



# What Matters Most

*Supporting older people to work out what is right for them*



## Health and Aged Care Worker Facilitator Guide to the *What Matters Most* resources

[dyingtotalk.org.au](http://dyingtotalk.org.au)

A *Dying to Talk* initiative through Palliative Care Australia

This project was funded by the Australian Government through the Dementia and Aged Care Services Fund





### Disclaimer

It is important to remember that while the Dying to Talk Initiative resources, including the *What Matters Most* 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 consumer has already agreed to have a conversation based on the *What Matters Most* resources, after being provided with all relevant information about the purpose of the resources.

When talking about *What Matters Most* with a person/consumer, health and aged care workers need to consider:

- The person's right to privacy and autonomy.
- The Charter of Aged Care Rights.

# Contents

<b>A Guide</b>	<b>4</b>
A note on decision-making capacity	5
What Australians think about preparing for the end of their lives	5
<b>The <i>Dying to Talk</i> Initiative</b>	<b>6</b>
<b>Developing the <i>What Matters Most</i> resources</b>	<b>7</b>
<b>Facilitating discussions using the <i>What Matters Most</i> resources</b>	<b>8</b>
The End-of-Life Planning Continuum	8
Working with people who have never reflected	9
Working with people who have reflected	10
Working with people who are prepared to discuss	10
Working with people who have discussed	10
<b>Supported decision-making when working with people living with dementia</b>	<b>11</b>
What is support for decision-making?	11
Key values in providing support for decision-making	11
What can support for decision-making involve?	12
<b>Using the resources in your setting</b>	<b>13</b>
Who should facilitate What Matters Most discussions?	13
Preparing for the discussion	13
Using the Discussion Starter and Cards	14
Follow up	15
A Communication Model – SPIKES	15
Support available to health and aged care workers	16
<b>Managing disclosures</b>	<b>17</b>
<b>Looking after yourself</b>	<b>18</b>

# A Guide

This Facilitator Guide supports health and aged care workers to initiate conversations using the *What Matters Most* Discussion Starter and Cards with consumers of home, community, or residential aged care services.

The *What Matters Most* resources were developed to support older people, including those living with dementia, to reflect and have conversations about *What Matters Most* to them and what they might want if they were very sick or at the end of their life.

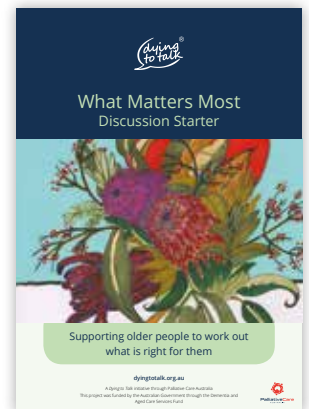
The Discussion Starter is written from the perspective of the older person and is divided into three sections:

- Section 1 is about you
- Section 2 is about your health
- Section 3 is about what you might want at the end of your life

Each section contains questions the worker can use to guide the conversation with the older person as they explore *What Matters Most* to them.

The *What Matters Most* cards can be used as prompts when working through the Discussion Starter to give examples of issues the person might like to consider. Alternatively the cards can be used as an ice breaker to get the person thinking about *What Matters Most* to them.

Working through the *What Matters Most* resources with an older person will also help health and aged care workers to get to know the person better, so as to better deliver person-centred aged care. The resources have been designed to normalise early conversations about the end of life within the aged care setting, rather than waiting until more time critical or medical focused discussions need to occur. In addition, the resources may help health and aged care workers and the consumer to have discussions with the person's family and friends.



My favourite music playing

Going on a holiday

## A note on decision-making capacity<sup>1</sup>

Making decisions about one's own life and having those decisions respected is an essential right of each person including those with cognitive impairment or living with a disability. A person's decision-making ability is to be presumed, and the presence of cognitive impairment is not a reason to exclude someone from decision-making.

Supported decision-making<sup>2</sup> is encouraged, which is the process of enabling a person who requires support to make, and/or communicate, decisions about their own life. The decision-making is supported, but the decision is still theirs.

