The Advance Project®

Resource for people living with dementia

Planning together

A guide to help you prepare for an advance care planning conversation about your wishes for future health and personal care

What is advance care planning?

There may come a time when you are unable to make decisions for yourself. Advance care planning is about having conversations and planning for your future health and personal care. This helps your family, close friends, and health care team know what is important to you.

Advance care planning can bring comfort and peace of mind to you, your family and your health care team who may have to make health care decisions for you if you are unable to make your own decisions in the future.

Who is this guide for?

This guide is for you if:

- You have been diagnosed with dementia and want to start to think about the care and support that you might want in the future.
- You don't have a formal diagnosis of dementia but want to think about and plan for your future health care.
- Someone in your family or a close friend has a diagnosis of dementia and you want to help them start to think about and plan for the future.

There is no age limit to completing this guide. You are never too young or too old to begin to talk about what is important to you.

What is this guide for?

- To help you think, talk about and record what is important to you now and in the future.
- To help you think and talk about who you may want to be making decisions about your health care on your behalf if you are unable to do so.
- To help you tell your family, close friends and health care team what you want.
- So you can have a say about the health and personal care you receive in the future if you are unable to make your own decisions.

Please note **this guide is not a formal legal document**. It is a communication aid to help you share what is important to you about your future care.

This guide may prompt you to consider writing down your wishes in a formal legal document called an Advance Care Directive. There are resources available about legally recording your decisions and how to appoint someone to make decisions for you. Further information about these resources is available on page **20** of this guide.

Why is advance care planning important for a person living with dementia?

- People living with dementia **can live well** with the right care and support in place around them.
- Everyone has a right to be involved in decisions about their care as much or as little as they want to.
- Many people living with dementia want to talk with their families and friends about their future care.
- As dementia progresses people living with dementia may be unable to make decisions for themselves.
- Many people living with dementia want to make sure that, if they can no longer make their own decisions, their family and friends know what they would want.
- People will only know what is important to you if you tell them.
- Although talking about the future and about dying can be hard, it can help family and friends feel more comfortable about any decisions they might have to make for you in the future.
- It can also help to think about these things **well ahead of time**, when it is not a crisis situation, in case you ever suddenly became unwell.
- Talking about what is important to you can help your family and friends feel more prepared and less stressed when making decisions for you if you unable to make your own decisions in the future.

When completing this guide, it is important to know that:

- This is **your guide** and the answers you write will be **unique to you**.
- You can never get a question wrong because this is about you, and there are no right or wrong answers.
- **You do not have to answer all of the questions.** You can skip questions altogether or return to them later if you do not want to answer them now.
- You can change your answers at any time.
- You may prefer to complete this guide on your own. If so, it is important to share your thoughts with the people who might be asked to make decisions for you, including your close family or friends and your doctor and nurse. You may like to show them your answers to the questions in this guide.
- You may like to have someone you trust help you to complete this guide. Working through this guide with this person may help them to understand what is important to you.
- There might not be space to write all your answers in this booklet. You might want to continue to record your wishes in a journal, or as a voice or video recording.
- Thinking about the future might make you upset, or angry. It is okay to feel these emotions. It may help you to talk to someone you trust about how you feel.

You may like to record your name and the date(s) you reviewed this guide below:

If anyone helped you to complete this guide, you may like to record their name and their relationship with you here:

1. What matters to me now

a) Who are the most important people in your life?

b) What brings you the greatest joy in life?

c) What brings you strength or makes you feel strong?

d) How do you like to spend your time?
Are there any routines or activities that are important to you?

e) You may have things you like to do that bring meaning to your life. Talking about this with your family or friends might help them to make decisions for you in the future. What makes your life fulfilling?

f) How would you like to be remembered?

g) Are there any cultural, religious or family traditions that are important to you?

2. The information I want to know about my future health

a) How much do you want to know about how dementia or other health conditions might affect your life in the future and the care and support options that are available? You may like to tick the box that best describes how you feel. You can also write your thoughts below.

☐ I don’t want to know
☐ I only want to know the necessary details
☐ I want to know all the details
☐ Other – please describe below

b) Do you have any questions, fears or concerns about your current or future health? If so, you might like to write them down here.

People often have fears or worries about the future. Sometimes it helps to talk about what is worrying you. If you are worried about your future, it may help to talk to your family, friends, doctor, nurse or other people in your health care team. There are resources available to support you and these are listed on page **20**.

3. How I want information about my health care to be shared with others

a) Are there people who you would like your health care team to keep updated about your health care? You may like to write their names and their relationships to you here.

b) Is there anyone you would *not* want to be informed about your health care?

