

# GETTING DEAD SET.

An overview of Australian attitudes  
and behaviours around death,  
dying and end-of-life planning



*Dying  
to know  
Day* 3 August

This survey was commissioned by The Groundswell Project Australia to help reshape the way Australians approach dying and death.

The insights from this survey aim to improve understanding of attitudes and behaviours related to planning for end-of-life, as well as the barriers to making informed choices about living and dying well.

The Groundswell Project Australia is powered by **CCNB Limited**. CCNB is a not-for-profit community-based organisation. It provides impartial information, advice and guidance to support people to access health and community services, with a focus on aged care and NDIS clients.

We acknowledge The Groundswell Project Australia team members who led this research:

- **Cherelle Martin** – National Campaign Manager for Dying to Know Day, The Groundswell Project Australia
- **Susan Goldie** – National End of Life Strategy Lead, CCNB

Visit [www.thegroundswellproject.com](http://www.thegroundswellproject.com) to learn more about our work.

**The Groundswell  
Project Australia**

# A word from Cherelle Martin, National Campaign Manager for Dying to Know Day

Kicked the bucket. Croaking it. Pushing-up daisies. Passed over, on, away.

Whatever you choose to call it, death and dying isn't easy to talk about – but the reality is that it's going to happen to us all.

We know that a well-planned death, which involves stepping into the space of your own mortality, can be truly life affirming. It empowers us to deeply consider our personal values, take steps to ensure this is reflected at end-of-life and just get on with living.

So, how many of us actually have a plan for our end-of-life? Do we even know where to begin? Are we prepared to talk about our death and dying openly?

As part of our annual Dying to Know Day (8 August) campaign, we asked Australian adults of all ages to share their thoughts and experiences around planning for end-of-life.

This Australian-first survey is a **very first step** in continuing to understand our evolving attitudes to death, dying and planning for end-of-life – topics that aren't discussed nearly enough, but are essential to helping those we care about.

People often feel ill equipped to act or start a conversation. The risk for us all is that we do not have the knowledge or understanding around how to best support our own planning for end-of-life and/or a loved one who is dying, caring or grieving. Sadly, this can mean that end-of-life experiences are not aligned with an individual's values and wishes.

By normalising conversations and empowering your curiosity, we can all 'get dead set' and find a positive state of preparedness around end-of-life that is unique and personal.

This is an opportunity to continue to strengthen our collective approach to these important matters and, as a community, do death better.

*Cherelle.*



**Cherelle Martin**

# About

Death is often over-medicalised and institutionalised. Our superstitions, fears, discomfort and lack of knowledge about dying affect our approach to planning for end-of-life.



*End-of-life planning is the process of organising your affairs with your death in mind. This involves considering what is important to you in all aspects of your life from memories to finances, from relationships to medical preference, from digital assets to funeral preferences.*

**However, our survey findings show that most Australians think planning for death is important.**

In fact, almost **9 out of 10 Australian adults believe in the importance of end-of-life planning.** But only one third of us has put that belief into action.

**Why?** The findings of this survey reveal that we experience a number of challenges and barriers when it comes to taking action.

Some Australians feel that death is too emotional to think about. Others told us that they don't know how to start planning for end-of-life or where to go for help and information. Lack of understanding about the choices we have was another significant barrier.

Australians were resoundingly clear in their view of the benefits of planning for end-of-life. We feel strongly that, should we die unexpectedly, having some end-of-life planning in place would help the people we love.

The insights from this survey can help us to 'get dead set', improve death literacy and reshape the way we approach death and dying in our homes, our communities, our workplaces, our hospitals and aged care services. This is all the more urgent at a time when the COVID-19 pandemic has changed how we live, die and grieve.

To 'get dead set' is to find a positive state of preparedness around end-of-life that is unique and personal to you.