Decision-making capacity may fluctuate over time and may vary depending on the decision to be made. It is important to note that just because a person may lack 'decision-making capacity' (even with assistance), this does not automatically justify substitute decision-making or overriding the person's will and preferences.

## What Australians think about preparing for the end of their lives

Assisting people to have early conversations about *What Matters Most* to them can be beneficial for the individual, their family, carers and their health and aged care workers.

Early conversations about *What Matters Most* can assist with making future decisions and can improve the delivery of culturally appropriate and person-centred care. Early conversations can help ensure the person's care best aligns with their values and preferences regarding both the type and place of care they want and their preferred place of death.

Palliative Care Australia (PCA) commissioned a national survey for National Palliative Care Week 2019, which indicated 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 do. 79% of people agree they should plan ahead for their end-of-life care, with key benefits of planning being identified as:

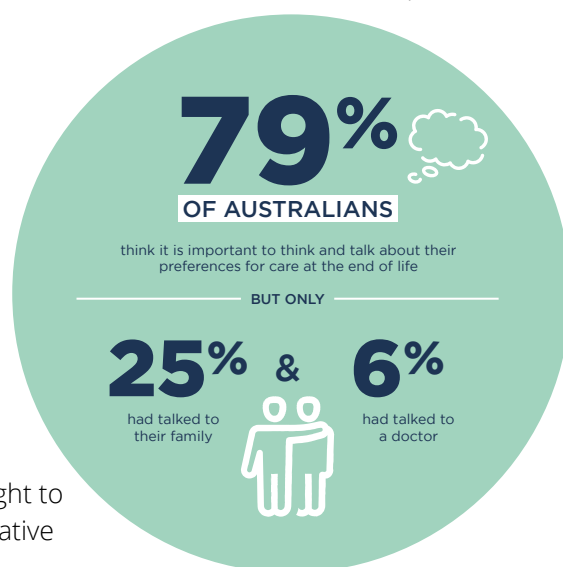
- control over their care
- having a say in where they spend their final days
- reducing the stress on loved ones.

Yet only 67% of Australians have a documented plan in place. Of those who have documentation in place:

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

The results showed that 73% of Australians felt that health professionals should raise the issue and encourage people to start the conversation about *What Matters Most*.

These results are consistent with those from previous surveys conducted by PCA and support the need for resources that assist people to start conversations about *What Matters Most*. Starting conversations about *What Matters Most* may not mean going straight to medical-based decisions or formal planning. The *Dying to Talk* Initiative



1 Sinclair, C., Field, S., & Blake, M. (2018). Supported decision-making in aged care: A policy development guideline for aged care providers in Australia. (2nd Edition) Sydney: Cognitive Decline Partnership Centre.

2 This is not to be confused with substitute decision-making, which gives the decision maker legal authority to act in relation to particular types of decisions.



## The *Dying to Talk* Initiative

The *Dying to Talk* Initiative, launched by PCA 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 conversation comes better support for people nearing the end of their 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 Discussion Starter and Card Activity. This was done in partnership with the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) and in consultation with other Indigenous health organisations, who identified the need for a specific resource for Aboriginal and Torres Strait Islander people.

With funding support from the Australian Government through the Dementia and Aged Care Services Fund, PCA has further added to these resources by developing the *What Matters Most* resources. *What Matters Most* has tailored the Discussion Starter and cards specifically for older people, including people living with dementia, who use community and residential aged care services.

# Developing the *What Matters Most* resources

The *What Matters Most* resources evolved from the Care Compass study resources, which were developed to assist aged care workers to facilitate conversations with people living with dementia, about their end-of-life preferences.

The 2018-19 study was conducted to trial the resources to see how well they supported aged care staff to have end-of-life conversations with people living with mild to moderate dementia, and the impact and feasibility of using the resources in aged care settings. The study was independently evaluated by researchers from the Australian Catholic University.

