

# Planning for the End of Life for People with Dementia



A report for  
Alzheimer's  
Australia

Paper 23 Part One  
by Professor Colleen Cartwright

March 2011



**Alzheimer's  
Australia**  
Living with dementia

**CONTENTS**

Preamble	5
From a Family Carer	6
Introduction	7
Glossary of terms	8
SECTION 1: A DIAGNOSIS OF DEMENTIA – WHAT DOES THIS MEAN?	9
What is dementia?	9
Taking advantage of an early diagnosis	9
SECTION 2: ADVANCE PLANNING FOR EXPECTED CHANGES	11
New diagnosis	11
Reactions of others	11
Setting up supports	11
Planning ahead	11
Legal issues	12
2.1 ADVANCE FINANCIAL PLANNING	12
Wills	12
Enduring Power of Attorney	13
Statutory Trusts	14
Family Agreements	14
2.2 ADVANCE CARE PLANNING	14
Advance Directive	14
Enduring Guardian	15
Person Responsible	18
2.3 CAPACITY	19
2.4 WHAT DOES THE LAW ALLOW?	20
Refusal of treatment	20
Refusal of food or fluids	20
Pain control	21
Refusal of antibiotics	21
Resuscitation	21
Terminal sedation	22
SECTION 3: PALLIATIVE CARE	23
What is palliative care?	23
Dementia patients’ need for palliative care	23

SECTION 4: CARERS	25
Moderate dementia	25
Advanced dementia	25
Deciding on residential care	26
Which residential facility?	26
Minimising admission to hospital	27
SECTION 5: FUNERAL ARRANGEMENTS	28
Brain donation	28
SECTION 6: BEREAVEMENT SUPPORT	29
CONCLUSION	30
Links and Resources	31
Support services	31
Helpful websites	31
Publications	32
Legislation for each state/territory	34
Contact details for Guardianship Tribunals and Public Advocates	35
Table 1: Terminology used in each state/territory for Advance Care Planning for health-related matters	37
Table 2: Summary of national law relating to Advance Care Planning June 2010	38
ALZHEIMER'S AUSTRALIA PUBLICATIONS	39

Disclaimer: The information in this publication is intended as a general guide only: it is not intended as a substitute for professional medical advice, diagnosis, or treatment. Neither is it intended as a substitute for professional legal advice about readers' own particular situations. Always seek professional medical and/or legal advice with any questions you may have regarding any medical condition or legal situation. Alzheimer's Australia expressly disclaims any liability caused to any person in respect of any action taken in reliance on the contents of this publication.

PREAMBLE

The role of Alzheimer's Australia as an advocacy organisation is to inform key debates on issues of importance to people living with dementia. Such an issue is planning for the end of life and promoting a better understanding of the rights and options that are available to people with dementia.

To properly inform this difficult issue, the Alzheimer's Australia National Consumer Advisory Committee set up a Sub-Group to work with Professor Colleen Cartwright with two objectives in mind.

First, to explain what the options are that people can exercise now in planning for the end of life, and to do so in a practical way that relates to issues such as preferred place to die, artificial nutrition and hydration and withdrawal of treatment. That is the purpose of this publication.

The second question is to ask "what additional options might help improve quality of life for people towards the end of their lives?" At the most basic level, it is important to be clear about what the different terms are that people use, including euthanasia. This will be the focus of a second publication to be issued later in the year.

We take the view that the debate on euthanasia is clouded in confusion, including about what the term means.

We are clear that the debate about end of life issues should not be a states' rights debate but a debate by people about the lives of the people themselves.

However, the second part of this publication will not attempt to tell people what choices they should make, but rather to explore the issues for and against more active approaches for termination of life. In doing so, we will attempt to focus on those questions that we think are most important to the community generally as well as people living with dementia.

We are deeply grateful to Professor Colleen Cartwright for undertaking this task and for working with the Alzheimer's Australia National Consumer Advisory Committee. This publication would not have been possible without the commitment and experience of Professor Cartwright in this difficult and complex area.

Lastly, Alzheimer's Australia owes a great debt to the members of the Ethics Subcommittee of the National Consumer Advisory Committee for their work on the publication and to our volunteer editor Jenny Laraman.

Glenn Rees

Glenn Rees  
CEO  
Alzheimer's Australia

## From a Family Carer

My husband John was diagnosed with dementia at age 54.

I am a nurse but soon realised that I knew very little about dementia. We participated in a **Living with Memory Loss** program through Alzheimer's Australia Vic and then were invited to a retreat for people with Younger Onset Dementia.

This was invaluable as it gave us information and taught us skills on how to manage with everyday problems. As John's illness progressed, I felt there was a lot of emphasis on the early and middle stages of dementia but little information on the later stage of dementia, especially dying.

I wanted answers to questions but there didn't seem to be anyone willing to confront some of these issues. John died when he was 62. Since then I have supported several friends as they have faced the death of their loved ones with dementia. The expectation is that everyone will be in an Aged Care Facility but that is not always the case and carers need information.

Colleen has put together a great resource to help people with dementia, carers and families, to know what to expect, how to prepare for the future and where to go for help. I know that this publication will be used widely to inform and guide people.

People diagnosed with dementia cannot exercise their rights if they do not understand what those rights are. And although the law in a federal system is complex it is important we all discuss and confront end-of-life issues to make our own choices as best we can and not leave it to family and friends or guardianship tribunals.

Every journey is different but if people read this publication, it may promote discussion about end-of-life issues which can only be beneficial.

**Lastly, I would like to thank Lucille Bloch, Ron Sinclair and Marianne Gevers who formed the Ethics Subcommittee and who took part in teleconferences with Professor Cartwright and commented on successive drafts of the publication.**

Elizabeth Fenwick  
Chairperson  
Ethics Subcommittee  
National Consumer Advisory Committee

## INTRODUCTION

**This booklet** provides people with dementia, and those close to them, with information about their rights regarding options and choices for care in the time leading up to the end of life. It also seeks to assist family members, friends and health care providers to understand what they can do to support the person and/or their carer to have their end-of-life care decisions respected.

**The booklet** considers what a diagnosis of dementia may mean for patients, their families and friends. It provides information to assist with understanding what legal mechanisms are available to put plans in place for a future time, including the time leading to the end of life, when the person with dementia will have lost capacity to make their own decisions. This can include:

- Advance Financial Planning
- Advance Care Planning
- Making Funeral Arrangements.

There is also a section which discusses bereavement care for carers/families/friends.

Understanding what Advance Care Planning options are currently legally available in Australia can assist people with dementia and their carers with planning to ensure that their wishes are known and respected and that their legal rights are protected.

The booklet **does not seek** to provide information on all aspects of dementia, such as the various stages of the disease, managing the illness or likely behavioural changes. A list of resources, including links to websites, is provided at end of the booklet.

GLOSSARY OF TERMS

(Note: In Australia, each state/territory makes its own laws about Advance Planning and there is different terminology in each state/territory. In this booklet, New South Wales terminology is used and the equivalent terminology for other states/territories is provided at the back of the booklet).

Advance Care Planning	Planning future care to ensure that your wishes are known when you can no longer make decisions for yourself or legally complete documents.
Advance Directive	A written, legally binding document, which allows you to record your wishes for general or specific treatment you consent to or refuse under certain conditions.
Carer	Person who supports, helps and cares for a person with dementia.
Enduring Guardianship	Authority you invest in a trusted person to make health care decisions for you when you can no longer make those decisions for yourself.
Enduring Power of Attorney	Authority you invest in a trusted relative or friend to deal with your financial affairs.
Palliative Care	Specialised care and support provided for someone living with a terminal illness which aims to help the patient live as well as possible until they die, and provides care and support for family and caregivers.
Person Responsible	Where there is no Advance Directive, Enduring Guardian or other similar appointment, legislation provides a list of people (in order of precedence) who have authority to make decisions for someone who can no longer make their own decisions.
Statutory Trust	Legally established fund to ensure that your dependents are provided for.
Substitute Decision-Maker	Person appointed to make decisions for someone who has lost capacity, either because of dementia or because of some other illness or injury, when that person can no longer make their own decisions.
Terminal Illness	Advanced stage of an irreversible illness.

SECTION 1:  
A DIAGNOSIS OF DEMENTIA – WHAT DOES THIS MEAN?

If you or someone you care for has been diagnosed with dementia, you may be feeling a range of emotions, including shock and grief. However, you may also be somewhat relieved that you now have a definite diagnosis and can start to plan to ensure the best quality of life possible in the time remaining (for both the person with dementia and their carer).

**What is dementia?** Dementia is a progressive disease with symptoms usually including problems with memory, understanding and reasoning that generally interfere with normal functioning and behaviour. It is an irreversible, terminal condition; at present there is no cure for this disease and it will, eventually, lead to death. As the disease progresses, there will be a time when the person with dementia loses the capacity to make decisions for themselves.

It is important to remember that, despite changes in mood, cognition and behaviour, the person with dementia remains the same person that they were before their diagnosis and remains of equal value to others without dementia<sup>1</sup>. They (and their carer) can experience good quality of life, and may continue to enjoy many of the things they most enjoy, for some years after receiving the diagnosis, provided they plan well and have good supports in place. This booklet will focus on planning for care in the last stage of life, that is, in the period leading up to the end of life. Good planning can help to maximise the independence of both the person with dementia and his/her carer(s) and to ensure that the wishes of the person with dementia are known and respected (within the limits of the law).

