



Working out what's right for you

Facilitator guide for health care professionals



PalliativeCare
AUSTRALIA

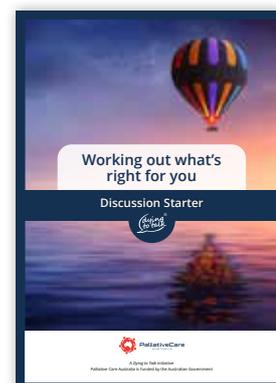
A *Dying to Talk* initiative
Palliative Care Australia is funded by the Australian Government

Working out what's right for you resources

This Facilitator Guide supports health professionals to initiate conversations using the *Working out what's right for you* Discussion Starter and Cards.

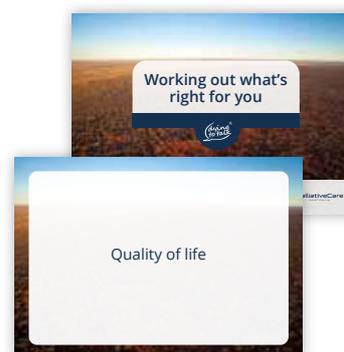
Working out what's right for you Discussion Starter

The *Working out what's right for you* Discussion Starter has been developed to support health professionals to start a conversation with patients about their end-of-life preferences. The initial questions focus on the person and then gradually move towards health and end-of-life preferences. The Discussion Starter acts as a facilitation tool for health professionals and a reflective tool for patients to support open dialogue. In some cases, the Discussion Starter may be a precursor to advance care planning but it is not an essential outcome – the important thing is that a person has started to move along the End-of-Life Planning Continuum.



Discussion Cards

The Discussion Cards have been developed as an icebreaker tool that health professionals can use with their patients to ease them into a conversation about end-of-life preferences. The Discussion Cards are phrased as statements as opposed to questions which can be less intimidating than answering directed questions. The cards may also assist people to speak to their family and carers.



Disclaimer

It is important to remember that while the Dying to Talk Initiative resources, including the *Working out what's right for you* Discussion Starter, may be used to assist in advance care planning processes, the resources themselves are not an Advance Care Plan or an Advance Care Directive.

People should always consult healthcare or legal professionals for advice about their specific circumstances, including the legislative requirements in their state or territory.

The information in this Facilitator Guide has been written with the assumption the person has agreed to have a conversation based on the resources, after being provided with all relevant information about the purpose of the resources.

When talking about what's right for you at the end of your life with a person, health professionals need to consider the person's right to privacy and autonomy.

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What Australia thinks about preparing for the end of their lives

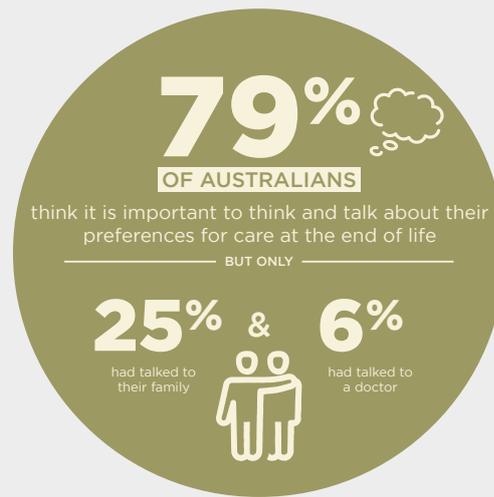
Evidence shows that assisting people to have early conversations about their end-of-life preferences can be beneficial for the person, their family, carers, and clinicians. Having conversations early can assist in making future decisions about prognosis, treatment, and the appointment of a substitute-decision maker, and improve the delivery of culturally appropriate and person-centred care.

This helps ensure their treatment and care best aligns with their values and preferences regarding both the type and place of care, and place of death. It is the mission of PCA as the Australian peak body for palliative care, to enable an environment in which this is a health care priority.

