DEMENTIA AND YOUR LEGAL RIGHTS

A PRACTICAL GUIDE TO HELP PEOPLE DIAGNOSED WITH DEMENTIA, THEIR FAMILIES AND CARERS, TO BETTER UNDERSTAND THE LEGAL ISSUES THEY MAY BE FACED WITH, THEIR LEGAL RIGHTS AND THE ACTIONS THEY CAN TAKE TO PROTECT THEIR RIGHTS.

By Ms Sue Field and Professor Colleen Cartwright
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Alzheimer’s Australia respectfully acknowledges Aboriginal and Torres Strait Islander people as Traditional Custodians of their land, we also acknowledge both past and present Elders, and their continuing connection to country.
INTRODUCTION

This booklet has been written to help people diagnosed with dementia, their families and carers to better understand the legal issues they may be faced with, their legal rights and the actions they can take to protect their rights.

The issues covered in this booklet include:

1. What mental capacity means, and how it applies to decision-making.
2. Your legal rights and decision-making with regard to your finances.
3. Your legal rights and decision-making with regard to your health care and personal matters.
4. Your legal rights and responsibilities in relation to other matters including employment; superannuation; criminal responsibility; voting, driving; travel; and your Will.

For the person diagnosed with dementia, the information in this booklet may include issues that you have not previously considered or discussed with others. This may seem like a lot of information to digest, and it may be helpful to review this document in sections over a period of time. It is important for you to discuss your views and wishes with your family and friends, and finalise relevant documents while you are still legally capable of doing so. There are services available to support you through this process, if you need them.

Your circumstances are unique to yourself, and the information provided in this booklet is of a general nature only. Please seek legal advice if you feel you need it.

It is important to remember at the outset that Australia has a federal system of government, therefore some areas of law are governed by Federal laws, and others are governed by State or Territory laws. These differences will become apparent throughout the booklet. The important thing is to be clear on what the law is in your State/Territory, and how it is administered.
1. **MENTAL CAPACITY AND DECISION-MAKING**

What does capacity to make decisions really mean?

For the person diagnosed with dementia, a very important thing to consider is what might happen at the point where you no longer have the capacity to make your own decisions.

The legislation across Australia is based on the international principle of “presumption of capacity.” This means that you are assumed to have capacity to make your own decisions unless someone can prove that you do not. Just having a family member or non-professional person claiming that you do not have capacity, is not enough for you to be prevented from making your own decisions. Capacity is decision-specific so even if you have been diagnosed with dementia, you may still have capacity to make all or at least some of your own decisions, especially if you have been diagnosed with early dementia. Decision-making capacity may fluctuate over time and depend on the context such as the time of day, location, noise, stress or anxiety levels, medication, or infection.

In Australia, the legislation regarding a person’s capacity to make their own decisions differs in each State/Territory. The Queensland legislation sets out the definition very clearly. It states that capacity for a person for a matter (i.e. any matter you may need to make a decision about), means that the person is capable of:

(a) understanding the nature and effect of decisions about the matter; and

(b) freely and voluntarily making decisions about the matter; and

(c) communicating the decisions in some way.1

If I no longer have capacity can I still be involved in decision-making?

The person who has been appointed to make a decision on your behalf should continue to involve you in the decision-making process to the extent you are able. In addition, sometimes people take part in supported decision-making. **Supported decision-making** is a term that has arisen from concerns about the lack of involvement between a substitute decision-maker and the person they are making decisions about. It is a more inclusive, consultative and shared way of making decisions that is generally viewed as being more in line with a person’s rights. Supported decision-making may be based on a formal agreement between a person with questionable capacity and their supporter, or an informal network of people who support an adult to achieve their own goals and decisions that are based on their own views and wishes.

Who decides when I no longer have capacity to make my own decisions?

The judgement about your capacity to make your own decisions is based on evidence, and usually requires a report from a health professional such as a doctor or psychologist. There are a variety of tests that these professionals may use to guide them in their judgements about your capacity to make your own decisions.

By planning ahead, discussing your wishes with family members or close friends and appointing someone, or more than one person, to make decisions for you if you do not have capacity, you can have peace of mind that your wishes will be legally respected.

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1. Schedule 4, Guardianship and Administration Act 2000 (Qld)
If you have appointed someone to make decisions for you for a time in the future, and they think that perhaps you now lack capacity, that person can discuss with your GP whether it is time for them to start making decisions for you.

Also, anyone who has a concern about your decision-making capacity\(^2\) can make an application to the relevant Board or Tribunal. The Board or Tribunal can then decide whether you can make your own decisions, or whether someone else or a government agency needs to make them for you. The decision of the Board or Tribunal is reliant on reports from doctors, or other health professionals such as psychologists. There is no “gold standard” assessment to determine your decision-making ability or capacity. Also, the orders that are put in place regarding the appointment of a substitute decision-maker often are not sensitive to any changes that may occur in your abilities from time to time.

Can I appoint someone to make decisions for me when I am no longer able to make my own?

While you still have capacity, you can choose to appoint someone (or more than one person) to make decisions for you if, at some future time, you lack capacity to make your own decisions. This person is called a substitute decision-maker. Although there are no laws that state that you have to appoint a substitute decision-maker, there are laws that state what will happen if you lose capacity and you have not appointed anyone to make financial, personal, and health decisions for you.

In Australia, each State/Territory has a different system for the appointment of people or agencies to make decisions for you when you no longer have capacity to make your own decisions. They also often have different terminology when referring to the substitute decision-maker, and different rules about the types of decisions substitute decision-makers can make.

