

CARESEARCH[®]

palliative care knowledge network



Dying2Learn

Find answers
to questions about
death and dying

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CareSearch is funded by the Australian Government
Department of Health and Aged Care



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Continuing a conversation about death and dying

So how do you have a national conversation about death and dying? Well, you design a massive open online course where participants are able to learn about and talk about euphemisms and language, legacy, art and music, medicine's role, funeral practices, cultural differences, online mourning. And after 5,000 people have participated you realise you need to be able to continue the conversation. Welcome to Dying2Learn in CareSearch.



What will I find on Dying2Learn?

Dying2Learn allows you to explore different aspects of living and dying.

1. You'll discover it's ok to be curious and that people and societies differ in how they view death and dying.
2. You can share what books and movies influenced your views about death and dying.
3. You can add to our database of euphemisms. There are a lot of words we use when we don't want to say that someone has died.
4. You can learn what is meant by "palliative care" and "advance care planning."
5. We asked over 500 Australians what they think about death and dying using three words. Now you have a chance to add your three words.

6. You could also take the time to plan your funeral or perhaps figure out what's on your bucket list.
7. And finally, you can visit the death library.

We are all part of the conversation

Birth and death are both part of our life. But when it comes to the latter, we can be reluctant to think about, talk about, and plan for it. Now that you know about Dying2Learn, feel free to share some resources and a conversation with your family or with a friend or neighbour.

Dying2Learn is just one way we can build death literacy and feel more comfortable talking about this important life matter.

If being a kid is about learning how to live, then being a grown up is about learning how to die. *Stephen King*



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Top 10 Books

- 1 Tuesdays with Morrie by Mitch Albom
- 2 The Book Thief by Markus Zusak
- 3 The Lovely Bones by Alice Sebold
- 4 Dying to Know: Bringing Death to Life by Andrew Anastasios
- 5 Being Mortal by Atul Gawande
- 6 The Prophet by Kahlil Gibran
- 7 When Breath Becomes Air by Paul Kalanithi
- 8 Top Five Regrets of the Dying by Bronnie Ware
- 9 Smoke Gets in Your Eyes by Caitlin Doughty
- 10 Die Wise: A Manifesto for Sanity and Soul by Stephen Jenkinson

Top 10 Movies

- 1 The Notebook
- 2 The Bucket List
- 3 Ghost
- 4 Beaches
- 5 Death at a Funeral
- 6 Up
- 7 Me Before You
- 8 My Sister's Keeper
- 9 The Fault in Our Stars
- 10 Love Story



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Providing evidence-based information about palliative care for everyone because death and dying will affect all of us.

Books to help kids understand death and grief

These are some recommended favourite books and resources from CareSearch staff for children. You can use them as starting point when talking to children about death and dying, how to cope with grief, and the importance of remembering loved ones who have died.

Babies and Toddlers (0 - 4 years)

Todd Parr (2015). The Goodbye Book

Told through the eyes of a pet fish who has lost his companion, this brightly illustrated book tells a moving story about saying goodbye and the big feelings that children can have.

Caron Levis (2016). Ida, Always

This is a touching story of death and the importance of remembering as told through the eyes of Gus and Ida, two polar bears living in a city zoo.

Margaret Wise Brown (2016). The Dead Bird

An uncomplicated story of friends finding a bird lying motionless on the ground. After discovering that the bird had died, the children sing their farewells and bury the bird in the park.

Jen Crowley (2015). Grandpa's Hat

Grandpa's Hat is the story of Jennywren and all her favourite animals, who help her discover that although her Grandpa is gone, he doesn't have to be forgotten. Currently used as a resource for [National Association for Loss and Grief](#) (NSW)

Brita Teckentrup (2014). The Memory Tree

A moving tale celebrating the memories left behind when someone dies. When Fox dies, his friends continue celebrate his life by remembering all of the things that they did together when he was alive.

[Beginnings and Endings episode on Playschool](#)

(ABC iView)

This Play School episode celebrates new life, and reflects on the love we have for those who have died. There are times to play and have fun, and there are also times to be sad and treasure memories of people and pets that are missed.

[Sesame Street in Communities - Helping Kids Grieve](#)

This website is full of interactive activities and videos specifically designed for children aged 2-6 to help explore and express their emotions after someone has died. Resources include a Grief Toolkit providing tips, stories and guides to help families to move forward through stages of grief.