In developing the Care Compass study resources, PCA worked with HammondCare and Dementia Australia to develop the content, and applied Dementia Australia's accessibility guidelines<sup>3</sup> for the design of the resources. The resources were reviewed through consultations with aged care providers, peak body representatives and people living with dementia and their carers.

Feedback from focus groups with people living with dementia highlighted the need for an adjusted format to cater for their specific needs. The Discussion Starter was divided into different booklets to provide natural pause points. The format served to provide breaks in what can be a confronting and difficult conversation for staff and consumers, allowing opportunities for reflection and recuperation. The format also catered for the time-limited environments in which these conversations take place.

PCA commissioned Les Makai to create the artwork which was featured in the Care Compass study resources and now the *What Matters Most* resources. Les is an artist who started painting following a diagnosis of Posterior Cortical Atrophy (a type of dementia).

Feedback from the Care Compass study evaluation and debriefing sessions with study participants showed that:

- Some people with dementia didn't identify as such and therefore didn't want to use the Discussion Starter in the study as it was 'for people with dementia'.
- Many people never receive or have not yet received a diagnosis of dementia and therefore would see the Discussion Starter as not appropriate for them.
- Aged care staff and people living with dementia said that all older people receiving aged care services could benefit from access to the resources.

The resources have now been reviewed, refined and renamed *What Matters Most* to be used by all people accessing aged care services, including those living with dementia.

The Discussion Starter and cards have been translated into the following languages: Arabic, Croatian, Greek, Hindi, Italian, Maltese, Polish, Simplified Chinese, Spanish and Vietnamese. The translated resources can be accessed from the [Dying to Talk](#) website.

---

<sup>3</sup> S Hennessy and A Reilly, What works for people with dementia? Guidelines for resource development. Alzheimer's Australia Vic, 2015



## Facilitating discussions using the *What Matters Most* resources

When working with consumers to use the *What Matters Most* resources, there may be times when a person may 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 and aged care staff in utilising the *What Matters Most* resources. The EoL Planning Continuum highlights the journey a person may take in relation to end-of-life planning. The *What Matters Most* resources are focussed on the first four (4) stages of the Continuum.

*What Matters Most* can be a difficult topic to discuss 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 *What Matters Most* to them. The *What Matters Most* 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.



The discussions held using the resources may result in someone choosing to progress to formally document their end-of-life care preferences but this is not a requirement or expectation of *What Matters Most*. *What Matters Most* is about encouraging reflection and discussion. The *What Matters Most* resources may be used during advance care planning processes, but are not Advance Care Plans or Advance Care Directives. It is important that the consumer is aware of this, and understands when the information discussed will be recorded and stored.

## Working with people who have never reflected

There may be many reasons why people have never reflected on *What Matters Most* or what they may want if they were very sick or at the end of their life. The reasons for not having reflected may include:

- Cultural or religious traditions.
- Fear of dying.
- Belief that they are too young.
- Belief that they are too healthy.
- Reliance on others to raise the conversation.
- History of trauma and abuse.
- Currently experiencing abuse and neglect.
- Not wanting to upset others talking about *What Matters Most*.
- Not having anyone to talk with about *What Matters Most*.

People who have never reflected will have varied experiences and thoughts on discussing *What Matters Most* which is why an individual approach to each person is crucial to having an effective conversation.

Section 1 of the Discussion Starter: *About you*, may be a good icebreaker for people who have not reflected on *What Matters Most* in the past and may not know where to start. The Section has questions to assist the worker to get to know the person. The questions should be utilised in a conversational manner rather than a strict question and answer method, to help the person to relax and feel less overwhelmed. The *What Matters Most* cards may also be useful – refer to the ‘Preparing for a discussion’ and ‘Using the Discussion Starter and cards’ Sections in this Guide.