PCA recently commissioned a national representative survey for National Palliative Care Week 2019. The results from this survey indicate that Australians are not preparing for the end of their lives. The survey of 1,003 Australians conducted by Pure Profile found that eight in ten Australians think it's important to talk about their end-of-life care wishes but only one in four have actually had the conversation.

The results of the survey highlighted a disconnect between what people think and what they do. 79% of people agree they should plan ahead for their end-of-life care, with key benefits of planning being identified as:

- Control over their care
- Having a say in where they spend their final days
- Reducing the stress on loved ones.



Despite these figures, only 67% of Australians have some type of documentation in place. Of the Australians who had some documentation in place:

- 43% of people have a will
- 18% have a power of attorney
- 18% have a nominated person to make health care decisions
- 17% have an Advance Care Directive, plan or other document outlining wishes for end of life.

The results also showed that 73% of Australians felt that health professionals should raise the issue and encourage people to start the conversation.

These results are consistent with those from previous surveys conducted by PCA and support the need for resources that assist people in starting conversations about their end-of-life preferences. Starting conversations about what is right for you may not mean going straight to medical-based decisions or formal planning.



Introducing the *Dying to Talk* Campaign

The *Dying to Talk* Initiative, launched in 2015, encourages Australians of all ages and health status to talk about death and dying. *Dying to Talk* aims to reach into the community to normalise dying and help Australians work out what's right for them at the end of their lives. With more conversations comes better support for people nearing the end-of-life, and less stress for their loved ones.

In 2017, PCA expanded the *Dying to Talk* resources by developing an Aboriginal and Torres Strait Islander specific Discussion Starter and Cards. This was done in partnership with the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) and in consultations with other Indigenous health organisations, who identified the need for a specific resource for Aboriginal and Torres Strait Islander people.

In 2019 PCA launched the *What Matters Most* Discussion Starter, Facilitator Guide and Card Set. *What Matters Most* is for older people, including people living with dementia, using aged care services. The *What Matters Most* Discussion Starter and Card Set has been translated into Croatian, Greek, Hindi, Italian, Maltese, Modern Standard Arabic, Polish, Simplified Chinese, Spanish and Vietnamese.





The End-of-Life Planning Continuum

The End-of-Life (EoL) Planning Continuum highlights the journey a person may take in relation to end-of-life planning. As end-of-life planning is a difficult topic to discuss, people may progress slowly over a period of months or years and may not follow the linear progression as indicated below.

Understanding the End-of-Life (EoL) Planning Continuum may assist health professionals utilising these resources as it highlights the journey a person may take in relation to end-of-life planning.

