



The Dementia Journey

Information and Workbook
for Planning Ahead



This Planning Template and Workbook is for people with dementia and their families. It has been developed by Palliative Care New South Wales in association with Alzheimer's Australia (NSW) and was funded by the Australian Department of Health and Ageing through their Local Palliative Care Grants Round 5.

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If you talk about what you want, you are
more likely to get what you want.

Start the conversation today

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Introduction

How to use this kit

Thank you for taking the time to work through the materials in this kit, which has been designed to help people with dementia as well as their families, carers and friends. It has information for people recently diagnosed with dementia and for families, carers and friends of someone with advanced dementia.

Much of the information in this kit can be quite challenging, but it might help you to improve the dementia journey.

This workbook is all about planning ahead. The introductory section gives you some information about Advance Care Planning, euthanasia, dementia and Palliative Care. Feel free to read this information in any order – when you need it.

The second part goes through some very important terms used in Advance Care Planning. You are strongly encouraged to read this before you start out on the actual plan.

The section on Medical Interventions has some very challenging information and it might be helpful to go through it with someone else. It's up to you of course.

The Advance Care Planning Workbook section has its own guide and it is recommended that you follow the steps outlined on page 17.

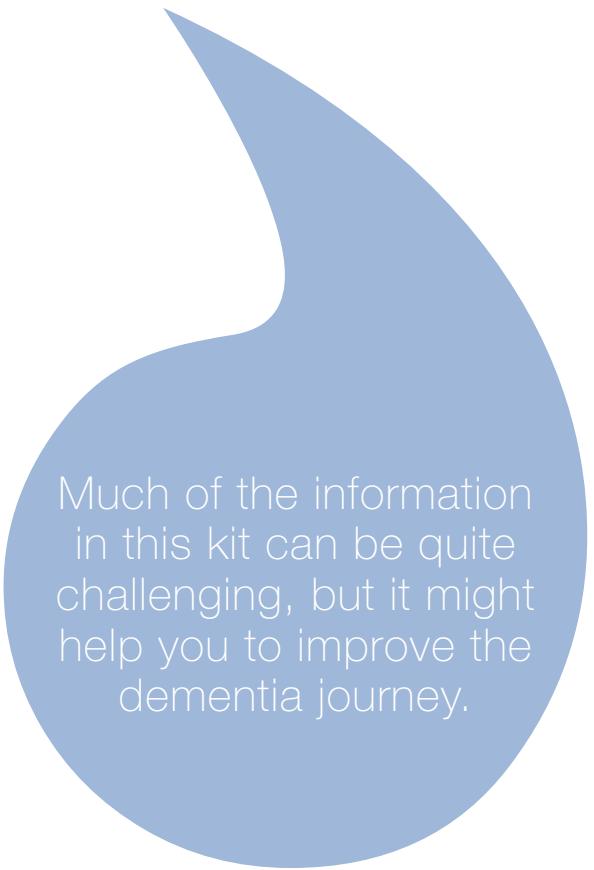
Included separately in the kit is a booklet called *Asking Questions about Dementia Can Help*. This book covers a range of questions that you as a person with recently diagnosed dementia or families, carers and friends of someone with advanced dementia, might want to ask the doctor. It's easy to forget which questions to ask, let alone the answers you've been given so feel free to scribble on it.

Some fact sheets are also included in the kit. These are separate from the main section because they cover specific issues and topics that you might not want to read about right now – but you will probably want to read about later.

More detailed information can be really helpful when you need to know about it and knowing that it's all here in the one place might give you some peace of mind.

Finally there is a DVD that has been produced by NSW Health. This is about planning for people with advanced dementia and is for families, carers and friends. You can play this DVD in your computer or on your DVD player at home.

