Capacity Australia

Decision-making capacity & dementia

A guide for Health Care Professionals in NSW
Mini-legal kit Series 1.12

Capacity is:

- ability to make and 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.

Under the common law, and consistent with Article 12 of the UN Convention on the Rights of Persons with Disabilities (CORPD) 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.

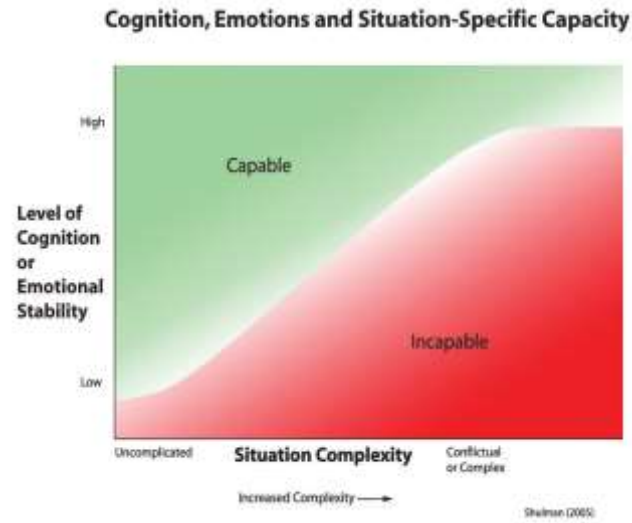
Capacity cannot be extrapolated from one decision to another. For example, a person's capacity to consent to medical treatment cannot be inferred from their capacity to make a decision to:

- execute a power of attorney;
- write a will;
- enter a contract or 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 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 Figure[1] Reproduced with permission from the American Journal of Psychiatry (Copyright © 2000) American Psychiatric Association



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, and for as long as possible. At the same time, when a person lacks capacity to make their own decisions, safeguards must be in place to prevent abuse, neglect and exploitation, consistent with **Article 12 of the CORPD.**

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. ASKME[2] is a practical model of supported decision-making, vis:

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.

How and when to assess capacity

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

- To facilitate **future planning** – a person may be encouraged to appoint:
    - an enduring guardian; or
    - general or enduring power of attorney; or
    - document their wishes with regards to future treatment (advance care planning).
- 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.
- **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 and 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 (ED) - Health and Personal decisions

An ED 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. Personal decisions may include accommodation decisions, lifestyle decisions, and decisions about access to persons. Health decisions are those medical and dental decisions which a "person responsible" can make under the *Guardianship Act 1987 (*NSW).[3]

In assessing capacity to appoint an ED, consider:

1. The "what" of the appointment:
    - Does the person understand that if disability renders them unable to manage their affairs and make decisions for themselves, their appointed guardian may make decisions on their behalf about accommodation, health care, personal services, and medical treatment? The guardian can decide the actual place in which they are to live, 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 enduring guardian (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 Directives (ACD) – Health decisions

An ACD is a written/oral 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 and/or the details of a preferred substitute decision-maker. It is used when the person loses capacity.[4]

In assessing capacity to execute advance care directives, consider:

1. The "what" of the ACD:
    - 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. The "who" of the ACD:
    - The same type of considerations may apply as in No. 2 of the "who" of the ED.
3. The "freedom" of the ACD:
    - 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"?

The process of advance care planning should 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? [5]

Powers of Attorney (General and Enduring) – Financial decisions

A general (or ordinary) power of attorney (GPOA) provides an attorney with authority to make financial decisions on behalf of the person making the GPOA (the principal). It operates immediately or at a date

specified in the GPOA. If the principal loses capacity, the GPOA ends.

An enduring power of attorney (EPOA) allows a principal to appoint an attorney to make financial decisions for them when they lose the capacity to manage their financial affairs. A principal can limit an attorney's power through instructions in the POA.

An attorney can act as both a GPOA and an EPOA if it incorporates all of the necessary legal requirements. It can therefore operate while a person has capacity, but will also continue when they lose capacity.

When assessing for capacity to make a power of attorney, consider:

1. The "what" of the appointment:
    - Does the person understand that they are authorising someone to look after and assume 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 principal'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 they understand that the attorney can do anything with the principal's property which they have authorised them to do?
    - Do they understand that the authority will begin, or continue, when they are incapable of managing their financial affairs (applies to Enduring, not General, POAs)?

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 a 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 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.[6]

Medical treatment consent

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; 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.

Consider the person's religious or cultural beliefs or other views when assessing capacity.

If the person lacks capacity to give informed consent about treatment, is not objecting to it, and the treatment is not urgent or special, then consent must be sought from a "person responsible" where there is no relevant enduring guardian appointed - see 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 [7] is a consensus-based discussion involving the person (who, regardless of not having capacity, may want to have some input into this discussion), carer, family 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 an assessment. This assessment guides others' decisions about whether they need to begin using an EPOA or (where there is no EPOA) apply to the NSW Administrative and Civil Tribunal (NCAT) for a financial management order.

In assessing capacity to manage financial affairs, consider:

1. 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?
   - The person does not have to manage financial tasks in the best possible way, but they must be able to manage them.
2. If the person lacks capacity to manage their affairs, they do not need a financial management order unless there is a need or it is in the best

interests of the person to have someone else make their financial decisions.

- 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, a Power of Attorney, an accountant)?