The term most often used throughout Australia to refer to substitute decision-makers appointed by you for financial matters is “Attorney”, and the term most often used to refer to substitute decision-makers appointed by you for personal and health care decisions is “Enduring Guardian”. These are the terms that will be used throughout this booklet, but you will need to check what terms are used in the State/Territory in which you live. The different names used for similar roles in each State and Territory are listed in Table 1.

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2. Also, people who have concerns about the decisions being made for you may make an application to the relevant Tribunal or Board in your state or territory.
<table>
<thead>
<tr>
<th>STATE/TERRITORY</th>
<th>FOR FINANCIAL DECISIONS</th>
<th>FOR PERSONAL and/or HEALTH CARE DECISIONS</th>
<th>FOR FINANCIAL DECISIONS</th>
<th>FOR PERSONAL and/or HEALTH CARE DECISIONS</th>
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<tbody>
<tr>
<td>ACT</td>
<td>Enduring Power of Attorney (EPoA) Financial</td>
<td>EPOA – Personal/ Health Care</td>
<td>Manager</td>
<td>Guardian</td>
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<td>NSW</td>
<td>EPoA</td>
<td>Enduring Guardian</td>
<td>Financial Manager</td>
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<td>NT</td>
<td>Substitute Decision Maker(s)</td>
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<td>Manager</td>
<td>Adult Guardian</td>
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<td>EPoA - Financial</td>
<td>EPOA – Personal/ Health Care</td>
<td>Administrator</td>
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<td>SA</td>
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<td>TAS</td>
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<td>VIC</td>
<td>EPoA</td>
<td>Agent EPOA (Medical Treatment)</td>
<td>Administrator</td>
<td>Guardian</td>
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<td>WA</td>
<td>EPoA</td>
<td>Enduring Guardian</td>
<td>Administrator</td>
<td>Guardian</td>
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You can appoint one person, or more than one person, to make your decisions for both financial and personal/health care matters. If you appoint more than one person, you need to say how you want them to make their decisions. For example, you may want them to make the decisions “jointly,” which means that they do it together, so they need to agree; you may want to say that they can do it “severally,” which means that any one of them can do it; or you may want to appoint people in a given order, that is, “serially” or “successively” so that the first person on the list makes the decision if they are available; if they are not available the next person on the list can be asked to make the decision, and so on.

What kinds of decisions can the substitute decision-maker make on my behalf?

There can often be differences within each category, so if a Board or Tribunal has made an order relating to guardianship or financial/administration matters, it is very important that the person or people appointed read the guardianship or administration order carefully, so that they understand what they can and cannot do in their position. For example, an administrator or financial manager appointed by the Tribunal or Board may have only been appointed to make financial decisions about a lump sum from a personal injury pay out, and not all matters relating to your finances or property.
Similarly, if you have appointed an Enduring Power of Attorney or an Enduring Guardian, it is important that the person appointed carefully read the document appointing them. For example, you may have appointed one Enduring Guardian to only make accommodation decisions, or to only make health care decisions, and you may have appointed another Enduring Guardian to make other personal decisions for you. The person or people appointed should clearly understand their areas of responsibility and the accountability required (such as submitting financial records for auditing).

Who has the legal right to make decisions for me if I have not appointed someone?

If you have not appointed an Attorney to make financial decisions for you and you are determined to no longer have capacity to make those decisions, then someone will have to make an application to the relevant Board or Tribunal in your State or Territory, for a substitute decision-maker to be appointed.

If you have not appointed an Enduring Guardian to make health care and personal decisions for you and you lose mental capacity, then someone designated in State/Territory law as a “Person Responsible” can make these decisions on your behalf. This is generally a family member or another person who has a relationship with you. This is explained further in the section below about health care and personal decisions. If there is no readily available “Person Responsible,” the doctor or other health care provider still and must seek consent from the relevant Guardianship Board or Tribunal before providing treatments that require consent. If it is likely that ongoing consent will be required, the Board or Tribunal would usually appoint a Guardian to make those decisions. If there is no family member or friend of the patient available, the Public Guardian will be appointed as the Guardian or ”last resort.”

When making a decision about who to appoint as a substitute decision-maker, the Board/Tribunal will take into consideration a number of factors. These factors may include the relationship between the person needing support and the person being considered for appointment, the financial skills of the person to be appointed (if the appointment is for a financial manager/administrator), and the ability of the person to undertake the role.

Even if you have appointed a substitute decision-maker yourself, if a family member, friend or your health care provider believes that the person is not acting in your best interests, they may make an application to the relevant Board/Tribunal to have the appointment reviewed. After considering all the material put to it, the Board/Tribunal may, or may not, appoint someone else to make decisions on your behalf.

Table 2 lists the various Boards/Tribunals in Australia (see page 8).

What is the difference between supported decision-making and substitute decision-making?

Despite the similar sounding names, supported decision-making and substitute decision-making are quite different in approach.

Substitute decision-making gives the decision-maker complete legal authority to act in relation to particular types of decisions about you. The substitute decision-maker should act in consultation with you to the extent that your remaining capacity makes this possible. Once you have lost capacity, they must follow your written instructions if you have provided these, or follow your verbal wishes if you have discussed your wishes with them. However, in some circumstances they may need to make the decision on their own, for example if
they do not know what your wishes would be in a particular situation. In some rare cases it may be that your substitute decision-maker believes that they should make a decision in opposition to your views. In such a case the substitute decision-maker will need the authority of the Board or Tribunal before they can override your wishes. Sometimes there is conflict between the substitute decision-maker and someone else, perhaps another family member or friend, and often the only way to resolve the issue is to make an application to the Guardianship Board or Tribunal who will decide the matter.

