

Advance Care Directive Direction in relation to Dementia

This Direction is made by:

Full name: _____

Address: _____

DOB: _____

This Direction is made to provide specific direction for my family, my medical team and my relatives to assist and inform them when making difficult decisions on my behalf.

This Direction is an attachment to my Advance Care Directive. For example, Section 3 (a), (b) or (d).

I understand that my Advance Care Directive comes into operation when I lose decision making capacity in relation to my health care. When my Advance Care Directive comes into operation I wish my Substitute Decision Maker nominated in my Advance Care Directive, and my medical team, to follow this Directive.

I have recently been diagnosed with dementia. I understand the consequences of the diagnosis are progressive loss of thinking abilities and physical skills until I die. I do not wish to live for the natural duration of this disease.

While I have mental competency to do so

1. I hereby request voluntary assisted dying when that becomes a legal choice through an Advance Care Directive.
OR
2. In the absence of the legal choice of voluntary assisted dying, when at least (specify number) of the following conditions are observed on a recurring basis by personal carers, family, and medical staff, I direct that I have no further medical treatments and no assistance with feeding or hydration.

(Tick any or all that apply to your Direction.)

- I am no longer able to recognise my closest family/friends
- I have become bowel and/or bladder incontinent
- I cannot maintain personal physical cleanliness on my own
- I am unable to dress myself without assistance
- I am unable to feed myself and require spoon feeding or artificial feeding
- I have become wheelchair-bound or bed-ridden and unsafe if I stand up
- I am unable to communicate my emotions to loved ones/carers
- I become angry, aggressive and/or fearful for no rational reason
- I behave in embarrassing or degrading ways alien to my competent personality, such as shouting, threatening or exhibiting other unacceptable behaviours.

(together called the **Relevant Conditions**).

**Advance Care Directive
Dementia Attachment**

To confirm:

If it is not possible to request assistance to die through an Advance Care Directive, when at least
(specify number) of the Relevant Conditions are observed by personal carers, family and medical
staff:

1. I wish to have no further medical treatments; and
2. If I am no longer able to feed myself I do not wish to be fed by spoon, through a nasogastric tube or a gastrostomy tube. I wish to be kept comfortable, with high level palliative care and careful management of symptoms such as a dry mouth and eyes.

My wishes should I appear to be content or happy at the time the conditions for this Direction are met:

My doctor has advised me that some people with dementia appear not to be unhappy in the later stages of the disease and might appear to be perfectly happy, even if, for example, they become incontinent and require high levels of care.

I understand that this might be the case for me when the conditions for this Direction are met. If I appear content or happy when that time comes:

(Tick one option and cross out the other)

- I wish the implementation of this Direction to be deferred, and carried out when it is considered I have undergone a relevant deterioration in my mood;
OR
 I wish, regardless of my outward appearance, to proceed with this Direction.

My wishes should I show resistance to this Direction at the time the conditions for this request are met:

My doctor has advised me that some people resist the medical, nursing and personal care which may be necessary to achieve assisted dying (if a legal choice) or my Direction not to be spoon fed or have nutrition delivered by any other means. For example, I may reject attempts to sedate me, inject life-ending medication, or alleviate other end of life symptoms. I understand that I might display resistance which may cause my doctor or my Substitute Decision Maker to believe that I have changed my mind about assisted dying or refusing nutrition or hydration, and no longer agree to it. In this case:

(Tick one option and cross out the other)

- I wish the implementation of this Direction to be deferred, and reviewed when it is considered I have become suitably accepting of the intended care or treatment;
OR
 I wish to proceed with the care or treatment as described in this Direction, with prior sedation as necessary.

Signed by me _____ Date _____

My full name _____

Witnesses

Medical Witness

Statement by witness:

I hereby certify that the above person _____
has decision making capacity and understands the meaning and implications of this **Direction**.

Signed _____ Date _____

Full name _____

Trusted third party: person known to the person making the Direction, for example, the Substitute Decision Maker.

Statement by witness:

I certify that the above person _____
appeared to freely and voluntarily sign this **Direction**.

Person making Direction:

Full name _____

Signed _____ Date _____

Full name of witness _____

Signed _____ Date _____

Independent Witness: person not knowingly being a beneficiary of the person's will and having no other pecuniary interests in their death.

Statement by witness:

I certify that (full name of person making Direction)

appeared to freely and voluntarily sign this **Direction**.

Full name of person making Direction _____

Signed _____ Date _____

Full name of independent witness _____

Signed _____ Date _____

Dementia and Voluntary Assisted Dying (VAD)

At present VAD is not an end of life choice for a person diagnosed with dementia in Australia.

There are two reasons:

Decision making capacity: A person must request VAD themselves and have decision making capacity at every stage of the VAD process, including when the VAD substance is delivered by the pharmacists.

Prognosis: To be assessed as eligible for VAD, a person requires two doctors to confirm a prognosis of six months, or 12 months for a neurological condition, such as dementia.

The combination of these two provisions in the VAD legislation means that by the time a person living with dementia has been assessed as having less than 12 months to live, they will have usually lost decision making capacity.

Advance Care Directive insert on dementia and loss of capacity

VAD laws in Australia do not allow advance requests for assisted dying.

You must have decision making capacity to request VAD.

Your ACD only comes into operation after you lose capacity.

No-one - including your substitute decision maker or responsible person - can request VAD on your behalf.

The purpose of this ACD insert on dementia is to provide guidance on thinking through your wishes if you lose capacity for a range of reasons, including if you have dementia. There are two ways you can include your directions in relation to dementia: attach the whole document, making reference to the attachment in the body of your ACD; or copy specific sections into your ACD.

If you have already prepared an ACD, and you now wish to include the wording in this dementia insert, you will need to prepare a new ACD. You cannot add additional directions to an ACD that was signed and witnessed previously. Similar to your ACD, each page of the Dementia Insert must be signed and dated by you and your ACD witness.

To attach the Dementia Insert in whole, please refer to the attachment in the body of your ACD, such as in Section 3 (a), (b) or (d).

For more information on VAD and Dementia, visit [vadsa.org.au/resources/dementia and VAD](http://vadsa.org.au/resources/dementia%20and%20VAD)