



AUSTRALIAN CENTRE for CAPACITY
and ETHICS and the PREVENTION of
EXPLOITATION of PEOPLE WITH DISABILITIES

Capacity & dementia

A guide for South Australian Health Care Professionals:
Mini-legal kit Series 1.6



Capacity is:

- the ability to make and communicate a decision;
- not a unitary or global concept;
- domain specific: particular to the type of decision being made (personal, health, financial); and
- decision or task specific: different for every decision made, even within one domain.

Under the common law, and consistent with Article 12 of the UN Convention on the Rights of Persons with Disabilities, a person is always presumed to have capacity to make decisions. Where a person has dementia this may be a trigger for a capacity assessment if a decision needs to be made. Broadly, there are three areas or domains of decision-making: personal, financial and health. Within these domains there are numerous types of capacity decisions or capacity tasks.

Capacity is decision-specific. Global capacity, where a person is either capable or incapable of making all

decisions, has been rejected in law. It is inappropriate to state that a person “lacks capacity” without further reference to the type of capacity task. A person’s capacity can vary in different circumstances, at different times, and even within domains for different types of decisions.

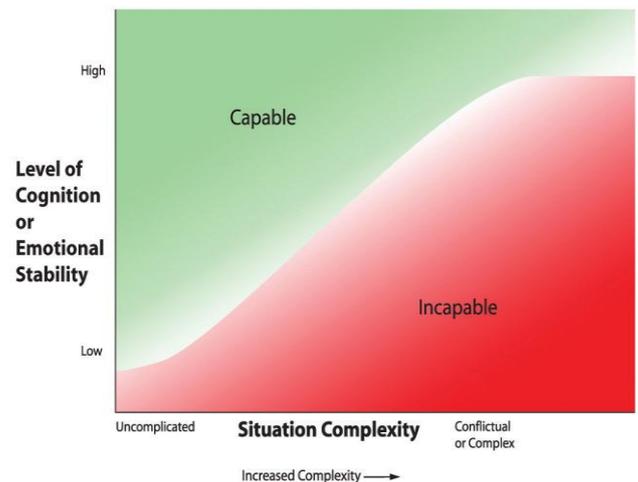
Capacity cannot be extrapolated from one decision to another. For example, a person’s capacity to consent to medical treatment cannot be inferred from their capacity to make a decision to:

- execute a power of attorney;
- write a will,
- enter a contract or deed; or
- appoint an enduring guardian.

Within each domain there is a spectrum or hierarchy of decisions. People may be capable of making simple decisions (e.g. having a blood test) but not more complex ones (e.g. amputation).

Capacity is situation-specific. The greater the complexity and/or conflict within the decision-maker’s environment, the higher the level of cognitive function or emotional stability/mental health necessary in order to be considered capable. See Figure below¹

Cognition, Emotions and Situation-Specific Capacity



Shulman (2005)

For example, the weighing up of multiple potential appointees as attorneys or guardians by a person with severe dementia in the face of family conflict may be difficult; while the appointment of one's spouse in an uncomplicated relationship may be possible for someone with mild to moderate dementia.

Dementia is a degenerative condition associated with an inevitable decline in decision-making ability over time. Each decision or capacity task is different in complexity; consequently it will be lost at different points of the trajectory of the illness.

People should be encouraged to make the decisions they are capable of making as soon as possible. Early planning with regards to appointments of substitute decision makers will maximise personal control over decisions, as will promoting supported decision making for those no longer able to make their own decisions independently. ASKME² is a practical model of supported decision making:

1. **A**ssess strengths and deficits;
2. **S**implify the task;
3. **K**now the person;
4. **M**aximise the ability to understand; and
5. **E**nable participation.

Definition of mental incapacity

In SA, mental incapacity means:

- the inability of a person to look after their own health, safety or welfare or to manage their own affairs,
- as a result of damage to, illness, disorder, imperfect or delayed development, impairment or deterioration, of their brain or mind
- or any physical illness or condition that renders them unable to communicate their intentions or wishes.