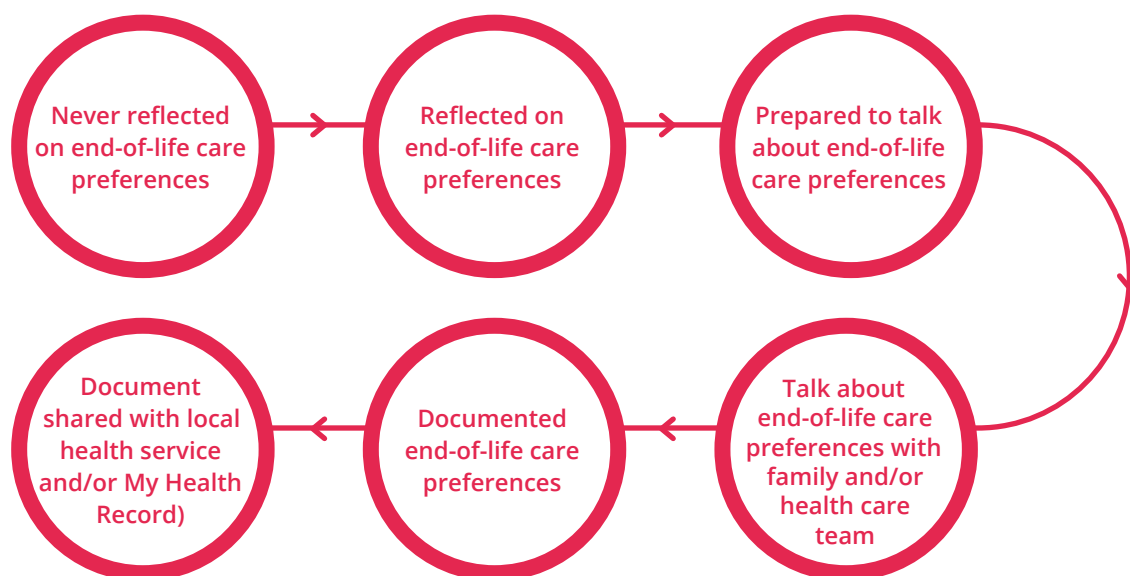


Figure 1: The End-of-Life Planning Continuum

At the end of the conversation, the person should retain the Discussion Starter booklet, or at least be given a copy of the information they provided. This information may be used by the person for their own self-reflection and/or for discussion with family and carers. This will also assist the person to prepare for follow up conversations. **Remember that the person needs to be aware that having a discussion about *What Matters Most* does not mean they are about to die.**

### Working with people who have reflected

A person who has reflected on *What Matters Most* will have a variety of reasons for reflection, as well as differences in the depth of reflection. Some people may have thought about *What Matters Most* 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 due to their own health crisis.

It is important to remember that although a person identifies as having reflected, they may not have discussed their thoughts and preferences with another person. Each person will differ in the level of information they share about their reflections but it should be acknowledged that this conversation is an important milestone.

If a person is open to discussing their reflections, you could start with the *Section 2: About your health, of the Discussion Starter*. However, if a person is finding it difficult to discuss their reflections, the *Section 1: About you*, may be a better place to start. **Remember, there is no right or wrong order in which to use the resources.**

### Working with people who are prepared to discuss

People who are prepared to discuss *What Matters Most* may have 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 time. This exercise will support the person to consider how and if their preferences have changed before building on these further with *Section 2: About your health* and *Section 3: About what you want at the end of your life*.

When using *Section 3*, be aware that people may be comfortable openly discussing the first questions but may need some additional time to reflect on the later questions. **Remember, a person should be reminded they are able to stop the discussion at any time and be supported if they show signs of distress.**

### Working with people who have discussed

When working with people who have discussed *What Matters Most* previously, it may be good to start with a general reflection exercise with questions such as:

- When did you last discuss *What Matters Most* to you and what you might want at the end of your life?
- Who did you discuss this with?
- What initiated the discussion?

This exercise will allow the person, to lead the conversation and give the worker an indication of their comfort level on the topic. If the person is comfortable in discussing the topic, you may consider skipping forward to *Section 3: About what you want at the end of your life*.

If you do skip ahead at any point, encourage the person to look back at the other questions/sections as this can still assist with reflection even if the person has considered *What Matters Most* to them previously.

