



Personal Health Records

Key facts

People with intellectual disability often find it hard to tell the doctor about their symptoms and 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 the doctor with information about the person 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, eg 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 the personal health record

Use a folder with a ring binder to organise the health record. It 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. A brief personal profile including how to communicate with the person and what the person is like when well - include a recent photo.
4. The person's current health care plan if there is one – this is a requirement for the NSW government accommodation services run by ADHC.
5. A "running sheet" listing significant conditions that have been diagnosed (eg diabetes, asthma) and procedures or operations (eg tonsils taken out).
6. A list of medications the person has used and their effects.
7. Lists of immunisations and allergies.
8. Major health conditions that family members have had.



9. A running sheet of each visit to a health professional, including the health issue, any medical tests or medications, and instructions from the professional.
10. All annual health reviews and other health assessments, reports and charts.
11. Any other material relevant to the person's health care, eg useful articles and contact details of useful organisations.

All this information should be clear and as brief as possible.

The Centre for Developmental Disability Health Victoria supplies Personal Health Record pages to cover most of the above items as well as pages for some common health problems and syndromes, eg autism, Down syndrome and epilepsy.

How to use the personal health record

Take the health record every time the person goes to health professional. Show them the folder at the start of the visit, especially the first summary page and personal profile.

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.

For more information

Personal health record pages of Centre for Developmental Disability Health
www.cddh.monash.org/products-resources.html

NSW Health has a basic My health record booklet
www.health.nsw.gov.au/resources/initiatives/myhealthrecord/mhr_booklet_pdf.asp

Health care policy ADHC NSW
www.adhc.nsw.gov.au/_data/assets/file/0007/228094/Health_Care_Policy_Sept_2010.pdf

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 **June 2011**.*

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.