**Taking advantage of an early diagnosis** Sometimes people wish that they had not been given an early diagnosis, because “things were going OK” or “I’d rather not know”. However, knowing the diagnosis at an early stage allows time for setting up good supports and planning for expected changes as the disease progresses. It also means that the person who has been diagnosed with dementia can take part in that planning, if they want to, thereby helping to ensure that their wishes for their end-of-life care are known. They may be reassured to know that there are legal mechanisms currently available that will help to ensure that those wishes are respected.

<sup>1</sup> Hughes JC. Ethical issues and decision-making in dementia care. Presentation to National Press Club of Australia, June 2010.

**Section 2** of this booklet provides information to assist you to think about the options that are currently legally available to you in planning for the end of your life (or the life of the person you care for). These include:

2 Advance Planning for expected changes

- 2.1 Advance Financial Planning
- 2.2 Advance Care Planning
- 2.3 Capacity
- 2.4 What Does the Law Allow?

**Section 3** discusses palliative care and its suitability for people with dementia and their carers.

**Section 4** is focussed on carers, for the time when the person with dementia has reached the stage of moderate and/or advanced dementia.

**Section 5** provides information to assist with planning for your funeral (or the funeral of the person for whom you care).

**Section 6** discusses bereavement care and support for carers and other family members and friends.

## SECTION 2: ADVANCE PLANNING FOR EXPECTED CHANGES

**New diagnosis:** A diagnosis of dementia, for you or someone you care for, marks the beginning of a challenging time. You may experience a range of reactions – disbelief, shock, anger, grief, or even relief that you now understand why some things have been happening (or happening to the person you care for), such as forgetting where you are, feeling confused, or not wanting to go to unfamiliar places. These reactions are normal and you may need help to deal with them.

**Reactions of others:** You may find that telling family and/or friends about the diagnosis produces a range of reactions; some people, especially those close to you, may have already noticed some changes in you and be very supportive and understanding. Others may not know how to respond or what to say or do, especially if they have had no previous experience of dementia, and may deal with it by avoiding you. If this is the case for someone close to you, and you want them to stay close, you may have to give them time to deal with their own feelings/reactions, and perhaps assist them by providing them with information (for example, *Help Sheet 3.3 Feelings*, available from Alzheimer's Australia website <http://www.alzheimers.org.au>) to help them to understand what is happening and what to expect. However, some people – especially those outside your immediate family - may never be able to deal with the situation. While this may be disappointing and add to your grief, you may just have to accept it and let that person move out of your life at this time.

**Setting up supports:** It is important that you and your carer/family build up a good support network to assist you to live well for as long as possible and to ensure that your carer also receives support. At the back of this booklet there are links to support organisations and websites that can assist you/your carer to access support. Your general practitioner should also be able to provide you with information, advise you what to expect as the disease progresses, ensure that your medication is appropriate for the stage of your disease and refer you to a dementia specialist or to community services if you so wish. **(Note: if you find that your general practitioner does not have the skills or knowledge to do this, it may be necessary for you to consider transferring your care to another general practitioner who can – and will – provide the support and care you need).** It can also be helpful to know that, if you have dementia and you need to spend more time with your general practitioner because of speech and memory problems, you can ask the receptionist for a longer appointment.

**Planning ahead:** There are a number of areas of your life that you can plan for, to ensure that your affairs are in order and your wishes are known when the time comes that you can no longer make decisions for yourself or complete legal documents. These include legal and financial matters, as well as planning in advance for your everyday living arrangements, health and personal care. Some people may want to make arrangements to donate their brain for medical research or to donate other organs. You may also want to make your wishes known about what arrangements you would like for your funeral.

Some of these issues, such as legal and financial planning, may not be particularly challenging for you as they relate to activities that you may already have undertaken or considered, such as making a will or giving someone Enduring Power of Attorney.



However, thinking about what medical treatment or health care you may or may not want if you can no longer make your own decisions, appointing a substitute decision-maker to see that your wishes are respected, or planning your funeral may be very confronting; initially they may be upsetting for you and for those supporting you. On the other hand you may be relieved to know that your wishes will be known and respected (to the extent the law allows) and this can give you back some control of your new situation.

**Legal issues:** In Australia, each state/territory makes its own laws about financial and health care matters and, unfortunately, these are different in each state/territory, with different terminology and different rules about when they come into effect. Although there is a National Working Group that is developing a National Framework for Advance Care Planning<sup>2</sup>, it is unlikely that this will change the laws in each state/territory in the short term. It is therefore important that you find out what the laws and related regulations are in your state/territory, including who can make decisions for you if you cannot do so, and that you understand what you or the person you appoint can or cannot do. For example, in New South Wales someone with Enduring Power of Attorney for another person can only make decisions about that person's financial and/or property matters and the person appointed to make health care decisions is called an Enduring Guardian. However, in Queensland, both are called Enduring Power of Attorney, with specification about their powers (for example, Enduring Power of Attorney for financial matters, Enduring Power of Attorney for personal and health matters, or Enduring Power of Attorney for both financial and personal/health matters).

At the back of this booklet **Table 1** and **Table 2** outline the most relevant laws in each state/territory, as well as electronic links to services in your state/territory that can assist you with this information. If you are unsure about the situation in your state/territory, you may need to discuss these matters with a solicitor who is experienced in this area of law, with your general practitioner or a social worker.

## 2.1 Advance Financial Planning

Knowing in advance that the time will come when you can no longer make your own decisions allows you to “put your affairs in order”. In relation to financial and property matters, this can include making your Will, appointing an Enduring Power of Attorney, setting up Statutory Trusts for dependents (where relevant) and, in some cases, establishing Family Agreements. Where possible, it is advisable to consult a solicitor and/or financial planner to assist with these matters. If you cannot afford to consult a private solicitor or financial planner you may be able to attend a community legal service or ask a social worker or a justice of the peace (JP) to assist you. A brief description of each of the financial options follows:

**Wills:** Most people understand what a will is: it is a document that comes into effect after a person has died, which sets out how they wish their financial resources, including property, to be distributed. There is legislation which governs some aspects of wills (for example, the responsibility of a person to provide for a dependent child or adult) and it

<sup>2</sup> Draft National Framework for Advance Care Directives in Australia: <http://www.hwlebsworth.com.au/acdframework/>

is not uncommon for wills to be the subject of legal disputes. Except in some rare cases where a Court may draw up a will for a person who has lost capacity, a will is only legal if it is signed by a person who has capacity and is witnessed by an independent witness, so getting this done as soon as possible after being diagnosed with dementia (if you have not already done so) can save a lot of trouble for your family or other beneficiaries.

**Enduring Power of Attorney:** For someone who has been diagnosed with dementia, it is extremely important to give authority to a trusted relative or friend to deal with your financial affairs, by appointing that person as your Enduring Power of Attorney. You may wish to give that person authority to start managing your financial affairs immediately, for example, to pay your bills or the cost of your care, or you may only want their authority to start when you can no longer manage your affairs yourself. “Enduring” means that the person's authority continues if you lose capacity (see p.19 for information about what “capacity” means).

However, even if you decide that your Attorney's power is to start immediately, that does not mean that they can do whatever they want with your money or property – they are your agent and should not do anything you do not authorise them to do. They must act in your best interest, and are actually taking on a significant responsibility. Whether you still have capacity or not, the law requires them to keep a record of any transactions they make on your behalf and to keep your property and their property separate. There are also limits on what gifts they can give to others on your behalf. Failure to keep proper records may result in them facing legal sanctions and penalties.

Although you may only wish to appoint one person to have Enduring Power of Attorney, it is generally advisable to appoint more than one person (in case one is not available when needed) and to say how they are to make their decisions. You can say that they must make their decisions “jointly” (that is, all must agree), “severally” (any one of them can make the decision), “serially” (that is, the first person on the list makes the decisions but if that person is not available, authority moves to the next person on the list, and so on) or if you are appointing more than two you can say that there must be a majority decision. You can also appoint one person (for example, your spouse/partner if you have one) to be the first in line to make decisions and then appoint others – jointly, severally, serially or as a majority – in case your spouse/partner is not available when a decision has to be made.

If you appoint two people to make decisions jointly, it is important to be sure that they are likely to agree and will not disagree just because that is what they have always done. Parents sometimes feel that they should appoint both children, so that they do not appear to be favouring one over the other but this is not always the best solution. In such a case it may be better to appoint a third, trusted person and to say that decisions require majority agreement. There are many other options for such appointments and these should be discussed with your solicitor. Although it is usually easier if everyone who is appointed lives near you – in case multiple signatures are needed on cheques or other documents – this is becoming less of an issue as technology improves. The most important thing is that you appoint people you trust, who are not likely to misuse your finances and property, and that they understand their obligations in relation to the appointment.

You may revoke or change an Enduring Power of Attorney any time that you have the capacity to do so. The Guardianship Tribunal may also revoke an Enduring Power of Attorney. If you do not give someone you trust Enduring Power of Attorney and you lose the

capacity to manage your own financial affairs, then the Guardianship Tribunal may have to appoint one of your family members or a friend to do so – and it may not be the person you would have chosen. Alternatively the Public Trustee may be appointed. A Power of Attorney is automatically revoked immediately on your death and your Attorney no longer has legal authority to act for you in any way. On your death, the executor appointed in your will takes over authority for managing your financial affairs.

