



## 6. END OF LIFE

Many people may have thought about their dying wishes when preparing wills or chatting with others about funeral preferences and organ donation. These discussions take on greater significance, however when confronted with advanced cancer. At some time after your diagnosis, it may be necessary to clearly outline your wishes for future medical care and death.

# Advance care planning

An advance care directive, sometimes referred to as a living will, is a written legal document that outlines your specific wishes for future medical care. It is implemented only if you are unable to make your own decisions.

It may cover issues such as assisted nutrition, life-sustaining treatments and resuscitation, as well as nominate someone to make decisions for you when you are no longer able if you wish. This person is often referred to as your enduring guardian or durable power of attorney.

The more guidance you can provide them on your preferences, the more likely your family and health care providers will make decisions that respect your wishes.<sup>60</sup>



## FACT

Research shows that people who prepare advance care directives are more satisfied and more comfortable about making end-of-life decisions.<sup>59</sup>

## What may help

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### Update your plans

You can review your advance care directive whenever you wish. Make sure that the people who are caring for you are always up to date with any changes and keep these papers in a safe place. Give a copy to your own doctor, your enduring guardian (if you have appointed one), a family member or friend and also your solicitor if you wish.

### Do the paperwork

Legislation regarding advance care directives varies from state to state. NSW, Tasmania and Western Australia do not have specific laws, but directives may still be valid under common law. Information can be obtained from the Department of Health in your state or you can go to [Care Search](http://www.caresearch.com.au) website at [www.caresearch.com.au](http://www.caresearch.com.au)

## For more information

- Contact the [Advance Care Directives Association](http://www.advancecaredirectives.org.au) at [www.advancecaredirectives.org.au](http://www.advancecaredirectives.org.au)
- [Palliative Care Australia](http://www.palliativecare.org.au/) <http://www.palliativecare.org.au/>

- Palliative Care Victoria has A Guide to Decision Making in Health Care, available at [www.pallcarevic.asn.au](http://www.pallcarevic.asn.au)
- The Australian Government has a website for people over 50, which has a section on living wills. Go to [www.seniors.gov.au/internet/seniors/publishing.nsf/Content/Making+a+living+will](http://www.seniors.gov.au/internet/seniors/publishing.nsf/Content/Making+a+living+will)

## Other decisions

At some stage during your illness decisions not related to your health care may need to be made on your behalf. These decisions may have to do with finances, legal matters or lifestyle (eg. where you will live).

Again you can consider appointing the equivalent of a general power of attorney to oversee your legal and financial matters or separate powers of attorney to look after different matters. The roles and terminology can differ from state to state.



## Q&A

Q: Is it strange to want to plan your own funeral?

A: For many people whose illness is considered terminal, this is a comforting part of preparing to die. You can be as general or as detailed as you like – even down to the music, readings and epitaph. You can put your instructions in your will, write notes for your family or lodge a formal plan with a funeral company (often with advanced payment).

## What may help

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### Get expert advice

The Justice Department websites for each state often have good information on the different types of guardianship and powers of attorney. You can also try looking up the Public Trustee in each state or territory which can also help you make a will (see the following section).

You may feel more comfortable letting a solicitor handle it all for you. They should be able to talk you through the planning decisions and draw up the papers.

## Clear the obstacles

You will want your family and those looking after your affairs to strike as little red tape as possible. It may be wise, to transfer a joint bank account into your partner's name to stop the account being frozen if you die. Your accountant or solicitor, or even a palliative care social worker may talk this through with you.

## Making a will

A will is a legally binding document that details how you want your assets and belongings to be distributed after you die.

You don't have to make a will since the law provides guidelines for distributing the assets of people who die without a will, but it is highly recommended that you do to give yourself the peace of mind that comes with control over one's own life; especially if you are married, in a de facto relationship, have dependents or have significant assets.

## What may help

### Talk to an expert

While you are entitled to draft your own will, you may prefer to ask a solicitor to do it especially if your affairs are complex or if you have specific matters to be addressed. Shared assets, broken marriages and blended families can all complicate things and a will can be declared invalid for any number of reasons.

A solicitor will enable you to ensure everything is in order as well as act as the will executor, help you appoint a power of attorney and even store the will in a safe place.

### Go public

Another option is to use the Public Trustee in your state. This is the government body responsible for making wills, managing deceased estates and overseeing powers of attorney.

Most Public Trustees will help you draw up a will for a nominal fee, store and execute the will, and then claim a small percentage of the estate in the end. Search online for "public trustee" in your state or go to the local phone book.



## Do it yourself

If you decide to draft a will on your own make sure the document is clearly marked and dated as the latest version of your "last will and testament".

Will kits which provide a template, are available in various forms and price ranges. You can usually pick up a basic and reliable kit from a post office or newsagency.

tips

When drafting a will:

- Set out your wishes in plain English (don't try for legalese).
- Sign and date all pgs.
- Have two witnesses (not beneficiaries of the will) sign and date the document.

