

Substitute Decision-Making

As a person ages, they may lose their ability to make decisions about health care or medical treatment. When this happens, these decisions will need to be made by someone else. That person is commonly referred to as a substitute decision-maker. This factsheet explains the law on substitute decision-making.

Clarifying the law

This factsheet explains:

- The role of a substitute decision-maker
- How a substitute decision-maker is appointed
- Who can be a substitute decision-maker
- What decisions a substitute decision-maker can make
- How substitute decision-makers make decisions
- When a substitute decision-maker's decision must be followed

What is the role of a substitute decision-maker?

A substitute decision-maker is a person who makes a health care or medical treatment decision for a person who has lost decision-making capacity.

The substitute decision-maker 'stands in the shoes' of the person to make the decision. Generally **the substitute decision-maker's decision has the same legal effect as if the person had capacity and had made the decision themselves.**

In most States and Territories, a substitute decision-maker will not be needed if the person has a valid Advance Care Directive that applies to the situation.

Supported decision-making for medical treatment

Supported decision-making is a process that involves providing support so that a person, such as an adult with a cognitive impairment, can make their own medical treatment and health care decisions with assistance and participate in decision-making.

Examples of support include:

- Providing information to the person in a way they can understand e.g. by adjusting language or using visual aids or technology, so that they can participate in decision-making.
- Giving the person more time to process and discuss the information with others.
- Helping a person in the decision-making process e.g. by talking through options with them.

Victoria, Queensland, the Australian Capital Territory, Tasmania, and the Northern Territory have laws on supported decision-making for medical treatment. In these jurisdictions, a person will have decision-making capacity for medical treatment if it is possible for them to make a decision with appropriate support. If the person cannot make their own medical treatment decision with support, then substitute decision-making can occur.

Learn more about supported decision-making for medical treatment at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/treatment-decisions/adults#guardianshiplaw>) or in this **End of Life Law for Clinicians** factsheet (https://cms.qut.edu.au/__data/assets/pdf_file/0005/1543091/ELLC-Supported-decision-making_final.pdf)

Supported decision-making about aged care

Decision-making about aged care services (e.g. accommodation, funding, aged care assessments) can also occur with support from a person known as a supporter. This is a different type of supported decision-making – the role of a supporter for aged care **does not include supporting medical treatment decision-making**.

For more information about supporters in aged care, and differences to supported decision-making for medical treatment, read this **End of Life Law for Clinicians** factsheet. (https://cms.qut.edu.au/__data/assets/pdf_file/0005/1543091/ELLC-Supported-decision-making_final.pdf)

Who will be the substitute decision-maker?

A person with capacity can plan for a later time when they may lose capacity by making an Advance Care Directive and/or **appointing someone to be their substitute decision-maker**. An Advance Care Directive can be used to appoint a substitute decision-maker in most States and Territories.

Learn which document is used to appoint a substitute decision-maker in your **State or Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws>)

If a person does not have an Advance Care Directive that applies to the situation, and has no appointed person to make decisions for them, then the **laws in all States and Territories set out who will be the substitute decision-maker**. This person is usually someone who has a close and continuing relationship with the person, such as a spouse or other family member. A person who is listed in records as the 'next of kin' will not necessarily be the substitute decision-maker.

Where there is more than one potential decision-maker, the law sets out, in order, who will be recognised as the substitute decision-maker.

If the person does not have someone close to them who can make health care or medical treatment decisions, **a public official e.g. the Public Guardian or Public Advocate may be able to make the decision** on their behalf. Sometimes, a tribunal will appoint a guardian to make the health decision.

Who may be a substitute decision-maker and the terminology given to them differs throughout Australia. Learn who may be a substitute decision-maker in your **State or Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws>)

Avant Mutual also has factsheets on substitute decision-makers in each **State and Territory**. (<https://www.avant.org.au/Resources/Public/Substitute-decision-makers/>)

What decisions can a substitute decision-maker make?

A substitute decision-maker **can make most health care or medical treatment decisions for a person who has lost capacity**. These decisions can include whether life-sustaining treatment should be provided or withdrawn.

Whether or not a substitute decision-maker has power to make a health decision will depend on the law of the State or Territory.

