



Working out what's right for you

Discussion Starter



PalliativeCare
AUSTRALIA

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





Why Palliative Care Australia created the Discussion Starter

Palliative Care Australia (PCA) created this Discussion Starter to help people to work out what is right for them at the end of their life, because:

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

Talking with your loved ones about what you want if you were to become 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 a healthcare professional or your care team. You can also find more information on page 21.

Palliative Care Australia (PCA) has undertaken this project in partnership with the Royal Flying Doctor Service (RFDS).

Background

Palliative Care Australia (PCA), in collaboration with the Royal Flying Doctors Service of Australia (RFDS), undertook a study to develop tools for rural and remote communities that:

- assist people to reflect on their preferences at the end-of-life and discuss these preferences with their health team and potentially their family;
- support clinicians to have conversations with their patients/clients about their end-of-life preferences.

The resources were developed with and tested by RFDS clinicians to make sure they were useful to both the clinicians and people living in rural and remote communities. The study found that:

- patients attending RFDS clinics considered it important to have end-of-life care conversations and were comfortable having these with clinicians working in the clinics.
- the resources were positively received by clinicians and could be adapted for every day practice.

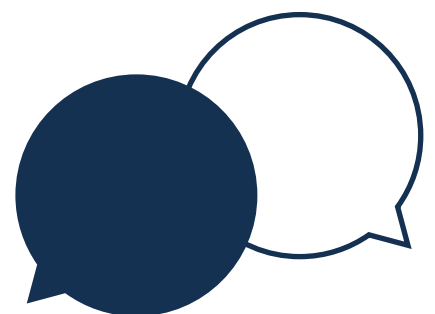
The resources have now been revised as a 'whole of Australia' resource so that they can be used regardless of where people, clinicians, carers or healthcare workers are located – in rural, remote, regional or metro locations. It is also able to be used as a resource for community discussions.

Working out what is right for you can be hard

Talking about what you want at the end of your life can help to ease stress for you and your loved ones, so they know how to meet your needs and what support is available to help.

However, thinking and talking about the end of your life can be difficult, and can sometimes raise more questions. If you have any questions or concerns, speaking with a healthcare professional can assist you to find support, and to help you to work out what is right for you.

The details of who to contact can be written down on the last page of this booklet.



How to use this book

① **Getting to know you**

Think about what is important to you. You may want to write things down, so people know what your goals are and what is important to you.

② **What you want for your health and care**

Think about what you would want if you were very sick or at the end of your life and who you would like to help you.

③ **Talking to people about what's right for you**

Share what is important to you with your friends, family and health care team.

④ **When things change for you**

You can change your mind about what you want – that is okay – let the people who you have talked to know.

PART 1

Getting to know you

Think about what is important to you. What would you like people to know if you were very sick or at the end of your life? By telling people, it helps you work towards your goals and the things that are important to you.

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 were not able to tell them.



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This image shows a blank sheet of white paper with horizontal blue dashed lines. The lines are evenly spaced and run across the width of the page, providing a guide for handwriting practice. There are no other markings or text on the page.

[illegible][illegible]

