



Capacity & dementia

A guide for Health Care Professionals in Western Australia

Mini-legal kit Series
1.9



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 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 make a deed; or
- appoint an enduring guardian.

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.

Within each domain there is a spectrum or hierarchy of decisions. People may be capable of

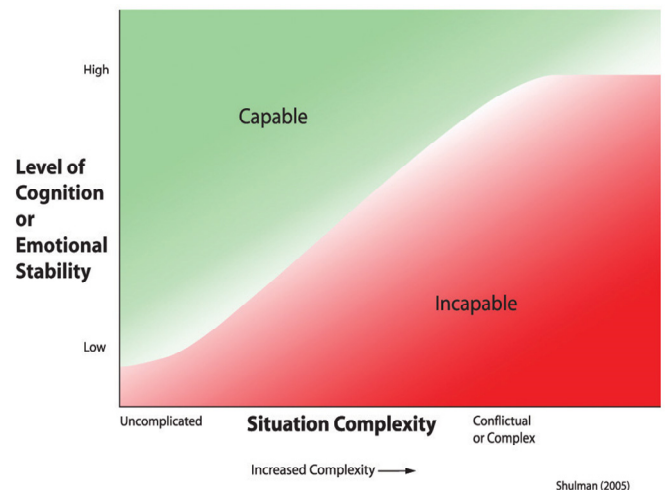
Capacity is:

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

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. 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. See Figure¹ Reproduced with permission from the American Journal of Psychiatry (Copyright © 2000) American Psychiatric Association

Cognition, Emotions and Situation-Specific Capacity



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 needing assistance to make decisions. ASKME² is a practical model of supported decision making, vis:

1. Assess strengths and deficits;
2. Simplify the task;
3. Know the person;
4. Maximise the ability to understand;
5. Enable participation.



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 appoint:
 - an enduring guardian; or
 - enduring power of attorney; or
 - document their wishes with regards to future treatment (advance care planning)
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 – these may have been raised by a lawyer, family member, carer or service provider, and an assessment may be requested.

Assess the person's ability to make a decision, not whether the decision is reasonable. A person has a fundamental human right to self-determination, and where they have capacity, to 'dignity of risk' - the right to take risks.

Any assessment of capacity must include a:

1. global assessment of the person's mental state and cognitive function (ideally with an estimate of severity and an assessment of the specific executive 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) in the domain in which they are making a decision (not just "yes, I understand").

Relevant legal tests

1. Assessment to aid future planning

Enduring Guardianship

- Health and Personal decisions

A person may appoint an enduring guardian (EG) to make certain personal and/or health decisions on their behalf after they lose capacity to do so themselves. Personal decisions may include accommodation decisions, lifestyle decisions, and decisions about the appointor's health care or access to other persons.

In WA, the person must be 18 years or older and have "full legal capacity" in order to appoint an EG (see *Guardianship and Administration Act 1990* (WA)). In assessing this capacity to appoint an EG, consider:

1. The "what" of the appointment:
 - Does the person understand that if they become unable to make decisions about these matters, the EG may make decisions on their behalf about accommodation, health care (including medical treatment), personal services, and other personal matters. For example, the EG can decide the actual place in which they are to live and the actual health care and personal services they are to receive.
2. The "who" of the appointment:
 - What is the rationale for appointing a particular person as EG for personal matters (has the person appointed any such attorney 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 Health Directive (AHD) – Health decisions only

An AHD is a written statement by a capable adult regarding wishes, preferences, values and beliefs about future treatment decisions, including end-of-life treatment. It may include instructions about future use or restriction of particular medical treatments.³

A person who has reached 18 years of age and has full legal capacity may make an advance health directive containing treatment decisions in respect of the person's future treatment (GUARDIANSHIP AND ADMINISTRATION ACT 1990 – SECT 110P).

According to the GUARDIANSHIP AND ADMINISTRATION ACT 1990 - SECT 110R:-

- (1) A treatment decision in an advance health directive is invalid if the treatment decision —
 - (a) is not made voluntarily; or
 - (b) is made as a result of inducement or coercion.
- (2) A treatment decision in an advance health directive is invalid if, at the time the directive is made, its maker does not understand —
 - (a) the **nature of** the treatment decision; or
 - (b) the **consequences of** making the treatment decision.