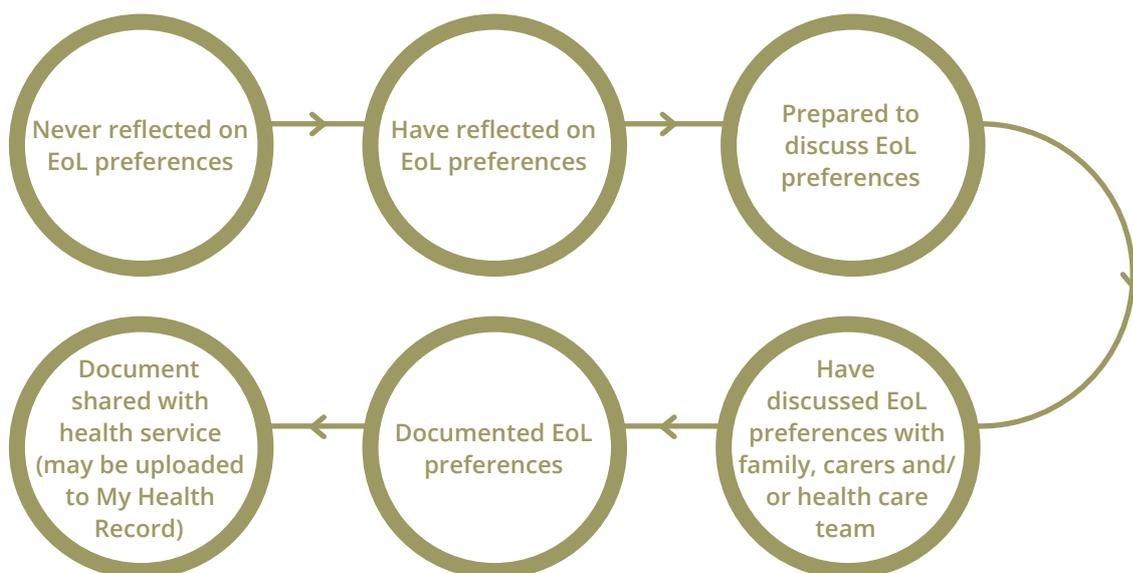


Figure 1: the End-of-Life Planning Continuum

Resources in Action

When working with people to work out what is right for them, there may be times when a person could find it difficult to understand the question or why the question is being asked, be unsure of their preferences, or may not want to answer a question at that point or at all.

It is important that you support people to understand that:

- There is no right or wrong answer.
- They can return to a question at a later time or session if they need time to consider their answers and/or speak with their family and carers.
- They do not need to answer all of the questions, only the ones they are comfortable with answering.
- There is no right or wrong order in which to go through the questions.
- It is OK for them to change their mind.
- They can revisit the questions and their answers at any time.
- It is OK to feel sad or another emotion, and they can stop at any time.

The End-of-Life Planning Continuum (Figure 1) can be a useful way to frame discussions with people by providing reference points for comparison against a consumer's individual circumstances.

The End-of-Life Planning Continuum

Understanding the End-of-Life (EoL) Planning Continuum may assist health professional having conversations with people about what is right for them at the end of their life. The EoL Planning Continuum highlights the journey a person may take in relation to end-of-life planning. These conversations can be difficult, meaning people may:

- Progress slowly through the Continuum over a period of months or years.
- Not follow the linear progression as indicated below.
- Not move through all of the steps in the Continuum.
- Become upset and require post-discussion support.

Nonetheless, it is important to start these conversations early so they have the opportunity to reflect and discuss their preferences. The Discussion Starter and cards were developed with this in mind, acknowledging the benefit of multiple conversations over a period of time as determined by the needs and comfort level of the person.

Working with people who have never reflected

Working with people who have never reflected on their own end-of-life preferences will have their own stories as to why this is the case. The reasons for not having reflected may include:

- Cultural or religious traditions;
- Fear of dying;
- No diagnosis;
- Feel that they are too young;
- Feel that they are 'too healthy';
- Think that their health care professional will raise it;
- History of trauma and abuse; or
- Currently experiencing abuse and neglect.

People who have never reflected will have varied experiences and thoughts on discussing care at the end-of-life which is why an individual approach to each person is crucial to having an effective conversation.

The Discussion Cards are a great icebreaker tool for people who have not reflected on their preferences in the past and may not know where

to start. The cards provide statements that the person can prioritise from very important to not important at all. Through providing the cards with statements to consider, it can be far less overwhelming as a starting point than responding to targeted questions. The Discussion Starter and Cards may be used for self-reflection and/or for discussion with family and carers.

Working with people who have reflected

A person who has reflected on their own end-of-life preferences will have a variety of reasons for why they reflected, as well as differences in the depth of reflection. Some people may have thought about their preferences after reading a book or watching a news story while others may have reflected after the death of a close friend or family member or their own health crisis.

It is important to remember that although a person identifies as having reflected, this may be the first time they have discussed their thoughts and preferences with someone. Every person will differ in the level of information they share about their reflections but it should be acknowledged that this first conversation about their preferences is an important milestone.

If a person is open to discussing their reflections, it would be good to start with the Discussion Starter. However, if a person is finding it difficult to discuss their reflections, the Discussion Cards may be best to help prompt thoughts and conversation.