How and when to assess capacity

Health care professionals may be asked to assess capacity in response to certain triggers:

1. To facilitate **future planning** – a person may be encouraged to, for example:
 - appoint an enduring guardian; or
 - make a medical power of attorney;
 - make an anticipatory direction; or
 - make an advance care directive under the common law.
2. As part of a **routine clinical care assessment** - it may be necessary to ensure that a person has the capacity to consent to medical treatment or to drive.
3. **Concerns from others** regarding a person's decision-making ability - concerns may have been raised by a lawyer, family member, carer or service provider, and an assessment requested.

Assess the person's ability to make a decision, not whether the decision is wise. A person has a fundamental human right to self-determination, and where they have capacity, to 'dignity of risk' - the right to take risks. Consider the person's religious or cultural beliefs or other views when assessing capacity.

Any assessment of capacity must include a:

1. global assessment of the person's mental state and cognitive function (ideally with estimate of severity and assessment of the specific executive/frontal functions of judgment, reasoning and planning which are relevant to decision making; and
2. a functional assessment of decision-making, i.e. whether the person can show, using their own words, an understanding of the decision as defined by the relevant legal test for capacity (see below) in the domain in which they are making a decision (not just "yes, I understand").

Relevant legal tests

1. Assessment to facilitate future planning

Enduring Guardianship (EG) - health and personal decisions

An EG is a document in which a person appoints a guardian to make certain personal and/or health decisions on their behalf after they lose capacity to do so themselves. See section 25 and the Schedule

Guardianship and Administration Act 1983 (SA). When a person lacks capacity, decisions must be made in accordance with any directions contained in the EG. Personal decisions may include accommodation decisions, lifestyle decisions, and decisions about access to persons. Health decisions involve the granting or refusal of consent to medical and dental treatment proposed for the person.

However, if the person has already appointed another individual as medical agent under a medical power of attorney (see below) and the agent is available and willing to act, that medical agent is the legal decision-maker for medical and dental decisions when the person lacks capacity to make them.

In assessing capacity to appoint an EG, consider:

1. The “what” of the appointment:
 - Does the person understand that if they lack mental capacity about any of the matters relating to their person or circumstances, their appointed guardian may exercise the powers specified in the EG. This usually means making decisions on their behalf about accommodation, health care, personal services, and medical treatment;
2. The “who” of the appointment:
 - What is the rationale for appointing a particular person as enduring guardian; e.g. has the person appointed any enduring guardians previously? If so, how frequently have there been changes (i.e. revocations and new appointments?) Is this appointment in keeping with previous appointments; e.g. has someone else been consistently appointed as enduring guardian in the past? What is the history of the relationship between the person and the appointee and has there been any radical change in that relationship coinciding with the onset or course of dementia?
3. The “freedom” of the appointment:



- Has all the relevant information been given to the person in a way they can understand?
- Are they making the appointment freely and voluntarily and not being unduly influenced or “schooled”?

Advance Care Planning – medical / dental decisions

Advance care planning (see below) is a process for making and writing down future health care wishes in advance. This can include.³

(a) Appointing an Enduring Guardian (see above)

(b) Appointing a Medical Agent under a Medical

Power of Attorney (MPOA): An MPOA allows a person to appoint another person (agent) to make medical treatment decisions on their behalf when they are unable to make their own decisions about medical treatment. It operates when the person loses capacity. The appointer must understand that the agent’s power applies only to medical treatment decisions, **not including** refusing the natural provision or administration of food and water, the administration of drugs to relieve pain or distress or medical treatment that would result in the person regaining capacity to make their own decisions. See section 8 *Consent to Medical Treatment and Palliative Care Act 1995* (SA.) Note that an EG has more of the powers of a guardian than a medical agent.

(c) Making an anticipatory direction: A person, while of sound mind, may give an anticipatory direction that, if at some future time they are in the terminal phase of a terminal illness or in a persistent vegetative state and are incapable of making decisions about their own medical treatment, they are to be taken to have consented to medical treatment that is in accordance with their wishes as expressed in the direction and to have refused medical treatment that is contrary to those expressed wishes. They must not have revoked the direction, See section 8 *Consent to Medical Treatment and Palliative Care Act 1995* (SA.) Such anticipatory directions are binding on the person’s treating doctors.