3. If the person cannot manage all of their affairs decide whether there are parts of their finances that they can manage.

Guardianship – Personal decisions

A person may need a guardian appointed by NCAT where they lack the capacity to make personal life or lifestyle decisions. A guardian may be appointed with an end of life decision-making function.

In assessing the need for a guardianship order, consider:

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. Is the person able to make decisions in regards to matters relating to lifestyle, health, welfare?
3. 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?
4. 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?

5. 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?

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

1. Capacity and the Law by N O'Neill & C Peisah at: http://www.austlii.edu.au/au/journals/SydUPLawBk/2011/1.html
2. The NSW Capacity Toolkit at: http://www.lawlink.nsw.gov.au/lawlink/diversityservices
3. Capacity Australia's website at: http://capacityaustralia.org.au/

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 (in press) International Psychogeriatrics.

3. Under the *Guardianship Act* 1987 (NSW) there is a hierarchy of people who can be a 'person responsible'. They are not necessarily the patient's 'next of kin'.

   A person responsible, in order of priority, is:
   - an appointed guardian (including an enduring guardian) who has been given the right to consent to medical and dental treatments or, if there is no guardian;
   - the most recent spouse or de facto spouse (including same-sex partner) when the spouse or de facto has a close and continuing relationship with the person or, if there is no spouse or de facto spouse;
   - the unpaid carer or the carer at the time the person entered residential care (note: recipients of a government carer benefit are not considered to be paid) or, if there is no carer;
   - a relative or friend who has a close personal relationship with the person.

   The person responsible can't or won't make a treatment decision, he or she must decline in writing. The next person in the list will then become the person responsible. A practitioner or other qualified person can remove the person responsible from their role by certifying, in writing, that the person responsible is not capable of carrying out the role.

5. Advance Care Directive Association, www.advancecaredirectives.org.au
6. Hertogh C.M.P.M. (2011) The misleading simplicity of advance directives. International Psychogeriatrics 23; 511-515.
7. Alzheimer's Association http://www.alzheimers.org.au/research-publications/driving-and-dementia.aspx.
8. http://www.advancecaredirectives.org.au/AdvanceCareDirectives-a-plan-of-care.html

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Appendix 1: Summary guide to consent to Health Care for adults 16 years and over who cannot consent

TREATMENT	INCLUDES	WHO CAN CONSENT
URGENT	Urgently necessary to: - save patient's life - prevent serious damage to health - prevent or alleviate significant pain or distress, except if the treatment is **special**	**No consent needed**
MINOR	All medical / dental treatments (except **major** or **special)** Includes: - treatment involving general anaesthetic or other sedation • for management of fractured or dislocated limbs • for endoscopes inserted through an orifice, not penetrating the skin - medications that affect the central nervous system • when used for analgesic, antipyretic, antiparkinsonian, antihistaminic, antiemetic, antinauseant or anticonvulsant purposes when such medications are used only once • PRN (as and when required) not more than 3 times per month • sedation in minor procedures	Person responsible can consent if patient not objecting. If no 'person responsible' or they cannot be located or cannot/will not respond and patient is not objecting, the doctor or dentist may treat without consent. It must be noted on the patient's record that treatment is necessary to promote the patient's health and wellbeing, and that the patient is not objecting.
MAJOR	- medical / dental treatment involving general anaesthetic or other sedation (except if **minor**). - medications affecting the central nervous system (except if **minor**). - drugs of addiction. - long-acting injectable hormonal substances for contraception or menstrual regulation. - any treatment for the purpose of eliminating menstruation. - testing for HIV. - any treatment involving substantial risk. - any dental treatment resulting in removal of all teeth or significantly impairing ability to chew food.	Person responsible can consent if patient not objecting. If no 'person responsible' or they cannot be located or cannot/will not respond and patient is not objecting, then only NCAT can consent. The request and consent must be in writing or, if not practicable, later confirmed in writing.
SPECIAL	- sterilisation (includes vasectomy and tubal occlusion) - termination of pregnancy - treatments intended or likely to result in permanent infertility - aversives – mechanical, chemical or physical - experimental treatments: • any new treatment that has not yet gained the support of a substantial number of doctors or dentists specialising in the area • use of central nervous system affecting medication where dosage, duration or combination is outside accepted norms • androgen reducing medications for behavioural control	NCAT only
CLINICAL TRIALS	- a trial of drugs or techniques that necessarily involves the carrying out of medical /dental treatment on the participants in the trial	NCAT only
OBJECTION	A patient who cannot give a valid consent to treatment is considered to be objecting if they indicate or have previously indicated that they do not want the treatment carried out and have not withdrawn their objection **Exceptions** to the above are: - consent is not required if the treatment is urgent (see **urgent** category above) - a patient's objection can be disregarded by the treating practitioner if: • the treatment is **not special** treatment; **and** • the patient has minimal or no understanding of **what** the treatment entails; **and** • the treatment will cause the patient no distress; **or** • if it will cause the patient some distress, the distress is likely to be reasonably tolerable and only transitory.	Only NCAT can override a patient's objection to treatment. A guardian who has been given the authority in a guardianship order from NCAT to override the patient's objections may consent to the treatment despite the patient's objections, but only if satisfied that the proposed treatment is manifestly in the best interests of the patient

Adapted from: Substitute Consent - what the law says, Part 5 NSW Guardianship Act 1987