

PLANNING AHEAD: DECISION MAKING CAPACITY AND THE LAW

This Help Sheet discusses how to prepare for the time when a person with dementia will lose their ability to make informed decisions. It explains substitute decision-maker arrangements and provides links to state and territory specific information.

Younger onset dementia is a progressive illness that can affect thinking, behaviour and the ability to perform everyday tasks. People with younger onset dementia will eventually reach a point where they no longer have the capacity to make informed decisions on important issues such as finances, accommodation or care. As a result, they will need to rely on others to help them with these decisions, or in some cases, to make the decisions for them.

Capacity

The ability of a person to make their own decisions about a number of legal, financial and healthcare issues is called *capacity*. Legislation regarding decision making capacity throughout Australia is based on the United Nations principle of “presumption of capacity”. This means that a person does not have to prove that they have capacity; it is assumed that they do, unless it can be proven that they do not. The laws that define capacity vary in each state and territory. However, the laws consider abilities such as whether or not the person can understand the information being given, keep it in mind long enough to make a decision based on that information and communicate their decision to another person.

Decision making capacity should not be confused with judgement. The issue is not whether a person is making a ‘good’ decision, but whether they are making an informed decision. Are they using all available information when making a decision or only a limited range of immediate facts? Do they understand when someone points out the consequences of their decision?

If there is some doubt about capacity, it is advisable to seek the advice of a medical specialist or a lawyer. If necessary, an assessment may be required to determine the person’s capacity to make informed decisions.

Each state and territory has different laws and in some cases different terminology about decision making capacity for legal, financial and health care matters. Additionally, the rights of a spouse or partner to make decisions on behalf of a person with dementia vary depending on the state or territory. It is therefore important to find out what laws exist in the state or territory in which you live.

Alzheimer’s Australia has an online resource to help people with and without dementia to work through the various issues related to planning ahead for legal, financial and healthcare decisions. This resource includes clear and up to date information on state and territory legislation, information for people with dementia, their carers, and for health care and legal professionals, and a number of online worksheets that people can use to put in place formal or informal plans for the future.

You can visit this website at start2talk.org.au

For further information about the laws in each state, you can also follow the links below.

ACT	ptg.act.gov.au/ acat.act.gov.au/application-type/guardianship
NSW	gt.nsw.gov.au/gt/gt_tribunalworks.html
NT	nt.gov.au/law/processes/power-of-attorney#5
QLD	justice.qld.gov.au/public-advocate/about-us/office/difference-between-public-guardianship-agencies
SA	sa.gov.au/topics/family-and-community/planning-ahead
TAS	publicguardian.tas.gov.au/ guardianship.tas.gov.au/home
VIC	publicadvocate.vic.gov.au/power-of-attorney#5 vcat.vic.gov.au/
WA	dotag.wa.gov.au/

FIGHTDEMENTIA.ORG.AU NATIONAL DEMENTIA HELPLINE 1800 100 500

Tips about decision making capacity and younger onset dementia

- The best way to manage issues of capacity and decision making is to plan ahead with family and friends well in advance – before or very soon after a diagnosis of dementia. Alzheimer’s Australia’s Start2Talk online resource has more information to help people with the process of advance planning, as well as links to the legal and other documentation required to put in place formal arrangements in each state and territory. Visit start2talk.org.au
- For peace of mind, it might be appropriate to obtain a ‘competency assessment’ from a qualified professional such as a medical practitioner or psychologist. The assessment would seek to measure the extent to which the person with dementia is presently able to:
 - Understand information
 - Make informed judgements
 - Reason through complex problems
 - Remember important information essential to the processes at hand.
- If a person with younger onset dementia does not have a substitute decision maker (for example, a spouse or close family member), or if decisions or authority to make decisions are contested, it is possible to involve a public guardian or trustee, or the guardianship tribunal. If a tribunal is involved, they will consider the wishes of the person with dementia if they have previously made them clear, and they may also consider the views of significant other people in the person’s life if they have been informed of the person’s wishes.

Planning ahead – recording and documenting future choices

A person can prepare for future decisions that they may not be able to make themselves by talking with family, friends and health care providers about the kinds of preferences and values that would influence their choices. Such preferences can be documented legally in the form of an ‘Advance Directive’ that will guide people in the future about what to do in certain healthcare and other situations. For example, an Advance Directive may document a person’s wishes regarding the use of life support systems to prolong life. When a person is diagnosed with younger onset dementia, it is important that they update their will and appoint appropriate person(s) as Enduring Powers of Attorney and/or Guardians, to make decisions on their behalf when necessary. The terminology and documents used for Powers of Attorney and Guardians will vary depending on state or territory legislation.

Make a Will sooner rather than later

A will is essential for the proper management of a person’s property and possessions after death. After a diagnosis of dementia, a self-written will could be open to challenge. To avoid this, a person with younger onset dementia should seek legal advice and/or seek medical verification of their capacity before preparing a legal will. If the expense of consulting a private solicitor is too high, advice can also be sought from a chamber magistrate or Legal Aid.

Appointing Powers of Attorney and Guardians

In Australia, legal documents are used to nominate an Enduring Power of Attorney and/or appoint an enduring Guardian. In doing so, an individual is appointing another person of their choosing to make decisions on their behalf. Powers of Attorney and Guardianship documents can appoint an alternate decision maker for legal, financial, medical, and/or lifestyle decisions. These documents can specify that the alternate decision maker can make decisions on behalf of the individual, when the individual has lost capacity, and is no longer able to make these decisions themselves.

Due to the progressive nature of dementia, it is important that these documents are prepared early in the disease process, when the capacity of the person with younger onset dementia to make their own decisions and appoint their nominated alternate decision maker is not in question.

Solicitors, financial planners and chamber magistrates can assist with decisions regarding making Powers of Attorney and appointing guardians.

Appointing Powers of Attorney and Guardians may be covered by one document or several different documents depending on the state or territory laws.

FURTHER INFORMATION

Alzheimer’s Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at fightdementia.org.au



For language assistance phone the Translating and Interpreting Service on **131 450**