**Supported decision-making** is a term that has arisen from concerns about the lack of involvement between a substitute decision-maker and the person they are making decisions about. It is a more inclusive, consultative and shared way of making decisions that is generally viewed as being more in line with a person’s rights. Supported decision-making may be based on a formal agreement between a person with questionable capacity and their supporter, or an informal network of people who support an adult to achieve their own goals and decisions that are based on their own views and wishes. This form of decision-making is more in keeping with our obligations under the United Nations Convention on the Rights of People with a Disability. Australia is a signatory to this Convention, and although the Convention is not part of Australia’s legislation it does influence the development of Australian public policy. Therefore we should expect to see policies affecting people with disabilities that are both inclusive and non-discriminatory.

Much of the discussion of supported decision-making has arisen in response to the National Disability Insurance Scheme, and the recent Australian Law Reform Commission Review, “Equality, Capacity and Disability in Commonwealth Laws”, released in 2014. You may like to read more about supported decision-making, and discuss your future involvement in decisions with your family or other people that you are considering appointing as your decision-makers.

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3. The Queensland Law Reform Commission has recommended that the UNCRPD principles be adopted into guardianship legislation.
2. YOUR LEGAL RIGHTS AND DECISION-MAKING WITH REGARD YOUR FINANCES

Should I consider appointing someone to manage my finances?

Even while you still have capacity, you may want someone else to manage your finances, including any property you own. You can do that through a Power of Attorney document. This can either be a General Power of Attorney, which only operates while the “Principal” (you, the person appointing the ‘Attorney’) has capacity; or it can be an Enduring Power of Attorney, which can come into effect at any time the Principal says it is to start, but it continues to have effect if the Principal loses mental capacity.

You can appoint one person, or more than one, to take care of all your financial matters, or you can appoint one person to take care of some financial matters and another person to look after other financial matters. For example, you may want one person to manage your property and another person to manage your bank accounts or shares. However, while you still have capacity the person you appoint is your “agent” and should do as you instruct them to do. They cannot just go and do whatever they want with your money or property, and as far as possible you should try to keep a check on what your agent is doing. This, however, raises the very important issue of appointing someone you trust.

How can I be sure the Attorney will act in my best interests?

The legislation requires the Attorney to act diligently, keep financial records, and not undertake financial transactions between you and them - these are known as “conflict” transactions. However, there is no formal oversight, or auditing, of these arrangements - unless, for example, you have specified in the document that you want your financial affairs audited on a regular basis.

In fact, it is not until someone notices that the Attorney is not acting in the best interests of the Principal (and the Principal has already lost mental capacity) that something can be done about the situation. What usually happens in such cases is that the person who has concerns about what is happening makes an application to the relevant Guardianship Board/Tribunal for a review of the Power of Attorney. If no-one notices that something is going wrong, or if no-one makes an application to the Board/Tribunal, then the Attorney could continue to misuse the power – to the obvious detriment of the Principal.
When you are making an Enduring Power of Attorney appointment, you can add a range of conditions or limitations on the powers that you are giving to your Attorney. For example you might state that you do not want your Attorney to engage in financial transactions over a certain amount (for example $10,000) without providing written authority from your accountant. In an example such as this you would need to consider whether there is sufficient money in your estate to cover the costs associated with the accountant. Another example is, you may decide that you do not want your Attorney to ever sell your home. However, in this example you would need to consider what would happen if you ever needed to enter a residential care facility and needed the funds from the sale of your home to fund your care. In such a situation your Attorney may need to contact the relevant Board or Tribunal and ask for a variation to your instructions. The important thing is to be practical about the limitations and not “overdo” them so that the document becomes unworkable for the Attorney.

Can I change my Power of Attorney arrangements?

As long as you still have capacity, you can revoke (cancel) an Enduring Power of Attorney appointment and appoint someone else to make these decisions for you. You may choose to do this if, for example, you realise that the person you have appointed is misusing your money or property, or your circumstances change.

It is also important to review your Power of Attorney regularly to ensure that the circumstances of your attorney have not altered. For example, if your Attorney were to lose mental capacity, become bankrupt, or even die before you, then you would need to appoint a new Attorney (or Attorneys).

There is usually a special form to use in each State or Territory to revoke a Power of Attorney appointment, Enduring or otherwise. It is important to remember that Powers of Attorney, whether General or Enduring, cease to have effect once the Principal has died. Once a person has died then their Executor, if the person has made a Will, takes responsibility. Wills are discussed later in this booklet.
3. YOUR LEGAL RIGHTS AND DECISION-MAKING IN REGARD TO HEALTH CARE AND PERSONAL DECISIONS

Should I consider appointing someone to make personal and health care decisions on my behalf?

For personal and health decisions you can choose to appoint an Enduring Guardian who can make decisions such as consenting to, or refusing, medical treatment or other health care, changing doctors, organising home care or community services, or deciding where you should live, including going into a residential aged care facility. Note that you would only be moved into residential care if you have been assessed by a doctor or Aged Care Assessment Team as needing that level of care, not just because your Enduring Guardian thinks that is where you should live. In most States and Territories an Enduring Guardian cannot refuse palliative care, or needed pain relief.

Unlike the appointment of an Attorney for financial matters, an Enduring Guardian cannot make these decisions for you while you still have mental capacity.

How should I choose an Enduring Guardian?