4. Who could make medical decisions for me if I couldn't

As dementia progresses, many people lose the ability to make decisions for themselves. It is important to think about who you would want to make decisions for you.

a) **Have you already legally appointed someone to make medical decisions for you in case you couldn't?**

☐ **Yes.** The name(s) of this person or people and their relationship to me are:

If you have already legally appointed someone to make medical decisions for you, it is important that your health care team have a copy of this document.

☐ **No.** Do you have any thoughts about who you would like to make medical decisions for you in the future if you couldn't decide for yourself? You might like to write their names and relationship to you here:

b) **If there were differences of opinion between family members about how best to care for you in the future, how would you want this resolved?**

Depending on your situation, it may be important to legally appoint one or more people you trust to make medical decisions for you. More information about how to do this is available in the accompanying resource called **"Who will speak for you if you can't speak for yourself?"**

5. My preferred place of care

a) **Many people living with dementia need increasing amounts of care and support. If you needed care, where would you want to live if possible? You may like to tick the box that best describes how you feel. You can also write your thoughts below.**

☐ In my own home
☐ Residential care home
☐ Living with someone. If so, who? ______________________________
☐ Other – please specify here

b) **How important is where you live to you?**

☐ Not important
☐ Somewhat important
☐ Very important

c) **Is there anything else you would want your family or health care team to know about where you would like to be cared for?**

6. My past experience with serious illness

You may remember someone close to you who was very sick or dying. Or you may have previously experienced serious illness yourself. Think about what went well and what did not go well. Is there anything you would or would not want for yourself based on these experiences?

a) Things I would want if I was seriously unwell or dying:

b) Things I would *not* want if I was seriously unwell or dying:

7. My personal goals

Some people make a list of people they would like to spend time with and activities they would like to try before they die. Is there anything that you would wish for?

It may help to talk to people about your wishes and work together to see how you can make these things happen.

8. My preferences for care at the end of life

Some people may already know the care they want at the end of their life. You may not have started to think about it yet. That is okay.

People have different views about medical treatments if they became very sick. Some people would want all the available treatments to prolong their life as long as possible, even if there were significant side effects. Others would only want treatments to make them comfortable, even if this meant they may live for a shorter period. Others are somewhere in between.

a) **If you had to decide *now*, what would you want *if you were very sick?***
Tick the box along this line to show how you feel or you can tick ‘I am not sure’.

☐	☐	☐	☐	☐
Quality of life I want treatments that focus on comfort and quality of life		**Equally important**		**Length of life** I want treatments to prolong my life as long as possible

☐ **I am not sure**

If you have any other thoughts about medical treatments if you became very sick you may like to write them here:

There may come a time when others need to make some difficult decisions for you. These might be about the type of treatment you receive or when to stop all life-prolonging treatment and allow you to die naturally. Although having these conversations is not easy, talking about this with your family and friends and health care team will help them to make these difficult decisions.

b) Are there circumstances where you would want to stop (or not start) receiving treatments to prolong your life? If so, what are they?

For example, some people would want to stop receiving treatments to prolong their life if they were no longer able to live in their own home, use the toilet independently, or have a conversation with their family.

c) Are there treatments that you would definitely *not* want at any time in the future? If so, what treatments would you definitely *not* want?

d) If you were dying, where would you prefer to be cared for (if possible)?

☐ At home
☐ In a residential care home
☐ In hospital
☐ In a palliative care hospital
☐ Other ______________________________

If you have any other thoughts about where you would like to die, you can write your thoughts here.

e) Is there anything else you would want your family and health care team to know about how you would like to be cared for if you were very sick or dying?

For example, some people want to be surrounded by family and friends, others want privacy. Some people want their favourite music playing, others want peace and quiet. What would you want?

f) Are there any religious, spiritual or cultural beliefs that you would like your family and health care team to know about if you were very sick or dying?

g) Some people decide to donate their organs or body parts (tissues) when they die. What are your views on this?

☐ I want to donate my organs or body parts (if it were an option for me)
☐ I do not want to donate my organs or body parts
☐ I am not sure

You can also make your wishes known about this on the Australian Organ Donor Register. If you would like more information about organ and tissue donation, ask your doctor or visit donatelife.gov.au

9. How I would like to be cared for after I die

What would you want your health care team and family to know about how you want to be cared for after you die?

For example, you may want to be buried, or cremated. You may want to wear a favourite outfit, or have a photograph of your family with you. You may want your family to celebrate your life with a big party, or you may hate the idea of all that fuss. What would you want to happen after you die?