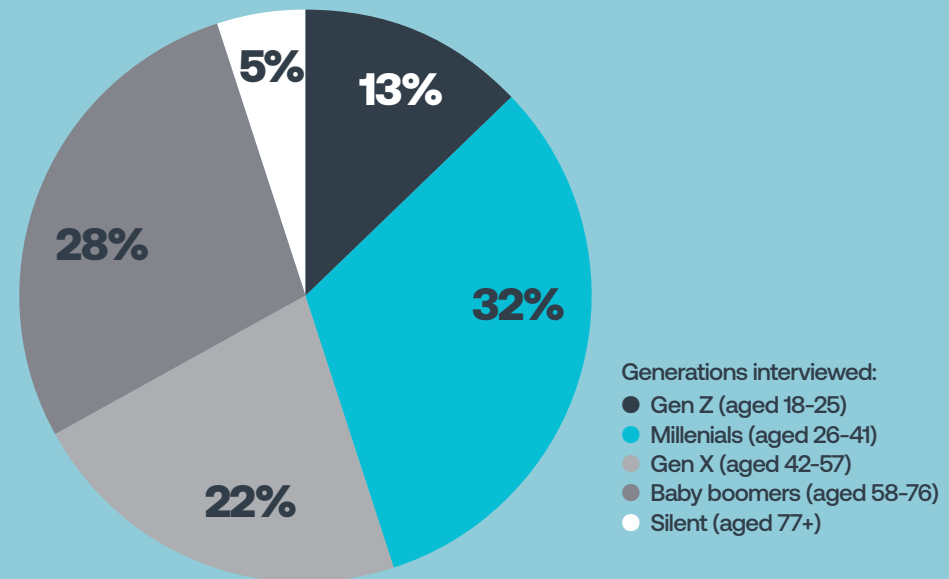
*Death literacy is the knowledge, compassion and practical skills that enable supportive action and active decision-making around someone's end-of-life choices.*

### Who did we speak to and why?

In June 2022, we worked with YouGov to survey a representative sample of 1,027 Australians aged 18 years and older. The group identified as 51% female and 49% male.

We asked a series of questions to understand their attitudes, behaviours and experiences around planning for end-of-life.

The data was weighted by age, gender and region to reflect the latest Australian Bureau of Statistic (ABS) population estimates.



# End-of-life planning is important!

**87% of Australians believe that end-of-life planning is important.**

However not many of us are getting on with it.

**35%**

have done some end-of-life planning

**28%**

are thinking about undertaking end-of-life planning in the next 5-10 years

**31%**

of us aren't considering it at all in the next 5-10 years

**This means millions of Australians have not taken steps to plan for end-of-life.**

**Australians aged 65 and older are much more likely to have done some end-of-life planning than younger Australians.**

**59%**

of people aged 65 and over have some end-of-life planning in place

**35%**

of 50-64 years olds have some end-of-life planning

But only

**16%**

of young Australians aged 18-34 years old have even given any thought to end-of-life planning

Australians that live in capital cities are less likely to have done some form of end of life planning than those who live in regional areas (32% compared to 39%).

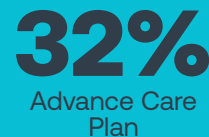
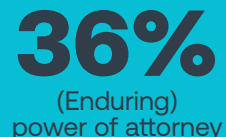
# What actions are Australians taking around end-of-life planning?

End-of-life planning looks different for everyone.

These are common steps taken by people with some end-of-life plans in place:



Other, less common steps taken by people with some end-of life planning in place include:



## Quick glossary:

- **A will** is a legal document that records a person's wishes about what happens to their possessions and assets after they die.
- **A funeral** is a death ritual which celebrates the life of someone who has died and connects those who are left behind to share the grief and joy of their legacy.
- An **Advance Care Plan** records choices made about future health care which a person would or would not want if they were unable to communicate their preferences or make decisions for themselves.
- **(Enduring) Power of Attorney** is a legal document a person can make that gives another the legal authority to make financial or property decisions on their behalf.
- **Substitute decision maker** is a trusted person who someone has chosen to help ensure that their health care and medical choices are honoured if they ever lose decision-making capacity.

# We have an opportunity to do more

A significant majority of Australians have not taken steps to plan for a good death at the end-of-life.

