
Legal Planning and Dementia

Alzheimer's Australia

Position Paper 5

April 2005

Lundbeck



Alzheimer's
Australia
Living with dementia



ACKNOWLEDGMENTS AND DISCLAIMER

This paper contains information for people with dementia and their families and carers about legal planning and legal issues related to dementia.

The paper is supported by an online summary of legal resources in each State and Territory which can be accessed by following the links from www.alzheimers.org.au/legal

Alzheimer's Australia thanks Sally Bolton and Dr Cameron Stewart, Macquarie University, for preparing this paper.

We also acknowledge the contributions from the many government officials and other professionals throughout Australia who generously volunteered their time to review this paper.

This publication was funded by an unrestricted grant from Lundbeck Australia Pty Ltd.

The photographs were provided by Lynton Crabb photography.

Important note

Whilst appreciable care has been taken in the preparation of this information paper, Alzheimer's Australia and its member organisations accept no responsibility for any inaccuracies or information that may be perceived as misleading.

The information contained in this paper and on the supporting pages on the Alzheimer's Australia web site is intended to support, not replace discussion with a professional person and is not to be taken as the giving of legal advice which can only be tailored to specific and individual circumstances.



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INTRODUCTION

If you have been diagnosed with dementia you may be wondering what sort of legal issues you may face. This information paper outlines some of the legal issues that may arise and explains some basic legal concepts that may be helpful for you to understand. The paper also highlights some of the ways in which you can plan ahead.

Planning ahead will enable you to have your say in the decisions that affect you. Planning will also make life easier for you and your family and friends by helping you to avoid legal problems in the future.

The ways in which you can plan ahead are a little different depending on which State or Territory you live in. The Alzheimer's Australia website at www.alzheimers.org.au/legal can point you to more detailed information on the legal planning resources that are available in each State or Territory. You may also obtain this information by calling the Dementia Helpline on **1800 100 500**.

This paper covers:

- Why you should plan ahead;
- Planning about financial arrangements;
- Planning about medical decisions;
- Legal issues about driving when you have dementia;
- Legal issues about dementia, discrimination and your employment;
- Other contact with the legal system.



WHY PLAN AHEAD?

The idea of 'legal capacity'

A person's 'legal capacity' (also called 'legal competence') is the ability of that person to make decisions that the legal system will uphold. In the absence of evidence to the contrary, the law presumes adults are 'of sound mind' and capable of making decisions affecting their lives – decisions such as:

- money management;
- medical treatment;
- buying and selling things; and
- making a contract with someone.

However, when a person becomes ill, they may not be able to make decisions about such things, and the legal system looks for alternative ways of managing a person's affairs.

Being diagnosed with dementia doesn't mean that you aren't able to make these decisions. However, there may be a time when your illness takes away your legal capacity to make these decisions.

When does a person have legal capacity?

The law says an adult has the capacity to make a particular decision when he or she can:

- understand the information being given;
- make a decision on the basis of the information given after having weighed and fully appreciated the positive and negative consequences of the decision; and
- communicate that decision to another person.

Doctors and lawyers can help to assess a person's capacity to make decisions. Other bodies such as public guardians and protective commissions may also be involved in helping guardianship tribunals or the courts to determine whether a person has capacity. You can find out more about the different organisations that can test capacity in your State or Territory at www.alzheimers.org.au/legal or ring the Dementia Helpline on **1800 100 500**.



Why planning is so important

Planning will enable you to have more of a say about decisions that may need to be made in the future. Many of the decisions you make in daily life also affect your family and friends. Planning ahead will help to minimize stress for you, your friends and your family.

Planning is essential if you live alone but is also necessary if you have a spouse or partner. The rights of your husband, wife or partner to handle your affairs and make decisions for you do vary depending on the State/Territory in which you live.

PLANNING FOR FINANCIAL DECISIONS

Things to think about

1. Your financial responsibilities

Dementia may affect your ability to manage your financial responsibilities. These responsibilities may include:

- Paying electricity bills, telephone bills, mortgage or rent;
- Paying credit card bills;
- Paying for health insurance, home and contents insurance, or car insurance;
- Lodging an accurate tax return each year.