Little kids (5 - 7 years)

Judith Kerr (2003). Goodbye Mog

In this story, we join the Thomas family as they deal with the sad death of their wonderful pet Mog and welcome a new kitten to their family. This book provides a gentle introduction to the subjects of grief and bereavement, narrated by the one and only, Mog herself.



Pat Thomas (2001). I Miss You – A First Look at Death

Providing examples of death (such as the loss of a grandparent or pet), this story helps younger children to come to terms with loss and the feelings that grief that are difficult to express.



Wolf Erlbuck (2007). Duck, Death and the Tulip

This is a story a duck and her unlikely friend Death, whose constant companionship leads to open, thought-provoking discussions on life, death, the afterlife and the importance of accepting death as part of the cycle of life.

E.B. White (2006). Charlotte's Web

A classic tale of friendship, love, death and the connections that make us human. Charlotte's Web tells of the firm friendship between a girl, rescued pig and a spider. This timeless story highlights the importance of friendship and the acceptance of death as part of living.

Mem Fox (2019). Tough Boris

Tough guys need to cry, even tough guy pirates! Tough Boris tells of the importance of acknowledging emotions, acceptance of death and experiencing grief. All of these big emotions are experienced by a boy who stows away on Boris' pirate ship helps Boris when his beloved parrot dies.

Patrice Karst (2018). The Invisible String

"The invisible string is the string that binds us as families together", says Liza and Jeremy's Mum who then explains that even when people are not here anymore, there is an invisible string that still binds us together. A story that explores love, separation and acceptance.

Bryan Mellonie & Robert Ingpen (2005). Beginnings and Endings With Lifetimes in Between

By posing and answering questions about life and death of everything that is alive, this story helps explain that dying is very much a part of living and is as important and remarkable as being born.



Big Kids (8 – 12 years)

Patrick Ness (2011). A Monster Calls

A dark but amusing fantasy tale of Connor and his ancient, wild backyard truth-seeking monster who has materialised from his subconscious as a result of dealing with the fear and anticipated grief of losing his mother to cancer. This story describes the impact that overwhelming feelings can have and the importance of taking these seriously.

Katherine Paterson (2006). Bridge to Terabithia

Terabithia is a magical kingdom ruled by two close friends, Leslie and Jess, but when Leslie unexpectedly dies by accident, Jess is faced with dealing with feelings of guilt, sadness and loss. This story presents first-hand narratives of coping with death and experiencing grief from a child's point of view.

J.K. Rowling. The Harry Potter Series

Harry Potter needs no introduction, a magical and fantastical adventure of the boy wizard and his friends as they grow up in the world of Hogwarts. All of seven of the Harry Potter adventures feature concepts of death as a part of life, acceptance of dying and grieving for those who have died. You may also [listen to J.K. Rowling speak about the how grief influenced her writings of Harry Potter](#) or perhaps to Beyond the Veil (Episode 23) [Podcast] on '[What Potter Can Teach Us About Life, Love, and Death](#)'

Tricia Irving (2001). When Tough Stuff Happens

This activity book is for 7-12 year old children who are dealing with or facing difficult periods in their life. There are many different types of activities asking kids to find the words to help to talk about what is happening and express how they are feeling. You can order this book through [Skylight Trust New Zealand](#)

[Winston's Wish Childhood Bereavement Podcast Series](#)

A UK based not-for-profit organisation, Winston's Wish, supports children and young people after the death of a parent or sibling. They have produced a series of five podcasts discussing practical after death support for children, including returning to school and the importance of talking about their feelings. These are all freely available on [Soundcloud](#) (website that provides free audio downloads to listen too and share).

[Apart of Me \[App – Game\]](#)

This interactive game has been designed by grief experts in collaboration with young people experiencing grief. Children move through magical worlds guiding them through dark periods after death of a loved one. By working through real-world 'quests', kids can validate feelings or emotions whilst building to help to move on. The Apart of Me app is available for download in both the Apple App Store and Google Play stores.



Teenagers (13 – 16 years)

Marc Zusak (2018). Bridge of Clay

This story explores the impact of parental death on family bonds and the importance of brotherhood in maintaining a sense of normality in relation to the real, adult world, especially when faced with a sense of abandonment and heartbreak.