**That includes considering medical and care choices or having an advocate who can ensure those choices are implemented.**



*A good death is to die in accordance with the values and choices which are consistent with what dying well means to you.*

There is a clear opportunity for more Australians to learn about and explore other steps to make choices to plan for end-of-life. This can prevent unnecessary distress, uncertainty and ambiguity around your wishes for end-of-life for you and the people who are most important to you.



# End-of-life planning helps the people we love

We asked Australians a confronting question:

If you died unexpectedly, would your end-of-life planning help the people you care about?

Even Australians who don't have end-of-life planning in place and who may not want to plan in the next 10 years still agreed that end-of-life planning would help the people they care about.

Almost half of us

## 48%

say it would reduce the mental burden experienced by our loved ones of organising our financial and legal affairs.

Nearly as many

## 40%

believe our loved ones would be comforted by knowing our wishes for after we die.

Over a third of us

## 37%

say their loved ones could spend more time remembering the good times instead of on decisions and paperwork.

One third of us

## 30%

believe that our end-of-life plan would help our loved ones grieve and heal more readily.



“About two years ago, my mother passed away at age 84. She was very careful to ensure that she had all her planning in place, and we regularly reviewed her end-of-life wishes. This made the process of dealing with her death very clear and straightforward.”

**Sally Boucher**

# Are we comfortable talking about end-of-life?

Most of us (77%) say we feel comfortable to talk about planning for end-of-life with the people who are important to us.

Almost a quarter

## 23%

of us say we are uncomfortable having conversations about end-of-life planning. That's 4.5 million Australians.

1 in 3 of those conversations

## 32%

have led to action related to planning for end-of-life.

Just over half of us

## 52%

say they have had a conversation about end-of-life.

**These hard conversations can be easier if we prepare for them first. Almost everyone who said they have done some planning said they were also comfortable talking about end-of-life.**



“Having conversations about end-of-life is important as it can help us embrace mortality because death happens to all of us. It can be hard, awkward and uncomfortable but, once you do that, you can face your fears and be prepared for death in a way that enriches your life.”

**Alyssa Wormald**

# How can we get comfortable talking about end-of-life?

Having some information about end-of-life helped Australians who have had conversations about end-of-life, to do so more comfortably:

Knowing my family and friends are comfortable talking with me about my end-of-life plans

**51%**

Having an experienced guide who can listen to us and answer our questions

**14%**

Knowing about my end-of-life health care choices

**38%**

Knowing about my funeral choices

**37%**

Knowing that I can afford my funeral choices

**35%**

**We know that end-of-life planning is – and should be – different for everyone. However, in all cases, it's important that these plans have been (or will be) communicated to people who can help you implement your plans.**

# What is holding us back?

Although we believe in the importance of end-of-life planning, two thirds of us (64%) believe there are barriers to taking action.

**14%**

of us feel that dying and death is too emotional to think about.

**16%**

of us are unsure where to go for appropriate information that would suit our stage of life.

**15%**

of us don't know what choices we have.

**17%**

of us say we simply don't know where to start.

**25%**

of us say that planning for end-of-life life is not a priority for us.

**The insights from our survey suggest that the more information we have about end-of-life, the more comfortable we feel to have important conversations about what living well and dying well means to us.**

Initiating conversations around end-of-life can be hard, but the positive impact it can have is significant.

Death does not discriminate so normalising conversations to share our end-of-life wishes with the people who are important to us is crucial.

# Young people don't see end-of-life planning as a priority.

Dealing with death and your mortality can often be considered topics to address 'later in life', for a number of reasons.

**Unsurprisingly, two thirds (62%) of Australians aged 18-24 say they have not done any end-of-life planning and are not considering doing so in the next 5-10 years.**

## Young Australians also told us that:

- **A third of people in this age group** are uncomfortable having conversations about end-of-life.
- **Of everyone who has had a conversation about end-of-life planning** Australians aged 18-24 are most likely to say that having an experienced guide who can listen and answer their questions is what has helped them in talking to their loved ones..
- **People in this age group** are most likely to not see end-of-life planning as a priority right now.

Australians of all ages are impacted by expected and unexpected death. Planning for end-of-life is for all Australians and it can look different for everyone.



