PGT | Northern Territory Public Guardian and Trustee

Determining the appropriate health care decision maker guideline

Version 3 – April 2025

Foreword

This Guideline has been produced by the Public Guardian and Trustee under section 55(a) of the *Health Care Decision Making Act 2023*. The Public Guardian and Trustee website provides more information on decision making capacity, the health care decision making principles and information that health care decision makers are entitled to receive prior to making a decision.

Before using this guideline please download the latest version from the Public Guardian and Trustee website.

This guideline does not apply to health care decisions for people under 18 years of age.

Acknowledgement of Country

The Public Guardian and Trustee acknowledges the Aboriginal and Torres Strait Islander peoples with whom we work and for whom we provide a service. We pay our respect to the Ancestors, Elders and Aboriginal communities who are the custodians of this land.

Public Guardian and Trustee Guideline

Determining the appropriate health care decision maker

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The term 'Aboriginal' is used respectfully in this guideline to refer to all people of Aboriginal and Torres Strait Islander descent who are living in the Northern Territory.

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About this Guideline

This Guideline is developed pursuant to section 55(a) of the *Health Care Decision Making Act 2023* which commenced on 1 July 2024.

It must followed by any individual who provides health care (health care provider) when determining an appropriate health care decision maker for a person with impaired decision making capacity.

See *Guideline – Determining decision making capacity for a health care decision*

The *Health Care Decision Making Act 2023*

The *Health Care Decision Making Act 2023* addresses the gap in Northern Territory law concerning health care decision making for people who have lost some or all of their capacity to make their own health care decisions.

It sets out a hierarchy of alternative health care decision makers including family and close friends, including formal recognition of First Nations kin who can lawfully provide consent on behalf of the person.

When is a health care decision maker needed?

Health care providers must gain consent from the person themselves or from another person(s) with legal authority to provide consent before administering health care (unless in an emergency).

All people are presumed to have capacity to make their own health care decisions even if they have a disability.[1] If there is concern that the person has impaired decision making capacity for the specific health decision needed the health care provider must follow the *Guideline – Determining decision making capacity for a health care decision.*

See *Flowchart – Adult Health care consent*

A health care decision maker is needed when:

- a health care provider has determined the person has impaired decision making capacity for the specific decision needed;
- the person has not made an advanced consent decision in their Advanced Person Plan about the health care needed and
- The health care is significant (implied consent cannot be accepted from the person);
- The person is not likely to regain capacity within a reasonable timeframe to enable the health care needed.

If an advance consent decision has already been made by the person in an Advance Person Plan (APP) the health care provider has authority to commence, continue, withhold or withdraw the health care in accordance with the person's advanced consent decision.

Note – is it a health care provider's responsibility to ascertain if the person made an advance consent decision in relation to the health care needed and if not, to contact the appropriate health care decision maker for the person with impaired decision making capacity. Recording requirements apply.[2]

See *Guideline - Initial responsibilities of a health care provider* for further information.

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[1] Section 5 *Health Care Decision Making Act 2023 (NT)*
[2] Section 23 ibid