If you own a business, if you are in a business partnership or if you are a director of a company or non-profit organisation you will have extra things to think about, such as:

- Your duty to keep accurate, detailed accounts
- Your responsibility to pay GST and other business taxes
- Other duties that come with being in a partnership or being a director of a company or non-profit organisation.

2. Your money and assets

You may find at some point that your ability to manage your finances will be affected by dementia. Planning ahead will allow you to safeguard against poor decisions, such as selling your home too cheaply, or giving away your car on the spur of the moment. Planning is especially important when you share some assets or bank accounts with your husband, wife, partner, other family or friends.



Financial planning tools

There are simple things you can do to safeguard your money and your ability to access your money, such as having joint signatures with a trusted friend or relative on your bank accounts.

Apart from simple measures like this, there are **two main legal tools** that you might want to use:

- 1. A Will.** A will controls what happens to your property after you die.
- 2. An Enduring Power of Attorney (EPA).** EPAs let you appoint someone to control your property and your financial affairs for when the time comes when you do not have the capacity to make these decisions for yourself.

1. Wills

Why make a will?

Making a will lets you choose what happens to your belongings and property when you die. It may also let you make arrangements for the care of dependent children or your pets. Making a will makes life less complicated for your family or friends, who will have to look after your estate. It also saves money.

Everyone should make a will. However, it is especially important for a person with dementia to make a will because to make a valid will, you need to have legal capacity. As explained above, at some point the symptoms of your illness may take away your legal capacity to make a will.

Ways to make a will

If you have been diagnosed with dementia you should seek the assistance of a lawyer (or the Public Trustee in your State/Territory) when you draft a will, especially if you have noticed your dementia affecting your decisions in other areas of your life.

Some people choose to draft their own will using a kit (such as the ones available from newsagents or Australia Post shops). However, to make a valid will, you have to be able to understand and appreciate the decisions that you are making about your assets and the effects of your decisions. If you make your own will using a kit, your family may later question whether you were mentally capable of making the will or the will may not be granted probate after your death.



When you tell a lawyer that you have been diagnosed with dementia, he or she can provide advice about whether you have the legal competence to make a will. If the lawyer is not sure that you are legally capable of making a will, he or she might ask a doctor to check your decision-making ability. In this way you can reduce the chance of family and friends arguing about the validity of your will after you have died.

Revisiting your will

If you already have a will, you may want to check to see that it still reflects your wishes and is appropriate for your current family circumstances. If you made your will a long time ago, it may no longer reflect your wishes.

You should also check that your friends and family know where to find a copy of your will. A lost will can cause distress, inconvenience and extra cost to your estate.

2. Enduring Powers of Attorney

What is an Enduring Power of Attorney?

A power of attorney is a document that allows the person who creates it (usually called a 'donor') to formally appoint another person as a substitute decision-maker (usually called a 'donee'). Once appointed, the substitute decision-maker has the power to make decisions about the donor's property (such as how to invest it, whether to sell it, or whether to lease it).

An ordinary power of attorney becomes invalid if the donor loses legal capacity. An enduring power of attorney ('EPA') is different because it remains valid even if the donor becomes unable to manage his or her affairs. This is why EPAs are more useful for people living with dementia. An EPA is one tool that you could use to appoint a substitute decision-maker and it will continue to be legally effective if you later lose legal capacity.

In most States and Territories, you can choose whether the EPA takes effect immediately, or only if you lose legal capacity. However, if you decide that it is to take effect immediately, in most States you will not lose all control or authority over your finances. If you appoint someone to have your EPA, that person should ask your permission before making decisions about your finances, and cannot legally make decisions that you do not agree with while you are still competent.

Why make an EPA?

Making an EPA lets you choose a person that you trust to manage your financial affairs if you later lose the capacity to make these decisions for yourself. By planning ahead, you can make sure that the person you select understands your priorities and how you want your financial affairs to be managed.



If you have no plans in place and you lose the ability to manage your financial affairs, then the court or tribunal in your State or Territory will need to appoint someone to make these decisions for you. This person might be a family member, your friend, or it might be a State body like a Public Trustee, which is set up to manage people's financial affairs.

How can I make an EPA?