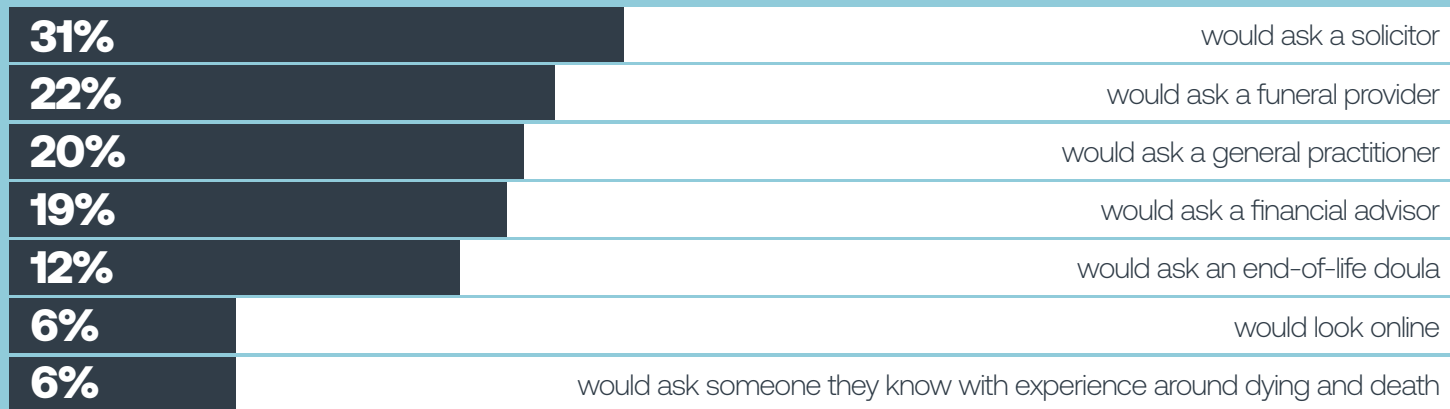
“My dad's death was also the catalyst for me to write down all of my ‘intentions’ around my death and some details about what I'd want my funeral to be like. I had my family sign it, take copies and then put it in my backpack, where it still lives.”

**Dom Foffani**

# Where can we get the information we need?

A quarter of Australians told us they don't know where to go for information.

But we can share where other Australians found information which has helped them with planning for end-of-life.



## There are so many different sources of information to consider when making end-of-life plans.

Information from a wide range of sources can help Australians at every stage to plan according to their culture, values and circumstances. It is important for everyone to explore their options as they make their personal end-of-life choices.



*An end-of-life doula (or death doula) is a non-medical professional trained to provide support, options and education assisting the dying and those around them have their end of life unfold in alignment with their wishes.*

# How do men and women plan for end-of-life?

Men and women sometimes approach end-of-life planning differently.

- **Women are more likely to have a will –**  
77% of women compared to 62% of men
- **Men are much less likely to talk with people close to them –**  
44% of men compared to 61% of women
- **Women are more likely to have a substitute decision-maker ensure that their wishes are implemented if they lose capacity to advocate for themselves –**  
43% of women compared to 30% of men
- **Men are more likely to have some financial advice –**  
37% of men compared to 21% of women

Almost 50% more men also told us they simply don't know what would help them have conversations about end-of-life planning — 28% of men compared to 19% of women.

# What comes next?

There are a number of things we can all do to start our end-of-life plan and get dead set:

- 1 Capture your choices in writing.**  
Like a will, substitute decision maker and guidance on your social media or organ donation. These could be documents, or as simple as a text or scribble on a serviette to start.
- 2 Have conversations**  
with loved ones and others so they understand your wishes – and you understand theirs.
- 3 Prepare your send-off.**  
Share what you want it to look like so you can be celebrated and remembered in line with your wishes.

**Visit [www.dyingtoknowday.com](http://www.dyingtoknowday.com) for support and resources to get you started on your end-of-life planning journey.**



The Groundswell  
Project **Australia**

[www.dyingtoknowday.com](http://www.dyingtoknowday.com)