Working with people who are prepared to discuss

People who are prepared to discuss their end-of-life preferences have probably reflected previously and may have a good understanding of their preferences. In this case, a soft introduction to the discussion may include a review of their previous reflections and how relevant they are at this point. This exercise will support the person to consider how and if their preferences have changed before building on these further with the use of the Discussion Starter.

The Discussion Starter is a great resource for people who are prepared to discuss their preferences as it provides a conversation framework that starts with questions about the person and progresses through to questions relating to health and end-of-life.

Working with people who have discussed

When working with people who have discussed their end-of-life preferences previously, it may be good to start with a general reflection exercise with questions such as:

- When did you last discuss your end-of-life preferences?
- Who did you discuss this with?
- What initiated the discussion?

This exercise will allow the person to lead the conversation and give the health professional an indication of their comfort level on the topic. If the person is comfortable in discussing the topic, it may be worthwhile skipping forward to Part 2 in the Discussion Starter to ensure that the person's willingness to discuss is optimised and documented.



Using the resources in a clinic setting

Preparing for the Appointment

It is important to be well prepared before an appointment takes place. Below are some points to consider before meeting with the person to discuss their end-of-life preferences:

- Identify who at the clinic should speak to the person about their preferences.
 - Ensure the person knows they are welcome to have a support person/s or health worker with them.
- Take time to read over their file and understand their medical history.
- Liaise with all key staff at the clinic who have worked regularly with the person to ensure you are well informed on their individual needs.
- Consider how the person's cultural and religious background may impact the conversation.
- Block out additional time in case the appointment is longer than usual (e.g. due to the person becoming distressed).
- Arrange for a clinic staff member to be available for the person after the meeting in case they require debriefing or further information.
- Organise an interpreter if required.

Using the Discussion Starter and Cards

Discussions about what someone might want at the end of their life should not just be in response to crisis situations and instead should be considered a part of routine practice. This approach will build respect and trust with the person and their family and carers, as well as assisting to normalise the integration of routine discussion regarding end-of-life preferences. Below are a number of points to consider for the first discussion:

- Remind the person if they are alone, that they are welcome to have a support person/s with them during the appointment.
- Clarify the person's understanding of the purpose of the appointment.
- Remind them they can end the conversation at any time.
- Talking through the End-of-Life Planning Continuum.
 - Explain why conversations about someone's end-of-life preferences are important.
 - Provide information and support to the person to assure them this conversation does not mean that their health condition is at a crisis point or they are about to die.
 - Explain that having these conversations before a crisis point is reached is the best option for everyone involved.



- Introduce the Discussion Starter and Cards and explain how these can help to prompt thoughts and discussion about end-of-life preferences.
- Explain that the resources are broken up into parts; and starts with getting to know the person.
- If the person agrees to have a discussion, use the resources to facilitate this conversation.
 - If the person does not wish to discuss their end-of-life preferences, this should be noted in their file. If appropriate, you may want to give them a copy of the Discussion Starter and Cards to take away for future reflection.
- Allow time for questions and open discussion.
- Do not just read directly from the Discussion Starter. It is important to engage the person in conversation using the questions as a guide.
- Allow time for pauses and recognise emotions that are expressed during the appointment.
- Use prompts to encourage discussion, elaboration and reflection. If working through the Discussion Starter, consider using the cards to help prompt discussion.
- A follow up appointment may be arranged to provide the person an opportunity to discuss their thoughts and any conversations they have had since the initial appointment.
- Summarise the person's responses and confirm the responses have been correctly understood and documented.
- Provide the person with a copy of the information written into the Discussion Starter during the conversation.

Follow Up

There a number of ways to ensure that the person feels supported after an appointment discussing their end-of-life preferences, these may include:

- Provide them with information to take home and details on who to contact if they are upset or distressed.
- A follow up phone call should be considered with the person 1-2 days after the appointment to ensure that they feel supported and have an opportunity to ask questions.
- Identify which clinic staff member will follow up with the person.
- Ask the person if there is other support(s) they would like.
- Confirm the timeframe until the next appointment, as required.

