quality of life. Writing an Advance Care Directive helps their family and the doctors and nurses caring for them make decisions about their care that suit their values and preferences.

Important issues to consider when your relative is nearing the end of their life are:

- Whether they want to make any changes to their preferences and goals while they can still make decisions for themselves.
- Whether they want treatment that will prolong their life, for example to be revived if they have a heart attack or stroke.
- When to use treatment to improve their quality of life, treat pain and improve comfort, for example pain medicine and massage.

As time goes by your relative might:

- Become weaker (frail), find it harder to do things and walk very slowly.
- Sleep a lot more including in the daytime.
- Lose weight without trying.

They might:

- Need to go to the emergency department or be admitted to hospital more often.
- Fall.
- Have more than three health problems. For example, foot infections, kidney problems and heart problems.
- Have infected foot ulcers that do not heal.
- Have low blood glucose levels they cannot treat themselves (hypoglycaemia).
- Seem to lose the will to live.



What can the family do?

- Talk with your relative about their life and other goals, the things they value, and the way they want to be cared for.
- Help them develop their Advance Care Directive. The Advance Care Directive has a section where they can write down their values, called a Values Directive, and a section where they write the care they want or do not want, which is called an Instructional Directive (see page 8).
- Ask them to appoint their medical treatment decision-maker and make sure that person or people has an up-to-date, signed and witnessed original copy of their Advance Care Directive.
- If they already have an Advance Care Directive ask them whether their goals and preferences are still the same.
- If they change their Advance Care Directive, make sure they destroy ALL copies of the old one.
- Make sure their Advance Care Directive states what they want to happen if they cannot tell their family, doctor and other health professionals, at the time.
- If your relative has to go to hospital make sure their Advance Care Directive goes with them and that emergency service providers (paramedics) know their preferences.
- If your relative needs to go into an aged care home, make sure the Advance Care Directive goes with them.
- If it is difficult for your relative to swallow their medicines by mouth ask their doctor whether there are other forms of medicines that might suit them such as patches, gels or liquid medicines.

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 you, other family members and friends.

However, it might be relief for some people to know their family member is no longer suffering or in pain.

Signs death is coming

The time just before death is often peaceful.

The signs on page 16 mean your relative's 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.

The time just before death is often peaceful. Be comfortable sitting in silence with your relative or talk quietly to them.



You and the health professionals might be more aware of the signs than your relative.

- Not wanting to eat or drink. This might be good, because it helps reduce fluid in the chest, bed wetting and vomiting, which can be exhausting, distressing and affects dignity.
- Drowsiness, sleeping a lot, not being able to 'think straight'.
- Changes in body temperature. Sometimes your relative might feel hot and sometimes they might feel cold.
- They might produce less urine and their urine might be a dark colour if they are not drinking much fluid.
- They may lose control of their bladder and bowels as their muscles relax.
- Coughing and swallowing slow down, so saliva and mucous can collect in your relative's throat and make a gurgling or bubbling sound. This can sound uncomfortable to witness and hear, but it is not painful.
- Their breathing might change. It might be noisy or quiet. Sometimes there are long gaps between breaths.
- Generally people slip into a coma but they may not be aware when this happens.



What can the family do?

- Say your final goodbyes to your relative.
- Make sure other family, carers, doctors and other health professionals know what your relative's Advance Care Directive says and respect their care preferences.
- Talk with your relative's doctor and other health professionals about anything that is worrying you.
- Make decisions for your relative if you are their medical treatment decision-maker and he or she can no longer make decisions.
- Sit with your relative, hold their hand and talk with them calmly, they might like to hear music, even if they do not respond, they find your presence reassuring.
- Ask their doctor whether if there is anything that could help slow down saliva to stop the distressing gurgling sounds and/or whether medicines could relieve pain and restlessness.
- Change your family member's position regularly to help keep them comfortable.
- Many people have end of life dreams and may want to talk about their dreams and what they mean. It helps if you can listen.
- Ask your relative 'are you at peace?' Peace can be religious and/or spiritual and can mean being at peace with their end of life decisions and have no unfinished business to worry about.

Signs your relative has died

- Your relative stops breathing.
- You cannot feel a pulse or heartbeat.
- You cannot wake your them.
- Their eyes might be open, appear to be staring or their eyelids may be half open.
- Their mouth might be open.
- Their body will begin to feel cold.

What can you do?

Say goodbye in your own time.

If your relative dies at home, straighten their limbs before they become stiff. The stiffness is normal and is called *rigor mortis*, which means the stiffness of death.

Attend to any religious or cultural customs.

Inform family and friends, and other relevant people such as a religious person and the doctor.

If your relative received end of life care at home the doctor will inform relevant professionals such as the undertaker.

Care for yourself

Acknowledge your grief.

Make sure you look after your own health. Many people become ill or emotionally distressed after a family member dies.

Explain the person died to children, comfort them and let them be part of the grief and dying process.

It is OK to feel relieved that your relative died and is at peace and no longer suffering.

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

Palliative Care Australia,

www.palliativecare.org.au

Advance Care Planning,

www.advancecareplanning.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 were included because you or your family might find it helpful to read about people's feelings and experiences and accept that death is normal.

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.

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) *Letting Go: How to Plan for a 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.