An EPA has to meet certain requirements for it to be valid. Usually, you will have to use a particular form and get a particular type of person to witness you signing it. You might also need to register an EPA. These requirements are a little different in each State and Territory. The Alzheimer's Australia website at www.alzheimers.org.au/legal can point you to specific information on how to make an EPA in your State or Territory.

Can I change an EPA?

You can revoke or change an EPA so long as you have the legal capacity to do so. In other words, as long as you have the capacity to make an EPA you have the capacity to change it. If you no longer have legal capacity, you won't be able to change or revoke an EPA. If it becomes necessary, the relevant court or tribunal in your State or Territory may change an EPA or appoint a different person if they think it is in your best interests to do so.

What powers do I give to the person I appoint?

The maximum power the person you appoint can have is the power to make all financial decisions on your behalf. This includes accessing your bank account to pay your bills, selling your house if you need to move into a residential care facility and, in some States, the person you appoint can make decisions about what medical treatment you receive (this will be discussed in greater detail below).

Alternatively, you can put restrictions on the power of the person you appoint. For example, you can say that you don't want the person to have the authority to decide where you will live. But remember, someone needs to be able to make these decisions for you if you become legally incapable of making them.

If you do not make legal arrangements to appoint an appropriate person to make these decisions for you, then the relevant government body in your State or Territory may need to appoint a family member, friend or official body to make such decisions for you.

What are the responsibilities of the person you appoint?

The person you appoint is generally responsible for managing your financial records and accounts, including lodging your tax return. This is an important responsibility. In some States, the person may be fined if he or she doesn't keep proper records or look after your financial responsibilities carefully. In all States and Territories, the person appointed has a responsibility to make decisions based on what they think is in *your* best interests.



PLANNING FOR DECISIONS ABOUT MEDICAL TREATMENT

Things to think about

It is a fundamental principle of our legal system that a person has the right to control what medical treatment she or he is given, from little things like a blood test, to big decisions like whether to have surgery. Doctors have an important role in helping their patients make decisions, but the decision to agree to a treatment is ultimately made by the patient and not the doctor.

At some stage, dementia might prevent you from being able to consent to medical treatment. Dementia may affect your ability to understand the nature of the medical procedure or the risks that may be involved. Your doctor may ask you to take a competency test if he or she is unsure of whether you are able to make the decision to have the treatment or medical test. This might be as simple as asking you a few questions, or if it is a serious medical treatment like surgery, your doctor might ask you to take a more formal or longer assessment.

Why plan ahead?

The advantage of planning ahead is that you can have a greater say in the types of treatment that you will be given. This is particularly important if you have personal or religious beliefs about different types of treatment. Everyone should make these sorts of plans, but it is especially important to plan ahead if you have been diagnosed with dementia.

Two things to keep in mind

1. If you lose the legal capacity to make decisions about your medical treatment then someone else needs to make those decisions for you. In all States except Western Australia you can appoint someone you trust to make these decisions. (You can find out about the options available for medical planning in Western Australia at www.alzheimers.org.au/legal) If you have not planned ahead, the law in every State and Territory allows a particular Court to appoint someone to make decisions for you. This is explained below.
2. You can write down your wishes about what medical treatment you do and don't want. This way you can have your say even if someone else is ultimately responsible for making the decisions on your behalf.



Who can make decisions about your medical treatment if you have lost legal capacity?

If you no longer have legal capacity, there are three alternative types of substitute decision-makers who can manage your health affairs for you.

1. In some States and Territories your family members have the legal power to consent to medical treatment that will promote your health and well-being. In other States and Territories your relatives do not have this legal power.
2. Your treating doctors can manage your health care. Doctors have the legal power to treat people in emergencies. In some States and Territories, doctors can also decide what treatment to give you if you have not appointed a substitute decision-maker.
3. The third alternative is that a tribunal or court will appoint someone to manage your health care. Each State and Territory has different regulations concerning guardianship, but they all provide for the appointment of *guardians*, (sometimes called *managers* or *administrators*) who can then manage your health care. These tribunals and courts can also review and regulate the conduct of guardians and can manage a person's health care directly.