When you appoint an Enduring Guardian, you should discuss with the person you are thinking of appointing whether they are prepared to make decisions that you would make if you still had capacity. You can assist them with this role by completing an Advance Care Directive which sets out your wishes for care and treatment under certain conditions. Advance Care Directives are discussed further below.

You should appoint someone who will be able to ensure your wishes are respected even if they do not agree with what you want, or are facing pressure from family members to agree to treatment that you stated you would not want. For example, you may have said that if you are ever terminally ill you do not want life-prolonging treatment to continue, but your spouse or other close person may be too distressed to ask for the treatment to stop. Or you may have said that you don’t want antibiotics, you just want to be treated with dignity and kept pain free and comfortable. However, if you developed a chest infection and it was painful to breathe, and the antibiotics would clear the infection and make breathing easier, would you still not want antibiotics? The really important thing is to think through the various scenarios and make sure you appoint someone who will do as you have requested.

Who has the legal right to make health care decisions for me if I have not appointed someone?

If you lose mental capacity and have not appointed someone to make health care decisions for you, the Guardianship law in all States and Territories sets out who can make the decisions. Although the terminology used to describe this person is different in some States/Territories, the most commonly-used term is “Person Responsible”. This does not mean that anyone who is prepared to accept responsibility can be “Person Responsible”.

All State and Territories have an “order of authority” for “Person Responsible.” As with other provisions, this is not the same in all States and Territories and the treating medical practitioner needs to know the “order of authority” in your particular State/Territory. As an example, in some States the order of authority is the first “readily available” of the following:

- Spouse, including de facto or same-sex partner, provided the relationship is close and continuing; if there is no spouse or partner it moves to:
- Non-professional carer (this means someone who is not being paid to care for you, although someone receiving a carer’s pension can be
“Person Responsible”). This may be your daughter, daughter-in-law, other close family member or even a neighbour; if there is no non-professional carer it moves to:

- Close friend or relative of yours.

This is an informal arrangement, which means that the person does not have to be formally “appointed” by anyone - in other words, there are no forms to complete. Usually the senior treating doctor has the responsibility to identify who is the first readily available person from the list for their State or Territory.

There are variations across States/Territories in how the system works. For example, in Queensland, if the first person in the hierarchy does not want to make the decisions, they are deemed to not be “readily available” and the order of authority automatically moves to the next person down the list.

However, in New South Wales, the person who is first on the list must renounce in writing if they do not want to take on the role, and so it goes on all through the list. In other words the person who is second or third in line cannot automatically take over unless the person higher up than them has written down that they do not want to take the role of “person responsible”. Furthermore, in New South Wales a medical practitioner, or some other person qualified to give an expert opinion on the condition of the person, can also put in writing that they do not believe that the “person responsible” is capable of carrying out their role. In situations such as this, the role would then move down to the next in line on the list.

It can be seen that the Person Responsible to make substitute decisions for health care matters is not necessarily “Next of Kin”. It is the first person in the relevant list who is readily available.

If there is no one readily available from the list above, keeping in mind the order of authority, the doctor or other health care provider still needs consent for most health care that is provided to you. They cannot provide anything except minor, non-invasive treatment or emergency treatment without consent and must seek consent from the relevant Guardianship Board or Tribunal before providing the treatment. If it is likely that ongoing consent will be required, the Board or Tribunal would usually appoint a Guardian to make those decisions (if there is no family member of friend of the patient available, the Public Guardian will be appointed as the Guardian of “last resort”).

Who will be responsible for making decisions for me if I live alone?

Whether you live alone or with others, you are able to make your own decisions up until you lose capacity. The decision-maker appointed by you (if you have appointed an Enduring Guardian), or appointed by a Board or Tribunal (if a Board or Tribunal has made an order appointing another person or an agency), can make decisions for you, if you lose capacity to make your own decisions about care. This substitute decision-maker also includes the “Person Responsible” referred to earlier.

What is an Advance Care Directive and is this something I should consider?

To increase the certainty that your views and wishes are followed, many States and Territories have a system that allows you to state your treatment preferences in writing while you still have the capacity to do this. In some States and Territories there are prescribed or set forms, usually called Advance Care Directives or ACD, such as the recently legislated ACD in SA. These forms must be completed and witnessed by certain people, that is, a lawyer, a Justice of the Peace or a medical practitioner (see Table 3). These are legally binding documents. In other States, such as NSW, because
there is no specific legislation relating to Advance Care Directives, there is no set form and people can use one of the many forms available from various agencies or design their own form.

Even though there is no legislation in NSW there have been recent cases in the Supreme Court of NSW which have confirmed the validity of Advance Care Directives. That means that these directives are legally binding on doctors or other health care providers. However, whatever form you use, it is strongly advised that you discuss the form with your medical practitioner and have it witnessed by an independent witness, such as a Justice of the Peace or lawyer.

Even if the form does not need to be used for some years, your wishes will have more protection if your doctor has also signed the ACD. If a doctor signs the page in your ACD which says that you had capacity when you completed the form, then it would be more difficult for a family member or other person to claim, at some time in the future, that you had already lost capacity at that stage.

Note that your ACD does not have an expiry date and will still be legally binding even if it is 10 years or more since you made it. However, it is advisable to review it at least every two years, so that everyone can be confident that it still represents your wishes.

**Do I have the right to consent to, or refuse, medical treatment?**

While you have capacity (including after a diagnosis of dementia) you have the legal right to accept or refuse any treatment, including treatment for the dementia or for other health conditions, even life-saving treatment. Even after you have lost capacity, if they are documented these views and wishes remain legally binding, and must be taken into account by your decision-maker.