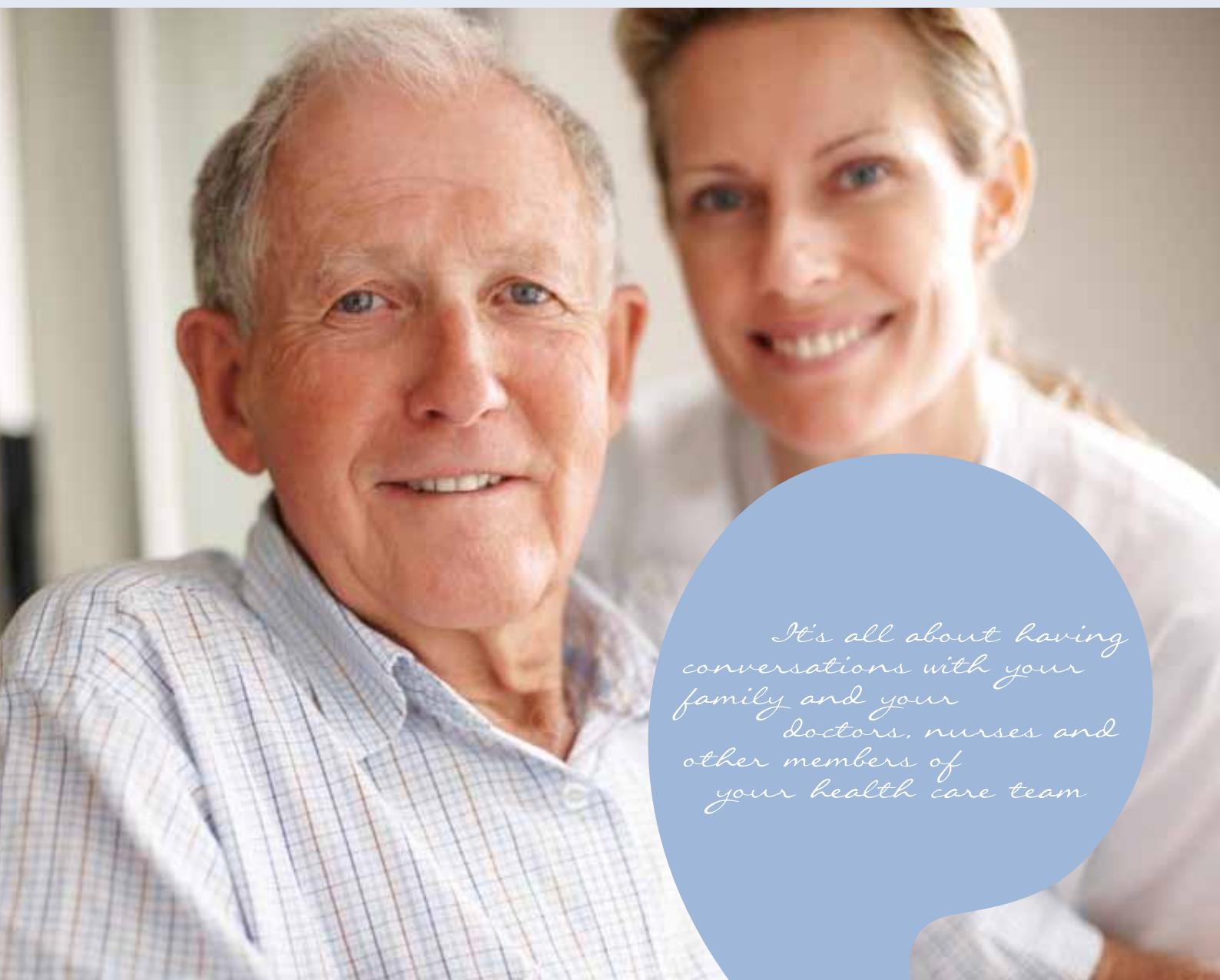
Most importantly of all, it's about starting the conversation with family, friends, carers, doctors, specialists and nursing homes. If you talk about what you want – you're more likely to get what you want.



Much of the information in this kit can be quite challenging, but it might help you to improve the dementia journey.

What if you are diagnosed with dementia, which affects your thinking and behaviour? In time, you will lose the ability to understand what is happening to you or to communicate what treatment you would want.

Do you know who is the best person to make medical decisions on your behalf? Do they know what you would want for your future health care?



What is Advance Care Planning?

Advance Care Planning means planning your care in advance of your condition worsening to the point where you are unable to make decisions for yourself. It is how you take control of your future health care decisions and may help you to feel more positive about the future.

The ability to decide what health care and health treatments we want is something we take for granted every day. However, there may come a time when illness makes us unable to make clear what we want from our health care providers. If you are diagnosed with dementia – that time will certainly come.

In NSW there are a number of things that can be done in advance of such a time, so that your wishes can be respected by health care workers and your family or carers.

There is a section with more information about Care Planning closer to the end of life, at the end of this workbook. There is also a DVD that has been produced by NSW Health called *Advance Care Planning: Making choices for someone with Advanced Dementia* and you will find a copy in the pocket at the back of this folder.

What is euthanasia

Let's get this out of the way from the beginning – Advance Care Planning is NOT about planning for euthanasia. Euthanasia is the active and deliberate intervention by a second party to end life, at the express wish of the first party. It is quite different from discontinuing or not starting treatment at a person's explicit request, given verbally or through an Advance Care Directive. Euthanasia is against the law in NSW.



Let's get this out of the way from the beginning – Advance Care Planning is not about planning for euthanasia.



There are a few fact sheets at the back of this workbook to give you more information about what to expect from Palliative Care services and other end of life issues.

What is dementia?

There are many types of dementia, but the most common are Alzheimer's disease and vascular dementia. There is a fact sheet at the back of this workbook that gives more information about the different types of dementia.

The onset of dementia is often very gradual but it does mean that a person's abilities will deteriorate, sometimes rapidly over a few months, in other cases more slowly over a number of years until 'advanced stage' dementia is reached.

Dementia is a terminal condition and there is currently no cure. The fact that dementia will result in death is not easy to come to terms with and can often be a surprise to learn. Dementia is

unpredictable and varies from person to person but generally speaking, people with Alzheimer's disease can live with it from 2 years to 20 years with about 8 years being the average time.¹

Whilst this information may not be easy to read, it may be helpful in planning ahead. There is a helpful fact sheet about severe and end stage dementia at the back of this workbook. It contains some challenging information so you may want to read it with a friend. In any case, take your time and read it when you are ready.

For more information you should talk to your GP or call Alzheimer's Australia (NSW) helpline on 1800 100 500 any time or go to www.alzheimers.org.au

What is Palliative Care?

In advanced dementia there are treatments and supports available that can help keep people comfortable and free of pain and discomfort. This is known as Palliative Care. Palliative Care can be provided at hospital, at home and/or in a Residential Aged Care Facility.

Some people think that Palliative Care is only for people with cancer. This is not true. Palliative Care is available for anyone with any life-limiting illness, including dementia.

Palliative Care can be provided at any stage as the dementia progresses, if it is needed. You can speak to the doctor about when a Palliative Care approach would be helpful and when a Palliative Care Team should be involved.

