



Down Syndrome
Australia

Hospital stays

Hospital visits can be a daunting experience. It is an unfamiliar environment with lots of noise and disruptions and can be stressful and confusing for a person with Down syndrome. Unfortunately, a hospital stay is sometimes unavoidable. This fact sheet aims to provide useful information and tips for people with Down syndrome and their families to make the hospital visit smoother.

Before the visit

Preparation and planning before the hospital stay can be an important part of making a hospital visit less stressful. Hospitals generally have a pre-admission procedure and this is a good time to provide as much information as possible to the hospital and raise any issues. Of course, sometimes this is not possible if the visit to the hospital is in an emergency situation.

Preparing for the visit – tips to help the person with Down syndrome:

- Talk about the procedure with the person with Down syndrome and how long they will be in hospital for.
- Discuss with the person with Down syndrome any concerns they may have.

- Show visuals/images to explain the hospital visit.
- If required, visit the hospital before the procedure to familiarise the person with the hospital environment.
- In some cases it may be helpful to create a simple story with pictures to help talk about what will happen when they go to the hospital.

Planning for the admission - Tips to provide the right information to the hospital staff:

- Ensure the person with Down syndrome is involved and is able to discuss their concerns with you and the medical team.
- Provide all the relevant information about the person's health or their personal health record if they have one.
- Provide information on the way the person communicates including any communication strategies used at home.
- Discuss any dietary requirements and any assistance required during mealtimes.
- Discuss any sensory issues that may be able to be minimised during the stay.
- Discuss personal care and how this will be managed in hospital.

During the hospital stay

Hospitals can be a difficult place to be for anyone. For people with Down syndrome the new noises, lights, and interruptions in routine can be particularly disruptive. Some tips to help the person whilst in hospital are:

- Label all medications and ensure they are taken to the hospital and discussed with the nursing staff.
- Explain the call buzzer to the person with Down syndrome and ensure they know how to use it if they need it. You could put together a sheet with visuals that explains the buzzer and when to use it using examples.
- Talk to the nursing staff rostered on. It is impossible for you to be at the hospital at all times, so ensuring the nursing staff are properly informed can help. Nursing staff generally do a shift changeover briefing with the next shift staff rostered on. However it can be useful to have any relevant information about the person highlighted on the whiteboard in the room, or a folder with the information in it on their bedside table.
- Ask all staff/doctors to speak directly to the person with Down syndrome who is the patient and not the parent or carer. Ask them to explain procedures before commencing them and to give any directions to the patient.
- If the hospital stay is likely to be longer than a night or two, then think about packing a few small personal items, like photos. This can help to create a familiar environment and ease stress.
- Hospitals have social workers on staff so, if required, ask to see the social worker as they may be able to help.
- Be an advocate. Hospitals can be busy and daunting but the person with Down syndrome deserves the same time and standard of care as anyone else. Hospitals have an obligation to adapt their services to meet the person's individual needs, so speak up if you don't think this is happening.
- A person's rights are covered by Codes of Conduct and legislation in each state or territory. If you believe the person with Down syndrome's rights have not been upheld then you can make a complaint directly to the hospital or to the health care ombudsman in your state or territory.

Discharge planning

Ensuring that all arrangements are in order and understood when being discharged from the hospital gives the person with Down syndrome the best chance of a smooth recovery. Some suggestions to consider are:

- Make sure you have clear instructions on post-hospital care. Ask to have these written down if that helps.
- Ensure you have any new scripts or medications and make sure all existing medications, that you provided for the hospital stay, are returned to you.
- Sometimes, people leaving hospital are discharged and referred to a community nursing service. If this is the case, make sure you have the contact details for who should be in touch with and when. This will allow you to follow up with them directly.
- If rehabilitation is required, make sure you have a summary of this to provide to any allied health professionals that may be working with the person with Down syndrome.
- If the person with Down syndrome lives independently, make sure there is a plan in place for post-hospital support and care. If the person is responsible for this themselves, make sure any instructions are communicated in a way they can refer back to. For example, instructions for medications with visuals/pictures.

For more information:

Down syndrome association contact details

There is a Down syndrome association in each state and territory. You can contact these associations for support and advice. We are here to help you. Our associations are made up of a wide range of parents, professionals and people with Down syndrome who work or volunteer with us. Please visit our website at www.downsyndrome.org.au or call 1300 881 935 to be automatically connected to your closest association.

Resources

Monash Health - www.cddh.monashhealth.org

My Health Matters - www.nswcid.org.au/my-health-matters.html

My Health Record - www.myhealthrecord.gov.au