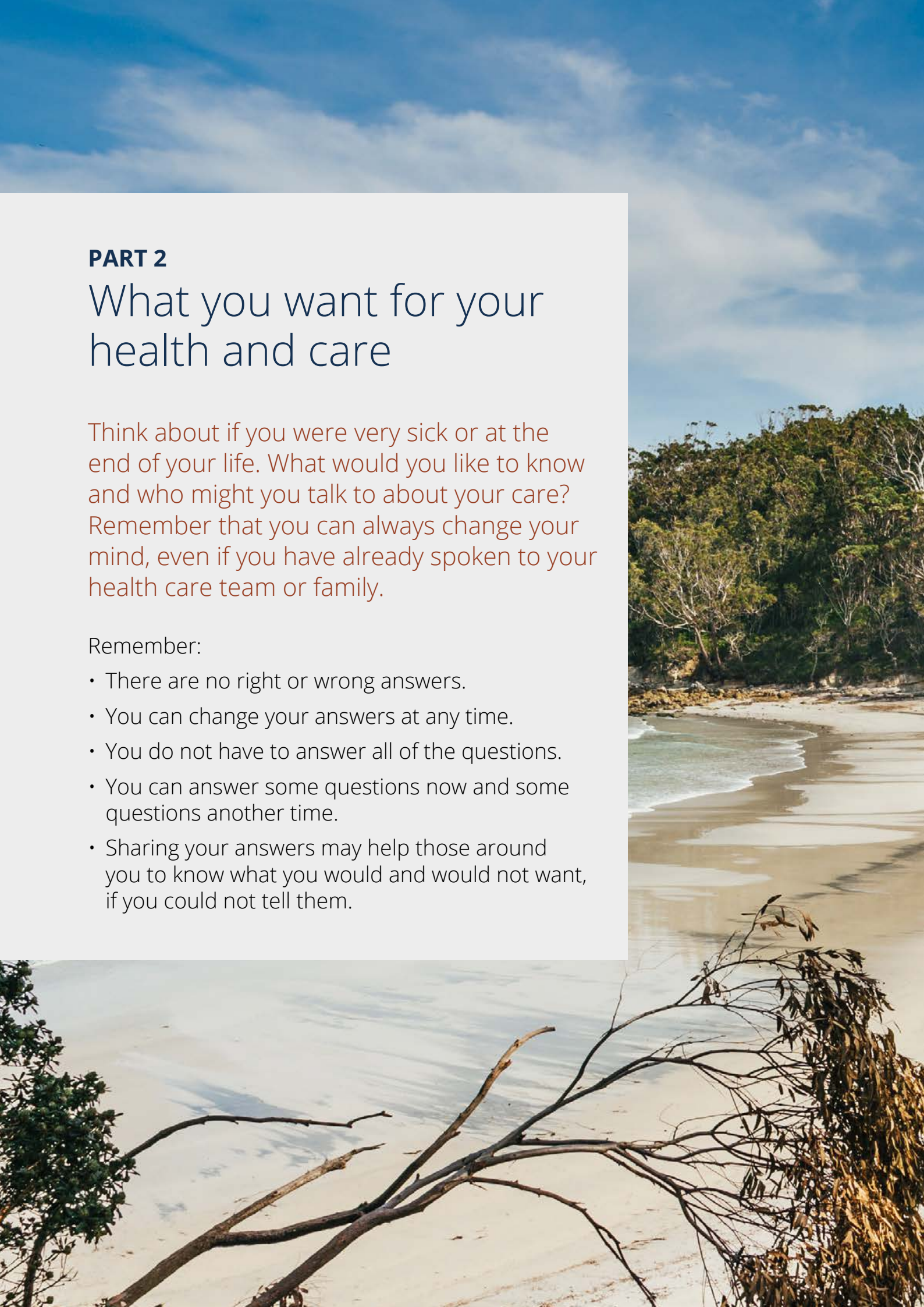
PART 2

What you want for your health and care

Think about if you were very sick or at the end of your life. What would you like to know and who might you talk to about your care? Remember that you can always change your mind, even if you have already spoken to your health care team or family.

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 to know what you would and would not want, if you could not tell them.



How much information would you like to know if you were very sick
(please tick all that apply)?

- ☐ **None**
- ☐ **If it was going to shorten your life**
- ☐ **What would happen if you didn't have any treatment**
- ☐ **Some of the treatment options, including the side effects**
- ☐ **All of your treatment options**
- ☐ **If you might have to travel for treatment**
- ☐ **How your illness will affect you**
- ☐ **If you may need a carer to assist you**
- ☐ **Everything**

Would you like to add anything else?

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

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How much would you like your family to know if you were very sick
(please tick all that apply)?

- ☐ **Nothing**
- ☐ **That you had seen a doctor**
- ☐ **How your illness will affect you**
- ☐ **Your diagnosis**
- ☐ **If it was going to shorten your life**
- ☐ **The treatment you are having at the moment**
- ☐ **All your treatment options**
- ☐ **If you would need to travel for treatment**
- ☐ **The support you may require, such as a carer**
- ☐ **Everything**

Would you like to add anything else?

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

This image shows a full page of blank primary-ruled paper. It features ten sets of horizontal lines across the page. Each set consists of a solid blue top line, a dashed blue middle line, and a solid blue bottom line, providing a guide for letter height and placement in handwriting practice. The background is white, and there are no margins or other markings present.

This image shows a full page of a document template. It consists of ten evenly spaced, horizontal dashed blue lines spanning the width of the page. These lines are designed to guide handwriting or typing. There are no margins, text, or other markings present on the page.