Margo Rabb (2007). Cures for Heartbreak

Mia is 16, who with her sister and father must face life without their mother after dying of cancer. Facing this loss, Mia struggles to process her own grief, but eventually finds a way through the tough times by remembering her Mum and rediscovering enjoyment and excitement in her own life.

Jason Reynolds (2015). The Boy in the Black Suit

Matt wears a black suit, partly because his mother died but mostly because he works part-time at a funeral home. Matt's story explores the importance of finding someone who can support you - showing you a way through the sad times and indeed, finding a friend who can understand what you are going through.

Molly Carlile (2010). Sometimes Life Sucks: When Someone You Love Dies

A guide for teenagers to help navigate death, and the feelings of shock and grief. This book includes some valuable tips, stories, and advice to support adolescents during tough times.

Smiles and Tears

[App] - iOS App Store

Smiles and Tears app has been developed to support all children and young people who have experienced death of a significant person in their lives. This app features interactive tools to help maintain connections and remembering the person who has died. Smiles and Tears app is only available for download from the App Store (Apple).

Cove

[App] - Available for download from Apple App Store and Google Play

Cove app was developed by Humane Engineering as part of the End of Life group at the Institute for Global Health Innovation in the UK. This app allows teenagers to compose their own music as a way to healthily express their emotions whilst coping with loss or when experiencing grief. Cove is available for download in both Apple App store and from Google Play.



Providing evidence-based information about palliative care for everyone because death and dying will affect all of us.

What is palliative care?

Palliative care is person-centred care and support for people with a life-limiting illness. This includes support for their family and carers. The aim is to help people live their life comfortably and as fully as possible by supporting their physical, emotional, social, and spiritual needs.

Examples of the care required might include:

- Relief from distressing symptoms including:
 - > Pain
 - > Depression
 - > Fatigue (tiredness)
 - > Nausea
 - > Breathlessness (dyspnoea)
 - > Anxiety
- Psychological and spiritual support
- A support system to help patients and family live as actively as possible until death
- Support to help the family cope during the person's illness and in their own bereavement.



Palliative care enhances quality of life. It intends neither to hasten or postpone death.

Who is palliative care for?

Palliative care is for people of any age with a life-limiting illness and their families. A life-limiting illness is one likely to cause death in the foreseeable future. This includes:

- Cancer
- Neurological disease
- Dementia
- Advanced kidney, heart, liver, and lung disease

Family can include partners, relatives, friends, or anyone who is considered so by the patient (including pets).

When is it provided?

Palliative care can be provided at any time depending on a person's needs. It is now accepted that combining palliative care with active treatment improves symptom control, quality of life, and family satisfaction.

When you receive palliative care is a decision for you and your family.

Who provides palliative care?

Palliative care can be provided by many different health and care professionals.

In a hospital setting care it is provided by doctors, palliative specialists, nurses, and allied health professionals.

In the community the palliative care team might include the person's GP, community and aged care nurses, visiting allied health professionals, careworkers, and support workers. Family, friends, neighbours, and acquaintances will also provide important support.

Where is it provided?

Palliative care may be provided in hospitals or the community setting. This includes:

- Private homes
- Residential aged care
- Accommodation for people experiencing mental illness
- Accommodation for people living with a disability
- Correctional facilities
- General practices
- Community palliative care clinics and day centres
- Hospitals

Not all people with a life limiting illness need specialist palliative care. Many people can be cared for at home and see specialist palliative care staff only when there is a need.

Being able to stay at home with a serious illness usually requires the help of family members or friends. Older people may be receiving palliative care alongside a homecare package or within a residential aged care facility.

Some may have more complex needs and symptoms that need careful management. In this case there may be the continuing involvement of a specialist team and short or longer stays in a hospice or palliative care ward.

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We all need a plan

What is advance care planning?

Advance care planning is about documenting your wishes to speak for you when you no longer can. This will help your family and friends to make decisions about your care if you cannot. Advance care planning generally covers three things:

- Thinking and talking about your healthcare values and preferences.
- Appointing a substitute decision-maker.
- Completing a document such as an Advance Care Directive.

