



Palliative Care
Australia
Matters of life and death

What Matters Most Discussion Starter



Supporting older people to work out
what is right for them

National Palliative
Care Standards

Tool for:

STANDARD 1

STANDARD 2

STANDARD 7

palliativecare.org.au

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

Why Palliative Care Australia created the Discussion Starter

The 'What Matters Most' Discussion Starter is for older people using aged care services. It is designed to be used with health or aged care staff. It can help people work out what would be right for them, if they were really sick or at the end of their life.

Palliative Care Australia (PCA) created the Discussion Starter to help older Australians talk about What Matters Most to them because:

- 8 in 10 people say it is important to think and talk about their preferences for care at the end of life.
- Only 1 in 4 people have spoken with their family about their preferences.
- Only 6% of people have spoken with a doctor about their preferences.

Talking with your loved ones about what you want if you were really sick or at the end of your life can help you, and them, when making decisions.

It is important to know that the Discussion Starter is not a legal document or an Advance Care Plan / Directive.

If you would like more information about Advance Care Plans, please speak to your care team. You can also find more information on page 25.

Background

The Discussion Starter was first developed to support people living with dementia to participate in discussions about what they might want if they were really sick or at the end of their life. We applied Dementia Australia's Accessibility Guidelines to ensure the Discussion Starter was dementia-friendly.

PCA ran a study to see if the Discussion Starter was useful. The study showed:

- The questions were simple and easy to understand.
- People could look back at their answers to remind them what they said.
- The questions helped aged care staff get to know the person better.
- The resources could be used in both residential and community aged care settings.
- The Discussion Starter would be good for all people receiving aged care services, including those living with dementia.

The Discussion Starter has now been updated to support all older people and their health or aged care team to work out 'What Matters Most' for them.

For more information visit the website palliativecare.org.au.

Talking is important

The Discussion Starter will get you thinking about 'What Matters Most' to you. Talking about what you might want if you were really sick or at the end of your life can help ease stress and worry. It can help your loved ones know what you want and can help people to support you.

Many things are important to us and make our lives fun or fulfilling. Some things might be well-known to people, for example, your love for your family. But people may not know that you would like to have your favourite music playing or that you want to stay at home for as long as possible.

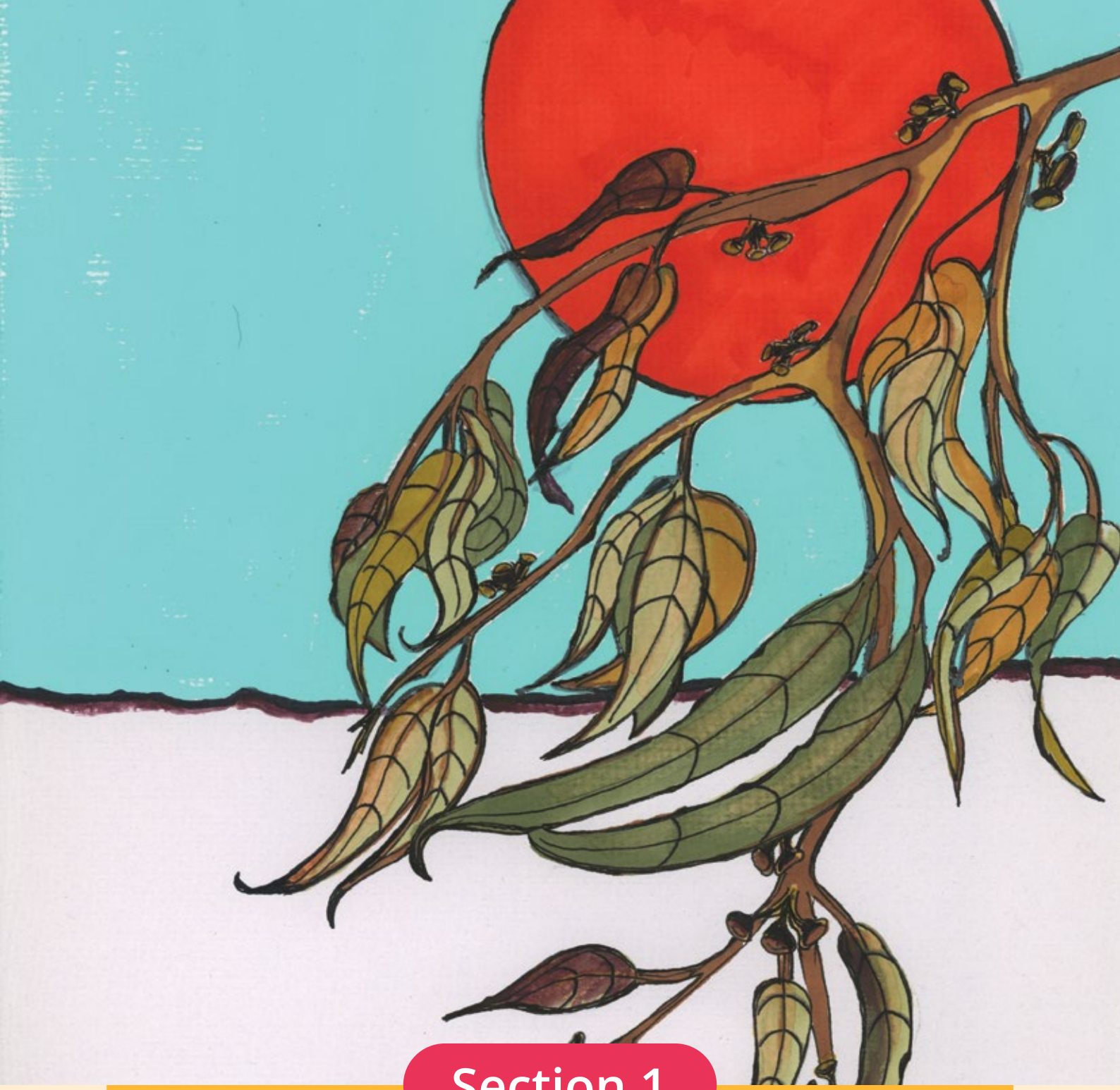
Working out 'What Matters Most'

