



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

Capacity & dementia

A guide for Victorian Health Care Professionals:
Mini-legal kit Series 1.5



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.

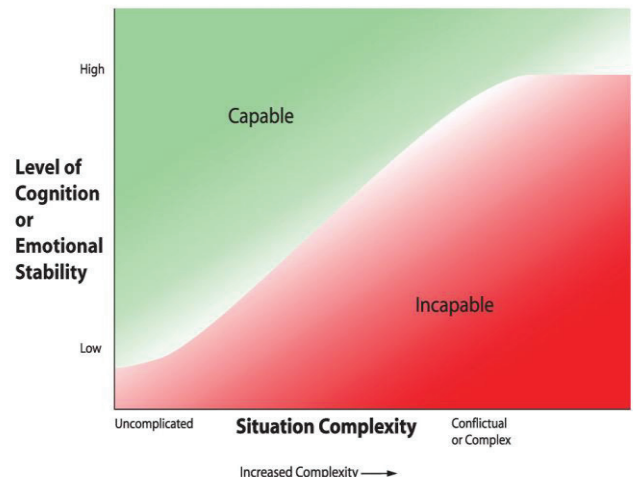
Capacity cannot be extrapolated from one decision to another. For example, a person’s capacity to consent to medical treatment cannot be inferred from their capacity to make a decision to:

- 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, 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
 - make a medical enduring power of attorney; or
 - make an advance care directive under the common law; or
 - make a refusal of treatment certificate.
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. an assessment of whether the person understands, in their own words, the relevant legal test for capacity 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

Guardianship and Administration Act 1986 (Vic) sections 35A-E and Schedule 4). 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'³ can make under the *Guardianship and Administration Act 1986* (Vic).

In assessing capacity to appoint an EG, consider:

1. The "what" of the appointment:



- Does the person understand that if, by reason of a disability they become unable to make reasonable judgments 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. (The guardian will be able to decide the actual place in which they are to live and the health care and personal services they will receive).
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 is a process for making and writing down future health care wishes in advance. This can include:⁴

(a) Appointing a Medical Enduring Power of Attorney (MEPOA): This is a legal document that allows a person to appoint another person (agent) to make medical treatment decisions on their behalf. It operates when the person loses capacity. The person must understand that it only applies to medical decisions (not financial or lifestyle decisions).

(b) Making an advance care directive: The *Medical Treatment Act 1988* (Vic) does not prevent a person making an advance care directive which involves refusing medical treatment. See s. 4(1) of the *Act*.

(c) Obtaining a Refusal of Treatment Certificate (RTC): Section 5 of the same *Act* provides that a patient can clearly express or indicate that they refuse medical treatment generally, or medical treatment of a particular kind, if it is in relation to a **current condition**. A registered medical practitioner and another person may then certify the decision, but before doing so they must each be satisfied that the person’s decision was made:

1. voluntarily and without inducement or compulsion;
2. after the person had been informed, and appeared to understand the information given to them about the nature of the condition, to the extent that was reasonably sufficient for them to be able to decide whether to refuse medical treatment generally, or particular medical treatment for that current condition

In assessing capacity to make a RTC consider both the person’s understanding of the nature of their condition and of the consequences of the treatment refusal. Additionally, assessment should include looking for conditions that might affect capacity, such as delirium or depression.

If the person has lost capacity but has appointed an enduring guardian or appointed an agent under a MEPOA, either the enduring guardian or agent may complete an RTC on their behalf.

(d) Writing down wishes for future medical care: A person may record their wishes regarding future medical treatments on a ‘Statement of Choices’. This documents health care values and guides those making decisions on the person’s behalf. It is not legally binding.

Enduring Powers of Attorney – Financial decisions

A general power of attorney (GPOA) allows a person (the principal) to appoint an attorney to make financial

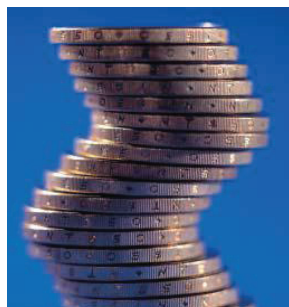
decisions for them. A GPOA operates immediately or at a date specified in the GPOA. If the principal loses capacity, the GPOA ends.

An enduring power of attorney (EPOA) allows the principal to appoint an attorney to make financial decisions for them when they lose the capacity to manage their financial affairs. An attorney can act under both GPOA and an EPOA if all necessary legal requirements are met. So, the attorney can act while the principal has capacity, but will also continue to act when the principal loses capacity.

Under the *Instruments Act (1958)* (Vic) a person must understand the nature and effect of a power of attorney (POA) for it to be valid. Section 118 of the *Instruments Act (1958)* (Vic) sets out matters to be considered in determining whether the test has been satisfied and also provides that it is “advisable” for the witness to make a written record of the evidence on which the witness considers that the principal has capacity. When assessing for capacity to make a POA, 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 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 when the power begins, and that it can be revoked at any time they have capacity?
- In the case of an EPOA, do they understand that the authority 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:

- Why has the persons elected for appointment as an attorney? Has the person executed any POA’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 a POA 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.⁵

Medical treatment consent

In Victoria, an adult is capable of giving a valid consent to their own medical or dental treatment if they are

capable of understanding the general nature and the effect of the treatment, and can indicate whether or not they 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;
 - 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 the person lacks capacity to give informed consent about treatment, is not objecting to it, and the treatment is not urgent or special, then a health professional must make reasonable efforts to find the ‘person responsible’.² The person responsible then makes treatment decisions.

