



Decision making, advocacy, Power of Attorney and Guardianship

How and when is decision making affected?

The cognitive changes that occur in dementia can affect people's ability to make reasoned and informed decisions. Some may lose these abilities quite early in the disease process, whilst others lose these abilities when the dementia is more advanced.

Dementia can reduce decision making across a variety of domains including the ability to self-manage finances, purchases, wills and estates or their capacity to make decisions about their work, driving, living circumstances, services or medical care.

People with dementia who lack decision making capacity and/or insight in to their disability may also end up in conflict with their family/carers over decisions in their interests.

For this reason, people with dementia are advised to put their financial and legal affairs in order as soon as possible after diagnosis.

It is important to recognise that people with dementia will not generally lose all of their decision making capacity at once and so capacity for different decisions needs to be individually assessed. For instance, the ability to state preferences for day to day activities is likely to be intact for much longer than more complex legal or medical decisions. Therefore, it is also important to respect the person with dementia's right for some self-determination in areas where there is remaining decision making capacity and for decisions that are considered to carry low risk to them/others.

Wills and Enduring Power of Attorney:

For wills and Enduring Power Of Attorney, ideally the person's solicitor should provide an assessment of capacity before they sign such a document. This ensures that the rights of the person with dementia are protected and reduces the risk of these documents coming under legal dispute/challenge. If the solicitor is concerned about capacity, they can request an assessment of testamentary capacity.

Certain capacity assessments such as testamentary capacity can't be undertaken by just any clinician or practitioner. If there is a dispute or a solicitor is unclear about someone's decision making capacity with regard to making wills, EPOA or lifestyle decisions, the person should be referred to their treating Neurologist, Geriatrician, Psychiatrist or a Neuropsychologist for more definitive capacity assessment.

What if the person has already lost decision making capacity by the time they are diagnosed?

This is not uncommon, especially in people with certain types of dementia such as FTD, where insight and decision making is impacted very early in the disease process. In general, the need to appoint a formal alternate decision maker for the person with dementia is based on the type of decision and whether there is any conflict to resolve.

If the person is accepting of the primary family carer's decisions about care, finances and services and there is no conflict of interests, evidence of financial or physical neglect/abuse, then not having an EPOA may not be a major issue.

If the primary carer does not have authority to access the person's accounts or manage their business affairs, then an application may need to be made to VCAT for financial guardianship/or to appoint a trustee.

Similarly, if there is conflict over any decision between the primary caregiver, the person with dementia and/or other stakeholders involved in the decision, then these conflicts may need to be resolved via a Guardianship application.

For medical decisions, if the person is thought to lack capacity then the decision will automatically defer to the next of kin even if there is no EPOA. However, if there is conflict between the care recipient and their family members, then an application for guardianship/ emergency medical treatment orders may be required.

Refer to the links below for local information and advice about:

- Enduring Power of Attorney (types of EPOA, EPOA law, EPOA responsibilities, how to complete an EPOA)
- Decision Making Capacity and when/how to appoint an EPOA or legal guardian for someone with dementia/cognitive disability
- Guardianship/Administration hearings and how to resolve decision making conflicts involving someone with dementia/cognitive disability

Office of the Public Advocate/Guardianship

Victoria

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

PH: 1300 309 337

New South Wales

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

PH: 1300 364 103

Australian Capital Territory

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

South Australia

<http://www.opa.sa.gov.au/>

PH: 1800 066 969 /08 8342 8200

Queensland

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

PH: 07 3224 7424

Western Australia

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

1300 858 455

Tasmania

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

03 6165 3444

What if there is concern that a person with dementia's rights are being abused or neglected?

There are laws in place to protect the rights of people with cognitive disability and ensure that they are not subject to abuse or neglect physically, emotionally or financially.

In addition to the links above, the following links may be useful:

<http://www.myagedcare.gov.au/legal-information/elder-abuse-concerns>

<https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap>