

## DWDV Form 3b

# How to fill in an Advance Care Directive

### Your Rights

Remember that if you have decision-making capacity, you have the right - at any time - to refuse medical treatment that you don't want. Medical treatment includes:

- physical or surgical therapy
- treatment with
  - prescription medicines
  - an approved medical cannabis product
- palliative care
- dental treatment
- treatment for mental illness.

However, if, sometime in the future, you don't have decision-making capacity - whether through illness, or accident - it's important you consider how you would want to be treated. Completing an Advance Care Directive form ensures your decisions will be known and respected.

### Advance Care Directive form

There are five parts to this Advance Care Directive form:

- Section 1: your personal details
- Section 2: the Instructional Directive
- Section 3: the Values Directive
- Section 4: your Medical Treatment Decision Makers
- Section 5: the Witnessing section.

You can choose to complete the Instructional Directive only or the Values Directive only, or both. To be legally effective, the Witnessing section *must* be completed.

Who is involved?

To be legally binding, at least three people must be involved in filling out the Instructional Directive section of this form: you, your doctor and another adult witness. All three must sign the document at the same time.

You should also make sure Medical Treatment Decision Maker(s) are aware of the decisions you record in this form.

## Section 1: Personal Details

If you are currently in good health, say so! However, if you have been diagnosed with a medical condition, check with your medical practitioner and describe it in the space provided. If your health remains good, it's enough to review this form and re-affirm your decisions every few years. However, if your health changes significantly, you should review your decisions and if you want to make changes, fill in another one.

## Section 2: Instructional Directive

The Instructional Directive is **legally binding** on the health practitioners treating you if at some stage you are not able to make decisions about your preferred medical treatment yourself (decision-making capacity). You should consult with your medical practitioner if you choose to complete this part of the form.

Firstly, you should consider *when* you want your instructions to apply. The choices you make on page 2 relate to the decisions you make about possible treatments listed on page 3.

Consider this: if you suffer only a *temporary* loss of decision-making capacity, or are suffering something more severe but your treating medical practitioners are of the opinion you will recover well, you may want your page 3 decisions not to apply. In that case, tick "Agree" (ie, you agree that the Instructional Directive should *not* apply under these circumstances). On the other hand, you may decide that your page 3 decisions should apply 'no matter what'. In that case, tick "Disagree".

Page 3 is the most important part of this Directive. It lists treatments that could be used to prolong or sustain your life. Together with your medical practitioner, consider each of these carefully and decide whether you want to tick the "I refuse" column or the "I accept" column. Remember these decisions are legally binding if you don't have decision-making capacity.

### Dementia

If you are diagnosed with dementia, you will most likely lose decision-making capacity, depending on the severity of the dementia at the time. It's important therefore to complete this section in case you develop this condition at some stage in the future.

Firstly, decide whether you would want your decisions in this section to apply no matter where you are being cared for, or, only if you have been admitted to institutional care.

Second, consider whether you would want your decisions to apply if, despite having dementia, you appear to be content. You may want to discuss this with your chosen Medical Treatment Decision Maker(s), as their assessment will be important.

As dementia progresses, there can come a time when a person loses interest in eating and drinking. The final decision to record is whether, if you get to that stage, you would want to refuse or to accept spoon feeding. Again, discuss this with your Medical Treatment Decision Maker.

### Section 3: Values Directive

The Values Directive is not legally binding, but provides your health practitioners with a guide about what's important to you and what sort of decisions you would want them to make when treating you.

To get going, try filling out the survey on the MyValues website ([www.myvalues.org.au](http://www.myvalues.org.au)). This survey produces a report that can be printed off and also uploaded onto your My Health Record. Then come back to fill out this section.

#### a) What matters most in my life (what does living well mean to you?)

What creates purpose and meaning to your life, the absence of which may mean life would be of much less value to you?

This may include family and relationships, personal challenge and making a contribution to society, personal peace or religious faith. If you are near end-of-life and believe your life has been a good one but you have no wish to extend it through further medical interventions, especially if these are burdensome or futile, say so.

Describe what gives you pleasure day-to-day, such as: reading, conversation, music, walking, gardening, exercise, contributing to children's or grandchildren's development, cooking, friendships, pets, clubs, personal autonomy, independence.