Palliative Care is not only 'for the very end', in fact it can be better to talk to the Palliative Care team as soon as possible.

The Palliative Care Team can provide advice on medical care including pain and symptom management. But it also provides specialised nursing care as well as spiritual or psychological support.

A social worker can provide counselling and support to both patients and their family. They can work as part of a specialist Palliative Care team or may work alongside other health professionals in providing care in the community setting. They are specialists in helping with grief and offer bereavement services.

In some larger hospitals there are physiotherapists, diversional therapists and other allied health services.

It's a team approach to end of life care!



Some important terms used in Advance Care Planning

Enduring Guardianship

An enduring guardian is a person, over the age of 18 who agrees to be appointed by you to make personal and lifestyle decisions and/or medical treatment and health care decisions on your behalf, only when you are no longer able to do so for yourself.

You may appoint more than one enduring guardian if you wish, and you may limit the functions of each one.

To appoint an enduring guardian you must do so in writing using an approved form. This is a legal document, and both you and your appointee need to sign the document in the presence of a NSW legal practitioner or a registrar of the local court. A fee may apply. In appointing an enduring guardian you need to help them to understand what your wishes, values and future care preferences are.

An Advance Care Directive is sometimes called a 'Living Will'.

Advance Care Directives

In NSW an Advance Care Directive (or ACD) is a written statement completed by you informing others of your health care preferences. There is no set format, although several examples are available. There is a form in this workbook that you can tear out and copy. Although there is no specific legislation for ACDs in NSW, the NSW Department of Health recognises ACDs as an extension of the individual's right, under common law, to decline medical treatment. The ACD acts as your voice when you are no longer able to express your health care preferences directly.

It is recommended that you discuss your thoughts about writing an ACD with an appropriate health professional who can assist you with understanding the health situations that may arise, and the possible treatment options available. It is also recommended that you date your ACD, that you review it regularly, at least every year, and that you make copies available for your treating doctor, enduring guardian (if appointed), and that you take a copy with you if you are admitted to hospital.

Capacity

The ability to make your own decisions is called 'capacity'. When you have the capacity you can make your own decisions about things that happen in your life. Generally when a person has capacity to make a decision they can:

- understand the facts and choices involved;
- weigh up the consequences; and
- communicate the decision.

Identifying your Substitute Decision Maker / 'Person Responsible'

If you are no longer able to make health care decisions for yourself, NSW law provides that such decisions fall to the next Person Responsible. This may not be the same as the 'next of kin'.

In order of appointment the Person Responsible will be:

1. A guardian or enduring guardian; or, if there is no guardian or enduring guardian;
2. The most recent spouse, de facto spouse or same sex partner with whom you have a close and continuing relationship; or, if there is no spouse, de facto spouse or same sex partner;
3. An unpaid carer who is now providing support to the patient or provided support before the patient entered residential care; or, if there is no carer;
4. A relative or friend who has a close personal relationship with the patient.

Please consider identifying your Person Responsible using this process, and discuss your health care wishes and preferences with them. They will then be able to speak for you in an informed way should the need arise. See page 26 of the Workbook to help you decide.



Planning ahead can be of great help to those who may one day need to make decisions on your behalf.

Enduring Power of Attorney and Wills

These are legal preparations you should consider that will ensure management of your financial affairs. They do not contribute to future health care decision-making.

An enduring power of attorney is a legal document that you can use to appoint a person to make decisions about your property or financial affairs while you are alive.

A will is a legal document that directs the distribution of your property and possessions upon your death.

It may be uncomfortable to consider ourselves affected by dementia to the extent that we would be unable to tell others what health care we wanted. Despite this, planning ahead can be of great help to those who may one day need to make decisions on your behalf.

Palliative Care NSW encourages you to have a conversation, about your health values and your care preferences, with your family, your health care provider and with your Person Responsible. Consider appointing an enduring guardian; consider writing an Advance Care Directive.

Above all else though, have a conversation with someone who can speak for you, should the need arise.





This section discusses medical interventions. It may not be easy to read, but it's very important to understand. If you need to talk to someone after reading this, please do so.

Medical interventions

As end of life approaches, carers, family and friends are often faced with some difficult and medically complex decisions at a very emotional time. It can be helpful to ask questions and seek professional advice about the most appropriate care and treatment at the time.

There are some situations where medical interventions might be suggested by medical staff but that may not be in the best interests of your relative or friend.

These interventions might include surgery, CPR, antibiotics, feeding tubs, blood transfusions, x-rays and scans. These procedures might cause distress and discomfort without significantly improving quality of life.

The reality of CPR for patients nearing the end of life²

Briefly, CPR (Cardio Pulmonary Resuscitation) is often expected by families to be used when someone's heart stops. It can be successful in younger healthy people but it is very rarely successful in frail older people.

CPR is used to restart the heart and lungs and can involve chest compression, electric shocks to the heart, injection of drugs into the bloodstream, fitting a mask to the face to provide oxygen and placement of a tube into the airway to help with breathing.

If it's been successful and the heart has been re-started, admission to intensive care usually follows with connection to a breathing and life support machine.

People who survive CPR may suffer fractured ribs, punctured lungs and ongoing brain damage.

Despite what you see on TV, survival rates range from 5–23%. For frail or older people, survival is less than 1%. Older patients who do survive CPR will often deteriorate further. They are likely to receive further intensive treatments that may be painful and intrusive.