You can find out more about the laws in your State or Territory at www.alzheimers.org.au/legal

Planning tools for decisions about medical treatment

There are two types of tools available:

- 1. An Enduring Power of Attorney covering health matters:** This tool allows you to appoint a person to be your substitute-decision maker for medical and lifestyle decisions. Some States and Territories, such as South Australia and New South Wales, call these *Enduring Guardianship Orders*.
- 2. An Advance Directive:** A written document expressing your wishes about medical treatment.

1. Enduring powers of attorney covering health matters

EPAs have already been discussed above in the context of financial planning. In some States/Territories you can also use an EPA to appoint someone you trust to make decisions about your medical treatment and your day to day living arrangements.



The advantage of using an EPA to appoint someone in this context is that *you* choose the substitute decision-maker, rather than a guardianship tribunal or court appointing someone. In some States and Territories EPAs also allow you to indicate your preferences concerning medical treatment. This gives your appointed substitute decision-maker some guidance as to how your treatment should be managed.

Important → In most States and Territories you will need to make a 'medical' EPA or appoint an Enduring Guardian specifically to look after decisions about your medical treatment as well as making an EPA to appoint someone to look after your financial affairs. You can select the same person to do both tasks.

Western Australia does not have this sort of planning tool. You can find out more about the specific planning tools you can use for medical and lifestyle decisions in your State or Territory at www.alzheimers.org.au/legal

2. Advance Directives

An advance directive is different to an EPA in that it does not appoint a substitute decision-maker. It is normally a document in which you say, in advance, what medical treatment you would like to receive if you become unable to make, or communicate, such decisions. An advance directive also allows you to tell your doctor what treatment you don't want in a particular situation. In some States and Territories, you can speak fairly generally when saying what treatment you do and don't want to receive. However in other States and Territories, you have to be very specific about the type of situation in which you don't want to receive certain treatments. It is always helpful to make a general statement of your wishes and/or values.

Other names for advance directives

You might hear advance directives described as *living wills*. Different States also call advance directives by different names. For example, in Queensland they are called *advance health directives*, in the Northern Territory they are called *directives* and in the ACT they are called *directions*.

How do I make an advance directive?

There are different procedures for making an advance directive in each State/Territory. Some States have legislation which requires you to use certain forms and have the document signed and witnessed. In other States it's not so formal. There are also different limitations on the circumstances in which you can refuse medical treatment ahead of time. For further information about advance directives in your State or Territory, go to www.alzheimers.org.au/legal



Remember

- Initially the best person to speak to about your wishes concerning medical treatment is your doctor. Your doctor should be able to inform you about the types of treatment decisions that might have to be made for you in the future and the consequences of having, or not having, those treatments. Try to get as much information as you can about your medical condition and use that information when you make an advance directive and when you decide who you want to appoint as your substitute decision-maker.
- It might also be a good idea to speak to a lawyer concerning the drafting of a health care EPA or advance directive, but do that after you have an informed opinion about the medical treatments.
- Finally, you might feel uncomfortable having to discuss these issues, but if your wishes concerning medical treatment are made known then it is more likely that you will receive the treatment you desire. It is also more likely that you will take away some of the stress and worry from your friends and family, who will be forced to make decisions for you if you have not completed an EPA or advance directive.

DRIVING WITH DEMENTIA

The symptoms of your dementia will eventually affect your ability to drive safely. Alzheimer's Australia can give you more information about driving with dementia. Visit the web site at www.alzheimers.org.au/legal or contact the Dementia Helpline on **1800 100 500**.

Do you have to disclose your illness to your driving licensing authority?

Yes. Drivers in all States and Territories except Western Australia have an obligation to tell their licensing authority of any medical condition that might affect their ability to drive safely. Diabetes, some heart diseases and dementia are all medical conditions that need to be disclosed because they may affect your driving ability.

What happens after you've told your State's driving licensing authority about your illness?

The licensing authority will generally ask you to see a doctor who will assess whether it is safe for you to drive. The licensing authority will give you a form which the doctor will fill out.

If your doctor determines that your illness is affecting your ability to drive, then the licensing authority in most States can place conditions on your licence. These conditions might be that you can only drive near your home, that you can only drive at certain times



or that you can only drive below 100km/h. You may be required to have regular medical tests as your dementia will cause your ability to drive to decline over time.

