Personal health records

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.

People with intellectual disability often find it hard to tell the doctor about their medical history. And often doctors are not experienced in treating people with intellectual disability. So it is very important for a person with intellectual disability to have a health record that provides their doctor with information about them and their medical history.

Collecting information

Usually, family, support workers and advocates are important partners with the person in putting the health record together and checking it is accurate and up to date. They may all have vital information to include. It is very important that the person with intellectual disability is involved. You should explain why the record is being developed and check the person is okay about the information that is included.

Find all the person's health related documents, for example medical and psychology reports, test results, X-Rays and medication charts. You may need to dig out old service files to find some important information.

If the person has complex health needs or has recently moved to Australia, consider getting a comprehensive health assessment done at a specialist clinic for people with intellectual disability. This is a good baseline for everyone.

How to organise a personal health record

A good starting point is using CID's My Health Matters folder www.cid.org.au/mh
Within the folder can be recorded a personal profile, preferred communication methods, health and behavoiur information. Addtional important information should also be added to the folder.

If you are unable to access a My Health Matters folder, use a ring binder to make your own.

All personal health records should contain:

1. A clear plastic sleeve for the person's Medicare card and Health Care card.

2. A one page summary of basic health details:

- The person's full name, date of birth, address and language spoken.
- Current medication, dosages and how it is administered.
- Height, weight, blood group, allergies.
- Medicare and pension numbers.
- Contact details of general practitioner and other health professionals.
- Contact details of guardian, person responsible and case manager (if relevant).
- Any special swallowing or nutrition needs.
- Any emergency information.

3. The person's current health care plan if there is one.

4. A running sheet listing significant conditions that have been diagnosed (for example diabetes, asthma) and procedures or operations (for example tonsils taken out).

These important things could be:

- If the person has a serious medical issue, what is it and what do people need to know about it?
- If the person has communication barriers, what are the important signs they use to let people know what they need or want?

5. A list of medications the person has used and their effects.

6. Lists of immunisations and allergies.

7. Major health conditions that family members have had.

8. A running sheet of each visit to a health professional, including the health issue, any medical tests or medications, and instructions from the professional.

9. All annual health reviews and other health assessments, reports and charts.

10. Any other material relevant to the person's health care, such as contact details of useful organisations.

How to use the personal health record

Take the health record every time the person goes to a health professional. Show them the folder at the start of the visit, especially the first summary page. Be sure you know what is in the folder so you can speak up if there is something relevant the doctor should know.

Keep updating the running sheets and other parts of the health record.

If the person spends time away from home, they should take a copy of important information.

My Health Record (eHealth)

The My Health Record (MHR) is an electronic health summary that has been set up by the Australian Government. Unless they have opted out of MHR, everyone now has one that includes some basic information.

An MHR will eventually contain key health information drawn from the existing electronic records of multiple healthcare providers involved in a person's care. MHR will include details like allergies, medical conditions and treatments, medications, and test or scan results.

Healthcare providers like doctors, specialists and hospital staff may be able to see the person's MHR online at any time if they need to, such as in an accident or emergency

The person can control what information goes into MHR and which organisations have access to their record.

If an adult with intellectual disability cannot be supported to make their own MHR decisions, another person like a family member can become authorised representative for the person. Parents can also be authorised representatives for their children.

See the link below to find out more about My Health Record. There is a fact sheet for people with limited literacy skills.

For more information

My Health Matters
www.cid.org.au/mhm

My Health Record – information on the electronic health summary established by the Australian Government.
www.myhealthrecord.gov.au

You might be interested in these fact sheets

- **Annual health assessments**
- **Consent to medical treatment**
- **Going to the doctor – tips and tricks**
- **Helping the doctor understand the person**
- **Specialised intellectual disability health services**

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 information is right for you.