

Substitute decision-making

As a person ages, they sometimes lose their ability to make decisions about health care. When this happens, health care decisions will need to be made by someone else. That person is commonly referred to as a substitute decision-maker. This factsheet explains the key legal principles 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 decision for a person who has lost capacity.

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

A substitute decision-maker will not need to make the decision if the person without capacity has an Advance Care Directive that applies to the situation.

Who will be the substitute decision-maker?

A person who has capacity can plan for a later time when they may lose capacity by appointing someone to be their substitute decision-maker. This is done by completing a formal document. The document used is different in all States and Territories.

Find out 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 has not appointed someone 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 an order to determine who will be recognised as the substitute decision-maker.

If the person does not have someone close to them to make these kind of decisions, then a public official 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. Find out more about 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>)

What decisions can a substitute decision-maker make?

A substitute decision-maker can make most health care decisions for a person who has lost capacity. These decisions can also include health care decisions about 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 particular law of the State or Territory.

Find out 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 make a decision?

The laws in each State and Territory differ on this. But generally a substitute decision-maker needs to consider the following things when making a decision about health care:

- what would the person have wanted if they had capacity; and
- what would be in the person's best interests after considering such things as potential risks, burdens and benefits of treatment?

Find out more about the substitute decision-maker's 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>)

In some cultures end-of-life decision-making is a collective process, involving the individual, their family and community. Be mindful that some people may wish to include their extended family and community members in decisions about health care and future planning discussions. Sometimes interpreters may be required. Learn more at **Caresearch**. (<https://www.caresearch.com.au/Caresearch/tabid/109/Default.aspx>)

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

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

A health professional might 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 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 situation is discussed further in the Legal Toolkit factsheet 'Futile and non-beneficial treatment'.

Find out more about the need to follow 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 decision for a person who does not have capacity, and has not set out their treatment decision in an Advance Care Directive.
2. If a person has not appointed a substitute decision-maker, a Tribunal can appoint a decision-maker for them. But often, the substitute decision-maker will be a spouse or other family member. If there is no one who can act in this role, a public official might make the decision.
3. The law in all States and Territories sets out who will be the substitute decision-maker in a particular situation. 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, even decisions about treatment at the end of life. However, the law can be complex and differs between States and Territories.
5. When making decisions about health care, substitute decision-makers must generally think about what decision the person would have made and what would be in the person's best interests.
6. A decision made by a substitute decision-maker about health care must generally be followed by a health professional.

Myth-busters: Substitute decision-making

Myth 1: If a person doesn't have decision-making capacity, decisions about health care 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.*

The person who will make a health care decision for a person who lacks decision-making capacity will be 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: My patient has lost capacity and has several close family members who visit regularly. I can ask any of them to make a treatment decision for my patient 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.*