Health Care Decision Making for Adults with Impaired Decision Making Capacity

What does the Health Care Decision Making Act 2024 do?

The Health Care Decision Making Act 2023 (the Act) creates a central health care decisions making framework for an adult with impaired decision making capacity.

The reforms establish a clear hierarchy of people, which includes family members and other persons who have an existing relationship to the adult, allowing them to make health care decisions on the adult's behalf. They ensure that, wherever possible, health care decisions are made for the adult by a person who is familiar with the adult's views and wishes.

It is a move away from the principle of best interests towards preference for the views and wishes, in line with the human rights of individuals to have their own choices and lifestyle respected.

What is a health care decision?

Health care decision is defined in section 6 of the Act as a decision whether to commence, continue, withdraw or withhold health care for an adult.

Health care is defined in section 7 of the Act broadly and includes health care provided by a registered health practitioner as well as services provided by other services specifically listed in the Act.

Presumption of capacity

An adult is presumed to have capacity to make a health care decision unless there is evidence to the contrary.

An impairment in any of the following is relevant in determining whether an adult's capacity to make a health care decision is impaired:

- (i) understanding and retaining information relevant to the health care decision;
- (ii) weighing information relevant to the health care decision in order to make the health care decision;

- (iii) communicating the health care decision in some way;
- (iv) understanding the effect of the health care decision.

Appropriate support should be given to assist an adult to make a decision and reduce any barriers to their capacity. This could include, for example, additional time for explanation, modified language, and visual or technological aids.

The degree to which an adult has impaired decision-making capacity may vary over time.

There is an onus on health care providers to make reasonable efforts to determine the extent of an adult's impairment and guidelines to assist may be issued by the Public Guardian.

Who is a health care decision-maker?

If an adult loses decision-making capacity and a health care decision is required, then the role of a health care decision-maker and any relevant advance care statement comes into effect (unless the adult already has a valid relevant advance consent decision in place, which then must be complied with).

If there is no health care decision-maker previously appointed by the adult under an advance personal plan and if there is no guardian appointed for health care, then another *decision-maker* with authority to make health care decisions must be identified. That decision-maker is an adult identified in the hierarchy of decision-makers as having the highest priority, and who is *willing and able* to make the decision.

Hierarchy of decision-makers

- A person with health care authority appointed in an advance personal plan under the Advance Personal Planning Act 2013;
- 2. A guardian with health care authority appointed under the *Guardianship of Adults Act* 2016;
- 3. A relative of the adult who is considered by Aboriginal or other customary law or tradition



to be the appropriate person to be a health care decision-maker;

- 4. A spouse or de facto partner;**
- 5. A carer, who is not providing that care as a service on a commercial basis;
- 6. A child with a close and continuing relationship with the adult;**
- 7. A parent; with a close and continuing relationship with the adult.**
- 8. A sibling with a close and continuing relationship with the adult.
- 9. A friend with a close and continuing relationship with the adult.

The decision-maker must be willing and able to make a decision

Section 9 states that a person is willing and able to make a health care decision for an adult with impaired decision-making capacity if that person:

- (i) has capacity to make the decision; and
- (ii) is reasonably available; and
- (iii) is willing to make the decision; and
- (iv) understands the obligation to act in accordance with the decision-making principles; and
- (v) has the information reasonably needed to make a balanced decision; and
- (vi) has adequate time to consider that information; and
- (vii) understands the effect of making the decision; and
- (viii) is able to make the decision voluntarily and without undue influence from any person.

What happens if the identified decision-maker is not willing and able?

If there is a person appointed for an impaired adult as an adult guardian or health care decision-maker under an advance personal plan, and that person is not willing and able to make a health care decision, that person must apply to the Northern Territory Civil and Administrative Tribunal (NTCAT) as soon as practicable.

The Public Guardian is taken to be the health care decision-maker for an adult if such an application is required but not made.

If there is no one appointed for the impaired adult as an adult guardian or health care decision-maker under an advance personal plan, then the next person in the hierarchy who is willing and able can make the decision.

Where there are multiple appointees

If there is more than one heath care decision maker appointed under an Advance Personal Plan and/or with authority under the *Guardianship of Adults Act 2016*, the decision must be made in accordance with their appointment however:

- a) if or one or the appointees is not willing and able to make the decision the remaining person/s can make the decision *unless they are jointly appointed;
- b) If 2 or more persons are severally appointed and agree to the decision, any one of them can make the decision;
- c) If 2 or more persons are jointly appointed and do not agree on the decision, neither of them can make the decision (and an application to NTCAT would be required).

No identifiable decision-maker

If there is no appointed decision-maker but there are more than one potential decision-makers under the hierarchy of decision-makers, determining priority may take place by referring to guidelines issued by the Public Guardian.

If there continues to be uncertainty or a dispute, an application can be made to NTCAT.

If there is no identifiable decision-maker at all, the Public Guardian can make the decision as the default decision-maker or an application can be made to NTCAT to either appoint an appropriate health care decision-maker or make the decision.

Specific healthcare decisions

The Act puts express limits on some types of health care decisions and clarifies the extent to which these decisions can be made by a health care decision-maker for an adult with impaired capacity. It also allows for the administration of some health care for a person with impaired capacity, without consent.

Routine health care

There is an express ability for a health care provider to administer routine health care, such as

personal hygiene or grooming. This does not apply in all circumstances (e.g. if it is objected to by the adult, consists of an ongoing course of treatment, or causes significant risk of harm, pain or distress).