A Communication Model – SPIKES¹

Some health professionals may find it useful to use a communication model to assist in undertaking a difficult conversation, one example is the SPIKES model, which is outlined below.

S Set up

If you are reaching out to a person to ask them to come and meet with you, the pre-planning meeting is just as important as the appointment itself. Identify who is responsible for organising the appointment and make time to:

- Clarify the reason for appointment so the person feels more comfortable about it as they may have experienced difficult or 'bad' meetings in the past and may think you know something about their health that they do not know.
- Ask the person to think about issues they may like to raise.
- Ask the person who they would like to be there. Ensure appropriate supports are available for the person (maybe a friend, relative or trusted staff member).
- Organise interpreter, if required.
- Ensure a private and quiet space is available where everyone can sit down.
- Minimise interruptions — keep phones outside if possible.
- If multiple health professionals are involved, arrange a time to meet beforehand to ensure consistency in the information to be given and to appoint someone to lead the discussion.
- Ensure the space feels supported and avoid professionals sitting on one side of the room or table and the person on the other.
- Ensure the person doesn't feel overwhelmed by having too many people in attendance. The number of people should be kept to a minimum and only include those who will be actively involved in the conversation and are familiar to the person.

P check Perception

Find out what the person's understanding is of the situation currently.

I Invitation

Let the person know that some of the conversation may be difficult. Find out if it is okay to discuss such things right now.

K give Knowledge/information

Provide information in small chunks. Try to speak in plain language. Stop at regular intervals and check understanding. Be aware that your own anxiety can lead you to speak quickly and in too much detail and that you may revert to the comfort of technical language.

E respond to Emotion

It is hard for people to process information when they are frightened or very sad. Allow room for the expression and acknowledgement of emotion. Sit with it. If you feel confident, respond to the emotion. The mnemonic 'NURSE' suggests five possible ways of responding:

- **Name:** State the emotion
 - If you are not sure, you can say, 'I'm wondering if you are feeling x'
- **Understand:** Empathise with and legitimise the emotion
 - Be careful not to say, 'I understand', because it is possible that you don't
- **Respect:** Praise the person for their strength or honesty
- **Support:** Show support
- **Explore:** Ask the person to tell you more about what they are feeling. You may be the only person in their circle who allows them to share how they feel. You don't need to 'fix it'.

S Summarise

Provide a brief summary and ask the person if they have understood. Make a plan even if it is only to keep talking. Ensure they know there will be opportunities to speak again and to ask questions.

1. The SPIKES model has been modified from Baile W, Buckman R, Lenzi R, Glober G, Beale E, and Kidelka A 2000, 'SPIKES - A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer' *The Oncologist*, vol. 5, no. 4, pp. 302-311.



Cultural, Traditional and Religious Considerations with Death and Dying

Different cultures and religions often have specific attitudes towards illness and death and may have different practices according to the age or sex of the person being cared for. This diversity leads to many varying beliefs about medical treatment and the care a person should receive.

Sensitive communication is an important component in planning ahead. The verbal and non-verbal cues used in these types of discussions should be considered, as planning ahead may cause the person distress if they think they are about to pass on. It may be helpful beforehand, for example, to speak to an Aboriginal Health Worker or Hospital Liaison Officer, if possible, with regards to caring for Australia's indigenous peoples. It is also valuable to note the non-verbal communication demonstrated by the family and community members who are present, and to note the language used by the person and their family.

Directly referring to 'death' and 'dying' may make people uncomfortable and instead, alternative terms can be considered, such as 'passed on' and 'not going to get better'. It is important to talk to the key family members and/or decision makers about what they would like to know. In doing so, relevant information on the symptoms experienced by the person with a life-limiting illness, including pain, and the options to manage these symptoms, can be provided. The family may express specific preferences, such as use of traditional medicine, space to accommodate more than one person to stay overnight and room for multiple visitors at once. Supporting people to observe their traditions for the end of someone's life can assist the person with a life-limiting illness, as well as help their family and community with their grief and bereavement.