(d) Making an advance care directive (ACD): An EG with directions about how medical treatment decisions

are to be made is similar to an ACD because the directions are binding. Although, the Guardianship Board of SA may order otherwise. Also anticipatory directions are binding. These directions limit the scope of operation of ACDs (see above), but do not prevent binding ACDs with broader directions from being made under the **common law** in SA (see below Advance Care Planning).

Enduring Powers of Attorney – Financial decisions

In SA, enduring powers of attorney (EPOA) are made under the *Powers of Attorney and Agency Act 1984* (SA). An EPOA allows a person (principal or donor) to appoint another person (attorney) to make financial decisions for them. An EPOA can be written so that the attorney can act while a principal has capacity and continues to act if they lose capacity to manage their financial affairs. Or, it can be written to commence only when the person has lost capacity.

A person must understand the nature and effect of the EPOA they are making for it to be effective legally. When assessing for capacity to make an EPOA, consider:

1. The “what” of the appointment:
 - Does the person understand they are authorising someone to look after and assume complete authority of their financial affairs? Do they understand the sort of things the attorney can do without further reference to them? Do they understand the attorney can do anything with the property/money which they themselves can do?
 - Do they understand that they may specify instructions, conditions or limitations on the exercise of the power?
 - Do they understand that the EPOA will begin, or continue when they are incapable of managing their financial affairs, and at that time, they will be unable to oversee the use of the power?



2. The “who” of the appointment:
 - Do they understand that the EPOA can be revoked at any time if they have capacity?
 - Why has the attorney been selected for appointment? Has the person made any EPOA’s previously? If so, how frequently have there been changes, i.e. revocations and new appointments? Is this appointment in keeping with previous appointments; e.g. has someone else been consistently appointed as attorney in the past? What is the history of the relationship between the person and the attorney and has there been any radical change in that relationship coinciding with the onset or course of dementia?
3. The “freedom” of the appointment:
 - Has all the relevant information been given to the person in a way they can understand?
 - Is the person making the appointment freely and voluntarily, not being unduly influenced or “schooled” to make the appointment?

The principles for assessment of capacity to make an EPOA apply equally to the assessment of capacity to revoke. The “who” of assessment applies particularly in regards to revocation. It is important to ask why the principal now feels that the attorney is inappropriate, as unfounded paranoid ideation and suspiciousness may underlie such changes in the case of dementia.

2. Assessment as Part of Routine Care – health and personal decisions

The capacity to drive

A diagnosis of dementia should be viewed as a warning sign that an individual may not be competent to drive, or will lose that competency at some stage in the future. However, a diagnosis does not determine individual ability to drive. There should be a routine review regarding the person’s ability to drive safely. ⁴

Medical treatment consent

In SA, a person who, by reason of their mental incapacity as defined above, is deemed incapable of giving a valid consent to their own medical or dental

treatment. When assessing capacity to consent to treatment consider:

1. The “what” of the consent:
 - Does the person understand the general nature and effect of the proposed treatment:
 - what it is and what it involves;
 - risks and benefits of the treatment; and
 - alternatives to, or consequences of not having, the treatment;
 - Can the person indicate their consent?
2. The ‘freedom’ of the consent:
 - Has all the relevant information been given to the person in a way they can understand?
 - Are they making the decision freely and voluntarily and not being pressured or coerced?
 - A person has a right to refuse treatment.

If a person lacks capacity to make a medical or dental treatment decision, has not made a relevant anticipatory direction or an ACD, and the treatment is not emergency medical treatment or a prescribed treatment, then a treating doctor must make reasonable efforts to find the “appropriate authority”⁵ to act as substitute decision-maker in relation to the proposed treatment, or seek consent from the Guardianship Board. The definition of the “appropriate authority” and the categorisation of medical and dental treatments in relation to whether substitute consent is required, and who should give it, is set out in the Appendix.

