

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.

It can be hard for a doctor to work out what illness a person with intellectual disability has, especially if the person has limited verbal communication. Most doctors are very busy and try to keep appointments as short as possible. So it is very important to be well prepared to make the most of a visit to the doctor.

Making an appointment

If the person with disability finds waiting difficult, you can try to book the first appointment of the day, or the first after the doctor's lunch break. Or the receptionist might be able to phone you to say you are next to see the doctor. It is always worth building a relationship with the receptionist and explaining any special needs the person has. If you have a lot to ask the doctor about, try to book a double appointment.

Who will go with the person to the doctor? It should be someone who gets on well with them and knows them well. If an accommodation worker is making the appointment, they should check if a family member or advocate wants to go too.



If an interpreter is needed

Tell the receptionist if you need an interpreter. The interpreter might come to the appointment or be available by phone. Interpreters for NSW health services are available free for people who are deaf or not fluent in English. GPs can use the Doctors Priority Line 1300 655 820. Or phone Translating and Interpreting Service (TIS) National on 131 450.

Be prepared

- Be clear about the reason for the visit. Write down any symptoms and questions you want to ask.
- Help the person to be ready for the visit. Explain why you are going and reassure them if they are anxious. What questions do they have for the doctor?
- Is there a disability professional the doctor should talk to, for example a psychologist who has
 assessed the person's behaviour? Maybe, they could attend, write a report or be available for the
 doctor to ring.
- Take the person's medical records, current medications and My Health Matters folder or a one page profile of the person which includes how they communicate.
- Is there other important information to take? For example, an article about intellectual disability that might help the doctor.
- Take a notebook and pen so you can write down what the doctor says.
- Make sure you and the person are dressed well. People make unconscious judgments about others based on their appearance.

During the visit

- Be aware that doctors don't always think about common problems when treating people with intellectual disability, for example hearing and obesity. Ask about anything that you or the person are worried about. Ask how to prevent health problems. Ask the doctor to do a comprehensive health assessment each year.
- Encourage the doctor to talk directly to the person with disability. For example the doctor should
 explain if they want to examine the person and check the person is okay with this. Suggest an
 icebreaker for conversation. Show the doctor how to talk to the person about health issues.
 Check if the person wants to ask any questions.
- Make sure the person (or you) gets all the information needed to decide about treatment options.
 Remember that the doctor needs consent from the person or a "person responsible" usually a family member.
- If new medication is prescribed, ask about side effects to watch out for.
- Ask the doctor to write down an action plan and to explain difficult words.
- Trust your instincts and ask questions. There is nothing wrong with asking for a second opinion or a referral to a specialist.



After the visit

Following up is important.

- · Check that the person understood what happened and what the doctor said.
- Make sure there is a system in place to carry out the action plan that you worked out with the doctor. Think about who needs to know about the action required and things to watch out for.
- Does any other professional need to know what the doctor said? For example, a psychologist who is helping with the person's behaviour or a speech pathologist who is helping with swallowing problems.
- If you are not clear on what the doctor recommended, ring the clinic. Also, some doctors are happy to clarify things by email.
- · Plan when the person should go back to the doctor for review.

For more information

Questions to ask your doctor www.healthinsite.gov.au/topics/Questions_to_Ask_Your_Health_Professional

For ways to help a person be ready for health checks like blood tests and x rays, see Desensitisation programs at www.qcidd.centre.uq.edu.au/resources/desensitisation-programs

You might be interested in these fact sheets

- · Annual health assessments
- · Consent to medical treatment
- Finding the right doctor
- · Helping the doctor understand the person
- · Personal health records

This fact sheet was updated in 2018.

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.