How many of us have taken the time to stop and think about what we would want to happen if we became seriously ill or if someone close to us was seriously ill what they would want?



Why do we need a plan?

We all make plans in our life for today and the future. We will all die one day so we should plan for that too. Having a plan can help us, our family and the health professionals who care for us to know what we want. You can start having a conversation at any age about what you want if something unexpected was to happen.

Making a plan becomes more important as you are getting older or if you learn that you have a serious illness. Being informed about what will happen can help in making preparations and can make decisions easier. When making plans and decisions you need to let people know what you have decided. This includes your family and friends. You should also tell your health professionals.

Remember health professionals will not know what you want if you don't tell them what is important to you. You may have particular beliefs or traditions that need to be taken into account in providing care.

Finding the right information

Each state and territory has different laws covering advance care directives. You can find out about relevant state or territory information via links below:

- [Australian Capital Territory](#)
- [New South Wales](#)
- [Northern Territory](#)
- [Queensland](#)
- [South Australia](#)
- [Tasmania](#)
- [Victoria](#)
- [Western Australia](#)

Helpful resources

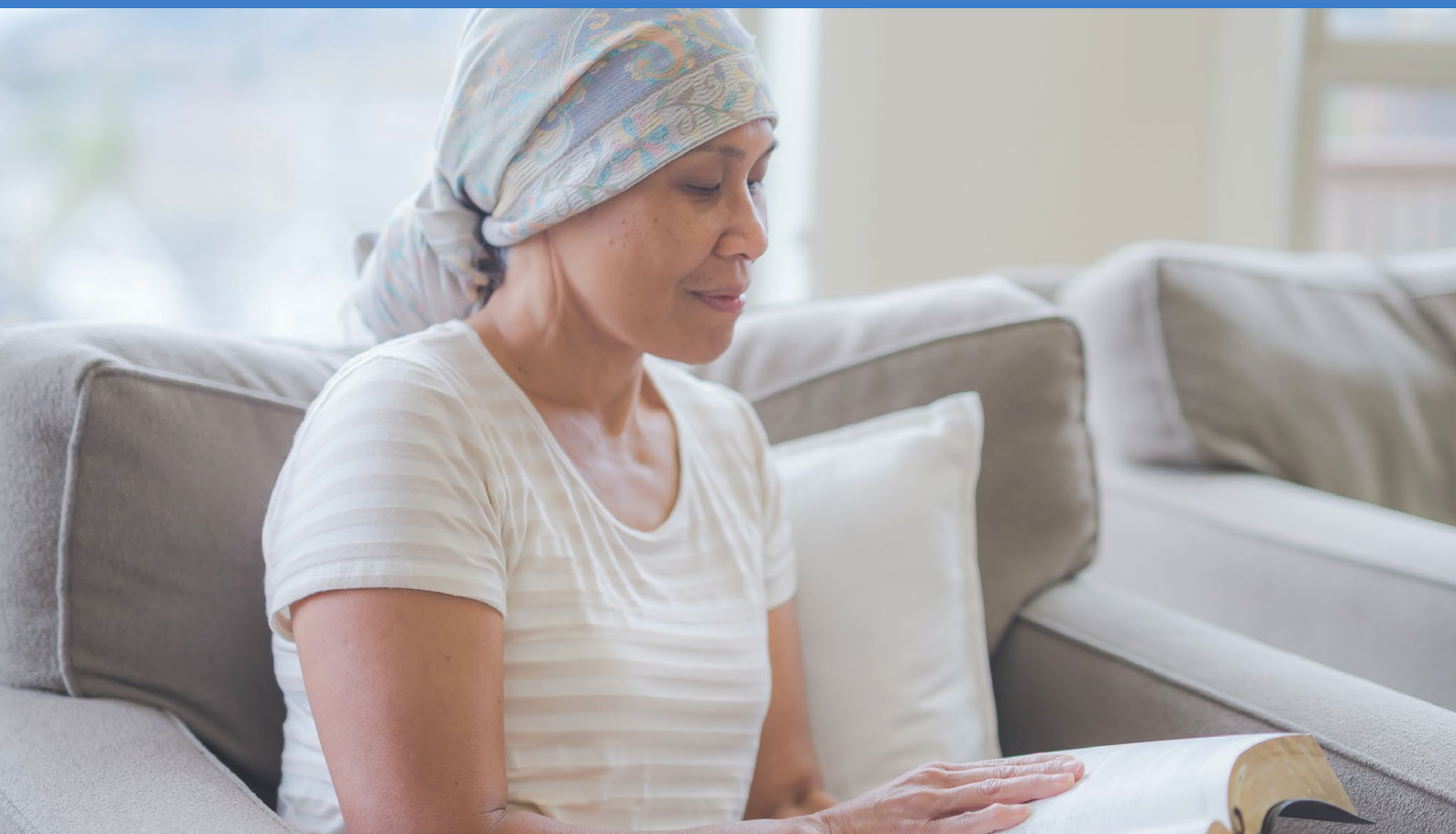
[Advance Care Planning Australia](#) has a range of resources including learning modules and factsheets.