## Talk to a social worker

If you are concerned about making a will a social worker may help. Ask your health care team about how to find such support.

## For more information



- The Cancer Council publishes a free booklet called *You Never Know Who it Might Help: Your Guide to Wills and Bequests*. Phone the Helpline on **13 11 20**

## Organ donation



### FACT

One organ and tissue donor can make a difference to the lives of up to 10 people.

The heart, pancreas, liver, kidneys and lungs can all be transplanted, as can heart valves and tissue from the bone, skin and eyes.

A serious illness does not necessarily stop you from donating. Even if dying is not on your horizon, it is still worth documenting your wishes regarding organ donation and what you want to happen with your body.

## What may help

### Register your organs

Many people incorrectly assume that the “organ donor” note on their driver’s licence means their intentions have been formally registered.

In fact, to record your formal consent (or objection) to donating organs, you will need to sign on to the [Australian Organ Donor Register](#), through Medicare. You need to be over 18 and you can stipulate which organs or tissue you would be prepared to donate. Authorised medical staff can use this database to verify your wishes regarding donations.

Go to [www.medicareaustralia.gov.au/public/services/aodr/register.jsp](http://www.medicareaustralia.gov.au/public/services/aodr/register.jsp) to register online. Otherwise, phone **1800 777 203** or visit a Medicare office.

### Talk to your family

Even if you have formally registered your consent to donating organs you should discuss your decision with your family since they may have an option to override your decision in the end.



- Grieving family members may well be more sensitive than you expect about how your body is treated after death, so make sure they understand your feelings about organ donation.

## For more information

- Medicare oversees the [Australian Organ Donor Registry](#). Go to [www.medicareaustralia.gov.au/public/services/aodr](http://www.medicareaustralia.gov.au/public/services/aodr)
- The [Australian Red Cross Blood Service’s LifeGift Program](#) helps hospitals coordinate organ donations. Go to [www.organdonor.com.au](http://www.organdonor.com.au)
- You can see some of the research the [National Health and Medical Research Council](#) is looking at regarding the ethics of organ donation at [www.nhmrc.gov.au/health\\_ethics/health/index.htm](http://www.nhmrc.gov.au/health_ethics/health/index.htm)

## A desire to die

You may have heard about or even know people with advanced cancer who decide it would be best – for themselves and those close to them – if they sped up their death. Some people give up on living because they feel they are a burden on their family or that they have little support.<sup>43, 44, 45</sup>

This is not necessarily the same as refusing treatment because you, and possibly your doctor feel it is futile and painfully prolonging the inevitable.

A desire to actively hasten death can be a sign that some sort of help or support is needed. This may include relief of physical symptoms, counselling for depression or more emotional support. It is common for someone who says they want to die to change their mind later.<sup>44</sup>

The wish to die is a difficult matter for all concerned and needs to be handled sensitively by all those involved – including health professionals – and with your dignity in mind.



### FACT

It is illegal in every state of Australia to help in speeding up a person’s death (otherwise known as euthanasia or assisted suicide)

## What may help

### Talk to your Doctor

Many issues such as depression or simply the feeling that you can’t cope may lie behind a desire to die. Start by talking to your doctor, nurse or social worker who may then refer you to a more appropriate person for you to talk to.

### Talk to others

Talking to someone who is in a similar situation may help. The [Cancer Council \(13 11 20\)](#) can help you get in touch with appropriate support groups or individuals.

### Seek professional advice

While the desire to die is a highly personal matter, you need to consider the implications – legal and otherwise – for those around you. Find a friend with legal knowledge, or even a trusted lawyer, you can talk to.

## For more information

The [Cancer Council Victoria](#) has information on treatment decisions and voluntary euthanasia. Go to [www.cancervic.org.au/about-cancer/advanced-cancer/treatment.html](http://www.cancervic.org.au/about-cancer/advanced-cancer/treatment.html)





## 7. THE PEOPLE WHO CARE FOR YOU

Caregivers come in all shapes and sizes and for people with advanced cancer they are often the secret to an optimum quality of life.

Caregivers can be spouses, partners, grown children, other family members, friends or neighbours. They may care for you full-time or they may call in now and then to cook meals, do housework, pay some bills, sit with you or provide emotional support.

Adjusting to being a caregiver can take time and can be fraught with strong and often conflicting emotions. For some, caring for someone close to them makes them feel good about themselves. It allows them to appreciate life and makes them feel useful and needed.<sup>61, 62</sup> Care giving can also strengthen relationships.

On the other hand providing care can be time consuming and emotionally draining. Long-term carers may also find that their employment, social activities and overall physical and emotional wellbeing suffer.<sup>58, 63, 64, 65</sup>

Identifying carers' needs is the first step in helping them overcome issues that may be causing much distress and anxiety. The Needs Assessment Tool (Patients & Families) included on pg 116 may help a caregiver identify the areas they may require additional help with. Please pass it on to anybody you think may benefit from it.