

Helping the doctor understand the person

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.

You are the only person who can fully explain your symptoms to the doctor. But doctors are often not experienced in communicating with people with intellectual disability and may not know how a particular person communicates. So it is important to help the doctor communicate with the person. This will help the doctor get information and explain the problem to the person, and help the person relax and participate in treatment decisions.

Also, the doctor needs to know what the person is like when they are well. Otherwise, the doctor might assume that some symptoms are just part of the disability. For example, if the person is unusually lethargic, the doctor needs to know how active they usually are.

General tips for communication

There are lots of ways to help the doctor communicate with patients with disability. Consider these ideas.

- Try to see a doctor the person is comfortable with and try to see the same doctor every time.
- Introduce the person to the doctor first before introducing yourself.
- If the doctor starts by asking you questions, repeat them to the person for them to answer. Or ask the person if it is okay for you to talk about their health problem.

- Explain to the doctor how the person communicates.
- Ask the doctor to speak slowly and clearly, and to explain difficult ideas in simple words. Sometimes, you may need to repeat what the doctor has said using easier language.
- Check that the person understands, for example by getting them to tell you what the doctor has said. See if the person has questions for the doctor.
- Ask the doctor to show the person diagrams, testing equipment or tablets.
- If an interpreter is used, tell them beforehand about the best way to communicate with the person.
- If the doctor is rushed or the health problem is complicated, offer to come back when the doctor has more time.

If available, refer to the person's 'My Health Matters' folder. If this hasn't been completed, fill out the Top 5 section which is the 5 most important things people need to know about the person. This could be about their disability, health, behaviour or communication.

Some people do not use many words, but have other ways to express themselves. Some people use sign language or pictures. Other people may have hand and facial gestures that have clear meaning. It is important that you understand the person's way of communicating, and explain it to the doctor – so that they can talk directly with the person as much as possible.

Preparation

You can help the person be ready to talk with the doctor. Explain to them what will happen at the visit. Help them to think about what they want to tell the doctor and questions to ask.

If the doctor wants to examine the person or take a blood sample, make sure they explain this to them and get their okay.

You may be able to relax the person during an examination by reassuring them and by using physical contact, such as holding their hand.

Making a personal profile

A profile of the person can help the doctor communicate with the person and understand what they are like when well. You can use the My Health Matters folder to create a detailed profile of the person. Family, support workers and advocates are important partners with the person in putting together a personal profile. You should explain to the person why the record is being developed and check they are okay about the information that is included.

The profile should cover:

- What the person is like when well – things they are good at and favourite activities. Is the person usually happy and active? Include a recent photo.
- How the person communicates. For people who do not use many words, cover other ways they communicate, for example signs used, how they show pain and contentment, how they express Yes and No.

- Suggestions for conversation starters, for example favourite football team or TV show.
- Strategies to help the person stay calm and cooperate with medical procedures.
- Any relevant religious or cultural practices - for example dietary restrictions or fasting periods, alternative therapies or herbal supplements.

The profile should usually be just one page. Include it in the person's personal health record.

How the personal profile is used

Always take the profile with you when visiting a health professional. Show it to them at the start of the visit.

Personal profiles should be regularly updated with input from the person, family, advocates and support workers.

For more information

Working with people with intellectual disabilities in healthcare settings Fact Sheet (Centre for Development Disability Health Victoria)

www.cddh.monashhealth.org/wp-content/uploads/2016/11/2016-working-with-people-with-intellectual-disabilities.pdf

You might be interested in these fact sheets

- **Going to the doctor - tips and tricks**
- **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.