There are 3 sections in the Discussion Starter, each one is about a different topic:

- 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.

It is important to know that being given the Discussion Starter doesn't mean you are about to die.

Thinking and talking about the end of your life can be hard and it might help to talk to someone. Your doctor or aged care worker are available to talk to. They can help you work out who you can contact if you have any questions or concerns. You may also want to look at the Information section on page 25 for some support options as well.



Section 1

About you

About you

This section is about you. It has questions about what is important to you.

The questions in this section can be the hardest ones to answer. You may want to take some time to think about the questions before you write anything down or only answer one or two at a time.

Some important things to think about:

- There are no right or wrong answers – this is about what you think and what you want.
- You can change your answers at any time.
- You might want to come back and think about the questions again later.
- You do not have to answer all of the questions.
- You can answer some questions now and some questions another time.
- Sharing your answers may help those around you know what you would and would not want, if you could not tell them.

Who are the most important people in your life?

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What brings you the greatest joy in life?

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What brings you strength or makes you feel strong?

What gives meaning to your life? What makes your life fulfilling?

Are there any cultural, religious or family traditions that are important to you?

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How would you like to be remembered?

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My notes

This is a page where you can write down anything that you might want to think about later or talk to your family, health or aged care worker about.



Section 2

About your health

About your health

This section is about your health. It has questions about what you would like to know and what you would like your carer or family to know about your health. It may help you or other people make decisions in the future.

Remember:

- There are no right or wrong answers.
- You can change your answers at any time.
- You do not have to answer all of the questions.
- You can answer some questions now and some questions another time.
- Sharing your answers may help those around you know what you would and would not want, if you could not tell them.

How much do you want to know about how your health issues or medical conditions* might affect you in the future? *(tick all that apply)*

- Nothing
 - As little as possible
 - The care and support options available to me
 - Everything
 - Other:
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How much do you want your family and carers to know about how your health issues or medical conditions* might affect you in the future? *(tick all that apply)*

- Nothing
 - As little as possible
 - The care and support options available
 - Everything
 - Different information depending on the person
 - Other:
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*Examples of a health issue or medical condition might be:

- Dementia
- Cancer
- High blood pressure
- or you may have other conditions.



How involved would you like to be in decisions about your care?

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How involved would you like your family and carers to be in decisions about your care?

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Is there anyone you would like to know everything about your health and care?

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Is there anyone you don't want to know anything about your health and care?

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Section 3

About what you want at
the end of your life

About what you want at the end of your life

This section is about what you might want at the end of your life.

It can be difficult to know what you might want. You may take some time to think about the questions before you write anything down or only answer one or two questions at a time. You may also want to look at our 'What Matters Most' cards to help you identify what is important to you. The cards are available on the website palliativecare.org.au.

Remember:

- There are no right or wrong answers.
- You can change your answers at any time.
- You do not have to answer all of the questions.
- You can answer some questions now and some questions another time.
- Sharing your answers may help those around you know what you would and would not want, if you could not tell them.
- It is important to know that being given the Discussion Starter doesn't mean you are about to die.

If you were very sick or at the end of your life, what would be some of the most important things to you?

Examples of what you may want might include:

- spending more time with loved ones
- having a pre-wake or get together.

For more examples, please look at the 'What Matters Most' cards.

If you needed increasing amounts of medical care or support* from family, friends or carers at the end of your life, where would you want to be?

- At home
- In a hospital
- In an aged care facility (a nursing home)
- Living with a loved one
- Other

*Examples of support might be having help with:

- showering
- toileting
- eating.

Are there any cultural, religious or family traditions that are important to you for the end of your life?

Examples of what you may want might include:

- visiting country
- having a priest or minister called
- having your family present.

Are there any cultural, religious or family traditions that are important to you after you die?

Examples of what you may want might include:

- being cremated as soon as possible
- being buried on country or at a special place
- being dressed in white.

If you were at the end of your life is there anything that you would not want?

Do you have any fears or concerns about the end of your life or dying?

Next steps

Now you have worked through the Discussion Starter, you might want to talk to someone about what you have written down.

