

Advance care planning and dementia

Making a decision for someone

Advance care planning is about planning for future health and personal care. It gives a person the opportunity to plan for what they want, if they were unable to say it for themselves. This factsheet is about advance care planning and dementia.

When you need to make a decision for someone ...

If you have to make a decision for another person:

- try to see the choices from the perspective they would have had, and
- try to make the decision the person would have made if they were able to.

It means 'standing in the person's shoes'.

Work out if the person is able to make the decision

It is important to consider if the person could make their own decision if they had support. Health professionals may be able to support the person to make the required decision. They can also help to assess how much of the decision the person can make for themselves, and how much you will need to do.

If the person cannot make the decision themselves, they may be able to provide some input. You may be able to get some information from them about their preferences.

Consider any written or spoken preferences of the person

The person may have written down their wishes. They may have written what they do, or do not, want in an Advance Care Plan or Advance Care Directive. It is important that these are followed when decisions are made.

Preferences may:

- be about specific medical treatments
- be more general, documenting the person's values and what is important to them
- include their goals for care, including their minimal acceptable outcome from treatment.

People often undertake advance care planning to assist family and others who may have to make decisions for them. They also want to ensure they receive care in line with their preferences.

Preferences may not have been written down. They may have been expressed through conversations. Speak with friends, family members or the person's GP. See if the person expressed anything relevant previously.

Consider what is important to the person

Consider the cultural, spiritual and religious beliefs of the person. These might influence what care is wanted.

If there are no written wishes, consider:

- how the person lived their life
- decisions they made in the past
- what things are important for them
- the likely outcomes and if the person would want these outcomes.

You should refuse health care that is likely to result in outcomes that the person wanted to avoid.

'Remember, you are trying to make the decision the person would have made. Not the decision you want. Nor the decision you would make for yourself in the same situation.'

Making a health decision

If you need to make a health decision for someone:

- ask questions and listen to the advice
- ask health practitioners about healthcare options and likely outcomes
- follow the person's written or spoken preferences, as far as possible
- make the decision that the person would make if they had the same information and advice that you have.

When there is more than one option the person would accept:

- choose the option that gives the most independence but still provides good care
- aim to maximise their health and wellbeing, as they would see it.

If you cannot work out what the person would have decided, make the decision that you believe is best for them.

‘Making decisions for someone else can be difficult and stressful. It may help to talk with a community nurse, hospital social worker, aged care staff or your GP.’

Making a decision about living arrangements

Living arrangements may depend on the availability of family and someone to provide care and assistance. The abilities and personal circumstances of those providing care should be considered. Most people would prefer to remain at home rather than entering residential care. However, they may also put a high value on their family and would not wish to cause ‘burn-out’. They may not want to impose an extended duty of care on those they love.

When making a decision about living arrangements:

- follow the person’s written or spoken preferences
- have a discussion with family members and others, especially anyone who will be helping to provide care
- consider costs linked to decisions
- speak to the financial decision-maker
- choose the option that gives the most independence but still provides care and maximises wellbeing.

For more information and assistance

- Your local doctor/GP
- Access information and documents for your state or territory at advancecareplanning.org.au
- Alternatively, call the National Dementia Helpline on 1800 100 500

Where can I get more information?

Advance Care Planning Australia:

advancecareplanning.org.au

National Advisory Service: 1300 208 582