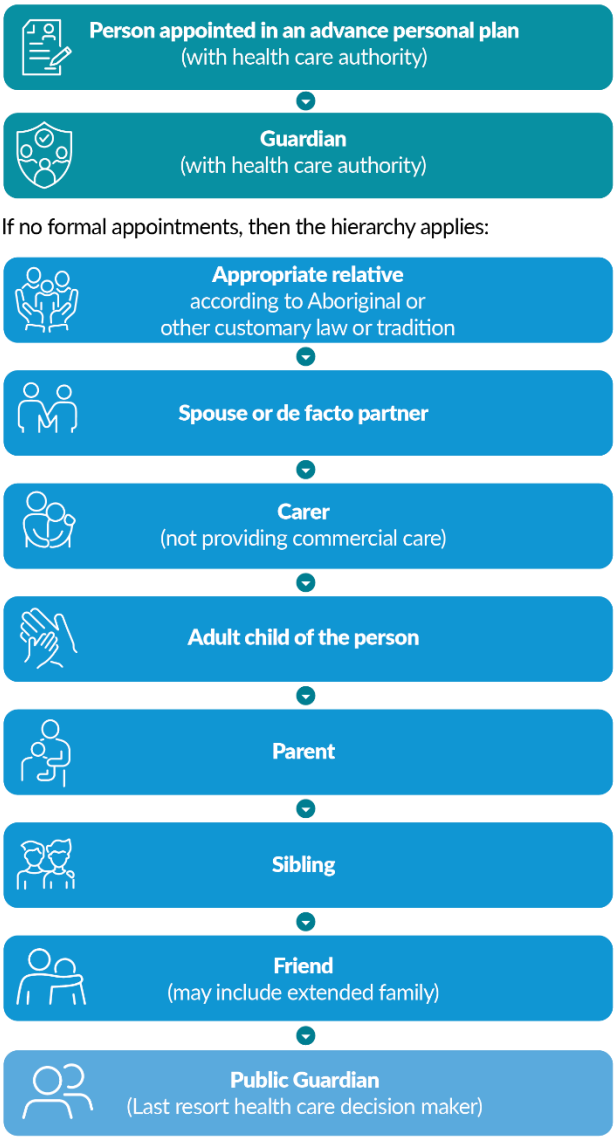
Who can be a health care decision maker?

Persons in the below Hierarchy of Health Care Decision Makers are potential health care decision makers, listed in descending order of priority[3].

The first two options are appointed under legislation and accordingly have statutory functions. The remaining options have familial or other connections to the person and must have a close and continuing relationship with the person[4].

Where there is no other option the Public Guardian has authority to make health care decisions as a last resort[5].

Hierarchy of Health Care Decision Makers



[3] Section 13 *Health Care Decision Making Act 2023 (NT)*
[4] Note 1 for Section 13 ibid
[5] Section 22(1)(c) ibid

Determining the appropriate health care decision maker

The appropriate health care decision maker is the person on the above hierarchy who meets the following *criteria* at the time the decision is needed (note, this may not be the same person on each occasion)[6];

(a) Is the option that holds the highest level on the Hierarchy of Health Care Decision Makers;
(b) an adult; and
(c) is willing and able to make the decision.

Meaning of 'willing and able'

A person is ***willing and able*** to make a health care decision for a person with impaired decision making capacity if the person[7]:

(a) has capacity to make the decision; and
(b) is reasonably available e.g. the person is available by telephone or video call and;
(c) is willing to make the decision; and
(d) understands the obligation to act in accordance with the decision making principles; and
(e) has the information reasonably needed to make a balanced decision; and
(f) has adequate time to consider that information; and
(g) understands the effect of making the decision; and
(h) is able to make the decision voluntarily and without undue influence from any person.

A health care decision maker cannot delegate their authority to another person. For example an adult child of the person cannot defer to the adult child's spouse. However, a health care decision maker (other than a person appointed under the *Advance Personal Planning Act 2013*, or the *Guardianship of Adults Act 2016)* may relinquish authority to make health care decisions at any time and for any reason. In that case, the next person in the hierarchy who fulfils the *criteria* for health care decision makers above is the appropriate health care decision maker.[8]

A person relinquishing authority as health care decision maker should notify this in writing to the health care provider.

Meaning of 'close and continuing relationship'

A 'close and continuing relationship' refers to a significant and ongoing connection between individuals. It is interpreted based on the specific circumstances, taking into account factors such as the duration of the relationship, the level of commitment and mutual support, financial interdependence, and the presence of any children or other dependents.

Assessing 'close and continuing relationship'

Assessing whether individuals have a 'close and continuing relationship' often involves evaluating various factors that indicate the depth and longevity of their connection.