For more information on the reality of CPR, please see the fact sheet that we've included in the back pocket of this kit.

Antibiotics

Infections are common in people with advanced dementia, especially pneumonia. In younger, otherwise healthy people the use of antibiotics to treat the infection is standard treatment.

In people with advanced dementia, however, studies have shown that even if the chances of survival are improved slightly, the person with dementia is less comfortable. The possible benefit of using antibiotics needs to be weighed up against any problems arising from their administration.

Feeding Tubes

When a person has swallowing problems from dementia it is sometimes suggested that a feeding tube be inserted into the stomach to give the person nourishment through the tube.

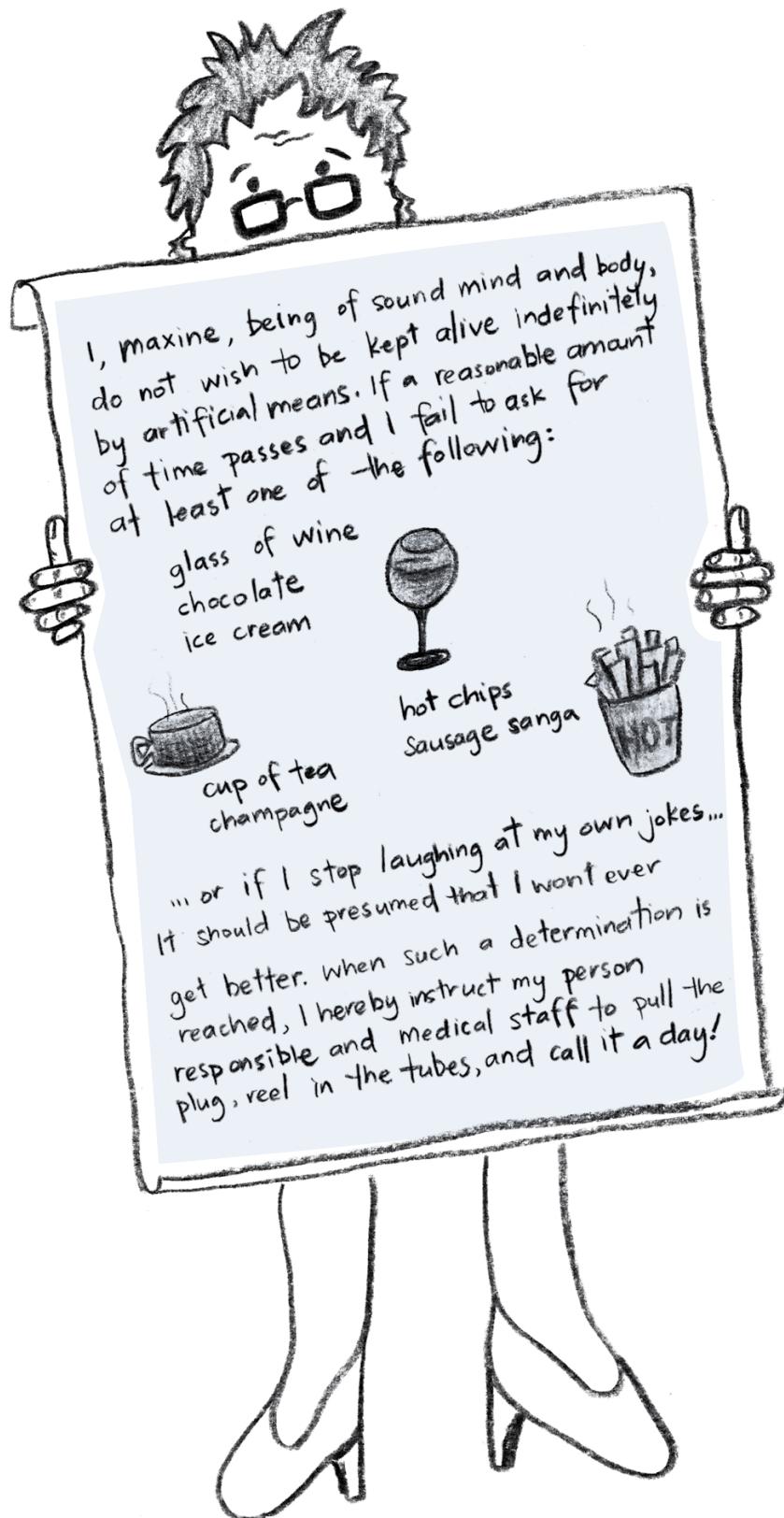
Recent expert opinion is that feeding tubes are not advisable for people with dementia. There is no evidence that they prolong life, prevent aspiration pneumonia, or improve the quality of life of the person with end stage dementia, which are the usual reasons for inserting them.

Transferring to Hospital

You may need to decide whether you wish to keep your relative at home/aged care facility or have them transferred to hospital.

It is increasingly recognised that, whenever possible, it is better for people with dementia to remain in their familiar environment rather than being transferred to hospital. An exception is when treatment at hospital will clearly improve the quality of life for the person.

Maxine's Advance Care Plan



I, maxine, being of sound mind and body, do not wish to be kept alive indefinitely by artificial means. If a reasonable amount of time passes and I fail to ask for at least one of the following:

glass of wine
chocolate
ice cream

cup of tea
champagne

wine glass
hot chips
Sausage sanga

... or if I stop laughing at my own jokes... It should be presumed that I won't ever get better. When such a determination is reached, I hereby instruct my person responsible and medical staff to pull the plug, reel in the tubes, and call it a day!

