



Going to hospital

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.

A stay in hospital can be stressful and confusing for a person with intellectual disability. If you plan the visit carefully with the hospital, the stay should go as smoothly as possible.

People with intellectual disability should receive the same quality of care in a hospital as anyone else. Sometimes, families, advocates and support workers need to speak up to make sure this happens.

Preparation and planning

Most hospitals will do pre-admission planning. You can raise all the issues that need to be worked out to make the hospital visit go smoothly. You should support the person with intellectual disability to be involved in this process. If a disability service has a nurse on its staff, involve the nurse in pre-admission planning.

Be ready to provide the hospital with these documents:

- A personal profile including information about how the person communicates
- Up to date information about the person's health
- Details of who can consent to any treatment that the person does not understand.

You should already have these documents in the person's health record, My Health Matters folder or an online My Health Record.

See the Personal health records fact sheet. The pre-admission plan should also include:

- How to make the hospital stay as stress free as possible. If the person is likely to need behaviour support, you may need to involve a psychologist.
- Providing information about the person's personal care needs such as feeding and bathing. How will these needs be met in hospital? Hospital staff may request families or support workers to help with this.
- If available, provide the '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.

Important information about the person with intellectual disability could be:

- If they have a serious medical issue, what is it and what do people need know about it?
- If they have a communication barrier, what are the important signs do they use to let people know what they want or don't want?
- How to make sure the person does not lose skills while in hospital.
- What arrangements need to be planned for discharge from hospital?

Emergency admissions cannot be planned for but it is useful to always have at hand a brief document that lists the person's medications, allergies, communication needs, swallowing and nutrition needs, etc. You should already have this information in the front of the person's health record. Also, take the person's current medications to hospital.

Supporting the person

Before the hospital stay, it may help the person to look at pictures of hospitals and health professionals or even visit the hospital. If the person will need things like crutches or a cast, try to explain this in advance or show them to the person.

It may help to take to hospital some personal items, such as photographs and games. Also try to organise visits from friends, workmates and housemates.

Hospital social workers and patient liaison officers can also support the patient and their family.

Hospital staff

Hospital staff have a duty to adapt their services to meet the individual needs of a person with disability. This happens better in some hospitals than others. You may need to speak up for the person to make sure they get the support and health care they need. Wherever possible, do this in a cooperative and non-threatening way.

Demonstrate to staff how the person communicates. This will help the person let staff know if they are in pain or want something. Encourage medical staff to speak directly to the person and fully involve them in decisions.

Hospital environment

Hospitals are busy places 24 hours a day. Bright lights, buzzers and regular observations can be disturbing and can cause challenging behaviours. Try to work with staff to minimise the negative impact of the hospital routine.

Discharge and follow up

Careful discharge planning and follow up will reduce the risk of problems with the person's recovery. Make sure that you get clear information about:

- Any wound care or new medication.
- Any extra support needs that the person has when they leave hospital.
- What follow up treatment is needed.

Work out with the person and hospital staff how these needs will be met. If the person lives in supported accommodation, their manager or case manager needs to be involved in this process.

For more information

My Health Matters

www.cid.org.au/resource/my-health-matters-folder

People with disabilities: responding to their needs during hospitalisation, NSW Health policy

www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017_001.pdf

The hospital communication book – a resource for patients, families and hospital staff

www.surreyhealthaction.org/downloads/Hospital%20Communication%20Book%20-%20version%202%20-%20web.pdf

You might be interested in these fact sheets

- **Consent to medical treatment**
- **Helping the doctor understand the person**
- **Personal health records**

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 information is right for you.