

What do you want for your end of life care?



MY END OF LIFE CARE

Talking about what matters to me



It's normal not to want to talk about "it", that is "death or dying".

82% of Australians feel that talking about their death and dying wishes is important but when it comes down to it, most people don't actually bring themselves to have the conversation. In fact, almost half of us (43%), fall into the 'out of sight out of mind' way of thinking.

Why don't we want to talk about it?

While it's becoming more normal as we grow older to ponder our funeral plans or make a will so as to not burden loved ones, our approach to our end of life care is still very much taboo as a conversation topic.

Common reasons for this are:

- Not thinking it is necessary—because we're too healthy or too young
- Not knowing how to start the conversation
- Not wanting to upset loved ones by talking about death or dying
- Not understanding what's involved in palliative care versus end of life care and what steps you need to take to make a future plan.

Why talk about end of life care?

While talking about end of life care isn't easy, there are good reasons to start the conversation early:

- It helps empower you to take control about your end of life care and dying wishes ahead of time and in line with the things you value most
- It helps take the burden off loved ones trying to understand your desires and wishes.

Palliative Care is commonly mistaken as the medical care provided only when death or dying is imminent. Understandably, this misconception alienates many of us from having this important conversation much earlier in our lives.

What is palliative care?

Palliative care is about improving your quality of life when facing a life-limiting illness. It focuses on your individual needs and aims to prevent and relieve suffering by treating not only the physical, but also the emotional, social and spiritual symptoms.

Care may include:

- Relief of pain and other symptoms
- Resources such as medical equipment
- Assistance for families to come together to talk about sensitive issues
- Support for people to help meet cultural obligations
- Support for emotional, social and spiritual concerns
- Counselling and grief support.

What is end of life care?

End of life care is for people of any age and is about the palliative care services you and your family receive when you are facing your end of life.

It often involves many health professionals bringing together a range of skills to manage your illness. Wherever possible end of life care is provided where you and your family want care—at home, in hospital, in a hospice or a residential aged care facility.

Conversation starter.

So how do you talk about something nobody wants to talk about?

The ability to prompt discussions about end of life care will be easier for some of us. There are many factors at play—your mindset, values, beliefs, culture, health, family relationships and so on.

Some things to keep in mind:

- There is no right or wrong way to go about having a conversation—it's very personal to you, your family and friends
- The conversation doesn't have to be rushed—take time to first self reflect on what's important to you
- Conversations like this are likely to happen and be resolved over time—embrace suitable opportunities as they arise
- Resources and support services are available to help you make a start when you're ready.



Taking your wishes and turning them into a plan.

The next important step after having conversations with your family and health care professionals is to create a plan that documents your wishes. This is known as an **Advance Care Plan (ACP)** and is the process of planning your medical care in advance regardless of your age or health. It is particularly important if you have a chronic illness, a life-limiting illness, or are aged over 75 years.

It talks about your values, beliefs and preferences so your family and health care providers can guide decision making if you cannot make or communicate your decisions in the future.

An **Advance Care Directive (ACD)** is different from an Advance Care Plan—it records your preferences in a document that is recognised by common law or legislation. It is usually discussed with your doctor and ensures your decisions are informed by your health. An ACD ensures your treating doctor understands your wishes.

As part of your ACD you can choose someone you trust to make decisions on your behalf. This person is known as a substitute decision maker (SDM) and they can act as your voice, if you are no longer able to.

While end of life care planning can be overwhelming, having the conversation and documenting your wishes early will help to provide clarity and ease potential conflict with family and friends at a time when emotions run high.

For more information about having the conversation visit www.health.gov.au/palliativecare