Instructions for completing this workbook and Advance Care Directive

1 Get the information you need to make informed decision

Make use of the *Asking Questions about Dementia Can Help* booklet at the back of this folder.

2 Think about your values and beliefs and what quality of life means to you

There are some questions soon that will help you to work this out.

3 Talk to your family and those closest to you

4 Decide who will be your Person Responsible

There are some questions in the Workbook to help you here.

5 Complete this Workbook

6 Complete your Advance Care Directive

You can use the form at the back of the Workbook or you can just write down your wishes in a letter.

7 Don't lock these documents away anywhere!

Give copies to your Enduring Guardian or Person Responsible, other members of your family and/or friends, tell your doctor or other health care provider and get them to keep a copy in your medical record.

8 Review your plan regularly

If you make any changes don't forget to replace all the copies you have left with people!

*Let's start planning! This planning guide and workbook
will help you to work out what is best for you.*

Get information

How much do you know about Dementia?

Ask Questions! Talk to your GP and your Geriatrician if you have one. If you don't understand what your doctor is telling you – ask questions. There is a booklet in this kit called *Asking Auestions About Dementia Can Help*. Use it whenever you need to – and scribble all over it! You can always get another one!

There is a lot of information in this kit about dementia – how it will affect you and what to expect.

In particular, there is also a lot of information about what to expect at the end stages of dementia. You and your family will need to know about this as time goes on. This information will help you to complete your Advance Care Planning. Your Advance Care Directive will only come into force when you are no longer able to make decisions for yourself.

Ask about specific treatments and ask about what is likely to happen to you. Take someone else with you when you visit the doctor so they can also listen and ask questions.

Doctors might assume that if you don't have any questions, you already know the answers!

Make a longer appointment with your GP so you can have a longer discussion, and take your 'Asking Questions About Dementia Can Help' booklet with you.

*Remember ... making a plan
can take a while, and may
seem overwhelming at first.*

When should I start Advance Care Planning?

With advanced dementia a person will not have the capacity to give consent so if you are caring for someone with advanced dementia, you might be required to make treatment choices for them. If you know exactly what the person with dementia wanted, you will feel more confident about the decisions that you make on their behalf.

So the time for Advance Care Planning is now. If you have recently been diagnosed with Dementia or someone in your family has, there is no time to lose! You should consider completing an Advance Care Directive before the capacity to make decisions is lost.

An Advance Care Directive will only be used when you are unable to make such decisions or are unable to communicate your preferences. If making an Advance Care Directive is too difficult at this time then the two most important things you can do are to appoint an Enduring Guardian, and to communicate your values and health care preferences to them.

What if I don't have a Plan?

If you haven't discussed your wishes or written down your preferences, your relative or carer might not be sure about what you would want.

If you don't have a plan, or if there is no suitable family member or friend to make decisions for you, someone may need to be appointed by the Guardianship Tribunal.

The Guardianship Tribunal is set up by the government to consider decisions affecting the lives and property of people who are no longer able to make decisions for themselves. If you do nothing to formalise your arrangements, it is possible that the Guardianship Tribunal will need to appoint people to make decisions on your behalf. This may or may not end up with a result that you would be happy with.

Now that we've convinced you to start planning, remember it can take a while and may seem overwhelming at first. It's important to start talking to your family, friends and health care providers sooner rather than later.

Beliefs and values

Your previous experiences shape who you are, what you believe and what you value. They can also influence the choices that you may make in the future. So it's important to take time to think about your values and beliefs, your current and future health issues and goals for the future knowing what you know about dementia and how it will impact on you.

You may prefer to work though the following section alone, or you may be more comfortable discussing things with another person. It's your choice.

It is probably not possible to think about all of the different types of health care decisions that may need to be made for you. The information you provide here will help others know what is important to you. Make sure your Person Responsible knows your values and beliefs about life and death. They can then use this information to make decisions that will respect your wishes.³

If there are any beliefs or values that you think will help your Person Responsible know what is important to you, please write them here.

For example: I would like to stay home as long as it is not too hard on my family or caregivers. Do everything possible to keep me alive until I can say goodbye to family who are coming to see me. It does not matter if I live until my next birthday.

So what do you think might make life unbearable for you?



What is most important to you about your physical or mental well-being?

For example: It is important for me to be able to communicate in some way, even if I cannot speak. I enjoy reading, writing and singing. It is important for me to be able to taste and touch.

Has anything happened in your past that may have influenced your feelings about health care?

For example: If someone close to you died how did that influence your thoughts ?

What makes each day meaningful for you?

For example: Life has meaning when I can communicate with my friends and loved ones, when I can enjoy nature and when I can practice my faith. I need to know I am making a difference to the well-being of others. Creative activities are important to my daily routine.

When you think about dying, what do you worry about?

For example: I worry that I will be in pain. I worry that I will be alone. I worry that my family will not know what to do. I worry that I will struggle to breathe.

When you are nearing death, are there things you would wish for?

For example: I would like music, prayer, religious or spiritual rituals/readings in my native language.

When you are nearing death and cannot speak or be understood, are there things you would like your family and friends to know?

For example: I love you. I forgive you. Please forgive me. Thank you.

When you are nearing death, are there things you would not wish for?

For example: I do not want music or flowers in my room.