The licensing authority will only revoke your licence if your doctor assesses that your illness is seriously affecting your ability to drive. Revoking a licence is a last resort and you can generally appeal the decision if it is something you feel strongly about.

What happens if you don't want to tell the driving licensing authority about your illness?

In some States you can be fined if you don't disclose your illness to the licensing authority. If you have an accident anywhere in Australia, you may face criminal charges for dangerous driving. You may also have problems in getting your insurance company to cover you for the cost of the accident. If someone else is hurt in the accident and they sue you, you may have to pay them compensation for their pain and suffering as well as paying for the damage to their vehicle.

Can your doctor tell the driving licensing authority about your illness?

Because of their obligation of patient confidentiality, a doctor won't tell the licensing authority about your illness just because you have been diagnosed with dementia, but your doctor will probably encourage you to do so. However, in most States a doctor **can** tell the licensing authority about your dementia **if** the doctor believes that your dementia has reached a stage where your driving is likely to endanger other people on the road.

In South Australia and the Northern Territory a doctor **must** notify the licensing authority if the doctor believes that any person is physically or mentally unfit to drive.

What if you need to drive for your work?

If you are a professional driver, the licensing authority will probably ask you to see a specialist before making a decision about your licence. The licensing authority will also take into account the nature of your driving task and the risk posed to the public if you have an accident.

If conditions are placed on your licence, your employer has an obligation to take reasonable steps to adapt the work to your needs. If you are assessed to be unfit to drive, your employer has an obligation to take reasonable steps to find you alternative tasks that you can do instead of driving. The Alzheimer's Australia website (at www.alzheimers.org.au/legal) has more information about this topic and can point you to resources available in your State or Territory. Otherwise ring the Dementia Helpline for advice on **1800 100 500**.



DEMENTIA, DISCRIMINATION AND YOUR EMPLOYMENT

People with dementia may experience discrimination for example, in areas like insurance and accommodation, as a result of their diagnosis. Seek legal advice if you believe that you have been treated unfairly.

Your employment

You may notice that the symptoms of your illness begin to affect your work. You may find, for example, that you have trouble concentrating, you forget important things, or you lose your confidence.

Most employers have a legal responsibility to take reasonable steps to help you find a way around the difficulties you are experiencing because of your dementia if you wish to continue working. Your employer has a different level of responsibility depending on the size of the business and whether you are a permanent employee, a casual or a contractor. The Alzheimer's Australia website can point you to further information about your rights and refer you to resources available in your State or Territory.

Visit www.alzheimers.org.au/legal or ring the Dementia Helpline on **1800 100 500**.

Remember

If your employer fires you because of your dementia, or fails to help you adapt your job to what you can do, they **may** be unlawfully discriminating against you. If you seek legal help, you may be able to get your job back or obtain compensation.



OTHER CONTACT WITH THE LEGAL SYSTEM

Apart from legal planning, you may find that you come into contact with the legal system in other ways at some stage.

Contact with the civil courts, criminal courts or police

Some people with dementia may get involved with the civil courts, perhaps because of some dispute related to your business activities or private situation. Examples include disagreements about contracts, custody of children and ownership of property.

You may be arrested and find yourself in court. It is not uncommon, for example, for a person with dementia to forget to pay for something in a shop. This may be seen as shoplifting. Many shopkeepers will be understanding about it. However, if you are arrested, you will need to get legal advice.

Seek advice from a number of sources to make sure that you get appropriate support and the best possible outcome for you and your family. There may be some special arrangements in place in your State or Territory to support people with dementia in their dealings with the legal system.

Legal Aid, the Law Society or a Community Legal Centre in your State or Territory may be able to give you free or affordable legal advice, or point you to a suitable legal adviser.

Note:

It is **very important** that you always tell your legal adviser that you have dementia. It may also be helpful for you to take someone you trust with you when you visit your adviser.

If your legal adviser knows about your dementia, he or she can check that you are legally capable and take special care to make detailed records so that if anyone later questions whether you were capable, the issue can be sorted out as quickly and as inexpensively as possible.

If the adviser believes that you do not have the capacity to be making decisions about the legal issue you face, he or she may need to take instructions from your substitute decision-maker (including seeking advice from the Guardianship authority in your State or Territory).