In assessing capacity to make an AHD consider:

1. The “what” of the AHD:
 - Can the person understand the nature and effect of the instructions given about their health care preferences, any treatment options they are requesting or prohibiting, and the consequences of doing so? Do they have enough information about treatment options and alternatives (including no treatment) available? Do they suffer from conditions that might affect capacity to make such a decision such as delirium or depression?
2. If the adult is appointing an attorney in their AHD, then the “who” of the AHD:
 - The same type of considerations may apply as in No. 2 of the “who” of the EG.
3. The “freedom” of the AHD:
 - 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”?

If a person does not wish to make an AHD, it is good practice to encourage a process of advance care planning by supporting 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? ⁴

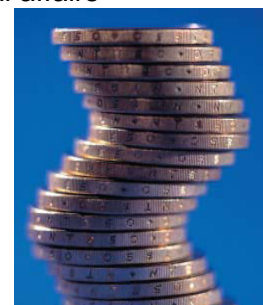
Powers of Attorney (General and Enduring) – Financial decisions

An enduring power of attorney (EPoA) allows the maker to appoint an attorney to make financial decisions for them when they lose capacity for financial matters (the capacity to manage their financial affairs). A person who has reached 18 years of age and has full legal capacity may create an EPoA. (GUARDIANSHIP AND ADMINISTRATION ACT 1990 - SECT 104). The donor of the power can declare that the power either —

- (i) will continue in force notwithstanding his subsequent legal incapacity; or
- (ii) will be in force only during any period when a declaration by the State Administrative Tribunal under section 106 that the donor does not have legal capacity is in force.

General principles for assessing capacity to make a power of attorney include:

1. The “what” of the appointment:
 - Does the person understand that they are authorising someone to look after and assume complete authority of their financial affairs?
 - Do they understand the nature and extent of what they are authorising the attorney to do (the more extensive and complex a maker's affairs are, the greater their understanding needs to be)
 - Do they understand the sort of things the attorney can do without further reference to them (e.g. selling their house or writing cheques on their behalf). Do the makers understand that the attorney can do anything with their property which they themselves can do?
 - Do they understand that the authority will begin, or continue, when they are incapable of managing their financial affairs
2. The “who” of the appointment:
 - Why has the person been selected for appointment as an attorney? Has the person executed any



Powers of Attorney previously? If so, how frequently have there been changes (i.e. revocations and new appointments)? Have they considered the trustworthiness and wisdom of the person they are appointing? 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 appoint an attorney under an enduring power of attorney apply equally to the assessment of capacity to revoke. The “who” of assessment applies particularly in regards to revocation. It is important to enquire why the maker 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.⁵

Medical treatment consent

In broad terms, an adult may give consent to their own medical and dental treatment if they are able to:

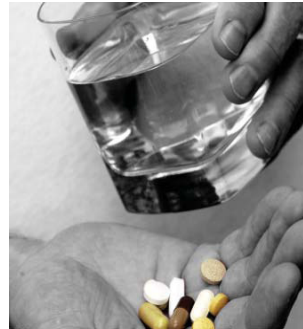
- (i) understand the nature and effect of decisions about the matter ;
- (ii) can freely and voluntarily make decisions about the matter; or
- (iii) can communicate their decisions in some way.

General principles for assessing for capacity to give consent for treatment:

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; and
 - Has the person indicated 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 unduly influenced?
 - A person has a right to refuse treatment.



N.B. Consider the person’s religious or cultural beliefs or other views when assessing capacity.

According to the GUARDIANSHIP AND ADMINISTRATION ACT 1990 - SECT 110ZJ, Order

of priority of persons who may make treatment decision in relation to a patient unable to make reasonable judgments in respect of any treatment proposed to be provided to the patient, are:-

- (i) If the patient has made an **advance health directive** containing a treatment decision in respect of the treatment, if not,
- (ii) an **enduring guardian** who, is authorised to make a treatment decision in respect of the treatment; and is reasonably available; and willing to make a treatment decision in respect of the treatment; if not,
- (iii) **a guardian** who is authorised to make a treatment decision in respect of the treatment; and reasonably available; and willing to make a treatment decision in respect of the treatment; if not:
- (iv) **a person responsible** (under section 110ZD), who
 - (a) is of full legal capacity; and
 - (b) is reasonably available; and
 - (c) is willing to make a treatment decision in respect of the treatment.