**Remember it is important that people understand they may revisit the information at any time, and are encouraged to review the responses, as circumstances may change.**



# Supported decision-making when working with people living with dementia

To support workers in their role to facilitate conversations with consumers, PCA recommends an understanding of the supported decision-making framework developed by the Cognitive Decline Partnership Centre, which underpins the approach of *What Matters Most*.

The information below is taken directly from *Supporting Decision-Making: A Guide for People Living with Dementia, Family Members and Carers*<sup>4</sup> and provides a summary of the framework. The complete document can be downloaded from [cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making/](https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making/) which also has a number of other useful resources available.

## What is support for decision-making?

Support for decision-making is a series of practical steps that can assist a person with cognitive decline to make their own decisions. Support for decision-making can help people to make choices about healthcare, lifestyle, finances and everyday activities and is not reliant on a specific set of laws.

## Key values in providing support for decision-making

When providing support for decision-making to people living with dementia, there are five key values to consider. These five values have been identified from research undertaken with people living with dementia and their family members.

The key values in providing support for decision-making are:

- **Inclusion**  
This value reflects the importance of including the person living with dementia in all stages of a decision-making process, to the extent that they choose to be involved. It might mean that they have active participation in gathering information about a decision, or instead that they are kept informed through the process.
- **Knowing and understanding**  
Decision-making support is most effective when it is provided by someone who has a close, trusting relationship with the person. This helps in understanding the person's values, likes and dislikes, and preferred approaches to decision-making.
- **Respect for rights**  
This value reflects an understanding of the person's rights in decision-making, including their rights to: have access to understandable information; have support in expressing their views; have advocates speak on their behalf where necessary and be free from undue influence.

4. Sinclair C, Field S, Williams K, Blake M, Bucks R, Auret K, Clayton J, Kurrle S. Supporting decision-making: A guide for people living with dementia, family members and carers. Sydney: Cognitive Decline Partnership Centre, 2018.

- **Dignity**

This value relates to the importance of taking the time needed to go through the process together. Importantly this enables the person who is receiving support to take initiative, or express concerns about how the process is unfolding.

- **Adapting to change**

This value reflects the understanding that the journey of living with dementia is a changing one. As the condition progresses, or as it fluctuates from day-to-day, different approaches may be required.

## What can support for decision-making involve?

People often make important decisions in collaboration with others. Support for decision-making often involves family, carers or professionals working with a person to assist them in making decisions without taking control or overriding a person's opinion.

By utilising a support for decision-making approach, aged care staff, family and carers provide a circle of support for the person living with dementia or experiencing cognitive impairment, when identifying *What Matters Most* for them.

Support for decision-making can be done in a variety of ways, some of these have been identified within the infographic below.<sup>5</sup>



5. Sinclair C, Field S, Williams K, Blake M, Bucks R, Auret K, Clayton J, Kurrle S. Supporting decision-making: A guide for people living with dementia, family members and carers. Sydney: Cognitive Decline Partnership Centre, 2018.



# Using the resources in your setting

This section provides suggestions on using the *What Matters Most* resources within aged care services and service provision.

## Who should facilitate *What Matters Most* discussions?

It is important to identify which health or aged care worker is most appropriate to speak with the person about *What Matters Most*. Ideally the worker should be someone the person knows and feels comfortable with. If this is not possible, additional time should be scheduled before using the resources to:

- Allow time to get to know the person.
- Establish rapport.
- Ensure the person is comfortable and willing to progress with the discussion.

The worker should be someone who feels comfortable or has experience in speaking about issues that are covered in the *What Matters Most* resources. Developing effective communication skills requires training, reflective learning, practice and a supportive working environment.