#### b) What worries me most about my future

The human body can change in unexpected ways, sometimes with unexpected speed. It can react well or badly to treatments. In many cases, doctors can make a fair estimate of your likely health in the foreseeable future: deterioration of breathing capacity, for example, the ability to walk, your likely response to medication. They are also reasonably good at predicting when death is imminent (within a few days or a week).

However doctors' predictions can sometimes be wrong by a wide margin. You may begin to deteriorate suddenly and unexpectedly, or your condition may continue in its current state, perhaps even with some improvement, for a long time -- months or even years.

Think of the five senses: sight, hearing, touch, taste and smell. Would losing your sight or hearing be a distressing blow or do you think you'd be able to adjust and cope?

What about other capacities? How would you feel if you lost the ability to feed yourself, to toilet or change a colostomy bag yourself, to keep a home and cook for yourself, to move around your home (unaided? With a walker?) What about if you lost intellectual capacity: the ability to understand the world around you, to engage in meaningful conversation, to recognise and remember your nearest and dearest. Does the thought of losing a particular capacity seriously affect your opinion of the value of continuing medical treatment or an attempt to extend your life?

People can find themselves able to adjust to new circumstances. For example, a hiker with cancer initially decided he would prefer to die rather than no longer be able to go hiking with his friends. When that became his reality, his perspective adjusted to preferring to die if he could no longer move around his country home and bask in the glow of a log fire. Later when that became his reality, his perspective adjusted to preferring to die if he could no longer move easily between his bed and his bathroom. Finally that became his reality and he then decided to refuse all medical treatment and receive maximum palliation, which had the consequence of shortening his life.

### c) Unacceptable outcomes of medical treatment after illness or injury

A doctor may assess that you have an 80% probability of dying in around three months; or that you have a 50% chance of making a reasonable recovery from illness or accident; or that you have a 30% chance of surviving but with significant brain damage.

In this section, describe your attitude to these kinds of probabilities. How important is certainty of recovery for you to endure aggressive (or any) medical treatment or rehabilitation? Would you prefer only 'comfort care' until death? Put another way, for you to refuse medical treatment, how certain would you want to be about a poor prognosis?

Faced with 'chancy' or burdensome treatments, would you be comfortable with the determination of your own treating doctor, who you might have been seeing for a long time, or would you prefer multiple specialist opinions? If medical opinions differ, would you lean more towards your own doctor's opinion, towards an independent specialist's opinion, or would you want to have multiple opinions agree? If you simply want your Medical Treatment Decision Maker(s) decide as best they can in the circumstances and you trust their judgement, say this.

Describe your attitude towards:

- Resuscitation: none at all; moderate measures; or anything and everything?
- Life support (artificial feeding and hydration via tubes to the stomach; artificial ventilation; dialysis; potentially life-saving surgery): refuse altogether; continue if there is prospect of improvement; continue regardless of any changes?
- Trial treatments: would you agree to participate in medical trials of new drugs, even if the effectiveness is unknown and might be burdensome?

#### d) Other things I would like known

When transitioning to palliative care, it's important your Medical Treatment Decision Maker(s) know your attitude towards the use of morphine to treat pain and suffering, and would act on your wishes.

In this section, say whether you would accept higher levels of morphine that would keep you unconscious and unaware of your pain ('terminal sedation') or whether you would prefer lighter levels of morphine ('light sedation') that would involve pain or suffering but might allow for some conscious interaction with loved ones. If there is a chance, even with significant suffering, would you want one final short period of lighter sedation so you might have a chance to wake up and say your goodbyes, or would you just prefer to remain unconscious? You should be aware that higher levels of morphine may result in accelerating your death by depressing your breathing.

If you want your loved ones to recall you as a coherent and competent person, you may want your Medical Treatment Decision Maker(s) to make decisions that partly result in shortening your life so that you don't have a prolonged period of incoherence and incompetence. On the other hand, you may prefer your family to experience your final chapter as just letting nature take its course, regardless of your condition leading up to death.

#### e) Other people I would want involved in discussions about my care

When you are facing end-of-life, those close to you may have their own views about what treatment is appropriate for you. But their wishes do not override your own decisions as recorded in your Advance Care Directive, and your Medical Treatment Decision Maker is obliged to act on your wishes, even if they differ from the wishes of the people close to you. However, you may want these people to be consulted.