Whatever you choose, it would be helpful to let your close family or friend(s) know. There are many resources available to help you to make these decisions and we have listed a few in this guide on page **20.**

10. Other questions or things I would like to discuss with my doctor, nurse or close family or friend about my future care

What do I do next?

- Start or continue having conversations with your close family or friends and health professionals about your answers to the questions in this guide.
- Ask your doctor or nurse any questions you have about your future care.
- If you haven't already done so, think about appointing a substitute decision-maker for health care decisions.
    - See the accompanying resource **'Who will speak for you if you can't speak for yourself?'**, for things to consider when choosing a substitute decision-maker for health care decisions and how to do this. Also think about how much flexibility you would want them to have when making decisions for you.
- Consider writing down your preferences in an Advance Care Directive.
    - An Advance Care Directive is a legal document that formally records your preferences. It only goes into effect if you are unable to make decisions for yourself. Your doctor can provide you with further information about this and advice whether this would be suitable for you. If you do complete an Advance Care Directive, it needs to be shared with your health care team, preferred substitute decision-maker(s) and any family members you would want to have access to it. It is also important to review it from time to time if your preferences change and share any changes with the people who have a copy of your Advance Care Directive. You can also upload and update your Directive in My Health Record myhealthrecord.gov.au
- Consider seeing your solicitor to update your Will and appoint someone to make financial decisions for you if needed in the future.

For more information and support

About advance care planning

- **Advance Care Planning Australia** provides further advice and advance care planning documents for your state or territory from advancecareplanning.org.au There is a National Advance Care Planning advisory service available from Monday to Friday, 9.00 am to 5.00 pm. You can call them on **1300 208 582**.

About dementia

- **Dementia Australia** has a wealth of information and resources about dementia, including factsheets and videos. Dementia Australia operates The National Dementia Helpline for people living with dementia, their carers, families and friends. The helpline operates from Monday to Friday, 9.00 am to 5.00 pm. You can call them on **1800 100 500**. More information is available at dementia.org.au
- **Dementia Support Australia** is a partnership led by HammondCare. Dementia Support Australia has a helpline for people living with dementia, their carers, families and friends. The helpline operates 24 hours a day, 365 days of the year. You can call them on **1800 699 799**. More information is available at www.dementia.com.au

Care and support options

- **My Aged Care** is the Australian Government service that provides information about, and access to, care services. My Aged Care has a helpline that you can call to talk about your care needs. The helpline operates from Monday to Friday, 8.00 am to 8.00 pm, and Saturday from 10.00 am to 2.00 pm. You can call them on **1800 200 422**. More information is available at myagedcare.gov.au
- **Carer Gateway** is the Australian Government service that provides information about, and access to, services and supports for carers. Carer Gateway has a helpline where you can call to talk about your care needs. The helpline operates 8.00 am to 5.00 pm Monday to Friday. You can call them on **1800 422 737**. More information is available at: carergateway.gov.au

Emotional support

- **Lifeline** is a national charity providing all Australians experiencing a personal crisis with access to 24-hour crisis support. You can call them on **13 11 14**. More information is available at lifeline.org.au
- You can also contact your doctor or nurse.

If you are a close family or friend of a person living with dementia and would like to support them to complete this guide.

It is great that the person has you to talk to. We know that it can be hard to begin these conversations.

A great place to start might be completing this guide for yourself. Thinking about what is important to you and what you might want in the future may help you to think about how you would want someone to help you.

When you have completed your own guide, you might share it with the other person and say: *'I have just filled out a booklet that I found online. It made me think about the things that are important to me and how I would want to be cared for if I became unwell in the future. Maybe you could do it too, and we could compare our answers. I can help you if you like.'*

Don't worry if the person does not want to talk straight away. Talking about the future can be frightening. Some people will want to talk; others may need time to think about what they want to say.

It is important that you let the person know that you are there to listen to them when they feel ready to talk.

Talking about the future and about the death of someone you love can cause you to feel strong emotions. It is important that you take care of yourself too.

Talking to other family members or friends and your own doctor or healthcare team about your feelings and concerns can help.

We have included a list of people and organisations that can help you to begin these conversations. You will find the list on page **20** of this guide.

In addition to the resources on page **20**, some guidance about supporting a person living with dementia to make decisions is available here ("Supported decision-making helpsheet" by the Cognitive Decline Partnership Centre) .

Further advice and support for carers is available at carergateway.gov.au/help-advice/end-life-planning

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