**Statutory Trusts:** A solicitor or financial planner can assist you to establish a Trust Fund to ensure that your dependents are provided for. Recent legislation, which allows you to set up a specific trust for a child or an adult with impaired capacity (for example, an adult child with an intellectual disability), allows you to set aside some of your financial assets immediately and these will then not be taken into account in calculating your entitlement to a pension, nor will they impact on the entitlement to a pension or other benefit of the person for whom the trust is established.

**Family Agreements:** These can be set up to support the person providing your care, who has often had to give up work and lose income and superannuation to care for you, by providing for regular financial payments to them from your estate during the time they are caring for you, or it can be written into your will for that person to receive specific compensation before the estate is divided among others after your death. It is not uncommon for one family member to provide many months – or even years – of care to a parent or sibling, without any payment along the way, but to then receive only the same as other family members in that person's will. Of course, the final decision about such matters remains with you.

## 2.2 Advance Care Planning

Every competent adult in Australia has the legal right under common law, and in some states/territories under statute law, to accept or refuse any health care or treatment, even life-saving treatment. Unfortunately, for someone with dementia the time will almost certainly come when they will no longer be able to communicate their wishes. One way to address this problem is Advance Care Planning.

Advance Care Planning is a process by which you can make and communicate, in advance, decisions about your health care for a future time when you have lost capacity to make your own decisions. It helps to ensure that your choices are respected if you can no longer take part in discussions about your medical care and treatment. Ideally, Advance Care Planning involves a discussion between you, your health care providers and your carer/family about your values, beliefs and goals in life and what medical treatments you would or would not want in particular circumstances in the future. Advance Care Planning can include the use of a written, legally binding document, most often called an Advance Directive, and/or the appointment of a substitute decision-maker.

**Advance Directive:** A written Advance Directive allows you to record your wishes for what general or specific treatment you consent to or refuse under certain conditions (see Section 2.4 for a discussion of some specific treatments that may be consented to or refused). It can assist health care providers to make decisions in line with those wishes and give you confidence that your wishes will be carried out when you lose capacity. You can also write a Personal Statement in your Advance Directive to help others understand what you would consider to be a good quality of life, even if you have lost capacity. This

might include such things as being kept pain free and comfortable, being able to listen to music or to be out in the garden. It could also include a statement of who you would – or would not – want to be around you at that time. Some people write in their Advance Directives where they want to be cared for at the end of their life. However, it is important not to write something that would increase the burden too much on your carer or family members; for example, if you say that you want to be cared for at home and not go into hospital or a nursing home, your carer/family members may reach a point where it is just not possible to care for you any longer at home – either because they are exhausted or because you require a level of care that cannot be provided at home - and they may feel doubly guilty if they cannot meet your request. If you do want to express a wish to be cared for at home, make sure you add “for as long as possible”.

Ideally, it is best if the Advance Directive is one that has been specifically developed for the purpose, with sections to be completed by you (the person who is making it), a section for your treating medical practitioner to sign which confirms that you had capacity to make the Directive at the time that you did, and a section to be completed by an independent witness. In some states/territories the document to be used is prescribed or recommended in legislation. In NSW, there is no “prescribed” Advance Directive form and, in fact, a decision in the NSW Supreme Court<sup>3</sup> confirmed that even treatment decisions/wishes written informally, for example on a plain piece of paper, will be legally binding if there is evidence that the person wrote it themselves, that they were competent to do so at the time and that there is no evidence that they changed their mind after writing it. The Court in this case held that the Directive would be binding even if the person had not been given all of the relevant information or did not understand all of the consequences of their decision.

Although it is not possible to be certain about what treatment may be required in the future, if someone already has a diagnosis (of dementia or some other illness or injury) their general practitioner or other treating medical practitioner should be able to provide some advice about the sort of treatments they may be offered, and what might happen if they choose not to have such treatments. It is important to understand that, no matter what the treatment is, every competent person has a right to accept or refuse it, either while they are still competent or through an Advance Directive for a future time when they are no longer competent, even if refusing it would lead to their death. This includes palliative care. While you are competent you also have a right to be told what treatment is being proposed, what alternatives to that treatment are available and what will happen if you choose not to have the treatment. This is called informed consent and it applies even if you are in hospital or a nursing home – you do not give up your right to informed consent just because you are in a hospital or other care facility. A health care provider (for example, doctor, dentist or nurse) who treats a competent person against their wishes may be charged with assault.

**Enduring Guardian:** As it is not possible to foresee all possible decisions that may need to be made in the future, and to include these in an Advance Directive, it is also important to appoint a substitute decision-maker for your health care decisions. In every state/territory in Australia except the Northern Territory, you can appoint someone (usually a

<sup>3</sup> *Hunter and New England Area Health Service v A* [2009] NSWSC 761; July/August 2009



trusted relative or friend who is at least 18 years old) to make personal, lifestyle and/or medical or dental treatment decisions on your behalf when you lose capacity to make those decisions yourself. In NSW the person appointed is called an Enduring Guardian. This person acts as your advocate to ensure that your wishes are respected and/or to consider the treatments that are offered and to consent to or refuse such treatment according to their best estimate of how you would have decided in the circumstances. This means that you need to discuss your wishes for future treatment with your Enduring Guardian, and ideally give him/her a copy of your Advance Directive, so that she or he understands your wishes and is prepared to advocate for them and to stand up for your rights.

Again, as for financial matters, you can appoint more than one person to make your health care decisions and say how they are to do so. It is usually the case that a decision about treatment that is made by your Enduring Guardian has the same legal effect as if it had been made by you. Consequently, it will be binding on the health professionals who are providing your treatment. The only difference is that while every competent adult can refuse any treatment, in some states/territories, a substitute decision-maker cannot refuse palliative care. It is important that anyone agreeing to be appointed as your substitute decision-maker understands that it is a very big responsibility. Not only should they try, as far as they possibly can, to make the decision that you would make if you were competent to speak (even if they do not agree with that decision) but they may be asked to make decisions that will result in your death, such as turning off life-support systems. **(Note: it is important for everyone to understand that it is the underlying disease that is the cause of death, not turning off the machine).** Some people may feel that they cannot take on such a responsibility and if this is the case then it is better for them to acknowledge this immediately and allow someone else to be appointed to this role. If you think that having to make such decisions would be too distressing for your family members, you may want to appoint a close friend instead – the choice is yours and the main thing is that you know you can trust the person you appoint to do their best to see that your wishes are respected. If you choose someone other than a family member, it could make things easier for all if you tell your family that you have done this as well as the reason for your decision.

All states/territories except the Northern Territory use a specific form to appoint an Enduring Guardian and you need to check what the requirements in your state/territory are regarding who can sign the document and who can witness it. It is usually not necessary that all signatures are witnessed on the same day or even in the same place.

Generally speaking, if a patient has made an Advance Directive and appointed a substitute decision-maker, the substitute decision-maker is legally bound to follow the Directive. So is the treating medical practitioner or other health care provider, as long as the Directive relates to the current situation and is not ambiguous or contradictory. Failure to do so can result in legal action being taken against the health care provider. Health care providers do not have the right to ignore their patients' competent and clearly expressed wishes, merely because they feel uncomfortable with the choices that their patients make. People will not always be wise and they can, legally, make their decisions for good reasons, bad reasons or no reason but competent people must always have the last say over what happens to their bodies (including for a time when they are no longer competent). Of course, if you request something that is illegal (for example, euthanasia) in an Advance Directive or through your substitute decision-maker, the treating medical

practitioner cannot provide that. In addition, a medical practitioner does not have to provide treatment which he or she believes to be medically futile, even it has been requested in an Advance Directive or by an Enduring Guardian.

### ***Is it essential to complete an Advance Directive and/or to appoint an Enduring Guardian?***

Completion of Advance Directive and/or Enduring Guardian documents is completely voluntary; some people may not want to complete such documents, preferring instead to leave such decisions to their family or to their doctor. However, research in Queensland<sup>4</sup>, the Northern Territory<sup>5</sup> and NSW<sup>6</sup> found that very few people want to leave such decisions to their family or doctor, with most preferring to make their own decisions. Others may prefer just to discuss their wishes and values for their end-of-life care with their carer, other family members and/or their treating medical practitioner, rather than write down their wishes in a document. For example, a person with dementia may say, "If the time comes when I can no longer recognise any of my family and I develop a life-threatening illness, I just want to be kept comfortable and not have my dying prolonged by the use of invasive technology or antibiotics". This is also a valid Advance Directive (even though it is an oral one) and should be recorded in the person's medical record and be respected when the time comes.

Advance Care Planning is a process, not just signatures on a piece of paper, and it is the discussion itself which is most important. However, completing the documents provides more legal certainty that your wishes will be respected and gives legal authority to the person you appointed as your substitute decision-maker. It can also help to avoid disputes among family and friends about what treatment you should or should not receive, if you have appointed someone to have the legal authority to consent to or refuse such treatment for you and have given that person a written Advance Directive, that is, your own words, to guide such decisions.