Learn more about substitute decision-makers' powers in your **State or Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws>)

What should a substitute decision-maker consider when making a decision?

The laws in each State and Territory set out principles to guide substitute decision-makers. These differ between States and Territories, but generally **a substitute decision-maker needs to consider the following principles when making a decision** about health care or medical treatment:

- what decision the person would have made, based on the person's views, wishes and conduct when they had capacity; and
- the person's interests and wellbeing (sometimes referred to as the person's 'best interests') after considering such things as potential risks, burdens and benefits of treatment.

Most States' and Territories' legislation prioritises a person's wishes over other principles.

Learn more about substitute decision-makers' powers and considerations for decision making in your **State or Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws>)

Shared decision-making can achieve consensus between individuals, families and health professionals about treatment and goals of care, and prevent conflict about withholding or withdrawing treatment.

This process involves, *'discussion and collaboration between an older person and their health care provider. It is about bringing together the consumer's values, goals and preferences with the best available evidence about benefits, risks and uncertainties of treatment, in order to reach the most appropriate healthcare decisions for that person'*.

Where the person does not have capacity, these discussions should occur with the person's family or substitute decision-maker.

Learn more at the *Australian Commission on Safety and Quality in Health Care*. (<https://www.safetyandquality.gov.au/our-work/partnering-consumers/shared-decision-making>)

Should a substitute decision-maker's decision be followed?

Generally, **a substitute decision-maker's decision should be followed**, even if the decision is to refuse life-sustaining treatment which could result in the person's death.

A health professional may be liable under criminal or civil law or subject to disciplinary action if they provide treatment that has been refused by a substitute decision-maker.

The situation is more complex if the substitute decision-maker is requesting treatment that a health professional considers to be futile or not in the person's best interests. This is discussed further in the *End of Life Law Toolkit factsheet Futile or Non-Beneficial Treatment*. (<https://www.eldac.com.au/Toolkits/End-of-Life-Law/Futile-or-Non-Beneficial-Treatment/Factsheet>)

Learn more about following a substitute decision-maker's decision in your **State or Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws>)

Key points to remember

1. A substitute decision-maker can make a health care or medical treatment decision for a person who does not have capacity, and has not made the treatment decision in a valid Advance Care Directive.
2. If a person does not have an Advance Care Directive that applies to the situation, and no appointed decision-maker, the substitute decision-maker will be a spouse or other family member with a close relationship to the person. If there is no one who can act in this role, the Public Advocate or Public Guardian may be able to make the decision.
3. The law in all States and Territories sets out who will be the substitute decision-maker. The legislation and terminology for a substitute decision-maker is different in each jurisdiction.
4. Substitute decision-makers can make most decisions about health care or medical treatment, including decisions to refuse treatment at the end of life. However, the law on substitute decision-makers' powers differs between States and Territories.
5. When making decisions, generally substitute decision-makers must think about what decision the person would have made and the person's interests and wellbeing.
6. Generally a decision made by a substitute decision-maker about health care or medical treatment must be followed by a health professional.
7. Supported decision-making involves supporting an older person with cognitive impairment to make their own medical treatment and health care decisions with assistance and to participate in decision-making. In some States and Territories attempts must be made to support a person to make their own medical treatment decisions before substitute decision-making can occur.

Mythbusters: Substitute Decision-Making

Myth 1: If a person doesn't have decision-making capacity, decisions about health care or medical treatment should be made by his or her 'next of kin'.

No. 'Next of kin' is an informal term commonly used to refer to a person's immediate or close family members. The term is not recognised in the laws about decision-making for health care or medical treatment.

The person who will make a health care or medical treatment decision for a person without decision-making capacity is known as the person's 'substitute decision-maker'. Who will be the substitute decision-maker for the person will depend on the legislation in your State or Territory.

Myth 2: A resident I care for doesn't have capacity and has several close family members who visit regularly. I can ask any of them to make a treatment decision for the resident if a decision is needed while they are visiting.

No. The guardianship and medical treatment legislation in each State and Territory sets out an 'order of priority' of people who can be a person's substitute decision-maker. The first person in that order who is willing, available and able to make the decision is the substitute decision-maker.