Capacity Australia

Decision-making capacity & dementia

A guide for Health Care Professionals in Queensland
Mini-legal kit Series 1.8

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, 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.

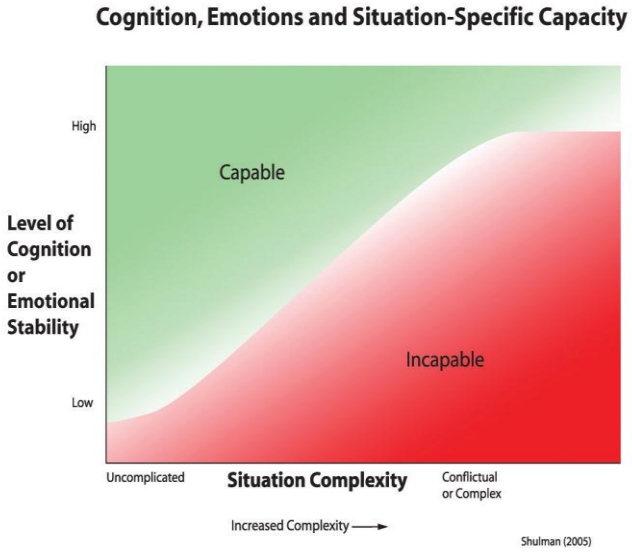
Capacity cannot be extrapolated from one decision to another. For example, a person's capacity to consent to medical treatment cannot be inferred from their capacity to make a decision to:

- 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. 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:

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 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 Power of Attorney for Personal Matters: EPoA (Personal) - Health and Personal decisions

An EPoA (Personal) is a document in which a person appoints an attorney to make certain personal and/or health decision 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 persons.

In assessing capacity to appoint an EPoA (Personal), consider:

1. The "what" of the appointment:
    - Does the person understand that if they become unable to make decisions about personal matters, including their health care, the attorney may make decisions on their behalf about accommodation, health care (including medical treatment), personal services, and other personal matters. For example, the attorney 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 attorney 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 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] The adult may appoint 1 or more attorneys to exercise power for a health matter if the adult's directions prove inadequate. The power can only be used during the time the adult lacks capacity for the matter.

If an adult makes an AHD, under the *Powers of Attorney Act 1998* (Qld), to withhold or withdraw one or more life-sustaining measures, that direction cannot operate unless at least one of the following situations applies:

1. the maker has a terminal illness or condition that is incurable or irreversible and as a result of which, in the opinion of a doctor treating the maker and another doctor, the maker may reasonably be expected to die within 1 year;
2. the maker is in a persistent vegetative state, meaning that they have a condition involving severe and irreversible brain damage which allows some or all of the maker's vital bodily functions to continue, including, e.g. heart beat or breathing;
3. the maker is permanently unconscious, meaning that they have a condition involving brain damage so severe that there is no reasonable prospect of them regaining consciousness; or
4. the maker has an illness or injury of such severity that there is no reasonable prospect that they will recover to the extent that their life can be sustained without the continued application of life-sustaining measures.

In addition, a direction to withhold or withdraw artificial nutrition or hydration, can operate if the proposed treatment would be inconsistent with good medical practice; and the maker has no reasonable prospect of regaining capacity for health matters.

If the person making the AHD has impaired capacity, but has made a direction about a particular health matter in the AHD, that matter is to be dealt with according to that direction. If there is no applicable direction, but the Queensland Civil and Administrative Tribunal (QCAT) has appointed a guardian(s) for the matter or has given an order about the matter, the matter can be dealt with only by the guardian(s) or under the order. If neither of those situations apply, but the adult has made an EPoA (Personal) dealing with the matter then the

attorney(s) may deal with the matter. If none of the situations set out above apply, then the matter is dealt with by the first available and culturally appropriate "statutory health attorney". See below for the hierarchy of statutory health attorneys.

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 consider the "who" of the AHD:
   - The same type of considerations may apply as in No. 2 of the "who" of the EPoA (Personal).
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 dynamic 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 (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 maker can limit an attorney's power through instructions in the EPoA.

In Queensland the *Powers of Attorney Act 1998* states that an adult may make an EPoA only if they understand the nature and effect of such a power of attorney, including understanding the following matters;

1. that in the power of attorney the maker may specify or limit the power to be given to an attorney and instruct an attorney about the exercise of the power;
2. when the power of attorney begins;
3. that once the power of attorney begins, the attorney will have full control over, the financial matters included in the EPoA subject to terms or information in the power of attorney about how it is to be exercised;
4. that they may revoke the EPoA at any time they are capable of making an EPoA (giving the same powers to the attorney);
5. that the power of attorney continues if they, the maker, becomes a person who has impaired capacity; and
6. that at any time they are not capable of revoking the EPoA, they are unable to effectively oversee its use by the attorney.