Once the documents are completed and witnessed, a copy of each one should go into your file in your general practitioner's office and you should give a copy to your Enduring Guardian(s). If you ever go into hospital or into a residential aged care facility (RACF – previously called a nursing home) you (or your carer) should ask for copies to be put into your medical record and for an "alert" to be put into your electronic record in the hospital or residential facility computer. You also need to keep a copy of the documents easily accessible at home. If you do not have a live-in carer and your Enduring Guardian or other family members do not live close by, you may also want to give a copy to a neighbour, if you have one you know well and can trust, in case of emergencies. Some people keep a copy with their solicitor and while this may be useful if a dispute arises, people often don't think of contacting the solicitor until after the person has died – which, of course, is too late to guide their care and treatment.

<sup>4</sup> Steinberg MA, Cartwright CM, MacDonald SM, Najman JM, Williams GM. Self-determination in terminal care: A comparison of GP and community members' responses. *Aust Family Physician*. 1997, 26:6: 703-709

<sup>5</sup> Cartwright CM, Robinson GW, Steinberg MA, Williams GM, Najman JM and Tyler WB. *End-of-life decision-making. Perspectives of Northern Territory doctors, nurses and community members*. Report, 1998. The University of Queensland & Northern Territory University.

<sup>6</sup> Cartwright C, Phillips J, Rodwell J. *A Multi-Disciplinary Approach to Advance Care Planning: Pilot Study Report*. Aged Services Learning and Research Collaboration, Southern Cross University, NSW. June 2006

For those who fear loss of capacity, Advance Care Planning can provide reassurance and take away some of the fear around the end stage of life. Unlike Enduring Power of Attorney, Advance Directives or Enduring Guardian appointments do not come into effect until you have lost capacity and not before then. You can change or totally revoke them at any time while you have the capacity to do so. Generally a person is said to have capacity if he or she is able to understand, in general terms, *the nature* and *the effect* of the decision to be made, and to communicate their decision in some way (not necessarily by speaking or writing – body language may be sufficient).

**The Links and Resources List at the end of this booklet provides details of Guardianship Tribunals and Public Advocates in each state/territory.**

***Who has legal authority to make decisions if the person with dementia has not written an Advance Directive and has not appointed an Enduring Guardian (or equivalent)?***

**Person Responsible:** If you have not written an Advance Directive or appointed the person you want to make your decisions, in most states/territories there is a list of people – in order of precedence – who are given authority to make decisions on your behalf. In NSW this person is called the Person Responsible and is the first in the following hierarchy:

- a spouse (including de-facto or same-sex partner, provided the relationship is close and continuing);
- a (non-professional) carer; or
- a close relative or friend of the patient.

This is NOT next of kin and may not be the person you would want to make decisions for you. While a spouse would be next of kin, their authority does not come from that position but from their ranking in the list above; a carer will often be a younger daughter or daughter-in-law and an older son or daughter may be next-of-kin and think that they should have authority to make the decisions but that is not the case legally: the carer has authority ahead of the next of kin. The NSW Office of the Public Guardian reported a case in 2008 where an elderly woman had three children who did not visit her very often but her next-door neighbour came in every day to help her out of bed and into the shower, and provided many other services for her. When there was a need for a substitute decision-maker, the neighbour was deemed to be the 'carer' and took precedence over the children.

The treating medical practitioner is responsible for establishing who has the legal authority to make substitute decisions and if she/he allows the wrong person to do so she/he could face legal consequences.

It is also important to note that, in some states/territories, a Person Responsible (or whatever the person is called) may not have as much authority as the person you appoint yourself; there are some decisions, such as those related to withdrawing or withholding life-sustaining medical treatment, which they may not have the authority to make (whereas the person you appoint does have that authority). This issue is still being tested in the courts and tribunals. It is therefore strongly advisable to appoint your own substitute decision-maker.

***When can a medical practitioner NOT follow the wishes in an Advance Directive or the directions of a substitute decision-maker (appointed or otherwise)?***

There may be times when a medical practitioner believes that an Advance Directive is unsound or uncertain, for example, where there are contradictory or ambiguous statements in the document, or where it contains statements such as "do not use heroic means" or "do not use extraordinary measures". What is heroic or extraordinary to the average person may be quite commonplace to their treating doctor. Such terminology would usually be too imprecise to guide medical practice. Also, as noted above, an Advance Directive may say that the patient is to be given treatment which their treating medical practitioner believes is medically futile. In such circumstances the medical practitioner should contact the legal authority in that state/territory (such as the Office of the Public Guardian, the Guardianship Tribunal or, in some cases, the Supreme Court) and ask for a decision on the matter.

In cases of dispute, for example, between a treating medical practitioner and an Enduring Guardian, or between the Person Responsible and other family members, or between the carer/family and the treating team or care facility staff, it may be necessary to apply to the Guardianship Tribunal for a resolution. In addition, if a family member or friend, or a health care or other professional believes that an appointed Enduring Guardian or the person designated as Person Responsible is making decisions that are clearly not in the best interest of the person with dementia, the concerned person can contact the Guardianship Tribunal and ask for an investigation, or request that the current Enduring Guardian's authority be withdrawn and another Guardian appointed.

**Contact details for Guardianship Tribunals and related officials are in the Links and Resources List at the back of this booklet.**

## 2.3 Capacity

***When is a person considered to have capacity to make their own decisions, or to complete an Advance Directive or appoint a substitute decision-maker?***

There are many assessment tools that are used to determine someone's capacity. One of the most commonly-used but least appropriate tools to use with older people is the Mini-Mental State Exam or MMSE. This is actually a screening tool which simply indicates if there is a problem which requires further assessment. If the MMSE is used to assess your capacity (or the capacity of the person you care for) you should request that another assessment is done, using a better tool such as the GPCOG<sup>7</sup> or the Six-Step Capacity Assessment tool<sup>8</sup> developed by Alzheimer's Australia.

Legislation throughout Australia is based on the United Nations principle of "presumption of capacity". This means that a person does not have to prove that they have capacity; it

<sup>7</sup> The General Practitioner Assessment of Cognition is a screening tool for cognitive impairment. See <http://www.gpcog.com.au>

<sup>8</sup> Who Can Decide? : The six step capacity assessment process, edited by Dr Peteris Darzins, Dr D William Molloy, Dr David Strang. <http://www.alzheimers.org.au/south-australia/resources-alzheimers-australia-sa.aspx>

is assumed that they have capacity unless it can be proven that they do not. Someone with mild or moderate dementia may still have sufficient capacity to make their own decisions, or to complete Advance Care Planning documents. They may have better capacity in the morning than in the afternoon. The law says that an adult has capacity if she/he can understand the information being given, keep it in mind long enough to make a decision based on that information and communicate their decision to another person. It is usually the responsibility of the treating medical practitioner to determine whether or not someone has capacity.

## 2.4 What Does The Law Allow?

**(Note: the term “competent person” in this section applies both to someone who is competent/has mental capacity now or who wrote down their wishes in an Advance Directive or gave instructions to their substitute decision-maker when they were competent).**

**Refusal of treatment:** Both the common law and statute law in Australia support the right of a competent person to refuse medical or other treatment, even if this will result in that person's death. To provide, or continue to provide, treatment that a person has specifically refused is against the law and a doctor or anyone else who does this can be charged with assault. If the person is in a condition outlined in their Advance Directive as one in which they would refuse the specific treatment, or if their substitute decision-maker advises the doctor that the person has said that if they are in their current condition they do not want that specific treatment, it should not be given; if it has already been started, it should be withdrawn. Some health care providers are more willing to withhold treatment than they are to withdraw it (possibly because of some confused idea that to withdraw it instigates some form of euthanasia, which it does not), yet the two actions are legally, morally and ethically the same if the treatment has been refused or it is doing nothing more than prolonging the person's dying.

**Refusal of food or fluids:** For a person with dementia, loss of the swallowing reflex is a normal part of advanced dementia, and a sign that death is approaching. To continue artificial nutrition and hydration when the person has reached this stage of their illness can actually increase their suffering<sup>8</sup>. They should continue to be offered whatever they will accept by mouth, even if that is just sips of water or crushed ice fragments, and their mouth should be kept clean and fresh.

The law in most states/territories also supports a person's right to refuse “normal” food and fluids; however, it is not certain that a substitute decision-maker can do so. It can be very challenging for carers and other family members to understand and accept that the person no longer wants or needs food or fluids. We are all used to connecting provision of food with care and nurturing, and a carer or other family member will sometimes say “If we could just get him to eat something, he might get his strength back”. At other times, carers or family members feel helpless and providing food for the person they love can make them feel as if they are “doing something”. Unfortunately, what they may be doing is causing the person distress and discomfort – or even actual suffering.

<sup>8</sup> Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia. *JAMA*, 1999; 282(14): 1365-1370

Some research<sup>10, 11</sup> has indicated that the human body is programmed to recognise when death is close, and to release chemicals, such as endorphins, that act like a natural analgesic to provide a peaceful death. However, if artificial nutrition and hydration is continued, the body does not get the signal that death is near and does not release the chemicals – thereby depriving the person of a peaceful death.

**(Note: Artificial nutrition and hydration --that is, food or fluid provided through a tube down the person's nose or a tube inserted directly into the stomach-- has been defined as medical treatment by both the Australian Medical Association and the British Medical Association, and can be refused by a competent person).**

**Pain control:** Every person (competent or not) has the right to adequate control of pain and other symptoms; to leave someone in pain or distress is abuse, yet research shows that people with dementia often die with inadequate pain control<sup>12</sup>. With good palliative care, almost all dying patients can be kept comfortable but still “awake” enough to communicate with family and friends. Unfortunately, many doctors and other health care providers have not had adequate, specific training in pain management – and do not call for assistance from the palliative care team until near the very end of the person's life. This means that many people with dementia are left in unnecessary pain and distress, when this could, and should, be prevented by contacting the palliative care team early in the patient's disease process and ensuring that strategies to ensure adequate pain and symptom control are put in place. These can usually be provided in the person's home, as well as in the residential aged care facility or in hospital. (Palliative care is explained in Section 3).

**Refusal of antibiotics:** “Pneumonia is common among patients with advanced dementia, especially towards the end of life” (Givens et al, 2010: p.1102)<sup>13</sup>. Although use of antibiotics may prolong the survival of the patient, research has found that it does not improve comfort in people in residential aged care facilities who have advanced dementia, which raises the question, “Is it ethical to prolong the life of a person in such a condition?”

**Resuscitation:** The most common order that is given in relation to withholding a specific treatment is Not For Resuscitation (NFR) or No Cardiopulmonary Resuscitation (No CPR). CPR is the mechanical compression of the heart to move blood around the body, sometimes using an electric shock as well, and the mechanical movement of air into the lungs. These orders are usually given when a patient is in a terminal condition and such treatment is considered to be futile. There is a very low rate of survival for frail older patients following CPR and often they are in a much worse state than they were before receiving it, for example, with cracked/broken ribs or other damage. However, because a patient has an NFR order does not mean that all other care and treatment will cease; they should still be given comfort care and have distressing symptoms treated. Other more aggressive, invasive treatments that are commonly withheld or withdrawn include dialysis,

<sup>10</sup> Eggenberger SK, Nelms TP (2004). Artificial hydration and nutrition in advanced Alzheimer's disease facilitating family decision-making. *Journal of Clinical Nursing* 13, 661-667.

<sup>11</sup> Berky PS. Withholding end-of-life medical nutrition and hydration: an ethically sound decision or an inhumane practice? *Maryland-Nurse*, 1998; 17 (8): 8-9.

<sup>12</sup> Sachs GA, Shega JW, Cox-Hayley D. Barriers to Excellent End-of-life Care for Patients with Dementia. *J Gen Intern Med*, 2004; 19: 1057-1063.

<sup>13</sup> Givens JL, Jones RN, Schaffer ML, Kiely DK, Mitchell SL. Survival and comfort after treatment of pneumonia in advanced dementia. *Arch Intern Med*, 2010; 170 (13): 1102-1107.



chemotherapy, antibiotics for infection and artificial ventilation. In many cases such treatments are not prolonging the person's life, they are just prolonging the dying process.

**Terminal sedation:** A recent, controversial addition to the discussion about what is legally allowed in relation to end-of-life care is terminal sedation. This refers to the use of sedative drugs to induce unconsciousness in terminally ill patients in order to relieve suffering, including anxiety, when other attempts at relief have failed. It includes withholding or withdrawing artificial nutrition/hydration (see above). As there is currently controversy about terminal sedation and its relationship to euthanasia, this issue will be discussed more fully in Part 2.

In summary, under the law every competent adult has the right to refuse treatment, to have treatment withheld or withdrawn and to receive effective pain and symptom control even if it hastens their death. Unfortunately these rights are often not respected. Research in Queensland <sup>14</sup> with carers of people who had died the previous year identified cases such as:

"Mum always said she wouldn't want to be resuscitated if her heart stopped, but they wouldn't listen."

(Competent man in his late 80s with multiple problems, voluntarily chose to stop eating and drinking). "First of all he was stubborn when he was in hospital; he wouldn't eat - he was just starving himself ... so they had to force-feed him. They put a tube down his nose and then they had to tie him in the bed, because he kept pulling it out. He just didn't want it".

**(Note: These are both cases of assault. Being in hospital does not negate the right to informed consent).**

So, is a good death possible for someone with dementia? Yes, Advance Care Planning and good palliative care can help almost everyone achieve a good death.

<sup>14</sup> Cartwright C. (2004) Factors impacting on the quality of life of terminally ill older people in the community. PhD, School of Population Health, the University of Queensland.

## SECTION 3: PALLIATIVE CARE

### What is Palliative Care?

"Palliative Care is specialised care and support provided for someone living with a terminal illness (which) also involves care and support for family and caregivers. The goal of palliative care is to improve quality of life for patients, their families and caregivers by providing care that addresses the many needs patients, families and caregivers have: physical (including treatment of pain and other symptoms), emotional, cultural, social and spiritual. Palliative care aims to help the patient live as well as possible." <sup>15</sup>

Some people think of palliative care as being just for the last few days of life, but this is not correct. Palliative dementia care is a continuum; a palliative approach to care can be implemented at any time during the course of an illness, with the emphasis being on quality of life, dignity and comfort. Palliative care can begin very early after a diagnosis of dementia, even if the patient is receiving active treatment for their illness/disease. Where possible, establishing a relationship with a palliative care team early in the disease process means that they will be able to monitor the patient's progress and know when additional support is needed. Palliative care is provided by general practitioners, specialist palliative care doctors and nurses, community and hospital-based nurses, allied health professionals, social workers, pastoral care workers and others. A person with dementia may not require the services of a specialist palliative care team in the early stages of their disease, but palliative care staff often feel frustration that people are not referred to them early enough, when they could help to improve the person's quality of life and functional status.

Palliative care can be provided in a person's home, in hospital or a hospice, or in a residential aged care facility. Where it is provided will depend on many things, including the nature of the person's illness and how much support they – and their carer – have from their family, friends and community.

The National End-of-Life Framework Forum document <sup>16</sup> notes that quality care at the end of life should be underpinned by the values of: dignity, empowerment, compassion, equity, respect, advocacy, excellence and accountability. These values are the basis of the 13 national palliative care standards, which have been adopted by all states/territories in Australia to guide the development of palliative end-of-life services.

#### Dementia patients' need for palliative care:

Traditionally, palliative care has been most often provided to people with cancer, and to their carers, but it is increasingly recognised that anyone who has a terminal illness can benefit from receiving palliative care. One of the key consultation messages that guided the development of the National Framework was that "quality end of life needs to be accessible to people with non-malignant conditions" (p34). However, Hughes (2010:8) notes that people with dementia "are less likely to receive palliative medication and pain relief, less likely to have attention paid to their spiritual and religious needs, and less

<sup>15</sup> Palliative Care Australia, [www.palliativecare.org.au](http://www.palliativecare.org.au), 2010

<sup>16</sup> *Health System Reform and Care at the End of Life: A Guidance Document* 2010: 20-21

likely to be referred to palliative care specialists than people who don't have dementia". Ouldred and Bryant (2008:308) noted a number of barriers to accessing good palliative care for people with dementia. These include "dementia not being recognized as a terminal disease like cancer, problems in recognizing the symptoms of terminal dementia, and decision-making conflict between family caregivers and other health and social care providers". Education is required to assist people with dementia and their carers/families to understand that palliative care can be of benefit to them, from early in the disease process, and to educate health care professionals – including general practitioners – to refer people with dementia for palliative care.

A further challenge is to ensure that palliative care services are delivered in a way that respects religious, cultural and gender diversity, with staff trained in cultural competency that allows them to respect different racial, cultural and lifestyle choices. As palliative care is currently provided most often to people with cancer, additional training of palliative care staff in provision of palliative care to people with dementia may be required.

---

<sup>17</sup> Hughes JC. Ethical issues and decision-making in dementia care. Presentation to National Press Club of Australia, June 2010.

<sup>18</sup> Oulred E, Bryant C. Dementia care. Part 3: end-of-life care for people with advanced dementia. *Br J Nurs*, 2008; 17(5): 308-314.

## SECTION 4: CARERS

**(Note: As the focus of this Section is carers, the terms “you” and “the person you care for” are directed at carers).**

Hughes (2010)<sup>19</sup> notes that, for many carers of people with dementia, a major stress is not knowing what is the right thing to do and being afraid of doing the wrong thing. Everyday decisions, such as when to take over tasks for the person with dementia (especially when that person always did all such tasks themselves) can be very challenging. However, some of the stress and burden on carers can be relieved with good Advance Care Planning.

**Moderate Dementia:** If the person you care for now has moderate dementia but still has some capacity, and no Advance Planning has been done so far, they should be supported to express their wishes to the extent that they can. Even someone with moderate dementia may still have the capacity to express their wishes, for example, after a good night's sleep. (The principles behind the legislation relating to Advance Care Planning include “maximum participation” and “minimal limitations”). In such cases it may be easier to make a tape recording or a video of the person saying what is important to them, and the sorts of treatments or other care they would or would not want to receive at the end of life, rather than writing down their wishes.

As the carer of a person with dementia, you will be taking on more responsibility and making more decisions for them as their disease progresses. If they have written an Advance Directive and appointed a substitute decision-maker (which may be you or someone else) you will not need to do anything related to that unless the person with dementia requires invasive medical treatment or is admitted to residential care. At that point it will be important that you (or their substitute decision-maker if it is not you) ensure that a copy of the person's Advance Directive and a copy of their Enduring Guardian form are put into their hospital or facility file and that the wishes expressed in that document are respected. If staff at the hospital or facility say “Oh we don't use those”, explain to them that they are legally binding documents and “we don't use those” is not a legal option. Point out that if the wishes in the documents are not respected you can take legal action. (This may seem a difficult thing to do but unfortunately many doctors, nurses and even solicitors are still ignorant of the law with respect to Advance Care Planning).