A close-up photograph of a smiling couple. On the left, a woman with dark hair, wearing a light blue patterned blouse, looks towards the right. On the right, a man with grey hair, wearing a green polo shirt, looks towards the left. They are both smiling broadly. The background is a soft-focus green foliage.

This a lot to think
and talk about. Take
your time and give your
family and friends time
to think it over too.

Start talking

Talk to your family and those closest to you. A close or loving relationship doesn't always mean that the other person knows or understands your wishes for future medical care.

Talk with your health professionals. They can help you to make sure your plan is clear and complete. This will be especially helpful down the track if you enter a Residential Aged Care Facility and you have your plan in your hand ready to give to the admissions nurse.

Talk with your friends. For some people these discussions can be confronting or distressing. Take your time to explain that it is about your choices and they are important to you.

Have you thought about how you could start the discussions with the people who matter to you? What if they make excuses like 'You've got plenty of life left in you' or 'You're memory seems ok to me'.

What might you say or do to get them to listen? Just jot some ideas down here.

How can I start discussions?

Acknowledge that you understand that the subject may make them feel uncomfortable but that you need them to hear what you have to say because it is important to you.

Start by explaining that you have been diagnosed with dementia and that you need to plan ahead for the time when you are unable to communicate what medical care you would want.

Tell them you want them to know your choices, so that they won't have the added stresses of trying to guess.

Talk to them about what makes your life meaningful, and what would make it unbearable. You can show them your Advance Care Plan as a starting point for discussions.

Other ideas that might work for me:



A close or loving relationship doesn't always mean that the other person knows or understands your wishes for future medical care.

Choosing my Substitute Decision Maker / my 'Person Responsible'

In NSW, the Person Responsible is not necessarily your next of kin. This is very important to know. The first person who is legally called on as your Person Responsible is a guardian, including an Enduring Guardian.

Your guardian consents to medical, dental and health care treatments. If there is no guardian (and in most cases there is not), then the second person legally called on as your Person Responsible is your most recent spouse

or defacto spouse with whom you have a close, continuing relationship. This includes same sex partners.

If there is no spouse or defacto spouse the third person considered will be an unpaid carer who is now providing support or provided support before you may have entered residential care. In last place in order of those appointed Person Responsible is a relative or friend who has a close personal relationship with you.

If there is no guardian appointed, have you thought about who you would want to make decisions for you if you were unable to speak for yourself?

Have you talked this over with them? Are they happy to take on that role for you? Do they need support from other people?

If there is no guardian or recent spouse or defacto spouse, who else might be comfortable to do this for you?

Think about who you would like to make health decisions for you, if you were unable to make these decisions for yourself. Write their names below, and then tick whether they would be able to carry out the responsibilities listed (see over).

Person one: _____

Person two: _____

Person three: _____



In NSW, the Person Responsible is not necessarily your next of kin.

Responsibilities	Person one	Person two	Person three
Name:	_____	_____	_____
Would be willing to speak on my behalf.			
Would be able to act on my wishes and separate his/her own feelings from mine.			
Lives close by or could travel to be at my side if needed.			
Knows me well and understands what's important to me.			
Could handle the responsibility.			
Will talk with me now about sensitive issues and will listen to my wishes.			
Has read this workbook.			
Will be available in the future if needed.			
Would be able to handle conflicting opinions between family members, friends and/or medical personnel.			
Before making a treatment decision, would s/he ask what life would be like for me: - following treatment, and - if treatment was not accepted.			

If the person who you would prefer to be your substitute decision maker is not comfortable taking on that role it is important that you respect that decision.

My Advance Care Directive

Personal information

First Name: _____ Middle Name: _____

Surname: _____

Date of Birth: _____ Male Female

Address: _____

Telephone: Home () _____ Work _____

Mobile: _____

Date: _____

I have reviewed and updated this workbook on the dates below:

My Advance Care Directive

My Substitute Decision Maker

I have discussed my wishes for future health care with the person(s) named below and I would like this person(s) to be my representative if I cannot speak for myself:

Name: _____

Relationship: _____

Address: _____

Telephone: Home () _____ Work _____

Mobile: _____

Name: _____

Relationship: _____

Address: _____

Telephone: Home () _____ Work _____

Mobile: _____

My Advance Care Directive

My medical situation

Are there any special conditions other than your dementia that your doctors should know about, such as asthma or diabetes?

Do you have any religious beliefs or cultural affiliation that may affect your treatment choices?

Yes No

If yes, how does this affect your health care choices? Eg because of my religious beliefs, I do not want to receive any blood transfusions or organ transplants.

Organ and tissue donation

There is no right or wrong answer when deciding if you want to be an organ and/or tissue donor. This is a personal choice and should be based on your own beliefs and values. If you wish to be considered as an organ/tissue donor, please talk with your family and your Substitute Decision Maker/Person Responsible about your wishes.

My Advance Care Directive

Cardio Pulmonary Resuscitation (CPR) *Tick the box that matches your choice*

If my heart or breathing stops due to my dementia or other incurable health problem my choice would be:

- Please try to restart my heart or breathing (attempt CPR);
- Please allow me to die a natural death. Do not try to restart my heart or breathing (NO CPR); or
- I cannot answer this question. Please let my doctor decide.*

* Depending on your particular situation, the doctor will decide whether to commence CPR or not based on a clinical assessment and goals of care, whilst always taking your known wishes into consideration.