## Preparing for the discussion

It is important to be well prepared before facilitating conversations using the *What Matters Most* resources. Below are some points to consider before the meeting:

- Familiarise yourself with the Discussion Starter and cards and review the strategies in the Facilitator Guide.
- When setting up the meeting, clarify the reason for the meeting to ensure the person, their family or carers are not concerned leading up to the meeting.
- Seek the person's agreement to participate in the discussion - they may want to consider and discuss with family and carers before committing to the first discussion.
- Ensure the person knows they are welcome to have a support person/s with them.
- Provide a copy of the Discussion Starter to the person to allow them to review and reflect on the questions.
- Take time to read over the person's file and understand their history (as appropriate).
- Liaise with key staff 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 meeting is longer than anticipated (e.g. due to the person becoming distressed).
- Arrange for an appropriate worker to be available for the person after the meeting in case they require debriefing or further information. The worker should be someone the person is familiar with and should be aware the *What Matters Most* conversation has taken place.
- Arrange a quiet location and put strategies in place to minimise disruptions (e.g. moving to a private room, letting other staff know so they do not interrupt).

## Using the Discussion Starter and Cards

Discussions about what someone might want at the end of their life need not be in response to a crisis situation but instead should be considered a part of routine practice. Approaching discussions in this way builds respect and trust with the person, their family and carers, and assists to normalise discussions about *What Matters Most*.

Below are a number of points to consider for the first conversation:

- Remind the person if they are alone, that they are welcome to have a support person/s with them during the meeting.
- Clarify the person's understanding of the purpose of the conversation.
- Remind them they can end the conversation at any time.
- Explain why conversations about *What Matters Most* are important.
- Provide information and support to the person to assure them this conversation does not infer that their health condition is at a crisis point or they are about to die.
- Explain to the person that having these conversations before a crisis occurs is the best option.
- Introduce the *What Matters Most* Discussion Starter and cards and explain how these can help to prompt thoughts and discussion about *What Matters Most* to them and what they may want at the end of their life.
- Explain that the Discussion Starter is broken up into three sections and begins with getting to know the person.
- Use the Discussion Starter if the person agrees to continue the discussion.
- If the person does not wish to continue the discussion, this should be noted in the person's file. If appropriate, you may want to leave the Discussion Starter and cards with them in case they would like to refer to them in the future. It is important to remember that participating in *What Matters Most* discussions is voluntary and people should never be forced to participate.
- 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 and acknowledge emotions that are expressed during the discussions.
- Use prompts to encourage discussion, elaboration and reflection. If working through the Discussion Starter, consider using the cards to help prompt discussion.
- Summarise the person's responses and confirm the responses have been correctly understood and documented.
- Provide the person with a copy of their responses.
- Encourage the person to consider the 'next steps' in the Discussion Starter.
- Arrange a follow up conversation with the person to provide an opportunity to discuss their thoughts and any conversations they have had since the initial discussion.
- Documentation about the meeting should be included in the person's file after gaining their consent to do so.

## Follow up

There are a number of ways to ensure that the person feels supported after the discussion including:

- Providing the person with information, which includes details on who to contact if they are upset or distressed (this should include people within the aged care service as well as the support services listed in the Information Section of the Discussion Starter).
- A follow up phone call or discussion should be scheduled with the person 1-2 days after the first discussion to ensure that they feel supported and have an opportunity to ask questions.
- Identify which nominated 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 discussion, as required.

## A Communication Model – SPIKES<sup>6</sup>

Some staff 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 meet with you, the pre-planning meeting is just as important as the meeting itself. Identify who is responsible for organising the meeting and make time to:

- Clarify the reason for meeting so the person feels more comfortable about it as they may have experienced difficult or 'bad' meetings in the past or 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) if they choose.
- Organise an interpreter, if required.
- Ensure a private and quiet space is available where everyone can sit comfortably.
- Minimise interruptions — keep phones outside if possible.
- If multiple staff 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 supportive 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 reason for the meeting.

### **I** Invitation

Let the person know that some of the conversation might be difficult. Find out if the timing suits them to have the discussion about *What Matters Most* to them and what they may want at the end of their life.

---

6. The SPIKES model has been modified from Baile W, Buckman R, Lenzi R, Glober G, Beale E, and Kudelka 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.

## **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 may 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 but be careful not to say, 'I understand', because you may not.
- **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.

