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

Capacity & dementia

A guide for Tasmanian Health Care Professionals:

Mini-legal kit Series 1.4

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.

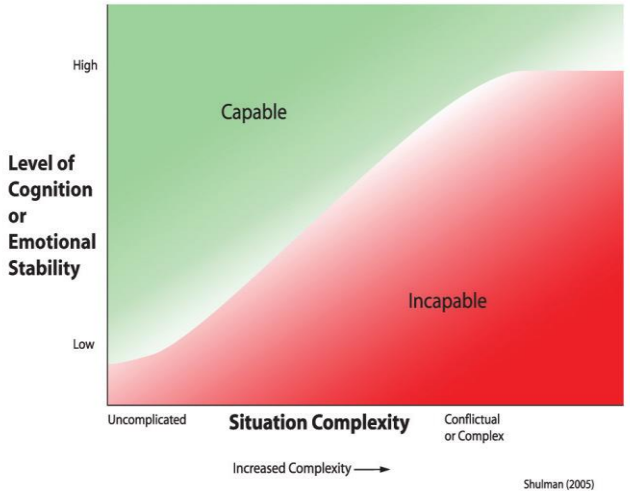
Capacity cannot be extrapolated from one decision to another. For example, a person's capacity to consent to medical treatment cannot be inferred from their capacity to make a decision to:

- 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 below[1]

Cognition, Emotions and Situation-Specific Capacity



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 . ASKME[2] is a 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;
5. **E**nable 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 an enduring power of attorney; or
    - make an advance care directive.
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. 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 an estimate of severity and an 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. 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 and Administration Act 1995* (Tas).[3]

In assessing capacity to appoint an EG, consider:

1. The "what" of the appointment:
    - Does the person understand that if, due to a disability, they are unable to make reasonable

judgments in matters relating to their personal circumstances, 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"?

Note for an EG to be in effect in Tasmania, it must be registered with the Guardianship and Administration Board.

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 is used when the person loses capacity.[4]

In assessing capacity to make an ACD, 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 "freedom" of the ACD:
   - Are they making the appointment freely and voluntarily and not being unduly influenced or "schooled"?

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 should not be based on a static document, but on a more dynamic practice that supports patients 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 ideas 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? [4-5]

Enduring Powers of Attorney – Financial decisions

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. However, it can operate immediately or at a date specified in it. But it 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 maker understand:
   - They are authorising someone to look after and assume complete authority of their financial affairs, unless they limit the power they give to the attorney in the EPOA?

- The sort of things the attorney can do without further reference to them (e.g. selling their house or writing cheques on their behalf). The more extensive and complex a principal's affairs, the greater their understanding must be;
- That while the maker may revoke the EPOA while they have capacity, the authority of the attorney will begin, or continue, when they are incapable of managing their financial affairs They won't be able to oversee the attorney's exercise of the power if they lose capacity

2. The "who" of the appointment:
   - Why has the person been selected for appointment as an attorney? Has the maker 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 maker 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 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

Medical treatment consent in Tasmania

A person with a disability is incapable of giving consent to the carrying out of medical or dental treatment on them if, they are:

(a) incapable of understanding the general nature and effect of the proposed treatment; or

(b) incapable of indicating whether or not they consent or do not consent to the carrying out of the 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; 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.

   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". 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 the person, any enduring guardian and family members), a **Plan of Care**.

A Plan of Care is a consensus based discussion involving the person (who, regardless of lacking capacity, may want to have some input into this discussion), their person responsible, their carer, family members and medical staff around best interests, as the person is no longer able to provide informed consent about their future treatment.[6] 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.

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. [7]

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 Guardianship and Administration Board for an administration order, if informal arrangements are insufficient to manage the person's financial affairs.

In assessing capacity to manage financial affairs, consider:

1. Does the person have a disability?
2. Because of that disability, are they unable to make reasonable judgments about matters relating to all or any part of their estate?
3. 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 affairs, they do not need an administration 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)?

4. 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 the Guardianship and Administration Board 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. Are they unable, by reason of the disability, to make reasonable judgments about all or any of the matters relating to their person or circumstances? Does dementia, for example, impact on the person's ability to make decisions about:
   a. Where they should live;
   b. What services they should receive;
   c. What medical treatment they should be given;
   d. To whom they should have access; or
   e. Whether the person should or should not be permitted to work and, if so, the nature or type of work, for whom they are to work and related matters.
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 or the wishes of the person, 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 see:

- *Capacity and the Law* by N O'Neill & C Peisah at: http://www.austlii.edu.au/au/journals/SydUPLawBk/2011/ 1.html
- *Tasmanian Capacity Toolkit* at: http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0008/98513/Web_Capacity_Toolkit_Tasmania.pdf ; or
- contact ACCEPD at: **accepd.capacity@gmail.com**

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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. Under the *Guardianship and Administration Act 1995* (Tas) there is a hierarchy of people who can be a 'person responsible'. This is not necessarily the 'next of kin'.
They are, in descending order:
   I. the person's guardian (including an enduring guardian where one has been appointed for this purpose) if there is an order appointing them to make medical treatment decisions- if none;
   II. the most recent spouse or defacto spouse in a close and continuing relationship with the person (including same sex) and if not under guardianship – if none;
   III. an unpaid carer – if none;
   IV. a close relative or friend who has a close personal relationship with the person.

Where the person is under 18 years of age it is their spouse, in a close and continuing relationship, or if no spouse, their mother or father.

4.Advance Care Directive Association, www.advancecaredirectives.org.au

5 Hertogh C.M.P.M. (2011) The misleading simplicity of advance directives. International Psychogeriatrics 23; 511-515.

6.http://www.advancecaredirectives.org.au/AdvanceCareDirectives-a-plan-of-care.html

7. Alzheimer's Association http://www.alzheimers.org.au/research-publications/driving-and-dementia.asp

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

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	**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 **Dental treatment i**ncludes any dental procedure, operation or examination normally carried out by or under the supervision of a dentist But **medical treatment** does **not** include: • Excluded treatment • Emergency treatment • Special treatment **If the person has no "person responsible" and is not objecting** to the treatment and the treatment is both necessary and the form of treatment that will most successfully promote the person's health and well-being, i**t can be given without consent unless it is one of the following treatments**: • Continuing or ongoing **medical treatment** that involves the administration of a restricted substance primarily to control the conduct of the person to whom it is given; or • the administration of a drug of addiction other than in association with the treatment of cancer or palliative care of a terminally ill patient; or electroconvulsive therapy (ECT); or • treatment involving a substantial risk to the person concerned of – death; brain damage; paralysis; permanent loss of function of any organ or limb; permanent and disfiguring scarring; extreme pain or distress. **Dental treatment** intended, or likely, to result in the removal of all or a substantial number of teeth.	**Person responsible** (See "Who is person responsible?" in the text) **No consent needed**
Excluded treatment	Any non-intrusive examination made for diagnostic purposes (including a visual examination of the mouth, throat, nasal cavity, eyes or ears) First-aid treatment The administration of a pharmaceutical drug for the purpose and in accordance with the dosage level: • 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	Emergency treatment needed to: • 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 treatments	Special procedures are: • Sterilisation • Termination of pregnancy • Removal of tissue for transplantation into another person • Psychosurgery • Treatment involving the use of aversive stimuli	**Guardianship and Administration Board must consent**