Other medical interventions

If I am no longer able to eat, I:

- Do not wish to be fed artificially
- Do wish to be fed artificially

Based on my workbook notes, I would prefer the following care:

- Palliative Care – Keep me warm, dry and pain free. Do not transfer to hospital unless absolutely necessary. Only give measures that enhance comfort or minimise pain (eg morphine for pain). Intravenous line started only if it improves comfort (eg. for dehydration). No x-rays, blood tests or antibiotics unless they are given to improve comfort.
- Limited Care (includes Palliative) – May or may not transfer to hospital. Intravenous therapy may be appropriate. Antibiotics should be used sparingly. A trial of appropriate drugs may be used. No invasive procedures (eg. surgery). Do not transfer to Intensive Care Unit.
- Surgical Care (includes Limited) – Transfer to acute care hospital (where patient may be evaluated). Emergency surgery if necessary. Do not admit to Intensive Care Unit. Do not ventilate (except during and after surgery ie. Tube down throat and connected with machine).
- Intensive Care (includes Surgical) – Transfer to acute care hospital without hesitation. Admit to Intensive Care Unit if necessary. Ventilate me if necessary. Insert central line (ie. main arteries for fluids when other veins collapse). Provide surgery, biopsies, all life support systems and transplant surgery. Do everything possible to maintain life.

Signed: _____ Date: _____

Witness Name: _____

Witness could be your Person Responsible

Witness Signature: _____ Date: _____

My other planning documents and appointments

Each of the documents listed below has a different purpose. An Advance Care Plan does not replace them. Write your initials in front of all documents you have. Draw a line through those you do not have.

I have legally appointed the following:

Enduring Guardian (health decisions) Yes No

Name: _____

Contact Number: _____

Enduring Power of Attorney (money / finance decisions) Yes No

Name: _____

Contact Number: _____

Power of Attorney (money / finance decisions) Yes No

Name: _____

Contact Number: _____

Copies of these legal documents are kept at:

Signed: _____ Date: _____

Witness Signature: _____ Date: _____

Review Date/s:

My other planning documents and appointments

Don't lock this information away

Once you've completed the workbook and written an Advance Care Plan the worse thing you can do is lock it away in a safe. You need to make copies and give them to a few people so everyone knows how to find them when the time comes.

Give copies to:

Your Substitute Decision Maker:

The person supporting the Substitute Decision Maker:

Other members of your family and/or friends:

Your doctor (and get them to include a copy in your medical records):

Review your plan

It's a good habit to review your plan regularly. In the case of dementia. Maybe every six months would be ok.

My review date: _____



*Advance care planning
is the process of
discussing and
choosing future
health care*

Frequently asked questions

How does an Advance Care Directive help?

It helps you to think about and talk to your family and doctor about your future medical care if you become seriously ill. A written guide gives family and doctors information that clarifies what you would have wanted in this situation. It helps families make hard decisions with the knowledge of what you have already told them.

How do I choose someone to make decisions for me?

This person should be someone you trust, who will listen carefully to your values and wishes for future care, and will follow those wishes. They should also be someone who will be comfortable making decisions in difficult situations.

Who can make decisions for me if I can't?

In NSW, there is a hierarchy that determines the person who is responsible for you (Guardianship Act 1987). A Person Responsible is not necessarily the patient's next of kin.

The Office of the Public Guardian booklet *Enduring Guardianship in New South Wales: Your Way to Plan Ahead* explains this process.

Do I need to see a lawyer to complete an Advance Care Directive?

No. The law does not require you to have a lawyer to complete your Advance Care Directive. If you appoint an Enduring Guardian, this process does require a legal officer to witness your signature on the appointment document. It may be of benefit to you to have your GP/ Specialist Doctor review and witness your Advance Care Directive so they can answer any questions you have about the benefits or burdens of medical treatment.

When is an Advance Care Directive used?

It will only be used if you are unable to make decisions or communicate on your own behalf, when it has been deemed that you no longer have capacity to make your own decisions.

What is capacity?

The ability to make your own decisions is called 'capacity'. When you have capacity you can make your own decisions about things that happen in your life. Generally when a person has capacity to make a decision they can;

- Understand the facts and choices involved
- Weigh up the consequences
- Communicate the decision

What happens in an emergency?

In an emergency, if there is no Advance Care Plan, life sustaining measures may be started. Following discussions with your decision maker/s and family, treatment can be stopped if it is clear that it is not what you would have wanted.

Can my Advance Care Directive be changed or revoked?

Yes. You can change your Directive at any time. If you change or revoke your Advance Care Directive, you need to inform your Person Responsible or enduring guardian that you have done so. If you have distributed copies of your Advance Care Directive to others, make sure that you let them know, and give them the up-to-date copy.

What is the difference between a 'Will' and a 'Living Will' or 'Advance Care Directive'?

A 'Living Will or 'Advance Care Directive' is only about your health care. It only comes into effect while you are still alive but unable to communicate. A 'Will' relates to your estate and property. It only comes into effect after your death.

Is my Advance Care Directive legal?

NSW currently has no legislation on Advance Care Directives or refusal of medical treatment. However under common law, any medical treatment can be refused by a competent adult at the time or in advance. Any written document about treatment preferences is strongly persuasive, both for medical practitioners and substitute decision makers. Such a document (an advance care directive) has the potential for legal effect if it is specific, current, and written by a competent person without undue influence from others.⁴

How is Advance Care Planning different from Euthanasia?