Whilst very little data is available, it is suggested that planning for the end of life is not often undertaken with Aboriginal and Torres Strait Islander people. However, planning may be a valuable process for Aboriginal and Torres Strait Islander people for a number of reasons, including the significance of connection to country, which may be a contributing factor to people wanting to pass at home.

For more information on provision of palliative care and end-of-life care for Aboriginal and Torres

Managing Disclosures

PCA acknowledges that conversations about end-of-life preferences can elicit a variety of emotional responses. It is important to consider the possibility of memories of prior trauma or abuse being triggered.

Some people may disclose their traumatic experiences to health professionals due to the vulnerability of discussing their end-of-life preferences.

Due to the sensitive nature of discussing end-of-life preferences, PCA recommends a trauma informed lens to support health professionals to understand a person's presentation in the context of their lived experience.

If you would like further information on trauma informed care, the Blue Knot Foundation National Centre of Excellence for Complex Trauma provide *Practice Guidelines for the Treatment of Complex Trauma & Trauma Informed Care and Service Delivery* as a clinical resource. The guidelines can be sourced from the Blue Knot Foundations website

blueknot.org.au/resources/Publications/Practice-Guidelines

If a person does disclose abuse, neglect or self-harm to a health professional during the course of a conversation using these resources, the health professional should manage, report and document the disclosure in line with their organisation's policies and procedures as well as mandatory reporting guidelines.

84% of Australians think it's important to be able to spend their final days at home



Only 65% of these people think it's likely they'll be able to do so

Supporting you and your practice

Many people who work in the health sector do so with a desire to help others. For some health professionals, this can come at a cost to themselves and potentially their personal relationships.

It is important for health professionals to be aware of their own vulnerabilities, triggers, stress and compassion fatigue, and develop coping mechanisms to try and avoid burning out. Self-awareness is essential for the person themselves to monitor changes in their health and how this effects those around them such as their families, colleagues and patients. Therefore, people may undertake their own periodic self-reflection to gauge where they are at, or to reflect on feedback from family or colleagues, indicating they may need to consider their current resilience.

There are times in most health professionals careers that self-reflection alone may not be enough. Often support can be as simple as an informal discussion with a colleague. Support can also be found in more formalised discussions such as case debriefs, mentoring and clinical supervision to aid self-reflection and increase resilience. Most organisations will have internal policies and procedures in place to support staff wellbeing and care. Some may also have formal arrangements in place for staff to access external services for counselling and debriefing, which may have particular relevance following a distressing or problematic experience. These can usually be accessed by talking to your supervisor or Human Resources team or management representative.

Outside of their organisation there are alternatives that health professionals can also access, including:

- Speaking with your General Practitioner about what support may be available.
- Contacting the CRANaplus' Bush Support Service for 24-hour/7-day phone counselling for rural and remote health practitioners on 1800 805 391.
- Contacting a support service such as Lifeline (13 11 14 or lifeline.org.au) or beyondblue (1300 224 636 or beyondblue.org.au).
- Visiting the Mental Health Australia website: mhaustralia.org/need-help
- Contacting the Doctors Health Advisory Service in your state or territory 24-hours/7-days – refer to the website for contact details (adhn.org.au).
- Contacting the RACGP GP Support Program (for RACGP members) by calling 1300 361 008 (Office hours are 8.30 am to 6.00 pm Monday to Friday) or 1300 361 008 (24 hours/7 days) for crisis counselling.
- Accessing the RACGP GP Self-care resource available at racgp.org.au/download/Documents/e-health/Self-care-and-mental-health-resources-for-general-practitioners.PDF



Acknowledgements

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For more information about the study please visit the website dyingtotalk.org.au.



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Palliative Care Australia (PCA) is the national peak body for palliative care. PCA represents all those who work towards high quality palliative care for all Australians.

Working closely with consumers, our Member Organisations and the palliative care and broader health, aged care and disability care workforce, we aim to improve access to, and promote the need for palliative care. More information is available at palliativecare.org.au

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