

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Doctors and dentists usually need to get consent before they carry out treatment. No-one can do things to your body unless you agree! But what happens if a person with intellectual disability does not understand the treatment?

If possible, the person should decide!

For people over 14, doctors should get consent from the patient whenever possible. They should do their best to explain the problem and the treatment to a person with intellectual disability. Families, advocates and support workers can help the person understand.

Here are some tips for helping the person understand and make their own decision:

- Involve someone who the person likes talking to.
- Talk about the treatment somewhere that is quiet and where the person feels relaxed.
- Try to use words the person knows. If you have to use difficult words, try to explain them simply.
- If the person has an alternative communication system, use that.
- Use pictures that show the problem and the proposed treatment.



- · Stick to the basic information. Do not overload the person with detail.
- Give the person time to think about the information and then have another talk.

What if the person cannot consent?

For children under 16 parents can give consent.

If the person is over 16 and does not understand the problem and the treatment, then the NSW Guardianship Act spells out who can give consent. Usually, it is a "person responsible".

The person responsible

There is a list of people who can be a person responsible:

- 1. The person's guardian.
- 2. A spouse.
- 3. An unpaid carer, eg a parent. And, if the person moves into supported accommodation, the previous carer continues to be the person responsible.
- 4. A close friend or relative who is actively involved in the person's life.

The person responsible is the first one on the above list that the person has access to. For example, if the person does not have a guardian or spouse, but has a carer, then the carer is person responsible.

The doctor needs to give the person responsible information about the health problem and treatment options. The person responsible can ask questions and also ask for a second opinion.

They should not give consent unless they are satisfied that the treatment is a good idea and in the interests of the person.

If there is no person responsible available, consent can be obtained from the Guardianship Division of the NSW Civil and Administrative Tribunal.

Are there treatments that a person responsible cannot consent to?

A person responsible can consent to most treatments. But they cannot consent to "special treatments" under the Guardianship Act. These are sensitive treatments like sterilisations, abortions, experimental treatments and medication to reduce sexual urges.

Also, if the patient is objecting to treatment, a person responsible usually cannot consent.

Where a person responsible cannot consent, the doctor needs to get consent from the Guardianship Division.



Consent is not always needed

In an emergency, the doctor can go ahead without getting consent.

Also, the doctor can go ahead with necessary minor treatments if there is no person responsible available and the person is not objecting. The Guardianship Act and Regulation spells out what are minor treatments. They are treatments that are not contentious or risky.

For more information

The Guardianship Division has more detailed information on medical consent. Phone (02) 9556 7600 Toll free 1800 463 928 TTY (02) 9556 7634 www.ncat.nsw.gov.au/Pages/guardianship/g

In other parts of Australia, the law is different to NSW. Contact your local Public Advocate or guardianship tribunal.

www.agac.org.au

The Capacity toolkit has practical information about supporting a person to make their own decisions and assessing if they have the understanding to do this.

www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf

You might be interested in this fact sheet

Rights and complaints

This fact sheet was updated in 2019.

The fact sheet contains general information only and does not take into account individual circumstances. It should not be relied on for medical advice. We encourage you to look at the information in this fact sheet carefully with your health professional to decide whether the information is right for you.