In this section, list the people you would like your Medical Treatment Decision Maker(s) to speak with, if possible. This may include close personal friends or partners (even those your family may not approve of), community elders, or ethical or religious support persons. If there are persons you do *not* want consulted and do *not* want to attend your bedside, mention them too.

While a degree of heightened emotion can be natural at these times and some conflict might arise, the clearer you make your preferences in your Advance Care Directive, the easier it will be for your Medical Treatment Decision Maker(s) to have respectful and reasoned discussions with those consulted.

#### f) If I am nearing death the following things would be important to me

If you are nearing end-of-life, are there some things you would treasure seeing before you go? A new grandchild born, a nephew graduate, a cousin married, your diamond wedding anniversary, for example? If you have no such specific goals, simply write 'None'.

Think about who and what you would like around you when you die: music playing, photos of loved ones, your pet? Imagine the scene and describe it as best you can.

NOTE: While voluntary assisted dying (VAD) is now legal in Victoria, it is only available to persons who have decision-making capacity (and are otherwise eligible). You cannot include an instruction for VAD in your Advance Care Directive.

## Organ Donation

Record whether you agree to donate your organs in the event of your death.

## Section 4: Medical Treatment Decision Makers

In this section, list the people you have appointed to be your Medical Treatment Decision Maker(s).

Note that actually appointing these people must be done via another separate form: the *Appointment of Medical Treatment Decision Maker*. If you have already appointed an Enduring Power of Attorney (Medical Treatment), this person or persons are considered to be your Medical Treatment Decision Maker(s).

## Section 5: Witnessing

It's important to complete this section correctly for the Advance Care Directive to have legal force.

**Before you sign**, have two adults there with you as witnesses to your signature. The first must be a registered medical practitioner and the second must be another adult.

## What to Do With your Advance Care Directive

Makes copies of your signed form and give to:

- your Medical Treatment Decision Makers
- your family members
- your regular doctor and any other doctor who is treating you for a serious illness
- if you are entering a hospital or hospice, or an aged care facility, ensure a copy is placed on your medical file.
- also upload your signed Advance Care Directive to your My Health Record: [www.myhealthrecord.gov.au](http://www.myhealthrecord.gov.au)

## Periodic Review

If you are relatively young and in reasonably good health, review the form every two or three years and if nothing has changed, sign and date in the space provided.

As you get older and particularly if you are diagnosed with a serious illness, review your form more regularly. If your instructions *change*, you must complete a new form and have it again properly witnessed.

## Frequently Asked Questions

**Q: Can I amend parts of my Advance Care Directive without completing a new one?**

No, you cannot amend or add to your Values Directive or Instructional Directive - you must complete a new Advance Care Directive. You can change your contact details, or details of your listed Medical Treatment Decision Maker/s.

**Q: Can Voluntary Assisted Dying be requested in my Advance Care Directive?**

No, you cannot.

**Q: How does a medical practitioner doctor know I have an Advance Care Directive?**

Your medical practitioner must make reasonable efforts to find out if you have completed an Advance Care Directive. Make multiple copies of your signed Advance Care Directive form and give a copy to all treating doctors and hospital admissions staff. You can also upload your signed Advance Care Directive to your My Health Record: [www.myhealthrecord.gov.au](http://www.myhealthrecord.gov.au). You can also fill out and print off copies of the MyValues survey: [www.myvalues.org.au](http://www.myvalues.org.au). This can also be uploaded onto your My Health Record.

**Q: What if I have an existing Advance Care Directive completed prior 12 March 2018?**

An Advance Care Directive completed prior to 12 March 2018 will be recognised as a Values Directive only. It will be taken into consideration by your Medical Treatment Decision Maker, but is not legally binding.

**Q: What if I have an existing Refusal of Treatment Certificate?**

Any Refusal of Medical Treatment Certificate in place on 12 March 2018 is still legal and valid.

**Q: Where can I find more information?**

- Read more about Advance Care Planning on the Department of Health and Human Services website: [www.betterhealth.vic.gov.au/havetheconversation](http://www.betterhealth.vic.gov.au/havetheconversation)
- Or the Office of the Public Advocate website: [www.publicadvocate.vic.gov.au](http://www.publicadvocate.vic.gov.au)