You could talk to your family, friends, doctor or your aged care worker.

You might want to come back to the questions in the Discussion Starter later or look at them again as things change.

It is important to remember the Discussion Starter is not an Advance Care Plan / Directive.

This resource should not be considered legal advice and is not an Advance Care Plan / Directive. People should always consult healthcare professionals for advice about their specific circumstances, including the legislative requirements in their state or territory.

Information section

You may want to find out more information when thinking about 'What Matters Most'. Listed below are places you can get helpful information, but speak with your doctor or aged care worker if you have questions.

Dementia support services

Dementia Australia has information and resources about dementia, including factsheets and videos. Dementia Australia operates the National Dementia Helpline for people living with dementia, their carers, families and friends. Dementia Australia also have the Start2Talk website dementia.org.au/living-dementia/what-next-after-your-diagnosis/planning-ahead with helpful information about planning ahead for people living with dementia.

For more information visit the website dementia.org.au or you can call their helpline on 1800 100 500 (9:00am – 5:00pm Monday to Friday).

Dementia Support Australia is a partnership led by HammondCare. Dementia Support Australia has a helpline for people living with dementia, their carers, families and friends.

For more information visit the website dementia.com.au or you can call their helpline on 1800 699 799 (24 hrs, 365 days of the year).

Support

Lifeline

A national charity providing all Australians experiencing a personal crisis with access to 24 hour crisis support. For more information visit the website lifeline.org.au or you can call 13 11 14 (24 hrs, 7 days a week).

Older Persons Advocacy Network (OPAN)

OPAN provides free advocacy, information and education services to older people to effectively access and interact with Commonwealth funded aged care services. For more information visit the website opan.com.au or you can call 1800 700 600.

QLife

QLife is Australia's first nationally-oriented counselling and referral service for Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) people. For more information visit the website qlife.org.au or you can call 1800 184 527.

Advance Care Planning

Advance care planning is a way people can identify what they want for the end of their life. Advance care planning is often an ongoing process and not just one conversation. An important part of advance care planning is being able to choose a person who could speak for you if you couldn't (a substitute decision maker). For more information talk to your doctor or aged care worker or visit advancecareplanning.org.au.

My Aged Care

My Aged Care is the Australian Government's phone line and website to help people find information and access aged care services.

For more information please talk to your care team or visit the website myagedcare.gov.au or call 1800 200 422.

My Health Record

My Health Record is an online summary of your key health information. When you have a My Health Record, your health information can be viewed securely online, from anywhere, at any time – even if you move or travel interstate. For more information talk to your doctor or aged care worker or visit the website myhealthrecord.gov.au or call the My Health Record helpline on 1800 723 471.

Support for Carers

Carers Australia

Carers Australia is the national peak body representing Australia's unpaid carers, advocating on their behalf to influence policies and services. There are carers associations throughout Australia that offer a range of support and services. For more information visit the website carersaustralia.com.au or call their helpline on 1800 242 636 (9:00am – 5:00pm Monday to Friday).

Carer Gateway

Carer Gateway is a national service funded by the Australian Government. Carer Gateway includes a website and phone service for carers to access practical information and support.

For more information visit the website carergateway.gov.au or call 1800 422 737.

Carer Help

Carer Help is a website to help people in Australia who are taking care of a partner, relative or friend who is very unwell, to find good quality information and helpful resources. It provides information, videos and resources you can use to make caring a bit easier. Visit the website carerhelp.com.au.

Palliative Care

Palliative care is not only about care at the end of life. It aims to help people to live as well as they can with a life-limiting illness. Palliative care focuses on the person's quality of life, managing symptoms and providing support for the whole family. For more information please talk to your health care team. You may want to also visit palliativecare.org.au or the Department of Health website health.gov.au/health-topics/palliative-care/planning-your-palliative-care/think-about-what-you-want.

Dying to Talk

Dying to Talk helps Australians of all ages and levels of health to talk about dying.

Death doesn't receive enough attention, despite being something that touches everyone. Dying to Talk aims to help Australians work out what is right for them at the end of their lives. For more information and to access the Dying to Talk resources, visit the website palliativecare.org.au.

Acknowledgements

An earlier version of these resources was developed with Dementia Australia and HammondCare to inform the study. Palliative Care Australia would like to thank both organisations for their involvement and support.

Palliative Care Australia would like to thank the people living with dementia and the aged care staff and organisations involved in the study for their help and feedback.

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



Palliative Care
Australia

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



Mabai
2019
LKM

About the artist

Canberra artist Les Makai, began his art career at the age of 41 having never picked up a paintbrush. He'd always been too busy to pursue this interest, until he was diagnosed with Posterior Cortical Atrophy, a form of dementia. Les finds art therapeutic and derives great pleasure from knowing that his artworks bring joy to others.

Palliative Care Australia commissioned Les to design artworks to feature in the 'What Matters Most' resources. Les included images that people could easily identify with and recognise in their own lives. Les has used high contrast and bold outlines that he finds easy to see and hopes that other people living with dementia have the same experience. The artworks reflect Les's unique style, realistic iconic images using an abstract style.



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