Plans of Care in the later stages

If the person does not have an:

- agent under an MPOA;
- EG relating to medical decisions;
- anticipatory direction; or
- ACD, under the common law which covers the situation; and they no longer have capacity, this should not



exclude the person from saying what they want or don't want for themselves in a Plan of Care.

A Plan of Care is a consensus based document based on a conversation between health professionals, the person (where possible), appropriate person, and family/carers around best interests and substituted judgment (i.e. an estimation of what the person would want).⁶ Although the patient may no longer have capacity, their wishes; preferences; values and beliefs about future treatment decisions, including end-of life treatment, should still be heard and taken into consideration. This will ensure medical, nursing and other health professionals know what type of treatment to provide if the person's condition worsens. It also helps all parties work together with a common understanding. However, it is still necessary for the treating doctor to discuss individual treatment decisions as they arise and to obtain consent to the proposed treatment from the appropriate person.

A Plan of Care is not a substitute form of consent. It is a guide to what, to the best of the carer/family's knowledge, the patient would have wanted (i.e. “substituted judgment”) had they been able to speak for themselves. It also encourages the person to participate in some way, e.g. provide “assent” (agreement, rather than informed consent) to decisions, to maximise patient autonomy.

While an ACD made by a person with capacity must be honoured if relevant to the person's current circumstances, it is preferable that the process of advance care planning not be based on a static document, but on a more dynamic practice that supports patients and their substitute decision-makers to think ahead and formulate goals of care as they confront the challenge of a progressive illness trajectory.

Such a practice should start early, be reassessed regularly with changes in health, and be sensitive to the patient's idea about their autonomy – do they want to know about and be involved in decision-making or

would they rather trust others to make treatment decisions on their behalf?⁷

3. Assessment prompted by concerns from others

Capacity to Manage Estate – Financial decisions

Other people's concerns about a person's decision-making in relation to their estate may trigger a health professional's assessment. This assessment guides others' decisions about whether they need to begin using an EPOA, or where there is no EPOA, to apply to the Guardianship Board for an administration order under the *Guardianship and Administration Act 1993 (SA)* or to the Supreme Court or District Court under the *Aged and Infirm Persons' Property Act 1940 (SA)*. In assessing the person's capacity to manage their estate where an application for an administration order is made to the Guardianship Board, consider:

- Does the person have mental incapacity?
- Does their mental incapacity mean they are unable to manage their financial affairs?
- What is the ability of the person to undertake financial tasks:
 - Does the person know their assets? Can they read a bank statement? Can they use a chequebook or ATM card? Can they identify currency and its relative value? Do they understand what bills they have and any debts they have? Have they planned for the future? Are they vulnerable to abuse or fraud?

The person does not have to manage financial tasks in the best possible way, but they must be able to manage them.

- If the person lacks capacity to manage their estate, consider:
 - Do they need an administration order? Is it in the best interests of the person to have to have someone else make their financial decisions?
 - If they are unfamiliar with their financial affairs, can't manage or have never managed their own estate, have they made appropriate alternative arrangements for its management?

- Is there a working alternative or informal arrangement already in place; e.g. family member looking after their affairs, a power of attorney, an accountant?
- Are they vulnerable to financial abuse? Will they be disadvantaged in the conduct of their financial affairs if they do not have someone? Is there a risk their assets will be dissipated due to their lack of capacity?
- Can they afford food? Do they pay crucial bills such as rent, electricity, water, rates or a crucial accommodation bond?
- If the person cannot manage all of their estate, consider whether there are parts of their finances that they can manage.

If the application were made to either the Supreme Court or the District Court, the capacity assessor has to consider whether the person is, because of age, disease, illness, or physical or mental infirmity:

- unable, wholly or partially, to manage their affairs;
- subject to, or liable to be subjected to, undue influence in respect of their estate, or of the disposing of it, or
- otherwise in a position in which in the opinion of the court renders it necessary in the interest of that person or of those dependent upon them that their property should be protected by a protection order over all or part of the estate.