For almost all health care, a doctor or nurse is legally required to obtain consent from you, or your substitute decision-maker if you have lost capacity, before providing health care. This includes most medications. Prescription medications can only be provided to you by consent, by either yourself or someone else with legal authority to consent on your

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behalf. However, non-prescription medications (such as cough syrup or “over-the-counter” medications such as aspirin or Panadol for headaches or minor pains) can be given without consent if you willingly take them when they are offered to you.

If you are treated without consent, you, or your Enduring Guardian, Person Responsible or other concerned person, have the right to take legal action. Apart from expensive civil lawsuits in Supreme or District Courts, health care complaints can be made to independent bodies, responsible for the regulation of doctors. These bodies are listed in Table 4.

Is my GP or specialist obliged to tell me that I have dementia?

Your doctor has a responsibility to inform you of the results of assessments (such as assessments for dementia) in order to gain your consent to treatment. It is to be expected that if your doctor was to perform an assessment on you, that you would have discussed the implications of the results, prior to giving your consent to the assessment. If you lack capacity to make health care decisions, the information and consent must be gained from your substitute health care decision-maker, that is, your Enduring Guardian or Person Responsible. This means that your health care decision-maker has a right to all relevant information from your health care provider in order for them to make decisions about your ongoing treatment and care.

In some cases, people may tell their doctor that if the tests show that they have dementia, they don’t want to know the diagnosis. This is a difficult circumstance for a treating doctor to be placed in, and their response would vary, depending upon their own ethical framework. They may tell your family member or personal decision-maker the outcome of the tests. However, in most cases it would be much better for you to be told, not only to ensure that they can discuss any available treatment with you, but also so that you can do the things you might want to do, or need to do, while you still have capacity. For example, you may want to appoint a substitute decision-maker and complete an Advance Care Directive if you have not already done this. You may also want to make sure your Will reflects what you want, or even make peace with someone from whom you are estranged.

**TABLE 4: LIST OF AGENCIES THAT RECEIVE HEALTH CARE COMPLAINTS**

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<tr>
<th>STATE/NATIONAL/TERRITORY</th>
<th>AGENCY</th>
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<tbody>
<tr>
<td>ACT</td>
<td>ACT Health Services Commissioner</td>
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<tr>
<td>COMMONWEALTH</td>
<td>Aged Care Complaints Scheme</td>
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<tr>
<td>COMMONWEALTH</td>
<td>Australian Health Practitioner Regulation Agency</td>
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<td>NSW</td>
<td>NSW Health Care Complaints Commission</td>
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<td>NT</td>
<td>Health and Community Services Complaints Commission</td>
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<td>Office of the Health Ombudsman</td>
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<tr>
<td>WA</td>
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<tr>
<td>TAS</td>
<td>Health Complaints Commissioner</td>
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What are my rights in relation to physical or chemical restraint in my home, or in a residential aged care facility?

Unfortunately the legal framework in relation to regulating and monitoring the use of restraint is under-developed in Australia. However, the following discussion outlines the principles that should be applied.

Essentially, you have the right to live in a “restraint-free” environment, with restraint only to be used if other strategies or interventions have failed. Restraint should only be used as a last resort, to prevent you from harming yourself or someone else. It can only be used lawfully without consent of a Guardian or Attorney with legal authority for this decision, in situations of immediate high risk or emergency.

If you are living at home, anyone, including family members or carers can only restrain you in the case of an emergency, and only for as long as the emergency lasts. Then the family member or carer needs to seek an assessment of your health and service needs, to ensure your safe care in the community. Often unsettled behaviour is an indicator of other health needs, such as an underlying infection or untreated pain, which requires assessment and treatment.

Even if the family member or carer is also your legal decision-maker it does not mean that they can indefinitely restrain you or lock you in. This behaviour on their part would constitute false imprisonment and is a criminal offence.

Similarly, aged care facilities require consent from you, or your legally appointed or nominated person or agency, to make accommodation and restraint decisions, such as placing you in a locked ward. While this decision can be made against your will, it still must have legal authority, so your Attorney or Guardian will need to consent on your behalf.

Chemical restraint refers to the use of medication to treat behavioural disturbance. As it is a medication, this should be consented to either by you, if you still have capacity to make healthcare decisions, or by your substitute healthcare decision-maker. Unless it is an emergency situation, either you or your substitute decision-maker should be informed and asked to consent.

The Commonwealth Government has produced a booklet on the use of restraint in residential aged care facilities; this booklet states that “A restraint free environment is seen as a basic human right for all residents living in a residential care setting.”

If you are being restrained for no apparent reason, or when there are other alternative ways to ensure your safety and wellbeing, then this matter should be discussed with the management of the facility as soon as possible and the Complaints Process followed. This can lead to your substitute decision-maker, or another person lodging a formal complaint with the Aged Care Quality and Compliance Group, within the Commonwealth Department of Social Services.

4. YOUR LEGAL RIGHTS AND RESPONSIBILITIES IN RELATION TO OTHER MATTERS

EMPLOYMENT

What rights do I have in the workplace after I receive a diagnosis of dementia? Can I be fired because of my disease?

Your employment cannot be terminated on the basis of your diagnosis of dementia alone. Essentially you have the same work rights as you have always had, plus protections given by Commonwealth legislation such as the Disability Discrimination Act 1992 (Cth) (DDA). Your employer is also legally obliged to keep your diagnosis of dementia confidential.