Objections to treatment

Anticipated objection of the incapable person

If either the treating doctor or the person responsible has reason to believe that the carrying out of the proposed treatment would be against the incapable person’s wishes, the doctor or person responsible must apply to VCAT for consent if they want the treatment carried out.

Objection by the person responsible

Persons responsible may voice their objection to treatment proposed for the person for whom they are person responsible by refusing to give their consent to that treatment. However, they may refuse consent to the

proposed treatment only if it is in the best interests of the incapable person to do so.

Plans of Care in the later stages

If the person has not appointed an agent under an MEPOA, or an RTC has not been made, and they are no longer competent, this should not exclude the person from saying what they want or don’t want for themselves. (If they have made an advance care directive under the common law this must be honoured.)

A Plan of Care is a consensus based document based on a conversation between health professionals, the person (where possible) and family/carers (including person responsible) 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 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 (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 maximize patient autonomy.

While an advance care directive 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 no EPOA) apply to the VCAT for an administration order. In assessing capacity to manage their estate, consider:

- Does the person have a disability?
 - By reason of that disability is the person able to make reasonable judgments about matters relating to any or part of their estate? 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 administrative 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.

Guardianship – Personal decisions

A person may need a guardian appointed by VCAT 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?
2. Is the person unable, by reason of that disability to make reasonable judgments about all or any of the matters relating to their person or circumstances? Such matters might include lifestyle, health and welfare. Does the dementia 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 be permitted to work;
 - d. What health care they should receive;
 - e. To whom they should have access?
3. Is there a need for an order? Is it in the best interests of the person for an order to 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?

4. What are the person's wishes? What are the wishes of close family members/carers? Is there a dispute?
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?

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.

ACCEPD acknowledges that this work is based on the NSW version of this Mini-kit, a collaboration between ACCEPD and the NSW Department of Attorney General and Justice



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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. Reproduced with permission from the American Journal of Psychiatry (Copyright © 2000) American Psychiatric Association.
2. Peisah C., Sorinmade D., Mitchell L., Hertogh C. (2013) Decisional capacity: towards an inclusionary approach (submitted document).
3. The person responsible is the first person listed in section 37 *Guardianship and Administration Act 1986* (Vic) who, in the circumstances, is not only reasonably available but also willing and able to make medical and dental treatment decisions on behalf of the incapable person. The list is as follows:
 - i. An agent under an enduring power of attorney (medical treatment), appointed by the person when they had capacity;
 - ii. A person appointed by VCAT to make decisions about the proposed treatment;
 - iii. A guardian appointed by VCAT with health care powers;
 - iv. An enduring guardian with health care powers appointed by the person when they had capacity;
 - v. A person appointed in writing (by the patient when they had capacity) to make decisions about medical and dental treatment including the proposed treatment;
 - vi. The incapable person's spouse or domestic partner;
 - vii. The incapable person's primary carer including carers in receipt of a Centrelink carer's payment but excluding paid carers or service providers;
 - viii. The incapable person's nearest relative (over 18), in order:
 - (a) son or daughter;
 - (b) father or mother;
 - (c) brother or sister (inc adopted siblings and step siblings);
 - (d) grandfather or grandmother;
 - (e) grandson or granddaughter;
 - (f) uncle or aunt;
 - (g) nephew or niece.
4. <http://www.racgp.org.au/content/navigationmenu/clinicalresources/racgpguidelines/advancecareplans/200906VIC>
5. Alzheimer's Association <http://www.alzheimers.org.au/research-publications/driving-and-dementia.aspx>.
6. <http://www.advancecaredirectives.org.au/AdvanceCareDirectives-a-plan-of-care.html>
7. Hertogh C.M.P.M. (2011) The misleading simplicity of advance directives. *International Psychogeriatrics* 23; 511-515.



Appendix One: Summary Guide to Medical and Dental Consent for adults 18 years and over who cannot consent for themselves

| Category | Treatment | Who can consent |
|------------------------------|--|---|
| Medical and dental treatment | <p>Medical treatment includes any medical or surgical procedure, operation or examination and any prophylactic, palliative or rehabilitative care normally carried out by, or under, the supervision of a doctor</p> <p>Dental treatment includes any dental procedure, operation or examination normally carried out by or under the supervision of a dentist</p> <p>But does not include:</p> <ul style="list-style-type: none"> • Excluded treatment • Emergency treatment • Special procedures • Medical research procedures | Person responsible (See “Who is person responsible?” in the text) |
| Excluded treatment | <p>Any non-intrusive examination made for diagnostic purposes (including a visual examination of the mouth, throat, nasal cavity, eyes or ears)</p> <p>First-aid treatment</p> <p>The administration of a pharmaceutical drug for the purpose and in accordance with the dosage level:</p> <ul style="list-style-type: none"> • if the drug is one for which a prescription is required, recommended by a registered practitioner; or • if the drug is one for which a prescription is not required and which is normally self-administered, recommended in the manufacturer’s instructions or by a registered practitioner. | No consent needed |
| Emergency treatment | <p>Emergency treatment needed to:</p> <ul style="list-style-type: none"> • Save a patient’s life • Prevent serious damage to health • Prevent suffering from significant pain or distress (except if the treatment is a special procedure) | No consent needed |
| Special procedures | <p>Special procedures are:</p> <ul style="list-style-type: none"> • Sterilisation • Termination of pregnancy • Removal of tissue for transplantation into another person | VCAT must consent |

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; or
- contact ACCEPD at: accepd.capacity@gmail.com.