Palliative Care Australia's [Starting to Talk Discussion Starter](#) can help you talk about your wishes and preferences for your care at the end of life.



This resource has been produced under our **Part of Life** project which aims to help people understand what palliative care is and why it matters. Visit caresearch.com.au for more information.

Planning your funeral - what do you want?



Funerals are usually planned during times of great stress.
But it doesn't have to be. We can all think about what
we want at our funeral.

Here are some of the things you might like to think about when thinking about or planning your own funeral. You can print it and fill it in.

This could be a good discussion starter, or you can leave it for your family to help them when they need it.

Remember, the only legal function of a funeral is to legally dispose of your body – as a burial or cremation.

How you choose to structure and personalise your funeral is up to you!

Planning your funeral - what do you want?

Planning your funeral service

You can have the option of having a single, dual (at two different locations), at the grave or a memorial service (held after the body has been interred) or have no service at all.

Think about whether you want a religious service or a service at the graveside or in the funeral home. What do you want to happen at your funeral service? Do you have music, songs, readings that matter to you? Who would you like to speak? Is there someone you would like to have conduct the service? And did you have some suggestions for sharing afterwards (at home, at a lunch or in the pub?).

What I want when it comes to my service?

Who I want to direct the service:

Who I want to give my eulogy:

My favourite poem, prayer, or readings:

I prefer donations to my favourite charity or flowers:

The music I would like played:

Don't forget to invite:

Planning your funeral - what do you want?

Remembering me

There are lots of ways that people can remember you. You might like to share your thoughts.

I would like a Headstone or marker:

- Flat marker set on the grave
- Flat tablet on concrete slab
- Headstone or statue

What I want to wear:

- Favourite dress or suit
 - Casual wear
 - My choice is:
-

I would like some digital options:

- Online memory book
- Digital tombstones (shows your life story)
- Legacy messages for my family after my death
- Digital avatar
- AI digital afterlife

Coffins and caskets – Choosing what you are buried or cremated in

It can get confusing with so much choice. There are traditional coffins and caskets, seagrass, and even mushroom composting options. Don't be afraid to explore what is now available, you may like to choose an option that reflects your personality or beliefs.

- Traditional casket or coffin
- A personalised casket or coffin that is handmade to my specifications

Environmentally friendly options

- Chipboard
- Cardboard
- Woven
- Wicker
- Seagrass
- No casket or coffin, I would like to be buried or cremated in just a shroud

Planning your funeral - what do you want?



Need some more information?

Here are some resources with more information about funerals, planning checklists and alternative funerals that you may like to explore.

[Australian Funeral Directors Australia](#) provides information on finding providers and planning funerals in Australia.

[CANSTAR website](#) provides information on how to plan funerals or memorial services.

[Gatheredhere website](#) has resources that can assist in planning and finding end of life services across Australia, this site also has the checklist on How to Prepare for the Death of a Loved One.

[Garments for the Grave](#) is a website by Dr Pia Interlandi who designs and creates burial garments including funeral shrouds.

[Gippsland Unwrapped](#) presents a blog written by Tammy Logan who is passionate about planning well for the end of our life and reducing on impact of death on the environment - Planning a Sustainable Funeral.

[Funeral Planner website](#) has information on the process of donating your body to science - How do you donate a body to science in Australia.

[Natural Death Advocacy Network website](#) has information, factsheets and checklists that can help you to plan funerals, including family-led services.

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