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 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 (subject to instructions or limitations in the Power of Attorney)?
   - 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 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 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

An adult may give consent to their own medical and dental treatment unless they have impaired capacity for a "health matter", that is:

(i) if they are in capable of understanding the nature and effect of decisions about the matter;
(ii) cannot freely and voluntarily make decisions about the matter; or
(iii) cannot communicate their decisions in some way.

General principles for assessing capacity to make a decision about a health matter include:

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.

Substitute decision-maker for health matters

If the adult with impaired capacity has not made an AHD, the substitute decision-maker for the adult will be the first person who qualifies in the following list:

1. any guardian for health matters appointed by QCAT;
2. any enduring attorney for health matters appointed by the adult in an EPoA (personal) – see above;
3. The first available and culturally appropriate "statutory health authority" from the list below.
   (i) a spouse of the adult if the relationship between the adult and the spouse is close and continuing;
   (ii) an adult person who has the care of the adult and is not a paid carer for the adult;
   (iii) an adult person who is a close friend or relation of the adult and is not a paid carer for the adult.

If no-one in this list is readily available and culturally appropriate, the Adult Guardian becomes the adult's statutory health attorney for the particular health matter.

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 AHD, 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, 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 substitute decision-maker – See Appendix 1.

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 QCAT for an administration order. Before QCAT may, by making an administration

order, appoint an administrator for the person the hearing is about, it must be satisfied that:

1. the person the application is about has impaired capacity for the financial matter;
2. there is a need for a decision in relation to that matter or the person is likely to do something in relation to the matter that involves, or is likely to involve, unreasonable risk to their health, welfare or property; and
3. without the appointment of an administrator;
   (a) the person's needs will not be adequately met, or
   (b) the person's interests will not be adequately protected.

The administration order may include all or some of the adult's property.

A person has impaired capacity for a financial matter if they are incapable of:

1. understanding the nature and effect of decisions about the matter;
2. freely and voluntarily making decisions about the matter; and
3. communicating the decisions in some way.

A financial matter for an adult is defined in the *Act* as, a matter relating to the adult's financial or property matters. It includes a matter relating to one or more of the following:

1. paying maintenance and accommodation expenses for the adult and the adult's dependants, including for example, purchasing an interest in, or making another contribution to, an establishment that will maintain or accommodate the adult or a dependant of the adult;
2. paying the adult's debts, including any fees and expenses to which an administrator is entitled under a document made by the adult or under a law;
3. receiving and recovering money payable to the adult;
4. carrying on a trade or business of the adult;
5. performing contracts entered into by the adult;
6. discharging a mortgage over the adult's property;
7. paying rates, taxes, insurance premiums or other outgoings for the adult's property;
8. insuring the adult or the adult's property;
9. otherwise preserving or improving the adult's estate;
10. investing for the adult in authorised investments;
11. continuing investments of the adult, including taking up rights to issues of new shares, or options for new shares, to which the adult becomes entitled by the adult's existing shareholding;
12. undertaking a real estate transaction for the adult;
13. dealing with land for the adult under the *Land Act 1994 (Qld)* or *Land Title Act 1994 (Qld)*;
14. undertaking a transaction for the adult involving the use of the adult's property as security (e.g. for a loan or by way of a guarantee) for an obligation the performance of which is beneficial to the adult;
15. a legal matter relating to the adult's financial or property matters, and
16. withdrawing money from, or depositing money into, the adult's account with a financial institution.

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 Enduring Power of Attorney, 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 QCAT where they lack the capacity to make personal life or lifestyle decisions. Before QCAT may appoint a guardian it must be satisfied that:

1. the person the application is about has impaired capacity for the personal matter;
2. there is a need for a decision in relation to that matter or the person is likely to do something in relation to the matter that involves, or is likely to involve, unreasonable risk to their health, welfare or property; and
3. without the appointment of a guardian;
   i. the person's needs will not be adequately met, or
   ii. the person's interests will not be adequately protected.

A personal matter, for an adult, is a matter relating to the adult's care including the adult's health care, or welfare. For example, it may be a matter relating to 1 or more of the following:

(a) where the adult lives;
(b) with whom the adult lives;
(c) whether the adult works and, if so, the kind and place of work and the employer;
(d) what education or training the adult undertakes;
(e) whether the adult applies for a licence or permit;
(f) day-to-day issues, including, for example, diet and dress;
(g) health care of the adult;
(h) whether to consent to a forensic examination of the adult;
(i) a legal matter not relating to the adult's financial or property matter;
(j) a restrictive practice matter;
(k) seeking help and making representations about the use of restrictive practices for an adult who is the subject of a containment or seclusion approval.