While there's no definitive checklist or formal assessment, there are some common criteria that may be considered:

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[6] Section 14(1) *Health Care Decision Making Act 2023 (NT)*
[7] Section 9 ibid
[8] Section 16 ibid

- **Views of the person with impaired decision making capacity about the relationship:** The person's own views about the relationship should be guiding.
- **Duration of Relationship**: How long have the individuals known each other or been involved in each other's lives? A longer duration typically indicates a more established relationship.
- **Frequency of Interaction**: How often do the individuals communicate or spend time together? Regular and consistent interaction suggests a closer bond.
- **Depth of Connection**: What is the level of emotional intimacy and mutual understanding between the individuals? Strong emotional ties and shared experiences contribute to a closer relationship.
- **Shared Responsibilities**: Do the individuals share financial, household, or caregiving responsibilities? Collaborating on important tasks can indicate a significant level of commitment and reliance on each other.
- **Joint Activities**: Do the individuals engage in activities together or participate in each other's hobbies and interests? Sharing common interests and participating in shared experiences can strengthen the bond.
- **Supportive Behaviour**: How do the individuals support each other during times of need or difficulty? Providing emotional, financial, or practical support demonstrates care and commitment to the relationship.
- **Recognition by Others**: How do family members, friends, or acquaintances perceive the relationship? External validation or acknowledgment of the relationship by others can provide additional evidence of its closeness.
- **Future Plans**: Do the individuals have plans or commitments that extend into the future, such as joint investments, shared living arrangements, or long-term goals? Having shared aspirations and commitments can indicate a serious and enduring relationship.

Assessing the 'close and continuing' nature of a relationship often involves considering a combination of these factors and evaluating the overall nature of the connection between the individuals. It is important to recognise that every relationship is unique, and the assessment should take into account the specific circumstances and dynamics involved.

Examples of 'friends' with a close and continuing relationship could include:

- A neighbour who has maintained a long term friendship with the person;
- An old friend from university who has remained in contact with the person and is aware of the person's current life circumstances;
- An ex-sister in law who lives in the same town and visits the person regularly.

Carers

A person is considered a carer if they provide daily care and attention to the person in their own, or the person's home and are eligible for or receiving a carer allowance.

A carer is not;

- A neighbour who visits regularly
- A friend who takes the person to the movies

A carer is often a family member or friend, and is given priority over other family members or friends in the decision-making hierarchy. This ensures that those who provide daily care have the authority to make health decisions, rather than a relative who is not directly involved in the person's care.

If there are any disputes or concerns about who should be appointed as decision maker, an application should be made to the NTCAT to decide who should be the appropriate health care decision maker.

Paid carers

Carers such as personal assistants, disability support workers, service providers, nurses and care coordinators cannot be the health care decision maker for the person they are paid to support in a commercial capacity.[9]

However, a friend, relative or carer is not precluded from being a health care decision maker because they are receiving a carer payment from the Commonwealth to be a carer of the person.[10] For example, a family member or friend who the person lives with and receives a carers benefit.

Appropriate relative by Aboriginal or other customary law or tradition

The hierarchy allows for consideration of cultural differences in interpreting familial hierarchies through enabling a family to nominate the most appropriate family member according to their customary laws or traditions.[11]

If there is a relative on the hierarchy, they are the appropriate health care decision maker unless they advise of a more appropriate alternative according to their culture. Families are also permitted to discuss the matter and nominate an appropriate option or act together by nominating a family spokesperson to be nominated as a health care decision maker.

In many Aboriginal or other customary traditions, decision-making within a family or community context is often guided by intricate social structures and cultural norms rather than individual autonomy. When it comes to health care decisions, these traditions often prioritise the collective well-being of the community and the respect for elders and family roles which may not fall within the commonly understood western family structure.

In such contexts, a relative who is considered the appropriate person to be a health care decision maker is typically chosen by the family or community based on several factors including:

- Cultural Knowledge and Wisdom
- Family Connection
- Spiritual and Emotional Connection
- Consensus and Consultation
- Respect for Eldership

Scenario: Jonny, an adult aboriginal person with impaired decision making capacity, has 4 visitors at his bedside. The exact relation of each person to Jonny is unclear. Jonny has no Advanced Personal Plan and is not under Guardianship.