Guardianship – Personal decisions

A person may need a guardian appointed by the Guardianship Board where they have a mental incapacity which render them unable to look after their own health safety, welfare or manage their own non-financial affairs. In assessing the need for a guardianship order, consider:

1. Does the person have a mental incapacity?
2. Does their mental incapacity mean they are unable to look after their own health safety, welfare or manage their own non-financial affairs?
3. Does the mental incapacity impact on the person's decision making about:

- a. Where the person should live;
 - b. With whom the person should live;
 - c. Whether the person should work;
 - d. What health care they should receive;
 - e. To whom they should have access?
4. Should a guardianship order be made? What is the current situation regarding practicability of services being provided without the need for an order? Is there any risk? Why might an order be needed or what are the consequences of making or not making an order?
 5. What are the person's wishes? What are the wishes of close family members/carers? Is there a dispute? Do you have any input into who should be guardian? Do you have knowledge of personal history and family relationships, keeping in mind the aim of preserving family relationships and cultural and linguistic environments?

Capacity and Wills

A will is only legal if the person made it with "testamentary capacity." The assessment of testamentary capacity is complex and highly specialised area of expertise. If there is doubt about a person's will-making capacity, when they are making or re-making their will, it is recommended that they are examined by a health professional with expertise in assessing will-making capacity.

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For additional information see:

- Capacity and the Law by N O'Neill & C Peisah at: <http://www.austlii.edu.au/au/journals/SydUPLawBk/2011/1.html>; or
- NSW Capacity Toolkit at: http://www.lawlink.nsw.gov.au/lawlink/diversity_services.

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5. See sections 3 and 59(2)(b)(i) of the *Guardianship and Administration Act 1993* (SA).
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Appendix

Who is the “appropriate authority”?

Where a person is unable to give a valid consent to their own medical or dental treatment, the appropriate authority from whom to seek substitute consent is found according to the list and associated comments below:

1. the medical agent appointed by them under a MPOA;
2. a guardian appointed under an EG where the EG includes to consent to medical and dental treatment;
3. a guardian appointed by the Guardianship Board where the order includes medical and dental treatment.

If there is no medical agent, guardian or enduring guardian, the following specified relatives can provide consent to medical or dental treatment:

- (i) a spouse or domestic partner
- (j) a parent;
- (iii) a brother or sister of or over 18 years;
- (iv) a daughter or son of or over 18 years;
- (v) a person who acts in loco parentis i.e. provides the main ongoing day to day care and supervision of the person (not being the person who is going to provide the treatment).

Where no one is available in the above categories to provide substitute consent, or where there is a dispute or conflict about the treatment, the Guardianship Board can provide consent to medical or dental treatment. This involves an application to, and a hearing conducted by, the Board. The application to the Board has to be made by:

- (i) a relative of the mentally incapacitated person;
- (ii) the doctor, dentist or other health professional proposing to give the treatment; or
- (iii) any other person who the Board is satisfied has a proper interest in the matter.

Summary Guide to Medical and Dental Consent for adults 18 years and over who cannot consent

Category	Treatment	Who can consent
Medical and dental treatment	<p>Medical treatment means treatment or procedures administered or carried out by a medical practitioner or other health professional in the course of professional practice and includes the prescription or supply of drugs</p> <p>Dental treatment means treatment or procedures carried out by a dentist in the course of dental practice</p> <p>But, for the question of can consent, does not include:</p> <ul style="list-style-type: none"> • Emergency medical treatment • Prescribed treatment 	Appropriate authority (See “Who is the appropriate authority?” in the text)
Emergency medical treatment	<p>Emergency medical treatment is any treatment, except prescribed treatment, given to:</p> <ul style="list-style-type: none"> • A patient who is incapable of consenting to treatment • By a doctor who is of the opinion that the treatment is necessary to meet an imminent risk to life or health and that opinion is supported by the written opinion of another doctor who has personally examined the patient; and • the patient (if 16 years or older) has not, to the best of the doctor's knowledge, refused to consent to the treatment. 	No consent needed
Prescribed treatment	<p>The only prescribed treatments are:</p> <ul style="list-style-type: none"> • Sterilisation • Termination of pregnancy 	Guardianship Board must consent