If the person with dementia has not completed an Advance Directive nor appointed a substitute decision-maker and they have lost capacity, no-one else can do so on their behalf. At this point you, as carer (and in many cases as both spouse and carer) will take on the role of Person Responsible.

**Advanced Dementia:** Whether the person with dementia has, or has not, completed their Advance Care Planning documents, or expressed their wishes in some other way, there will almost certainly be other decisions that you/their substitute decision-maker will need to make during this time. These may include where the person with dementia is to live and where they will die.

---

<sup>19</sup> Hughes JC. Ethical issues and decision-making in dementia care. Presentation to National Press Club of Australia, June 2010.



Many people will say that they wish to be cared for at home – and sometimes they write this in their Advance Directive – but being cared for at home may not always be possible. Caring for a person with dementia can be a long and exhausting role and no matter how willing you may be to take on that role, the time may come when you are no longer physically or emotionally able to continue to provide good care. Or it may be that the person you care for requires a level of care that is not possible to be given at home, or that is not available where you live (for example, in rural or remote areas). At such a time it may be appropriate for the person you care for to go into residential care. Although you may need to be guided by the general practitioner, respite care staff, Aged Care Assessment Team (ACAT) or other community nurses in making this decision, it is also important for you to know that you also have rights, including the right to say “enough” when the burden becomes too great.

**Deciding on residential care:** Accepting that the time has come for the person with dementia to go into residential care may cause you grief and feelings of guilt. You may also not receive appropriate support from other family members or friends, who may be angry because they feel that they were not part of the decision-making process or who feel that you “should” continue to care for the person at home. However, often these people will be dealing with their own guilt – perhaps for the way they treated the person with dementia in the past, or for not giving you more assistance in caring for the person. The Alzheimer's Australia Help Sheets *3.3 Feelings*; *4.1 Deciding on residential care*; and *4.5 Coping with placement* may be of assistance, to you and to other family members. It is also important that you seek help and counselling. Alzheimer's Australia provides a free counselling service for families and carers of people with dementia. You may also find it helpful to arrange a meeting with the general practitioner, facility staff and other family members, so that everyone understands why it is necessary for the person with dementia to go into residential care.

**Which residential facility?** Once the decision has been made, the next step is finding the right care facility. The Alzheimer's Australia *Help Sheet 4.2 Which residential facility?* provides guidance and a check-list of things to look for when judging whether or not a facility is a dementia-friendly environment. The attitude of the staff and the quality of the care provided is more important than a “fancy” building. Also, if the person you care for has been going to a particular facility during the time you have been caring for them, and they have been happy there, that can make the transition to full-time residential care less difficult. If they have not been going to respite, perhaps you can arrange for them to do so for a few days or weeks at the facility you are considering, so that you can judge whether or not it is likely to meet your needs – and those of the person with dementia. However, depending on where you live, your financial resources and the availability of a room in the facility, your options may be limited.

If the person you care for made an Advance Directive, you can ask for that to go into their file in the facility and for an alert to be put onto the file and the computer, notifying staff that it is there. You also need to ensure that staff members know who the appropriate substitute decision-maker is (which may be you or someone else). You (or the person you care for if they still have some capacity) can also state on admission that you wish the person to receive palliative care only and not to be transferred to an acute hospital without your agreement.

**Minimising admission to hospital:** Whether the person with dementia is being cared for at home or in a residential aged care facility, avoiding or minimising admission to hospital is strongly advised where possible. Hospitals are not really designed to provide good care for people with dementia and can be very frightening for someone in that condition as they are usually loud, noisy, busy places, with no staff that the person recognises. Where possible, it is better for them to stay at the facility, especially at the very end stage of life. However, there may be times when there is no option, for example, if the person requires a level of treatment to keep them comfortable that can only be provided in a hospital. Sometimes people are sent to hospital from residential aged care facilities because the general practitioner is not available to come to the facility, but if care plans are made in advance of any emergency, often the general practitioner does not need to come because arrangements are already in place to care for the person at the end of their life. If this has been done it is important that everyone knows about it – not only family and friends but everyone in the facility, so that if a new staff member is on duty they do not feel that they have to call the ambulance. Good advance care planning is the key.

## SECTION 5: FUNERAL ARRANGEMENTS

Some people want to make their own funeral arrangements; others prefer to leave it to their family or friends. It can be helpful for the carer/family if the person with dementia does express their preferences for their funeral arrangements. For example, some people may want to say who they want to do the eulogy, or what flowers, music or specific readings they would like and who should do these. It may be that the person with dementia has very definite ideas about whether they want to be buried in a traditional way or have a bush burial, or perhaps they would prefer to be cremated.

However, the whole concept of “being dead” and needing a funeral may be too confronting for many people, so one of the first things to determine is, does she/he want to talk about this or not? If it is still soon after diagnosis, the person with dementia may not yet have had time to come to terms with what is happening to them and may become distressed if the issue of their funeral is raised too soon. On the other hand, it is important not to leave it too late to at least give the person the option of being involved in planning their funeral.

Whether or not the person with dementia wants to be involved in planning their funeral, management policies at most residential aged care facilities require that a funeral director is nominated so you need to think about this at an early stage. It is also possible to pre-pay for a funeral, which may relieve carer and family stress immediately after the person with dementia has died, as this is one less thing for them to decide.

**Brain donation:** There are additional issues to consider if the person has asked that their brain or other organs be donated for scientific purposes, because of the need for a speedy response and for everyone involved, such as the general practitioner, residential aged care facility, funeral director and hospital to understand the situation. Brain donations require that the funeral director is named on the documentation held by the brain donation department of the Brain Bank, who work in coordination with the funeral director for collection and return of the body after the brain removal. All of those details have to be completed on the required forms long before death. However, even with the best planning, including completing all the paper work, leaving instructions in an Advance Directive and having the full agreement of the general practitioner and residential aged care facility, problems can arise. In one case, where it was apparent that death would occur on the weekend, the general practitioner left a letter with all necessary details for the locum – who then refused to issue a death certificate. The Brain Bank had to ‘convince’ the ambulance service to collect the person's body and take it to hospital where a doctor signed the death certificate. (See Links and Resources Section for additional information).

## SECTION 6: BEREAVEMENT SUPPORT

When the person you are caring for dies, you may experience a range of emotions; these can include grief, shock (even following a death that was expected), guilt, anger, relief (both for yourself and for the person who has died); loneliness and a sense of loss, including loss of the caring role which has possibly been a major part of your life for a number of years. It is important that, if at all possible, you seek help to cope with these feelings. The Alzheimer's Australia *Help Sheet 3.5, Coping after the death of someone with dementia*, may help you to understand what you are experiencing and gives details of where to seek professional counselling and help.

Creating some structure in your life is most important after the passing of the person with dementia. You could, perhaps, continue to attend your support group for a while, and resume some past activities, for example, a sport, bridge, reading or volunteering. You could also consider making an opportunity to revive old friendships which may have lapsed because of the workload you accepted during the illness and passing of the person with dementia.

The Australian Centre for Grief and Bereavement is one of a number of organisations which support bereaved people. Churches, LifeLine, and other groups, also provide support. These include the Alzheimer's Australia state and territory offices, which are included in the Links and Resources Section at the back of this booklet.

## CONCLUSION

This booklet has provided information on a range of options that are available to assist people with dementia and their carers and families to plan for the end stage of life. This has included a discussion of Advance Financial and Care Planning, which can help to provide security about end-of-life care and also help to ensure that the wishes of the person with dementia for their end-of-life treatment are known and respected. Although Advance Care Planning is still not widely used in Australia, its use is increasing. It is hoped that this booklet will provide people with dementia and their carers with sufficient information to assist them to put such planning in place.

The laws in each state/territory of Australia relating to Advance Care Planning are different and use different terminology; nevertheless some options are constant across all jurisdictions, including the right of a competent person (either contemporaneously or through an Advance Directive) to refuse treatment including life-saving treatment, or to have treatment withdrawn, and the rights of everyone to adequate control of pain and symptoms.

The main task at present for those providing services to people with dementia and their carers is to make the present system work better and to encourage health care providers to, at least, understand and implement the options that currently exist within the Australian legal system to make the end stage of the lives of people with dementia the best that they can be.

Other options for end-of-life care may become available over time but that will require more widespread debate and discussion.

## LINKS AND RESOURCES

### Support services

Alzheimer's Australia provides practical information on managing some of the day to day issues when caring for someone with dementia.

<http://www.alzheimers.org.au/>

>Services and Support >Support for families and carers

#### **Alzheimer's Australia in each state/territory: contact details:**

<http://www.alzheimers.org.au/>

>Go to your state

#### **Alzheimer's Australia telephone help service:**

Contact the National Dementia Helpline on 1800 100 500.