How far would you be prepared to travel for your treatment if you were very sick?

☐ **You would not travel for treatment**

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☐ **You would only travel half a day for treatment**

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☐ **You would travel as far as you needed to for treatment**

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☐ **Other**

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If you were not just very sick but you were at the end of your life, how far would you travel for treatment?

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If you were at the end of your life, where would you want to receive most of your care?

☐ **At home**

☐ **In a hospital**

☐ **In an aged care facility (a nursing home)**

☐ **In a hospice**

☐ **Other:**

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

Some examples are: being in pain; or having to move away from your family; being on country.

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Is there anything else that is important to you that you would like to write down?

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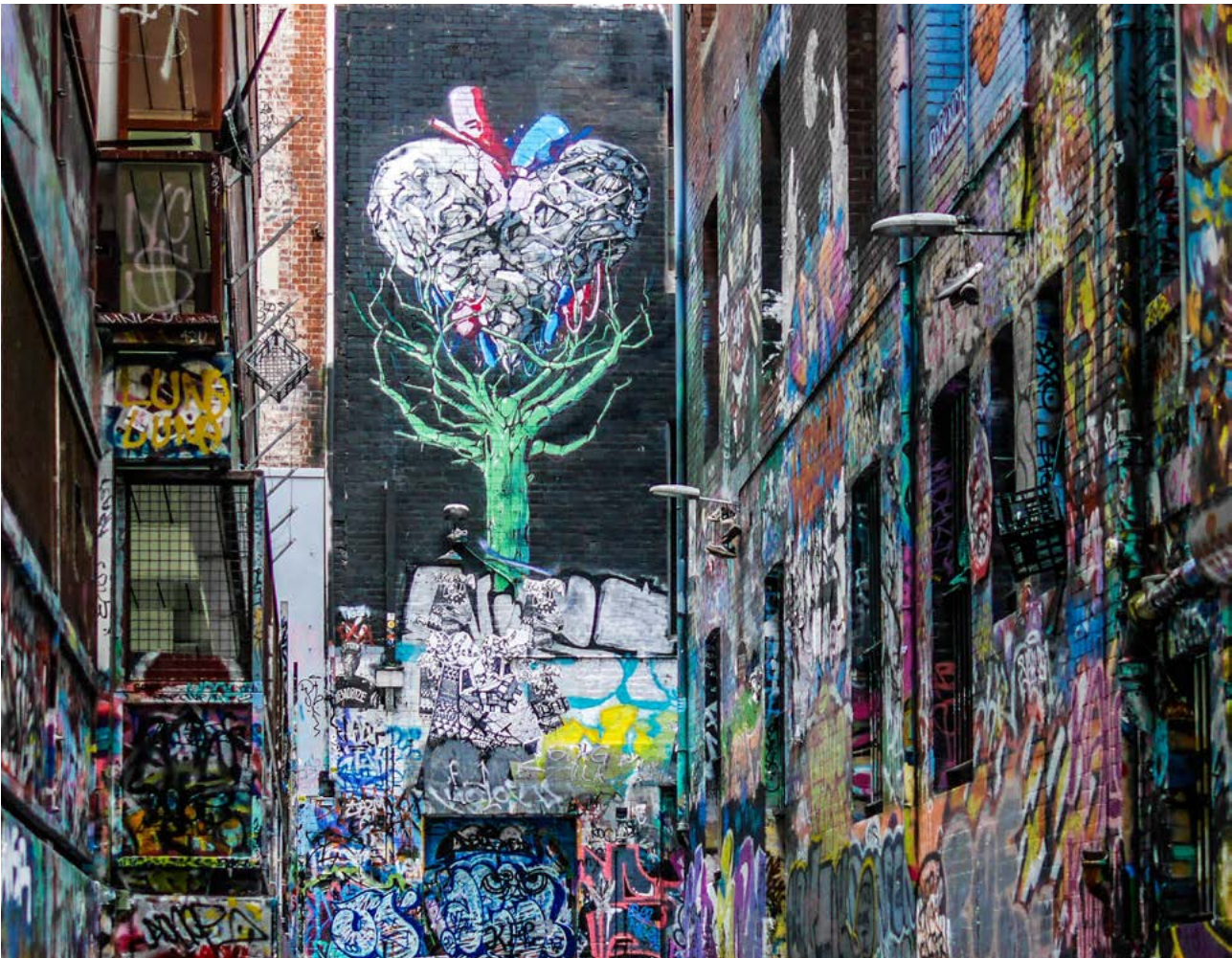
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PART 3

Talking about what's right for you

It is important to talk about what you would want if you were very sick or at the end of your life. Who would you want to know about your health decisions if you couldn't make them for yourself?