There are very significant differences between Advance Care Planning and euthanasia. Advance Care Planning is the process of discussing and choosing future health care and medical treatment options. The process of individuals making decisions about their own medical treatment is legally supported in Australia. Euthanasia is the practice of actively terminating life to hasten death. Euthanasia is illegal in Australia.

Resources and information for dementia and Advance Care Planning

Palliative Care NSW

Information about Palliative Care, End of Life Care and Advance Care Planning.

Ph: (02) 9206 2094

Fax: 02 9281 0157

Email: info@palliativecarensw.org.au
www.palliativecarensw.org.au

Advance Care Planning

Advance Care Directive Association

Ph: 0423 157 003

(leave message for order form only)
www.advancecaredirectives.org.au

Benevolent Society

Your Future Starts Now: A Guide for Over 50s'

Contains information about planning for the future, Wills, Powers of Attorney and Enduring Guardianship. Available to download online.

Ph: (02) 9339 8000

www.bensoc.org.au

Care Search

Information for carers, families and health care providers about Palliative Care. Advance Care Planning information and support available.

www.caresearch.com.au

Department of Veteran Affairs

Planning Ahead – A Guide to Putting Your Affairs in Order

Ph: 133 254 or 1800 555 254

VAN office: 1300 55 1918

www.dva.gov.au

Family and Community Services Department of Ageing, Disability & Home Care

Planning Ahead Kit

Information on Enduring Powers of Attorney and Enduring Guardianship. Available to download from the ADHC website or phone to request a copy.

Ph: (02) 8270 2000

TTY: 8270 2167

www.adhc.nsw.gov.au

Hard Choices for Loving People 5th Edition June 2009

CPR, Artificial Feeding, Comfort Care, and the Patient with a Life Threatening Illness, by Hank Dunn, Chaplain.

www.hardchoices.com

Hunter New England Health

Advance Care Planning

Phone for a copy of the DVD.

Ph: (02) 4924 6003

www.hnehealth.nsw.gov.au/acp

My Wishes Program

Contains information about Advance Care Planning.

[www.sswahs.nsw.gov.au/sswahs/
mywishes/default.html](http://www.sswahs.nsw.gov.au/sswahs/mywishes/default.html)

NSW Health

Using Advance Care Directives (NSW) & Guidelines for end-of life care and decision making.

Booklets available from Better Health Centre or can be downloaded from website.

[www.health.nsw.gov.au/policies/
gl/2005/GL2005_056.html](http://www.health.nsw.gov.au/policies/gl/2005/GL2005_056.html)

Planning What I Want

Advance Care Planning website, offering information, support and tools to assist you in planning for your health care future.

www.planningwhatiwant.com.au

Respecting Patient Choices – Advance Care Planning

A website that offers information and support for Advance Care Planning.

www.respectingpatientchoices.org.au

Dementia

Alzheimer's Australia (NSW)

Information about legal issues related to dementia, including the booklet Legal Planning and Dementia.

Ph: (02) 9805 0100

24 hour Dementia Helpline:
Freecall 1800 100 500

www.alzheimers.org.au

Legal

Department of Justice and Attorney General, Diversity Services Capacity Toolkit

Ph: (02) 8688 8460 or (02) 8688 7507

TTY: 02 8688 7733

www.lawlink.nsw.gov.au/diversityservices

End Game

When Someone Dies – The Funeral and Afterward.

This book may be downloaded free of charge.

www.lawconsumers.org

Guardianship Tribunal

How to appoint an enduring guardian, or an enduring power of attorney.

See their website under Publications > Plan for your Future.

Ph: 1800 463 928

TTY: 9552 8534

www.gt.nsw.gov.au

Land & Property Information Division (NSW Dept of Lands)

Information on how to register power of attorney and fees involved.

Ph: (02) 9228 6666

www.lands.nsw.gov.au

Office of Public Guardian

Enduring Guardianship: Your Way to Plan Ahead

Free booklet containing information on appointing an enduring guardian.

Ph: (02) 8688 2650

Freecall: 1800 451 510

TTY: 1800 882 889

www.lawlink.nsw.gov.au/opg

Public Trustee NSW

Ph: 1300 364 103

www.pt.nsw.gov.au

Ageing

Seniors Information Service

Provides confidential information on a wide range of issues. Referrals to appropriate services available if necessary.

Ph: 13 12 44

One more thing – think about clearing the skeletons out of the closet. Family secrets often come out when people die so it might be worth telling the family now.



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Advance Care Planning DVD

You will find a DVD included with this kit entitled *Making Choices for Someone with Advanced Dementia*.

NSW Health has developed this DVD for anyone who will be making health care decisions for someone with advanced dementia.

The DVD shows why it is important to plan ahead for medical decisions that might need to be made for the person with dementia as their time for natural dying approaches.

The Advance Care Planning workbook in this kit will help you to work through the steps to plan. Briefly they are:

1. Identify the Person Responsible
2. Talk to family and friends
3. Talk about your beliefs and values and your goals of care
4. Talk to the doctor about treatments
5. Write things down – thoughts, decisions, medications – it will help you down the track.

Thank you to NSW Health for allowing us to use this DVD in our kit.



Palliative Care NSW

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Fax (02) 9281 0157
Email info@palliativecarensw.org.au
Web www.palliativecarensw.org.au



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Corner Coxs & Norton Roads
North Ryde NSW 2113

Phone (02) 9805 0100
Email admin@alznsw.asn.au
Web www.alznsw.asn.au