The visitors are asked who should be the health care decision maker for Jonny. One visitor reports that he is Jonny's son however Paul, Jonny's uncle who is an elder in their community, should make health care decisions for Jonny.

An interpreter is used to explain the role of a health care decision maker to the 4 visitors who also confirm the information provided by the son.

The uncle, Paul is the appropriate health care decision maker in this circumstance.

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[9] Section 13(e) *Health Care Decision Making Act 2023 (NT)*
[10] Note 2 for Section 13 ibid
[11] Section 13(c) *Health Care Decision Making Act 2023 (NT)*

Advice from family or community regarding the appropriate health care decision maker should be accepted based on the information provided to the health care provider at the time. It is not expected that information be verified by multiple parties or investigated. However, it is recommended that a record is kept of parties consulted and discussions had.

Efforts should be taken to ensure communication occurs in a culturally appropriate way including the use of interpreters. An Aboriginal Liaison Officer, Cultural Advisor, Social Worker or equivalent should be utilised where practical and appropriate to the circumstances.

Extended family

Other family members not listed on the hierarchy, such as grandchildren, aunts and uncles should also be considered as possible health care decision makers before the Public Guardian as a last resort.

Like all options on the hierarchy, extended family members must have a *close and continuing relationship* with the person and be *willing and able* to act as a health care decision maker.

Extended family should be taken to fall at the level of 'Friend' in the hierarchy, being that formal appointments and immediate relatives must be prioritised.

Noting that extended family members may also fall within other options on the hierarchy including 'appropriate relative according to Aboriginal or other customary law or tradition' and/or a 'carers'.

When there is more than one appropriate health care decision maker

When there is more than one appropriate health care decision maker on the same level of the Hierarchy of Health Care Decision Makers such as multiple adult children, the following approach should apply wherever possible:

1. **Ask the person**

   Where practicable and appropriate to the situation, the person's preferences of health care decision maker should be sought.

   In these instances, asking non-leading questions and simplified language may be useful to the person, such as;

   Tell me about your children?

   Which child do you trust to make health decision for you?

2. **Reconsider the 'close and continuing' criteria**

   In some cases, the presence or lack of a 'close and continuing' will be clear and invalidate some potential health care decisions makers. There may also be a clear difference between the levels of 'close and continuing' relationship. For example, one adult child may be providing daily in home support whereas the other adult lives overseas.

   However, it is important to treat each case individually and ask clarifying questions to avoid assumptions. For example, a person's adult child living overseas may have a positive intimate relationship consisting of daily phone contact whereas the person's child providing support into the home may have a highly strained relationship with the person.

   Social workers, liaison officers or others could be utilised to seek clarifying information if required and practical within the timeframe the health care needs to be administered.

   Note, a health care provider is not bound to the 'burden of proof' in considering how a relationship meets the 'close and continuing' criteria but rather may rely on information provided at the time.

3. **Multiple parties should act together**

   Where there are multiple appropriate health care decision makers on the same level of the hierarchy, with a similar level of 'close and continuing' relationship, those people should be given an opportunity to act together to come to an agreement about the health care decision.

4. **Nomination**

   The group of potential health care decision makers could nominate one person among them to be the health care decision maker.

If there is disagreement about the health care decision or nominating a health care decision maker, an application to NTCAT is required to determine the appropriate decision maker. The application must be made by an interested party (including the health care provider).

If more than one person is appointed to make health care decisions under the *Advance Personal Planning Act 2013* or the *Guardianship of Adults Act 2016*, all of those people are considered to be the health care decision makers and must act jointly or severally according to the authority in the Advanced Personal Plan or guardianship order.

Multiple people may be appointed as Guardian or APP decisions to act jointly, severally or jointly and severally[12]:

- **jointly**, they must exercise their authority unanimously. (If unable to reach a unanimous decision. They must seek orders from the NTCAT under s33(2)(b)).[13]
- **severally** or **jointly and severally** should consult each other but are able to proceed with a decision independently.