If you are unsure about what to talk about with your health care team or family, you could use the Discussion Cards. They can help you decide which topics to talk about now and others that you might want to talk about later. The Discussion Cards can be downloaded at dyingtotalk.org.au



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This image shows a full page of blank primary-ruled paper. It features ten sets of horizontal lines across the page. Each set consists of two parallel blue lines forming a writing row, separated from the next row by a single green margin line. The pattern repeats down the entire page, providing a structured space for handwriting practice.

You may find it helpful to set a target event or day to speak to the people you have listed. If this is something you would like to do, you can record the specific date or event below.

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

This resource should not be considered legal advice. Always consult healthcare professionals for advice about your specific circumstances, including the legislative requirements in your state or territory.

PART 4

When things change for you

Remember you can change your mind later. It is important to let the people who you have already talked to know if anything changes for you.

It is a good idea to think about these things every two years to check if they are still what you want. Things may have changed for you.

There may be other things you are not ready to think or talk about yet – that is okay. Looking at this booklet and using the Discussion Cards is an important first step.



This image shows a full page of a document template designed for handwriting practice. It consists of approximately 20 evenly spaced, horizontal blue dashed lines running across the entire width of the page. The background is plain white, providing a clear guide for letter height and placement. There are no margins, text, or other markings present.

Resources

You may want to find out more when thinking about what is right for you. Below is some information. Speak with your healthcare professionals or health care team, if you have questions.

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 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 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 call 1800 184 527.

Advance care planning

Advance care planning is a way people can identify what they want at 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 nominate someone and prepare a person who could speak for you.

For more information please talk to your health care team. You can also 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 health 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 health care team. You may also visit 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 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/planningyour-palliative-care/think-about-what-you-want

Organising a Will

A Will is a legal document. It can tell people what you want to happen to your assets, as well as items of cultural and/or sentimental value. It can also state who would look after your children or pets if you pass away. For more information please visit moneysmart.gov.au

Organ and tissue donation

People who need an organ transplant are often very sick or dying because an organ is failing. This can happen to people at any age, including babies. People who need a tissue donation can also be very sick and a donation can help to improve their life. If you want to register as an organ or tissue donor, please speak to your health care team. You can also visit register.donatelife.gov.au

Planning your funeral

Sometimes people find it comforting to plan their own funeral. It can reduce stress and disagreements within the family when the time comes. Planning can also help to understand how much a funeral costs and what services are available. You may want to speak to your family about what you want and do not want, or you could write it down for them.

My notes

This is a section where you can write down anything that you might want to think or talk about later.

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Acknowledgements

An earlier version of this Discussion Starter was developed and trialled with the Royal Flying Doctor Service (RFDS). Palliative Care Australia (PCA) would like to thank the RFDS for its involvement and support. Palliative Care Australia would like to thank the patients, clinicians and staff involved in the study for their help and feedback.

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

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

This resource should not be considered legal advice. People should always consult healthcare professionals for advice about their specific circumstances, including the legislative requirements in their state or territory.

Disclaimer

Palliative Care Australia (PCA) thanks The Conversation Project and the Institute for Healthcare Improvement in Boston, MA, USA. Their Conversation Starter Kit is, in many ways, the inspiration for this resource.

Any resource provided by PCA for the purpose of the 'Dying to Talk Campaign' is strictly informative and should not be considered as legal advice or legally binding. None of the resources provided by PCA for the purpose of the 'Dying to Talk Campaign' should be considered as a substitute for the prescribed or recommended 'Advance Care Plan' forms of each state or territory. PCA makes every effort to ensure the quality of information provided however will not be liable for any loss or damage suffered by any person arising in connection with any information provided.

All information provided is general in nature. For additional information relating to advance care planning, please speak to your health professional for advice about your specific circumstances, including the legislative requirements in your state or territory, or visit the Advance Care Planning Australia website www.advancecareplanning.org.au or call the advisory service on 1300 208 582, 9am–5pm (AEST) Monday to Friday.



PalliativeCare
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

Working out what's right for you



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