For more information, see the Alzheimer's Australia web site at www.alzheimers.org.au/legal or call the Dementia Helpline on **1800 100 500**.



A FINAL NOTE TO CARERS, FAMILY AND FRIENDS

If you are concerned that:

- the person with dementia might not be able to make decisions competently; or
- the person with dementia is making/acting on decisions to the detriment of other family members; or
- the person's guardian, or other substitute-decision maker is not acting in the person's best interests; or
- the person with dementia is being (or is at risk of being) abused, neglected, or mistreated

or if you are a substitute decision-maker for a person with dementia and you want help or advice about your responsibilities, you should contact the Guardianship authority in your State or Territory.

Alzheimer's Australia has further information on its website at www.alzheimers.org.au/legal or you can call the Dementia Helpline on **1800 100 500**.



GLOSSARY

Advanced Health (Care) Directives: see **Advance Directive**

Anticipatory Grants or Directions: see **Advance Directive**

Capacity: see **Legal Capacity**

Advance Directive

A written statement by you specifying what treatment you do and don't want to have in the future.

Advance directives are also called **Advanced Health Directives** and **Advanced Health Care Directives** and in South Australia these are called **Anticipatory Grants** or **Anticipatory Directions**.

There are substantial differences in **Advance Directives** in different States and Territories in Australia. In some States you have to use a particular form and satisfy particular requirements, such as having particular people witness you sign it. In other States you do not need to be so formal.

Discrimination

Treating someone less favourably because they have a disability or they are of a certain sex, age, race or nationality. It is generally unlawful for employers and other people to discriminate against you on the basis that you have dementia.

Enduring Power of Attorney

A formal document appointing a person to be your substitute decision-maker. It is called an *Enduring* Power of Attorney because it endures even after you lose legal capacity to make decisions.

People with dementia can use an Enduring Power of Attorney to appoint a person to make decisions on their behalf after they lose the legal capacity to make decisions. The person you appoint (sometimes called a **donee** or **attorney**) can make decisions about your financial affairs. When you make a power of attorney, you are called the **donor** or **principal**. In some States the person you appoint can also make decisions about the medical treatment you receive and make decisions about your day-to-day life.



Legal Capacity, also called **Legal Competence** and in South Australia, **Mental Capacity**.

Legal capacity is the ability of a person to make decisions that the law will uphold. As the symptoms of your dementia increase, it is possible you will lose your legal capacity. This means you should appoint someone you trust to make decisions on your behalf in case you lose the legal capacity to make the decisions yourself.

Power of Attorney

A formal document appointing someone to be your substitute decision maker. A Power of Attorney stops being valid once you lose your legal capacity to make decisions. A Power of Attorney is useful if you want to go on a holiday overseas and appoint a person at home to look after your financial affairs while you are away. Because dementia eventually takes away your legal capacity, Powers of Attorney are not very helpful for people with dementia. See **Enduring Power of Attorney**

Public Trustee

A body set up by the government in most States and Territories to manage the financial affairs of people unable to look after their own financial affairs. A court, board or tribunal that looks after guardianship matters in your State or Territory can appoint the Public Trustee to look after your finances if there is no other appropriate person to appoint.

The Person Responsible

In Tasmania and Victoria, this is the first person on a list of people who can legally make a decision about a person's medical treatment when the person is unable to make that decision. The idea of **the Person Responsible** is to make it clear which family member, friend or other person, will be the one to make the decisions about a person's medical treatment when a patient is unable to make the decision. Other States and Territories do not use this system. Queenslanders: see **Statutory Health Attorney**

Statutory Health Attorney

This is Queensland's version of **the Person Responsible**. Where a person has not appointed a substitute decision-maker using a power of attorney or guardianship order, and has lost the ability to make a decision about his or her medical treatment, the first person on a list of people (such as the person's spouse or child over the age of 18) will be the person who can make a decision about the medical treatment. Other States and Territories do not use this term.





Visit the Alzheimer's Australia website at
www.alzheimers.org.au
for comprehensive information about:

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

Otherwise, for further information and advice contact:
the **Dementia Helpline** on **1800 100 500**