#### **Australian Centre for Grief and Bereavement**

<http://www.grief.org.au/>

>Grief & Bereavement Support

#### **Better Health Channel Victoria**

<http://www.betterhealth.vic.gov.au>

>Conditions and Treatments >Dementia

#### **Health Insite**

<http://www.healthinsite.gov.au/>

>A-Z Health Topics >Dementia

#### **Seniors.gov.au**

<http://www.seniors.gov.au/>

>A-Z Index >Dementia

### Helpful websites

#### **Advance Care Directives Association Inc**

<http://www.advancecaredirectives.org.au/>

#### **Alzheimer's Australia in each state/territory: contact details**

<http://www.alzheimers.org.au/>

>Go to your state

#### **Australian Government Department of Health & Ageing**

<http://www.health.gov.au>

>Information by health topic >Dementia

**Australian Government Department of Veterans' Affairs**

<http://www.dva.gov.au>

>about DVA >publications >health publications >Living with Dementia

**Benevolent Society**

<http://www.bensoc.org.au/>

>Resources

**Brain Bank**

<http://www.nnf.com.au/platforms/abbn>

**Council On The Ageing (COTA)**

<http://www.cota.org.au>

**GPCOG (General Practitioner assessment of Cognition)**

The GPCOG is a screening tool for cognitive impairment. It has been designed for the primary care setting (i.e. general practitioners, primary care physicians, family doctors, etc).

<http://www.gpcog.com.au>

**Helpguide.org**

<http://helpguide.org/>

>Seniors & Aging >Alzheimer's/Dementia

**Respecting Patient Choices®**

An Australian model of advance care planning.

<http://www.respectingpatientchoices.org.au>

**Publications****Alzheimer's Australia Help Sheets**

These provide advice, common sense approaches and practical strategies on the issues most commonly raised about dementia.

<http://www.alzheimers.org.au/>

>Understanding Dementia and Memory Loss >Help Sheets and Update Sheets

**Alzheimer's Australia: Library**

The collection focuses on dementia, ageing, disability and caring.

<http://www.alzheimers.org.au/>

>Services and Support >Library

**Alzheimer's Australia Online Bookshop**

<http://www.alzheimers.org.au/>

>Services and Support >Bookshop

**Alzheimer's Australia Quality Dementia Care Initiative: part of which is development of a toolkit with carers, service providers and legal practitioners to implement established advance care planning (AASA):**

<http://www.alzheimers.org.au/>

>Research & Publications >Research >Quality Dementia Care Initiative

**Australian Government Productivity Commission**

Caring for older Australians: Productivity Commission Issues Paper May 2010.

<http://pc.gov.au>

>Projects >Commissioned Projects >Current

**Australian Health Ministers' Advisory Council**

Draft National Framework for Advance Care Directives in Australia

<http://www.hwlebsworth.com.au/acdframework/>

**Early planning and younger onset dementia**

<http://www.alzheimers.org.au/>

>Services and Support >I have dementia >Younger onset dementia

**Grief Matters: The Australian Journal of Grief and Bereavement**

<http://www.grief.org.au/>

>Resources >Grief Matters: The Australian Journal of Grief and Bereavement

**Health System Reform and Care at the End of Life: a Guidance Document:**

[www.palliativecare.org.au/](http://www.palliativecare.org.au/)

**Hospice Foundation of America**

<http://www.hospicefoundation.org/>

>Grief >Selected Articles

**How do I apply for an aged care home? Aged Carer: Australians caring for their ageing families at:** <http://www.agedcarer.com.au/topic/aged-care-assistance/residential-aged-care-nursing-homes/how-do-i-apply-aged-care-home>

**Hudson, Rosalie, Ethical issues in end-of-life dementia care. Dementia Care Conference Rokeby, Tasmania February 2008.**

<http://www.alzheimers.org.au/>

>Research & Publications >Conference Papers

**Hughes, Julian. Ethical issues and decision-making in dementia care.**

Alzheimer's Australia Paper No 20, June 2010. Presentation to the National Press Club, Canberra. <http://www.alzheimers.org.au/>

>Research & Publications >Alzheimer's Australia Numbered Publications

**My health, my future, my choice: The Advance Care Directive Association Inc.**

<http://www.advancecaredirectives.org.au>

**Palliative care and dementia: Alzheimer's Australia Discussion Paper No 7, February 2006.**

<http://www.alzheimers.org.au/>

>Research and Publications >Alzheimer's Australia Numbered Publications

**A Plan of Care: a book to help people make health and personal care decisions for a person in NSW who has dementia.**

<http://www.advancecaredirectives.org.au/>

**Research into better ways of diagnosing dementia.**

<http://www.alzheimers.org.au/>

>Research and Publications >Research >Areas of dementia research

**Take control: a kit for making powers of attorney and guardianship: free 60 page booklet. Office of the Public Advocate, Victoria.**

<http://www.publicadvocate.vic.gov.au/publications/121/>

**Towards a National Carers Strategy: Discussion Paper December 2010.**

[www.palliativecare.org.au](http://www.palliativecare.org.au)

**Who can decide? The six step capacity assessment process, edited by Dr Peteris Darzins, Dr D William Molloy, Dr David Strang. ...**

<http://www.alzheimers.org.au/south-australia/resources-alzheimers-australia-sa.aspx>

## Legislation for each state/territory

**ACT: Powers of Attorney Act 2006:**

<http://www.legislation.act.gov.au/a/2006-50/default.asp>

**NSW: Guardianship Act 1987:**

[http://www.lawlink.nsw.gov.au/lawlink/opg/ll\\_opg.nsf/pages/opg\\_yourwaytoplanahead](http://www.lawlink.nsw.gov.au/lawlink/opg/ll_opg.nsf/pages/opg_yourwaytoplanahead)

**Northern Territory: Natural Death Act 1988:**

[http://www.austlii.edu.au/au/legis/nt/consol\\_act/nda1988134/](http://www.austlii.edu.au/au/legis/nt/consol_act/nda1988134/)

**Queensland: Powers of Attorney Act 1998:**

<http://www.legislation.qld.gov.au/LEGISLTN/CURRENT/P/PowersofAttA98.pdf>

**Guardianship & Administration Act 2000:**

<http://www.legislation.qld.gov.au/LEGISLTN/ACTS/2000/00AC008.pdf>

**South Australia: Consent to Medical Treatment and Palliative Care Act 1995:**

<http://www.legislation.sa.gov.au/LZ/C/A/CONSENT%20TO%20MEDICAL%20TREATMENT%20AND%20PALLIATIVE%20CARE%20ACT%201995/CURRENT/1995.26.UN.PDF>

**Tasmania: Guardianship and Administration Act 1995:**

[http://www.austlii.edu.au/au/legis/tas/consol\\_act/gaaa1995304/](http://www.austlii.edu.au/au/legis/tas/consol_act/gaaa1995304/)

**Victoria: Medical Treatment Act 1988:**

<http://www.health.vic.gov.au/>

>Legislation >Health legislation >Medical Treatment

**Advance Directives: the legal issues: presentation by Beth Wilson, Health Services Commissioner, at:**

[http://www.health.vic.gov.au/improvingcareforums/1107/b\\_wilson.pdf](http://www.health.vic.gov.au/improvingcareforums/1107/b_wilson.pdf)

**Western Australia: The Acts Amendment (Consent to Medical Treatment) Act 2008:**

[http://www.austlii.edu.au/au/legis/wa/num\\_act/aatmta200825o2008449/](http://www.austlii.edu.au/au/legis/wa/num_act/aatmta200825o2008449/)

## Contact details for Guardianship Tribunals and Public Advocates in each state/territory

## ACT

**ACT Office of the Public Advocate**

*The Public Advocate Act (2005)* came into effect on 1 March 2006, changing our name from Community Advocate to Public Advocate of the ACT.

This new Act defines PA ACT clients as including young people and adults in the community who suffer from a condition or situation that makes them potentially vulnerable to abuse, exploitation or neglect. This includes people 'in care' such as in a mental health facility or supported community accommodation. The Act further legislates for the ACT Public Advocate to be appointed as Guardian, in line with the Guardianship and Management of Property Act 1991, for those people who have 'impaired capacity' and for whom there is no-one else suitable or available to act as their guardian and make substitute decisions on their behalf.

<http://www.publicadvocate.act.gov.au/>

## NSW

The Guardianship Tribunal is a legal tribunal established under the Guardianship Act 1987. The Tribunal has a key role in the protection and empowerment of people living with a decision-making disability. It exercises a protective jurisdiction and facilitates substitute decision making by hearing and determining applications for the appointment of guardians and financial managers for adults with decision-making disabilities.

<http://www.gt.nsw.gov.au/>

## NORTHERN TERRITORY

Adult Guardianship gives someone the legal responsibility to make decisions for someone else, over the age of 18, who is unable to make reasonable judgements or decisions about their daily living because of an intellectual disability.

[http://www.health.nt.gov.au/Aged\\_and\\_Disability/Adult\\_Guardianship/index.aspx](http://www.health.nt.gov.au/Aged_and_Disability/Adult_Guardianship/index.aspx)

## QUEENSLAND

The Adult Guardian looks after the interests of adults with impaired capacity, and can also be the guardian of last resort for adults who have nobody else to be their guardian.

<http://www.justice.qld.gov.au/justice-services/guardianship/adult-guardian>

## Public Advocate.

The role of the Public Advocate is systemic advocacy which promotes and protects the rights and interests of adults with impaired decision-making capacity. The Public Advocate does not deal with individual cases.

<http://www.justice.qld.gov.au/justice-services/guardianship/public-advocate>

## SOUTH AUSTRALIA

**Office of the Public Advocate**

The role of the Office of the Public Advocate (OPA) is to promote and protect the rights of people with mental incapacity in South Australia.