Including in order —

- the patient’s spouse or de facto partner if that person, has reached 18 years of age; and is living with the patient;
- the patient’s nearest relative who has reached 18 years of age (in order of spouse or de-facto partner, child, parent, sibling) who maintains a close personal relationship with the

patient and has frequent contact of a personal nature with the patient and takes a genuine interest in the patient's welfare;

- the person who has reached 18 years of age; and is the primary provider of care and support (including emotional support) to the patient, but is not remunerated for providing that care and support; and
- any other person who has reached 18 years of age; and maintains a close personal relationship with the patient and has frequent contact of a personal nature with the patient and takes a genuine interest in the patient's welfare.

If no-one in this list is readily available and culturally appropriate, then a guardian can be appointed. For more information see the summary guide to medical and dental consent for adults who cannot consent to their own treatment in Appendix 1.

In the moderate to advanced stages of dementia if there is no advance care directive, it is strongly recommended that the person's General Practitioner or specialist develop (with family members and the person), a **Plan of Care**.

A Plan of Care ⁶ is a consensus-based discussion involving the adult (who, regardless of not having capacity, may want to have some input into this discussion), carer and medical staff around best interests, as the person is no longer able to provide informed consent about their future treatment. This will help medical, nursing and other health professionals to know what type of care the person would want if their condition worsens. It also helps all parties to 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 person responsible.

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, had they been able to speak for themselves.

3. Assessment prompted by concerns from others

Capacity to Manage Financial Affairs – Financial decisions

Other people's concerns about a person's financial capacity may trigger a capacity assessment. This assessment guides others' decisions about whether they: need to begin using an EPOA; or (where there is no EPOA) apply to the State Administrative

Tribunal (SAT) for an administration order. Before SAT may, by making an administration order, appoint an administrator for the person the hearing is about, it must be satisfied that the person:

- is unable, by reason of a mental disability, to make reasonable judgments in respect of matters relating to all or any part of his estate; and
- is in need of an administrator of his estate,

General principles for assessing capacity to manage financial affairs include:

- Does the adult 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?
- The adult does not have to manage financial tasks in the best possible way, but they must be able to manage them.
- 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 they are unfamiliar with their financial affairs or have never managed their own affairs, have they made appropriate alternative arrangements for the management of their estate?
- Is there a working alternative or informal arrangement already in place (e.g. a family member looking after their affairs, an attorney under a power of attorney or an accountant)?

If you assess that the adult cannot manage all of their affairs consider whether there are parts of their finances that they can manage.

Guardianship – Personal decisions

A person may need a guardian appointed by SAT where they lack the capacity to make personal life or lifestyle decisions). Before SAT may appoint a guardian it must be satisfied that the person is:

- **18 years or older**
- **incapable** of looking after their own health and safety, or
- unable to **make reasonable judgments** in respect of matters relating to their person, or
- **in need** of oversight, care or control in the interests of their own health and safety or for the protection of others, **and**

- is **in need** of a guardian

A plenary guardian or a limited guardian may be appointed. According to the GUARDIANSHIP AND ADMINISTRATION ACT 1990 - SECT 45, plenary guardian has all the functions in respect of the person under their guardianship (the represented person) as if the represented person were a child lacking in mature understanding, including doing any of the following —

- deciding where the represented person is to live, whether permanently or temporarily;
- deciding with whom the represented person is to live;
- deciding whether the represented person should work and, if so, the nature or type of work, for whom he is to work and matters related thereto;
- subject to subsection (4), making treatment decisions for the represented person;
- deciding what education and training the represented person is to receive
- deciding with whom the represented person is to associate;
- as the next friend of the represented person, commencing, conducting or settling any legal proceedings on behalf of the represented person, except proceedings relating to the estate of the represented person;
- as the guardian *ad litem* of the represented person, defending or settling any legal proceedings taken against the represented person, except proceedings relating to the estate of the represented person.

Where someone is appointed a limited guardian, they may have such of the functions mentioned above in section 45 as SAT vests in them in the guardianship order.