Emergency situations

Consent is not required if a health care provider believes on reasonable grounds that the health care is necessary and urgent in order to save their life or prevent serious injury, and it is not practicable to delay in order to obtain consent.

This applies to adults and children.

Palliative care

Palliative care can be administered to an adult with impaired capacity without the consent of the health care decision-maker (including if the decision-maker objects) but only where the adult with impaired capacity:

- (a) has an active, progressive and advanced disease; and
- (b) has little or no prospect of cure and is expected to die.

However, the health care provider must consult with the health care decision-maker before administering palliative care, and must have regard to any preferences and values of the impaired adult known to the health care provider.

Mental health care

A health care decision-maker has no authority regarding any treatment under the *Mental Health* and *Related Services Act 1998* for complex cognitive impairment or mental illness, or of a mentally disturbed person. This may change with the proposed new Mental Health Bill 2024.

However, a health care decision-maker for a patient under the *Mental Health and Related Services Act 1998* can consent to other types of non-mental health care for that patient e.g. for a broken limb or antibiotics for an infection.

Types of restricted health care

Section 30 of the Act provides that there are certain practices that a health care decision-maker has no authority to make a decision for. These include sterilisation, termination of pregnancy, electroconvulsive therapy, removal of nongenerative tissue for transplant to another person,

and special medical research/experimental health care.

However, this restriction doesn't apply to sterilisation or termination of a pregnancy where the primary reason for the procedure is to treat a health condition and the procedure is necessary to prevent serious or irreversible damage to the adult's health.

Generally, the listed treatments can only be consented to for an adult with impaired capacity by the NTCAT.

Restrictive practices - limited consent

Generally, health care decision-makers do not have authority to consent to restrictive practices. Restrictive practices in a health setting, can include anything from holding still a person's arm to administer a vaccination to sedation.

However there is ability for health care decision makers to consent to restrictive practices in some circumstances and subject to a range of safeguards, including that they must be the least restrictive method of treatment in the circumstances.

Children

The Act does not apply to children, except in relation to emergencies.

Parents and guardians will continue to be the health care decision-maker for all children, unless there are other court or tribunal orders in place. However, the *Gillick principle* will continue to apply. This is a common law term that relates to children's ability to consent to treatments and procedures, depending on their level of understanding and maturity, and the nature and complexity of medical treatment.

How will a health care decision-maker exercise their authority?

There are clear decision making principles set out in section 17 of the Act, which reflect supported substituted decision making. These principles are also reflected in the *Advance Personal Planning Act* 2013 for health care decision-makers appointed under that Act.

Before exercising their authority, a health care decision-maker must make reasonable efforts to use supports to assist the adult to make their own decision.

The health care decision maker must give effect to any advance care statement made by the adult.

If no advance care statement was made, the health care decision-maker must exercise their authority in the way the health care decision-maker believes on reasonable grounds the adult would in the circumstances.

If they are unable to identify how the adult would have made the decision, the decision-maker must exercise authority in the way they believe on reasonable grounds it is in the best interests of the adult.

Role of Public Guardian

The Public Guardian is the default decision-maker, in circumstances where all the following apply:

- (i) No relevant advance consent decision has been made; and
- (ii) There is no identifiable health care decisionmaker; and
- (iii) No application has been made to NTCAT.

The Public Guardian also has authority where they have been appointed under the Guardianship of Adults Act 2016 or the Advance Personal Planning Act 2013, or ordered to be the decision-maker by NTCAT.

The Public Guardian may also make guidelines to assist in interpreting and applying the Act. They are accessible from the Northern Territory Public Guardian and Trustee's website.

Advanced Personal Plans - Advance Care Statements and Advance Consent Decisions

An advance personal plan can be made by an adult who has decision making capacity.

A decision-maker can be appointed by the adult for any aspect of the adult's care and welfare (including health care) and also for property and financial affairs. An advance care statement in an advance personal plan sets out the adult's views, wishes and beliefs to guide a decision-maker when making decisions for the adult once they have lost capacity.

An advance consent decision has effect as if it were a health care decision made by a fully informed adult at the time. A health care provider has authority to administer health care to an impaired adult in accordance with that decision.

A health care decision-maker must give effect to a relevant statement or decision unless exempted under a relevant NTCAT order.

The only time a health care decision-maker is not required to comply with an advance care statement or advance care decision is if it would be impracticable, unlawful, unreasonably burdensome on another person; or it would be so unreasonable as to justify overriding the wishes of the person with the impaired decision-making capacity.

Personal and financial decisions

For adult guardians, other personal and financial decisions are to continue to be made in accordance with existing guardianship principles under the *Guardianship of Adults Act* 2016.

Decision-makers appointed under an advance personal plan for other personal and financial decisions are to continue to exercise their authority in accordance with the Advance Personal Planning Act 2003. These principles are consistent with the Health Care Decision Making Act 2023.

Conflict resolution - NTCAT

Disputes can be resolved by application to the NTCAT. Applications may be made by a health care provider, health care decision-maker, the public guardian or another interested person:

Criminal offences

Various criminal offences have been created under the Act. These include but are not limited to false representation, providing misleading information, improper exercise of authority and acting without authority.

Other legislation

The Act brings together all health care decision-making provisions from the following Acts: the Advance Personal Planning Act 2013, the Guardianship of Adults Act 2016, and the Transplantation and Anatomy Act 1979, as well as the Emergency Medical Operations Act 1973, which is being repealed.

Further information

Members of the public

Website - https://pgt.nt.gov.au/

Phone - 1800 810 979

Email - public.guardian@nt.gov.au

[insert AGD website link]

Health care providers

Website: https://health.nt.gov.au/