<http://www.opa.sa.gov.au/cgi-bin/wf.pl>



The Guardianship and Administration Act 1993

This Act recognises that people who are not able to make decisions for themselves may need additional support and assistance to ensure that a certain quality of life is maintained. It also contains a number of provisions to protect a person from the risk of neglect, abuse or exploitation. The Guardianship and Administration Act 1993 allows the Guardianship Board to make certain orders in relation to a person with a mental incapacity.

[http://www.opa.sa.gov.au/cgi-bin/wf.pl?pid=&mode=cd&file=../html/documents//12\\_Links>Guardianship and Administration](http://www.opa.sa.gov.au/cgi-bin/wf.pl?pid=&mode=cd&file=../html/documents//12_Links>Guardianship and Administration)

TASMANIA

The Office of the Public Guardian promotes, speaks for, and protects the rights and interests of people with disabilities and acts as the guardian of people with disabilities when appointed by the Guardianship and Administration Board. Part 3 of the Guardianship and Administration Act 1995 establishes the Office and gives the Public Guardian her/his powers and functions.

<http://www.publicguardian.tas.gov.au/>

VICTORIA

**Victorian Civil and Administrative Tribunal (VCAT)**

VCAT hears and determines applications under the Guardianship and Administration Act 1986 in relation to adults who have a disability. "Disability" means: intellectual impairment; mental disorder; brain injury; physical disability; dementia.

<http://www.vcat.vic.gov.au/CA256DBB0022825D/HomePage?ReadForm&1=Home~&2=~&3=>

**Office of the Public Advocate (OPA)**

The OPA is an independent statutory body established by the Victorian State Government, working to protect and promote the interests, rights and dignity of people with a disability.

<http://www.publicadvocate.vic.gov.au/>

WESTERN AUSTRALIA

**Office of the Public Advocate**

The Office of the Public Advocate works to promote and protect the human rights of more than 65,000 Western Australian adults with decision-making disabilities.

<http://www.publicadvocate.wa.gov.au/>

**Department of the Attorney General:**

This department offers advice and help on guardianship.

<http://www.dotag.wa.gov.au/>

**TABLE 1: Terminology used in each state/territory for Advance Care Planning for health-related matters**

(Note: all states/territories have legislation which allows a Guardianship Board or equivalent to appoint a formal Guardian).

	Written Instructional Directive	Patient-Appointed Agent/Proxy	If No-one Appointed by Patient
ACT	Health Direction	Medical Agent; or Attorney for Medical Treatment under Enduring Power of Attorney	Health Attorney: in priority order - domestic partner; carer; close relative or friend
NSW	Common Law Advance Directives	Enduring Guardian	Person Responsible: in priority order – spouse (includes de facto and same-sex); carer; close relative or friend
NT	Advance Directive	No provision	No provision
QLD	Advance Health Directive	Enduring Power of Attorney for Personal/Health matters	Statutory Health Attorney: priority order same as NSW
SA	Advance Directive or Living Will	Medical Agent appointed under a Medical Power of Attorney; or Enduring Guardian	Contact the SA Office of the Public Advocate for directions
TAS	Common Law Advance Directive	Guardian	Person Responsible: in priority order – spouse; carer; close relative or friend
VIC	Refusal of Treatment Certificate	Medical Agent – appointed under EPoA Enduring Guardian with health care powers Person appointed in writing to make decisions about medical/dental treatment including the proposed treatment	Person Responsible (apart from patient or VCAT- appointed person) in priority order – domestic partner, primary carer, nearest relative over 18
WA	Advance Health Directive	Enduring Power of Guardianship	Contact the Office of the Public Advocate WA for directions

Table 2: Summary of National Law Relating to Advance Care Planning, June 2010

	Written Directive	Patient-Appointed Agent/Proxy	Comments
ACT	YES	YES	<i>Powers of Attorney Act 2006</i> allows an adult to give a direction about the refusal or withdrawal of medical treatment. There is no requirement for the condition to be current or terminal. It also provides for appointing an Enduring Power of Attorney/agent for medical decisions.
NSW	YES	YES	The NSW Health document <i>Using Advance Care Directives (2004)</i> encourages the use of common law advance directives; NSW Supreme Court case 2009 confirmed that they are legally binding. <i>The Guardianship Act 1987</i> allows a person 18 years or over to appoint Enduring Guardians as substitute decision-makers.
NT	YES	NO	<i>Natural Death Act 1988</i> allows a person 18 years or over to make an advance directive to refuse extraordinary treatment in the event of a terminal illness.
QLD	YES	YES	<i>Powers of Attorney Act 1998</i> and <i>Guardianship &amp; Administration Act 2000</i> allow a person 18 years or over to make an advance directive to consent to or refuse treatment and to appoint an Enduring Power of Attorney for health matters to consent to or refuse medical or dental treatment.
SA	YES	YES	<i>Consent to Medical Treatment and Palliative Care Act 1995</i> allows a person 18 years or over to write an advance directive that refuses consent to medical treatment for the terminal phase of a terminal illness and appoint an agent/ medical power of attorney as a substitute decision maker.
TAS	NO	YES	<i>Guardianship and Administration Act 1995</i> allows a person 18 years or over to appoint Enduring Guardians as substitute decision makers.
VIC	YES	YES	<i>Medical Treatment Act 1988</i> allows a patient to write a 'refusal of treatment' certificate, but only for a current illness, which does not have to be terminal. The legislation also allows appointment of an agent/substitute decision maker who can refuse treatment.
WA	YES	YES	<i>The Acts Amendment (Consent to Medical Treatment) Act 2008</i> allows an adult to write an advance directive to consent to or refuse treatment for a current condition or terminal illness and to appoint an Enduring Power of Guardianship as a substitute decision maker.

ALZHEIMER’S AUSTRALIA PUBLICATIONS

Quality Dementia Care Series

- 1. Practice in Residential Aged Care Facilities, for all Staff
- 2. Practice for Managers in Residential Aged Care Facilities
- 3. Nurturing the Heart: creativity, art therapy and dementia
- 4. Understanding Younger Onset Dementia
- 5. Younger Onset Dementia, a practical guide
- 6. Understanding Dementia Care and Sexuality in Residential Facilities
- 7. No time like the present: the importance of a timely dementia diagnosis

Papers

- 1. Dementia: A Major Health Problem for Australia. September 2001
- 2. Quality Dementia Care, February 2003
- 3. Dementia Care and the Built Environment, June 2004
- 4. Dementia Terminology Framework. December 2004
- 5. Legal Planning and Dementia. April 2005
- 6. Dementia: Can It Be Prevented? August 2005 (superceded by paper 13)
- 7. Palliative Care and Dementia. February 2006
- 8. Decision Making in Advance: Reducing Barriers and Improving Access to Advanced Directives for People with Dementia. May 2006
- 9. 100 Years of Alzheimer's: Towards a World without Dementia. August 2006
- 10. Early Diagnosis of Dementia. March 2007
- 11. Consumer-Directed Care – A Way to Empower Consumers? May 2007
- 12. Dementia: A Major Health Problem for Indigenous People. August 2007.
- 13. Dementia Risk Reduction: The Evidence. September 2007
- 14. Dementia Risk Reduction: What do Australians know? September 2008
- 15. Dementia, Lesbians and Gay Men November 2009
- 16. Australian Dementia Research: current status, future directions? June 2008
- 17. Respite Care for People Living with Dementia. May 2009
- 18. Dementia: Facing the Epidemic. Presentation by Professor Constantine Lyketsos. September 2009
- 19. Dementia: Evolution or Revolution? Presentation by Glenn Rees. June 2010
- 20. Ethical Issues and Decision-Making in Dementia Care. Presentation by Dr Julian Hughes. June 2010
- 21. Towards a National Dementia Preventative Health Strategy. August 2010
- 22. Consumer Involvement in Dementia Research August 2010

Reports commissioned from Access Economics

The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, March 2003  
Delaying the Onset of Alzheimer’s Disease: Projections and Issues, August 2004  
Dementia Estimates and Projections: Australian States and Territories, February 2005  
Dementia in the Asia Pacific Region: The Epidemic is Here, September 2006  
Dementia Prevalence and Incidence Among Australian’s Who Do Not Speak English at Home, November 2006  
Making choices: Future dementia care: projections, problems and preferences, April 2009  
Keeping dementia front of mind: incidence and prevalence 2009-2050, August 2009  
Caring places: planning for aged care and dementia 2010-2050. July 2010

Other Papers

Dementia Research: A Vision for Australia September 2004  
National Consumer Summit on Dementia Communique, October 2005  
Mind Your Mind: A Users Guide to Dementia Risk Reduction 2006  
Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities, November 2006  
National Dementia Manifesto 2007-2010  
Dementia: A Major Health Problem for Indigenous People August 2007  
In Our Own Words, Younger Onset Dementia, February 2009  
National Consumer Summit Younger Onset Dementia Communique, February 2009  
Dementia: Facing the Epidemic. A vision for a world class dementia care system. September 2009



**Alzheimer's  
Australia**  
Living with dementia

Visit the Alzheimer's Australia website at  
[www.alzheimers.org.au](http://www.alzheimers.org.au)

for comprehensive information about

- dementia and care
- information, education and training
- other services offered by member organisations

Or for information and advice contact  
the National Dementia Helpline on  
1800 100 500

(National Dementia Helpline is an  
Australian Government funded initiative)