General principles for assessing capacity to manage personal affairs include:

1. Does the person have a disability, as a result of which they are unable to manage their person and are restricted in their activities of daily living?
2. Does the person have **capacity** in regards to the matter ie are they able to make decisions with regards to matters relating to lifestyle, health and welfare? Does the dementia impact on the person's decision making about:
 - a. Where the person should live;
 - b. What services they should receive;
 - c. What medical treatment they should be given;
 - d. To whom they should have access.

3. Is there **a need** for an order? 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?
4. Do you have any input into who should be guardian? Do you have knowledge of personal history and family relationships?

Testamentary Capacity

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 remaking their will, it is recommended that they are examined by a health professional with expertise in assessing will-making capacity.

For additional information on capacity, go to

Capacity and the Law by N O'Neill & C Peisah at: <http://www.austlii.edu.au/au/journals/SydUPLawBk/2011/1.html>

and NSW Capacity Toolkit at:

<http://www.lawlink.nsw.gov.au/lawlink/diversityservice>

References

1. Shulman, K., Cohen, C.A., Kirsh F.C., Hull, I.M., & Champine, P.R. (2007). Assessment of testamentary capacity and vulnerability to undue influence. American Journal of Psychiatry, 164, 722-727.
2. Peisah C., Sorinmade D., Mitchell L., Hertogh C. (2013) Decisional capacity: towards an inclusionary approach International Psychogeriatrics. 25 (10): 1571-9
3. Advance Care Directive Association, www.advancecaredirectives.org.au
4. Hertogh C.M.P.M. (2011) The misleading simplicity of advance directives. International Psychogeriatrics 23; 511-515.
5. Alzheimer's Association <http://www.alzheimers.org.au/research-publications/driving-and-dementia.aspx>.
6. [http://www.advancecaredirectives.org.au/AdvanceCare Directives-a-plan-of-care.html](http://www.advancecaredirectives.org.au/AdvanceCare-Directives-a-plan-of-care.html)

Authors

- Conjoint Assoc Prof Carmelle Peisah, UNSW, MB BS(Hons) MD FRANZCP, old age psychiatrist;
- Jenna Macnab, BA LLB(Hons). NSW Lawyer, Senior Policy Advisor, NSW Department of Attorney General & Justice, NSW Capacity Toolkit author ;and
- Nick O'Neill, LLB(Melb), LLM(Lond), Professorial Fellow, Faculty of Law, UNSW , formerly President, Guardianship Tribunal NSW;

Acknowledgement to: Anne Meller, Advance Care Directive Association Inc

© ACCEPD and the State of NSW through the NSW Department of Attorney General and Justice 2008. You may copy, distribute, display, download and otherwise freely deal with this work for any purpose, provided that you attribute the owners. However, you must obtain permission if you wish to:

- (a) charge others for access to the work (other than at cost);
- (b) include the work in advertising or a product for Sale; or
- (c) modify the work.

Disclaimer: This document has been prepared for general information purposes. While every care has been taken in relation to its accuracy, no warranty is given or implied. Further, recipients should obtain their own independent advice before making any decisions that rely on this information.



Appendix One

Summary Guide to Consent to Health Care for adults 18 years and over who cannot consent

Category	Treatment	Who can consent
Urgent medical treatment	<ul style="list-style-type: none"> • if a patient needs urgent treatment; and • the patient is unable to make reasonable judgments in respect of the treatment; and • it is not practicable for the health professional who proposes to provide the treatment to determine whether or not the patient has made an advance health directive containing a treatment decision that is inconsistent with providing the treatment; and • it is not practicable for the health professional to obtain a treatment decision in respect of the treatment from the patient’s guardian or enduring guardian or the person responsible. 	No consent
Medical and dental treatment		<p>Consent obtained in following order of priority:</p> <ul style="list-style-type: none"> • treatment decision in patient’s advance health directive, • enduring guardian authorised to make treatment decisions for the patient • guardian authorised to make treatment decisions for the patient • person responsible, in following order:- • the patient’s spouse or de facto partner; • the patient’s nearest relative (in order of spouse or de-facto, child, parent, sibling) who maintains a close personal relationship with the patient; • any other person who has reached 18 years of age; and maintains a close personal relationship with the patient <p>For more detail see substitute consent requirements under heading “Medical treatment consent”</p>
Sterilisation		Consent of the State Administrative Tribunal required