Advance care planning and dementia

Why planning ahead can help if memory is becoming more difficult

Advance care planning is about your future health and personal care. It gives you the opportunity to plan for what you would want, if you were unable to say it yourself. This factsheet is about advance care planning and dementia.

Why do people have memory difficulties?

Becoming a little forgetful is a normal part of ageing. This is nothing to worry about. However, if changes in memory interfere with normal activities, it could mean you have dementia. This is not a normal part of ageing. You should see your doctor.

Dementia affects the functioning of the brain and can affect more than memory. It is not a mental illness. There are many types of dementia and most of them are not inherited. If you do have dementia your doctor may prescribe medication. Medication may slow down the progress of dementia or reduce symptoms.

Living well with dementia

There are strategies you can use to help you remember important things. There are things you can do to manage other symptoms. It is also important to eat well. Get plenty of exercise. Stay involved in social activities. Another good thing to do is to plan ahead. This is because dementia can mean that over time you may not be able to make decisions. For example, you may not be able to decide where you will live or how you would like your money to be spent caring for you.

Benefits of planning ahead

Planning ahead involves thinking about, talking about and sometimes writing down what you want to happen in the future. Planning ahead makes it easier and less stressful for family members. It can help to ensure your preferences are known and followed. It allows you to choose who can make decisions for you.

Importance of discussions

Talk with your family and anyone else who may make decisions for you in the future, so they know what is important to you. Talk about:
- preferences for future care, lifestyle and health
- how you go about making decisions
- your concerns and hopes for the future.

This information can help guide them in the decisions they may need to make.

Documenting your preferences

You can complete documents that will make it easier for your family. It is best to complete any documents early as you need to be legally competent. Being competent means you are able to understand the document you are signing and the implications of it. The documents and the terms used vary in each Australian state and territory.

Money matters

With dementia the ability to understand numbers and manage money can become more difficult. Mistakes can be made or others may try to take advantage of you. There are a number of simple things you can do:

Nominate a person to manage your finances

Many people have this arrangement in place even when they are well, in case there is an accident. The legal document can:
- help family if they need to assist you in the future
- provide guidance in how decisions should be made
- limit what decisions can be made. For example, they can use money to pay bills and expenses but they can’t sell the house.
Organise your financial affairs

• Have joint accounts for banks and utilities, such as phone and electricity.
• Nominate someone to deal with Centrelink in relation to your pension.
• Review financial arrangements to ensure they are up-to-date and recognise future needs, e.g. superannuation, insurance, living arrangements.
• Review or make a Will, to set out how you want your belongings to be distributed.
• Keep important documents in one place and ensure family know where to find them.

Future care and living arrangements

Deciding where you will live as you get older depends on many things:

• The availability of a family member or someone able to provide care.
• The abilities and personal circumstances of the carer and their wishes.
• The financial resources available.

Talk with family members in advance about what you would like. This can help them to be prepared for the future.

Health and personal matters

If you are unable to make a decision in relation to your care or medical care, someone else will be asked to make those decisions. This person is called a ‘substitute decision-maker’.

Appointing a substitute decision-maker

There are laws in each state and territory setting out a priority order of decision-makers. If you have not appointed someone, these laws will determine who would be your substitute decision-maker. However, you can appoint a different person if you want to. This does not have to be a family member, it could be a close friend or neighbour. It is important to speak with them about what is important to you.

Advance Care Directives

Writing down your preferences gives them greater authority. These preferences can be written in an Advance Care Directive. Advance Care Directives are legally recognised. They can include information about your future care, lifestyle and healthcare preferences. Recording your preferences can help those who will be asked to make decisions. It will help them to discuss your preferences with doctors or with other family members if there is conflict.

‘The most important consideration is to have someone you trust.’

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