When the person objects to their health care decision maker

Although a person needing a health care decision maker has impaired decision making capacity in relation to one or more health care decisions, they are not precluded from offering a view about who should make health care decisions for them if someone is not already appointed in a Guardianship Order or an APP (with authority for health).

The person's views about the relationship should be guiding, but consideration to how their impaired decision making capacity may be impacting their views should also be applied. Where the person objects to the decision maker highest on the hierarchy, the decision maker should be informed and requested to consider if they are willing and able to exercise authority in the circumstances. Where the potential decision-maker agrees not to act (and therefore they are not willing and able), the next person on the hierarchy should be considered, again taking into account all considerations including the person's views.

However, where the potential decision maker highest on the hierarchy is not willing to step down, the hierarchy prevails and they have authority to make the decision. This may occur in circumstances where the person's capacity is affecting their decision making, such that their previously long-held beliefs are no longer intact, such as a person with dementia believing that their supportive sister is untrustworthy.

If there are any disputes or concerns about who should be appointed as decision maker, including with consideration to the person's views, an application should be made to the NTCAT to decide who the appropriate health care decision maker is.

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[12] Section 14 *Guardianship of Adults Act 2016 (NT)*
[13] Section 22(2) ibid

Concerns about a health care decision maker

If a health care provider believes a health care decision maker is not fit or able to make the health care decision an application must be made to NTCAT to determine:

- who should be the health care decision maker or
- make the health care decision

Steps to be taken if a health care decision maker is both:

- refusing to consent to 'significant' treatment for a person with impaired decision making capacity (See *Guideline – Routine health care*)

  and
- does not know, and cannot infer, the wishes and views of the person with impaired decision making capacity.

1. An interested party must apply to NTCAT (unless not reasonably practical to do so) to;
   a. determine who should be the health care decision maker or
   b. make the health care decision.
2. The health care provider must provide written notice to the Public Guardian[14] via the form - *Report to the Public Guardian regarding a health care decision maker*.
3. *(The Public Guardian has powers under the Guardianship of Adults Act 2016 to take action if appropriate in the circumstances[15].)*

Note – A health care decision maker cannot refuse health care that provides relief from pain or distress[16] or comfort care on behalf of a person who is considered to be palliative, if the person has[17]:

(a) an active, progressive and advanced disease; and

(b) little or no prospect of cure and is expected to die.

Health care decision maker of last resort

The Public Guardian has authority to make health care decisions as a last resort in the following circumstances:

- The person has impaired decision making capacity for the specific health care decision needed; and
- The person has not made an **advance consent decision** in an Advance Personal Plan in relation to the health care needed; and
  - There are no identified health care decision makers willing and able to make the decision[18]; or
  - The appointed Guardian or Advanced Personal Plan decision maker is not willing and able to make the decision and an application to NTCAT has not been made[19]; or
  - The Public Guardian is ordered to be the health care decision maker by NTCAT.[20]

Requests to the Public Guardian to make a health care decision in these instances can be made via

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[14] Section 56 *Health Care Decision Making Act 2023 (NT)*
[15] Note for Section 56 ibid
[16] Section 27 ibid
[17] Section 26 ibid
[18] Section 22(1) *Health Care Decision Making Act 2023 (NT)*
[19] Section14(4) ibid
[20] Section22(2)(c) ibid

completing the *Health Care Decision Request Form*.

Before making a request to the Public Guardian please consider the *Flowchart – Adult health care consent* to ensure all other options have been exhausted and your *responsibilities as a health care provider* have been met, including:

1. **Ascertain if the adult has already made an advance consent decision** in an Advance Personal Plan (APP) in relation to the health care needed.[21]
2. **Contact the appropriate health care decision maker** for the adult with impaired decision making capacity (if after reasonable efforts the health care provider is not aware of an advance consent decision).[22]

   Including ascertaining the person is subject to a Guardianship Order in relation to health care.
3. Determine the person's capacity to make the specific health care decision needed.[23]

See *Guideline – Initial responsibilities of a health care provider* for further information.

[21] Section 23(1) ibid
[22] Section 23(3) ibid
[23] Section 24 ibid