## Support available to health and aged care workers

There are many other sources of information to support health and aged care workers have these discussions. Some suggested sources include:

- **CareSearch [caresearch.com.au](http://caresearch.com.au)**  
CareSearch provides information about palliative care for patients, carers and families as well as for the health professionals providing their care.
- **Centre for Dementia Learning (Dementia Australia) [dementialearning.org.au](http://dementialearning.org.au)**  
Informed by current research and contemporary practice, a comprehensive suite of education resources forms part of an integrated learning pathway incorporating both accredited and non-accredited courses.
- **Cognitive Decline Partnership Centre [cdpc.sydney.edu.au](http://cdpc.sydney.edu.au)**  
The Cognitive Decline Partnership Centre is a collaborative multidisciplinary research centre that provides research evidence in dementia care, including an extensive range of guidelines, tools and resources to improve the health care and quality of life of people with dementia.
- **End of Life Directions for Aged Care (ELDAC) [eldac.com.au](http://eldac.com.au)**  
ELDAC provides information, guidance, and resources to health professionals and aged care workers to support palliative care and advance care planning to improve the care of older Australians.
- **Palliative Care Curriculum for Undergraduates (PCC4U) [pcc4u.org](http://pcc4u.org)**  
PCC4U promotes the inclusion of palliative care education as an integral part of all medical, nursing, and allied health undergraduate and entry to practice training, and ongoing professional development.
- **PalliAGED [palliaged.com.au](http://palliaged.com.au)**  
palliAGED is a palliative care evidence and practice resource for aged care, allowing aged care staff and health professionals to find evidence easily and know how to use it in providing care.





## Managing disclosures

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

Some older people or people living with a dementia, may disclose their traumatic experiences to staff due to the vulnerability of discussing *What Matters Most*. Due to the sensitive nature of these discussions, PCA recommends a trauma informed lens be used to support staff 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](https://blueknot.org.au/resources/Publications/Practice-Guidelines).

If a consumer does disclose abuse, neglect or self-harm to a staff member, staff should manage, report and document the disclosure in line with their organisation's policies and procedures and relevant state, territory and/or aged care legislation.



## Looking after yourself

Many people who work in the health and aged care sectors have a desire to help others. However, for some people, this can come at a cost to themselves and potentially, their personal relationships. *What Matters Most* conversations can be difficult for workers and it is important to look after yourself.

It is important for workers to be aware of their own vulnerabilities, triggers, stress and compassion fatigue, and develop coping mechanisms to avoid burning out.

Self-awareness is essential for health and aged care workers so they can monitor changes in their health and mood and recognise how these changes may affect them and those around them. Staff are encouraged to undertake regular self-directed reflection to assess their wellbeing.

There are times in most health and/or aged care worker's careers when self-reflection alone may not be enough and it is important to seek out additional support. Often support can be as simple as an informal discussion with a colleague. However, support can also be found in more formalised discussions such as case debriefing, mentoring and clinical or case supervision.

Most organisations will have 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 such as an Employee Assistance Program. These can usually be accessed by talking to your supervisor or Human Resource team or management representative.

In addition to workplace supports, assistance can be found by:

- Speaking with your General Practitioner about what support may be available.
- Contacting a 24 hour help line such as Lifeline on 13 11 14.
- Contacting a support service such as [beyondblue](https://www.beyondblue.org.au) via their phone, online chat, email or support forums – phone 1300 224 636 or [beyondblue.org.au](https://www.beyondblue.org.au)
- Visiting the Mental Health Australia website: [mhaustralia.org/need-help](https://www.mhaustralia.org/need-help)
- Accessing aged care specific resources on self-care available on the PalliAGED website: [palliaged.com.au](https://www.palliaged.com.au)



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](https://palliativecare.org.au)



## What Matters Most

### Health and Aged Care Worker Facilitator Guide 2019

A *Dying to Talk* initiative of Palliative Care Australia

This project was funded by the Australian Government through the Dementia and Aged Care Services Fund