

# Informed Consent

## Practical guidance for substitute decision makers

Informed consent is an important part of health care and works best when there is good communication between you, the patient and their healthcare professional. Understanding what to expect can help you to prepare and participate in key conversations and make decisions that are right for the patient.

### Why informed consent matters

#### Informed consent in health care

Informed consent is a person's agreement, given voluntarily, to a healthcare treatment, procedure or other intervention. This requires the provision of accessible, accurate and relevant information about the healthcare intervention, and the expected outcomes, benefits, risks and alternative options, relevant to that person, including:

- doing nothing
- watching and waiting
- and/or lifestyle interventions.

People have the right to make choices and decisions about their health and care. Informed consent is both a process and an outcome that recognises and respects the patient's healthcare rights. It is an important part of [person-centred care](#) which is care that respects the patient, their family and carers and responds to their needs and values.

When done well, informed consent:

- enables you, as a substitute decision-maker to understand the risks, benefits, alternatives, possible outcomes and costs of medical treatments and tests
- supports you to weigh options and consider the expressed will, preferences and interests of the patient, on whose behalf you are making decisions
- can have a positive impact on the patient's healthcare experience and outcomes.

### About decision making ability

All adults are presumed to have capacity to decide if they wish to receive health care and should be included in decision-making and supported to fully participate.

## **Decision-making ability, capacity and supported decision-making**

- A person's skill and ability to participate in decision-making can change over time and depend on their underlying health condition, acute condition and the type of decision being made
- If after supports have been optimised, there are concerns a person is unable to participate, a clinical assessment of their decision-making ability may be required
- Where a person's physical, emotional or behavioural state means they do not have the ability to make a particular decision, the framework for obtaining substitute consent that applies in each state or territory must be used. This involves the healthcare professional engaging substitute decision-makers or nominated persons, in line with legislation
- The legal test for whether a person has capacity to make a decision varies depending on the state or territory in which they are receiving health care
- Where a person other than the patient is legally appointed as a decision maker, they may only act in line with the authority outlined in the instrument of appointment
- People may be able to make some decisions with support from a family member, friend or healthcare professional. This is called supported decision-making
- A supported decision-making process provides the patient with information in a way they can understand and the means of communicating their will and preferences in response
- In some situations, you may be supporting the patient to decide, while in others, you may be deciding on their behalf. This is because decision making ability can change, including based on the type of decision being made
- The patient should remain at the centre of the decision-making process, and their current wishes, values and preferences should be sought and respected wherever possible, even if a substitute decision-maker is involved.

## **What to expect**

Making decisions on behalf of another person can be stressful and emotionally challenging. Knowing what to expect can help you feel confident having conversations about care and treatment options with healthcare professionals, and to involve the patient wherever possible through supported decision making.

## **When is consent needed?**

Healthcare professionals have ethical, legal and professional requirements to obtain consent before any procedure, test or treatment, and when prescribing medicines.<sup>1</sup> Depending on the risks involved or how complex the treatment is, consent can be given in different ways. You may give consent verbally, sign a form (written), or show agreement by

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<sup>1</sup> Unless legislation in a state or territory, or case law, permits the treatment, procedure, or other intervention without consent. For example, treatment provided in an emergency, or for certain mental health interventions.

your actions (implied). Some treatments, including most surgeries, blood transfusions and chemotherapy always need written consent.

As a substitute decision maker, it is your choice to say yes, say no, or ask for changes before you agree, on behalf of the patient. You can also change your mind and withdraw consent before or during a procedure, test, or treatment. Your decisions, as a substitute decision maker, should consider and be based on the expressed will, preferences and interests of the patient.

Some decisions involve balancing safety with independence and quality of life, particularly when patients are receiving care at home. You have the right to accept reasonable risks if this aligns with the patient's goals, preferences and interests.

### **What should be part of an informed consent process?**

Informed consent works best when [shared decision making](#) is used. This involves the healthcare professional asking about and understanding the patient's goals, concerns, needs, and preferences, as well as discussing:

- what are the options? (including wait and watch)
- what are the possible benefits and harms of those options?
- how likely are each of those benefits and harms to happen?

You can use a model like [Ask Share Know](#) to help make shared decisions.

### **When should key conversations occur?**

The timing of important conversations matters. While this may not be possible in an emergency, you should be given enough time before being asked to make a decision about any procedure, test or treatment to:

- consider, clarify and understand the information provided
- discuss and consult with the patient wherever possible
- discuss and consult with those close to you, including by having them be part of the visit if you choose
- come back for another visit or seek a second opinion if needed.

### **What supports should be given?**

Healthcare professionals need to support you and the patient to participate and give you and the patient information that is easy to understand.

Everyone is different and things like culture, language, disability and how a person learns can affect how they understand health information. Healthcare professionals should ask about the needs you and the patient may have and take steps to help you better understand so you are able to give informed consent, or refuse to give consent, if that is your choice. They can do this by:

- showing information in different ways like using models, diagrams, printed, video or audio materials and media
- including a support person of the patient's or your choice in the conversation
- arranging interpreter services if English is not the patient's or your preferred language

- recognising the importance of family, kinship systems and community to Aboriginal and Torres Strait Islander peoples' health and wellbeing, and supporting them to be included
- getting the support of an Aboriginal or Torres Strait Islander Health Worker, Practitioner of Liaison Officer if the patient or you identify as an Aboriginal and/or Torres Strait Islander person.

### **Checking understanding**

Healthcare providers should make sure the patient and you understand the information they give you. If something is not clear, they should explain it again or in a different way. They may check understanding by:

- asking the patient and you to repeat what has been said using your own words
- encouraging the patient and you to ask questions and answering them in a way that can be understood.

### **When is informed consent reached?**

You have the right to refuse treatment or withdraw consent before or during treatment on behalf of the patient. Informed consent is reached when you:

- are legally able to give consent for that decision
- have enough information to understand the patient's condition, their treatment options and alternatives, as well as the benefits and risks relevant to them
- have enough time, opportunity, and support to think about the information, ask questions, and talk about concerns
- choose to give consent freely, without pressure
- agree to the specific test, treatment or procedure.

### **Top tips for informed consent**

When preparing for or taking part in informed consent processes remember you can:

- Ensure all efforts have been made to involve the patient
- Have a support person attend the visit with you
- Ask for an interpreter if the patient or you need one
- Share any communication needs the patient or you may have
- Ask for things to be repeated, explained in a different way or for more information
- Ask questions
- Take time to talk with other people before making a decision
- Do your own research or look for more information
- Seek a second opinion, if you're not sure what's right for the patient

- Ask for another visit or appointment before you decide.

## Useful resources

- [Australian Charter of Healthcare Rights](#)
- [Australian Charter of Healthcare Rights – Easy English version](#)
- [About healthcare rights for people with cognitive impairment – Easy English Guide](#)
- [User Guide for the Health Care of People with Intellectual Disability](#)
- [Person-centred care](#)
- [Ask Share Know](#)

## Disclaimer

This fact sheet is for general information purposes and is not a substitute for professional legal advice in individual circumstances and cases.

### For more information

Please visit: [safetyandquality.gov.au/informed-consent](https://safetyandquality.gov.au/informed-consent)

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