However under the DDA, your employer has rights as well. While they are expected to make some effort to meet your new situation, such as providing memory prompts or lists of tasks to be done at certain times, they are not expected to accommodate your needs if it leads them into unjustifiable hardship, or if you are unable to perform your role, even with reasonable changes to where or how you perform your work. Therefore if you are unable to perform your role, even with reasonable accommodation of your needs, your employer may have the right to cease your employment.

Can an organisation refuse me a job or another position such as Board membership, based on my diagnosis of dementia?

The DDA covers employment, contracts, commission agents and partnerships. For example, under Part 2, s21 of the DDA it is unlawful for an employment agency to discriminate against a person with a disability
(a) by refusing to provide the person with any of its services; or
(b) in the terms or conditions on which it offers to provide the person with any of its services; or
(c) in the manner in which it provides the person with any of its services.

S15 of the Act makes it unlawful for an employer, or someone acting on behalf of the employer, to discriminate against a person with a disability
(a) in the arrangements made for the purpose of determining who should be offered employment; or
(b) in determining who should be offered employment; or
(c) in the terms or conditions on which employment is offered.

Employers are able to take into account the potential employee’s ability to fulfil the requirements of the position in deciding whether...
they are suitable for the position. If it is the view of the employer that the candidate would not be able to meet the requirements of the position (even if reasonable steps are taken to adapt the role) they can take this into account in determining whether to offer employment or other positions.

What protections do I have under disability legislation? Does this only apply to people under the age of 65?

Whilst disability services usually cease at 65 and aged care services commence then, the DDA does not work in that way. There is no age limit in relation to employment issues. There are also separate State/Territory and national Age Discrimination Laws.

SUPERANNUATION

What do I need consider in regard to superannuation?

Compulsory superannuation was introduced in Australia in 1992. By law, employers must pay their employees a percentage of their salary into a superannuation fund. The percentage is set by the Commonwealth Government and currently it is 9.5%. This is the money that the Government would like people to use to fund their retirement – and for this reason it cannot usually be accessed until you reach what is known as “preservation age”. Preservation age is dependent on your date of birth, but usually somewhere between 55 – 60 years of age.

When you complete the details for your superannuation fund it is normal to state who you would like to be the beneficiary of your superannuation on your death. This is called your “nominated beneficiary”. However, by law, unless this is a Binding Nomination as explained below, it is at the discretion of the Trustees of the superannuation fund to determine which dependants benefit from your superannuation. They may, notwithstanding that you have nominated a beneficiary, decide to pay the superannuation to someone who is classified as your dependant, or they may decide to pay the money to your estate.

However, in more recent years the introduction of what is known as a Binding Death Benefit Nomination, or simply “Binding Nomination”, now binds the Trustees of the Superannuation Fund to pay your superannuation to your “binding nominee” whom you have nominated using a special Binding Nomination form. You need to check with your superannuation fund whether they have Binding Nominations. Binding Nominations usually have to be renewed every three years. This raises the question “What happens if I am not mentally capable of renewing my Binding Nomination”? Some superannuation funds permit an Attorney (appointed under an Enduring Power of Attorney) to renew the Binding Nomination however, this is also something you will need to discuss with your own superannuation fund.

Prior to the death of a member of a superannuation fund, if the member is in receipt of a superannuation pension, they can nominate a person to be the recipient of that pension on their death, in other words it becomes a Reversionary Pension. A reversionary pension is different to a Binding Nomination, and while there are advantages and disadvantages to both Reversionary Pensions and Binding Nominations it is essential to discuss these with your own superannuation fund and financial advisor.

Further information on superannuation can be found in the ‘Further Resources’ found at the end of this booklet.
CRIMINAL RESPONSIBILITY

What happens if I commit a crime because of my dementia, for example, accidentally leave a store with merchandise without paying? Will I be prosecuted?

If you are charged with a criminal offence as a result of your condition, you will need to notify the Police or Prosecutor of your condition, and contact your treating doctor so that s/he can prepare a report for the Court. However, the charges will not automatically be “dropped” because of a report of your dementia and you should seek legal assistance, as it will be a complex area of law to resolve. The Court will consider your condition as long as they have a report from your doctor, or another relevant specialist and the Court should include that fact in weighing up the evidence but, as noted, that does not automatically mean that the charges will be “dropped”.

VOTING

Do I have to give up voting after a diagnosis of dementia?

You do not have to give up voting on receiving a diagnosis of dementia. However, should you or another person consider that you lack capacity to vote, you can notify the Australian Electoral Commission, who will seek medical evidence in support of your notification.

Because capacity is decision-specific, it is entirely possible that you may retain capacity to vote, longer than you retain other capacities, such as managing your finances. Many people value the right to vote, and seek appropriate support to enable them to participate in this democratic process.

DRIVING

What are my responsibilities in reporting a diagnosis of dementia to my driver’s licensing authority?

All drivers have a responsibility to themselves and the general community to drive in a safe and responsible manner. States and Territories have different systems in place for balancing a person’s need to continue driving with the need to ensure community safety.

A diagnosis of dementia doesn’t necessarily mean that you need to stop driving straight away, however you will need to stop driving at some point. You are required by law to tell your local licensing authority of any medical condition that might affect your ability to drive safely. Dementia is one of the medical conditions that needs to be disclosed because it affects driving ability. The licensing authority will ask you to see a doctor who will assess your medical fitness. After this, you may need a formal driving assessment. Based on the results of these assessments, the licensing authority will decide if you can continue to drive. If the licensing authority decides that you can continue to drive you will be issued with a conditional licence. Conditional licences are valid for a maximum of 12 months, after which time you will be reassessed. Also, in some states, including NSW, there are age-related provisions requiring an annual doctor’s report prior to renewal of your licence, along with yearly compulsory testing from age 85. In other states, such as Victoria, this scheme is not in place, and the state relies on self-reporting, or reporting from doctors, friends or family, if a person is no longer safe to drive.
What happens if I am involved in a car accident? Will my dementia be taken into consideration in deciding who is at fault?

There is no consistent approach by the courts in considering how a diagnosis of dementia affects your obligations to disclose your condition and also to discuss with your doctor whether you are safe to drive.

It is not possible to say, in any general sense, how courts will take your diagnosis of dementia into consideration, particularly if you have had the diagnosis for some time. However, if you have driven negligently or dangerously, you could be penalised for not notifying the appropriate authorities or discussing the risks of your driving with your treating doctor.

TRAVEL

Can I be refused travel insurance based on my dementia?

Travel insurance companies all tend to have their own policies around what they will and will not insure. Most airlines now offer disability support for people with dementia, however consumer feedback indicates inconsistencies across the insurance companies, with differing levels of insurance from various different insurance companies. You should consult with the relevant insurance company prior to making your travel arrangements, to ensure their level of cover will meet your needs.

Do airlines offer any financial assistance if I have dementia?

Financial assistance is available on some domestic and international flights for passengers who need physical assistance during flights. Whilst not all airlines offer reduced fares for both a passenger who requires assistance and a carer, some do. However, it is important to read carefully the conditions that have to be met before this concession applies. You should consult with the relevant airline to get up to date information about what concessions are available for carers, prior to booking your travel arrangements.

The situation is quite different for international flights flying in or out of the United States of America. As a result of amendments to United States legislation and their rule associated with ‘Non-discrimination on the Basis of Disability in Air Travel’ it is possible, if the requirements are met, for the accompanying person to travel without charge. The following two hyperlinks will take you to the relevant sections on the Qantas website. Again you should request up to date information from your airline prior to booking travel.

**WILLS**

**Do I need a Will?**

You are not required to have a Will but preparing a Will ensures that you have a say in what happens to your estate after you die. A Will is a document in which the Will-maker (the Testator) bequeaths (or leaves) their estate to someone or some organisation (the Beneficiaries). A Will only takes effect once the Will-maker has died. Wills, just like Powers of Attorney, Enduring Guardianship, and Advance Care Directives are governed by State/Territory legislation and therefore, the laws relating to them are different between the various States and Territories.

It is important when preparing a Will that you know exactly what it is you own. This statement is not as strange as it may sound, as many people are not aware of the implications of the various types of property that they own. For example when looking at home ownership, does the Will-maker own the property outright in their own name, or as joint tenants (where on the death of one party the property reverts to the remaining party) or as tenants in common (where you can leave your share of the property to whomsoever you choose)? It is also important to know what forms part of your estate. For example, trust structures and superannuation may sit outside of your estate.

Another important aspect of Wills is to remember that although they are not time limited (in other words, they don’t expire), our circumstances can and do change, and it is essential to update our Wills so that they reflect our current situation. Some examples of changes include births, deaths, marriages, divorces, separations, moving to another State or Territory, or country and even being in receipt of an unexpected financial windfall which would mean you had more assets to distribute!

As with the appointment of an Attorney, it is just as important whom you choose to be the Executor of your Will. The Executor has the task of bringing together all the assets of the deceased person, paying all the debts, including those associated with the funeral, and then distributing the estate to the named beneficiaries.

An important document to consider preparing, at the same time as the Will, is a document generally known as an “Executor’s Dossier.” This is a document that you can draw up yourself, and in the document you make a note of all the relevant information which will assist your Executor to administer your estate. For example you would include the details of any life assurance policies you may have, your bank/credit union details, title deeds to your home (or other properties), shares and your debts. Although it is a time consuming document to prepare, it is of immense assistance to your Executor.

**What happens if I die without having made a Will?**

If a person dies without a Will then they are considered to have died “intestate.” As there is no Executor (because there is no Will) then someone has to make an application to the Court to be appointed an Administrator, so that the estate can be administered. There are laws which determine who will benefit from the estate if there is no Will.
This booklet has outlined some of the major legal issues that people with dementia and their carers/family members may need to deal with as the dementia progresses. The booklet outlines the importance of planning for the future through preparing documents such as Powers of Attorney, Enduring Guardianship, Advance Care directives and Wills in order to ensure that the wishes of the person with dementia are well documented.

The authors hope that it will be a useful resource for everyone dealing with dementia and its challenges.

This booklet has been developed to provide basic information about legal issues in relation to dementia. It is not possible to cover, in such a booklet, every legal issue that may arise, or every possible aspect of these legal issues. This booklet should not be used as a substitute for formal legal advice. We strongly recommend that if you require legal advice about your own situation or have questions about the law in your State or Territory that have not been answered in the booklet, you consult a solicitor, your financial adviser, or the relevant Guardianship Board or Tribunal. Please note that the information in this booklet was accurate at the time of publication but laws and policies may change over time.
FURTHER RESOURCES

This section includes hyperlinks to the legislation for both commonwealth and states and territories and further readings on the following topics:

Substitute Decision Making – Mental Capacity, Advance Care Directives, Powers of Attorney, Enduring Guardianship;

Driving;

Employment;

Restraint;

Superannuation; and

Travel.

It is important to remember that some of the areas are covered by State and Territory legislation, therefore care is required when reading the resources as legislation, and the requirements, vary between States and Territories.

The following hyperlinks will take you to the legislation for the Commonwealth and for each State and Territory.