General principles for assessing capacity to manage personal affairs include:

1. Does the adult 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 adult have capacity in regards to the matter i.e. 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.

Further Information

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
- the NSW Capacity Toolkit at: http://www.lawlink.nsw.gov.au/lawlink/diversityservices
  and
- Capacity Australia's website at: http://capacityaustralia.org.au/

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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/AdvanceCareDirectives-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;

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Capacity Australia

CAPACITY, ETHICS and the PREVENTION of EXPLOITATION of PEOPLE WITH DISABILITIES

CONTACT Capacity Australia at:
capacityaustralia.org.au

Appendix One:

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

Health Care is care or treatment of, or a service or a procedure for, an adult to diagnose, maintain, or treat the adult's physical or mental condition; and carried out by, or under the direction or supervision of, a health provider. It also includes withholding or withdrawal of a life-sustaining measure if the commencement or continuation of the measure would be inconsistent with good medical practice.

It does **not** include first aid treatment; non-intrusive examinations made for diagnostic purposes (for example a visual examination of an adult's mouth, throat, nasal cavity, eyes or ears) or the administration of a pharmaceutical drug which is normally self-administered and for which a prescription is not needed, provided the administration is for a recommended purpose and at a recommended dosage level.

Special health care is excluded from the definition of health care because of the particular consent provisions relating to them. (See below)

Health provider means a person who provides health care, or special health care, in the practice of a profession or the ordinary course of business..This covers doctors, dentists and other recognised health professionals including, psychologists, physiotherapists, optometrists, speech therapists and occupational therapists.

Category	Treatment	Who can consent
Minor uncontroversial health care	Health care that the health provider reasonably considers is minor and uncontroversial can be carried out on a patient if the health provider reasonably considers that: 1. the adult has impaired capacity for the health matter; 2. it is necessary to promote the adult's health and wellbeing; 3. it is of the type that will best promote the adult's health and wellbeing; and 4. the health care provider does not know, and can not reasonably be expected to know, of: (i) a decision about the health care by a tribunal appointed guardian, an enduring attorney appointed under an EPoA (Personal) or a statutory health attorney, or (ii) any dispute among persons the health provider reasonably considers have a sufficient and continuing interest in the adult about— (a) the carrying out of the health care; or (b) the capacity of the adult for the health matter	May be carried out without consent unless the health provider knows, or could reasonably be expected to know, the adult objects to the health care. Also the health provider must certify in the adult's clinical records as to the various things enabling the health care to be carried out because of this section. Examples of minor and uncontroversial health care are: • the administration of an antibiotic requiring a prescription • the administration of a tetanus injection

Category	Treatment	Who can consent
Urgent	1. the health care should be carried out urgently to meet imminent risk to the adult's life or health; or 2. the health care should be carried out urgently to prevent significant pain or distress to the adult and it is not reasonably practicable to get consent from their attorney for health matters or their guardian for health matters (if they have one) or their statutory health attorney	No consent needed
Special health care	Special health care has been defined as: 1. removal of tissue from the adult while alive for donation to someone else; 2. sterilisation of the adult; 3. termination of a pregnancy of the adult; 4. participation by the adult in special medical research or experimental health care; 5. electroconvulsive therapy or psychosurgery for the adult; 6. prescribed special health care of the adult. (Nothing has been prescribed as at 30-8-13).	If the adult has impaired capacity for a special health care matter but has made an AHD giving a direction about that matter, then the matter may be dealt with only under the direction. If there is no AHD, QCAT can deal with the matter unless it is electro-convulsive therapy or psychosurgery. The Mental Health Review Tribunal deals with those matters.
Health Care that is neither minor and uncontroversial, urgent, nor special health care	Sources of consent – in hierarchical order: 1. If adult has made an AHD which gives a direction about the health matter – matter dealt with only under direction 2. If QCAT appointed guardian(s) or made order – matter dealt with only by guardians or under order 3. If adult has made 1or more enduring documents – matter dealt with only by the attorney(s) for the matter appointed under the most recent enduring document 4. When none of the above apply the matter may only be dealt with by first available, culturally appropriate statutory health attorney in the hierarchy of such attorneys.	Consent required Statutory health attorneys hierarchical list: 1. spouse of adult if relationship between adult and spouse is close and continuing 2. adult person who has the care of the adult and is not a paid carer for the adult; 3. adult person who is a close friend or relation of the adult and is not a paid carer for the adult. If no-one in list is readily available and culturally appropriate, the Adult Guardian becomes the adult's statutory health attorney for the particular health matter