**Commonwealth**

**Queensland**

**New South Wales**

**Victoria**

**South Australia**

**Tasmania**

**Australian Capital Territory**

**Northern Territory**

**Western Australia**

**General coverage of some of the issues**

Australian Human Rights Commission ‘Your rights at retirement’ [includes, mental capacity, powers of attorney, advance care directives, making a will and superannuation death benefits]
Available online at:

Legal Services Commission of South Australia ‘Law Handbook on Line’ [Includes - powers of attorney, advance care directives, guardianship and administration, wills, estates and funerals]
Available online at:

**Driving**

Alzheimer’s Australia ‘Dementia and Driving’
Available online at:

Carmody, J., Traynor, V. and Iverson, D. ‘Dementia and Driving an approach for General Practice’ Australian Family Physician, Vol 41, No 4, April, 2012.
Available online at:

**Employment**

Alzheimer’s Australia ‘Employment and Dementia’
Available online at:
Restraint

Available online at:

Available online at:

Superannuation

Alzheimer’s Australia (2015) ‘Superannuation and Dementia’
Available online at:

Early Release of superannuation – media release
Available online at:

Australian Government, Department of Human Services ‘Early Release of Superannuation’
Available online at:

Travel

State Government of Victoria ‘Dementia – Driving and Travelling’ Better Health Channel
Available online at:

QANTAS ‘Travel to and from the US’
Available online at:

SUBSTITUTE DECISION MAKING

Mental Capacity:

New South Wales Government, Attorney General’s Department ‘Capacity Toolkit’

Hard copies available - Diversity Services on 02 8688 8460 or 02 8688 7507


Advance Care Planning:

Start to Talk provides comprehensive advice and information on Advance Care Planning.
http://start2talk.org.au/

A range of Advance Care Planning documents for New South Wales and Queensland, including relevant Fact Sheets, and for NSW, a Statement by Person Responsible are available online at:
http://cartwrightconsultingaustralia.com.au

Advance Care Planning documents for every State and Territory, and in a range of languages, are also available online at:
http://advancecareplanning.org.au/

Available online at:
www.advancecaredirectives.org.au

Hard Copies available - 0423 157 003 or email info@advancecaredirectives.org.au

Available online at:
www.advancecaredirectives.org.au

Hard copies available - 0423 157 003 or email info@advancecaredirectives.org.au
VICTORIA

Powers of Attorney and Enduring Guardianship:
Available online at:

SOUTH AUSTRALIA

Information sheets and brochures:
• Advance Care Directive (Government of South Australia), ‘Advance Care Directive DIY Kit Make your future health and life choices known.’
Available online at:
• Consumer brochure available online at:
Available online at:
• Legal Services Commission of South Australia (2015), ‘Powers of Attorney’
Available online at:

Forms:
• ‘Advance Care Directive Form and Information Statements’ available online at:
• Sample form available online at:

WESTERN AUSTRALIA

Information sheets and brochure:
Available online at:
• Sample available online at:
• Information kit available online at:
• Brochure available online at:
Available online at:

QUEENSLAND

Information Sheets:
• Public Guardian Enduring Power of Attorney Information Sheet
Available online at:

Forms and brochure:
Available at:
Available at:
Available at:
Available at:
AUSTRALIAN CAPITAL TERRITORY

Booklets:
• Public Advocate of the ACT (2013), ‘Guardianship Standards’

Information Sheets:
• Public Advocate of the ACT, ‘Substitute Decision Making’
• Public Advocate of the ACT, ‘Guardianship and Management of Property’
• Public Advocate of the ACT, ‘Health Attorney for Consent to Medical Treatment’
• Public Advocate of the ACT, ‘Guardianship and Management Orders’

Forms:
• Enduring Power of Attorney Form
• Health Attorney (for consent to medical treatment) Form
• Application for The Appointment Of An Emergency Guardian Form
• Health Direction Form

NEW SOUTH WALES

Information sheets and brochures:
• Public Guardian - Attorney General and Justice (2014), ‘Enduring Guardianship in New South Wales: Your way to plan ahead’

Forms:
• NSW Trustee and Guardianship, ‘Appointment of Enduring Guardian (NSW)’
• Land and Property Information (LPI) ‘General Power of Attorney’
• Land and Property Information (LPI) ‘Enduring Power of Attorney’
NORTHERN TERRITORY

Information sheets and brochures:

• Advance Personal Planning
  Available online at:

• NT Government Department of the Attorney-General and Justice (2015), ‘Power of Attorney’
  Available online at:
  http://bit.ly/PoA-NT

• Office of the Public Trustee NT Government, ‘Advance Personal Planning’ Brochure
  Available online at:

Forms:

• NT Government Department of Attorney-General and Justice, ‘Advance Personal Plan’

TASMANIA

Information sheets and brochures:

• Guardianship and Administration Board (2013), ‘Enduring Guardian’s Handbook’

• Department of Primary Industries, Parks, Water and Environment Tasmania, ‘Enduring Powers of Attorney Fact Sheet’
  Available online at:

• Public Trustee of Tasmania, ‘Enduring Powers of Attorney’
  Available online at:

Forms:

• Department of Primary Industries, Parks, Water and Environment Tasmania, ‘General Enduring Powers of Attorney Form 4’
  Available online at:
Visit the Alzheimer's Australia website for comprehensive information about dementia, care information, education, training and other services offered by member organisations.

Or for information and advice contact the National Dementia Helpline on

1800 100 500

The National Dementia Helpline is an Australian Government funded initiative