



## Navigating the hospital system and supports

### Helpful facts / links when navigating the hospital system and the supports available to you.

As a parent of a child with Down Syndrome, you MAY, like many other parents, find yourself having to visit a hospital when your child is seriously unwell.



### Seeking help for your child with Down Syndrome in an emergency or a life-threatening situation.

If you are unsure what to do ring **Health Direct Australia 1800 022 222** for free health advice 24 hours a day, 7 days a week.

You may be asked to go to hospital. In this case you must make your way to the nearest hospital emergency department. **If you need to call an ambulance for a life-threatening condition ring 000.**

Perth Children's Hospital, Emergency Department provides treatment and services to children 15 years and under. In some cases, this can be extended to 18 years for treatment of a pre-existing condition. You will find details about Perth Children's Hospital Emergency Department [here](#). 🌟📍

Visiting and staying in hospital may become necessary for several reasons:

- A. Due to an unforeseen Accident or Emergency
- B. A planned hospital admission (planned surgery)
- C. Or a prolonged hospital stay because of complications or complexity.

If you are concerned about your child's condition getting worse while you are waiting, follow the [Care Call steps in Emergency](#). 🌟📍

Finding yourself in hospital can be a daunting experience, particularly if this is your first time.

It is important to know that you are not alone. There are several ways you can get support depending on what you need.

- 1) Contact **Down Syndrome WA (DSWA)** on (08) 6253 4752. [DSWA Family Support program](#) 🌟📍 can be of valuable assistance
- 2) You can also contact **Kalparrin** for help - Kalparrin is Western Australia's oldest member organisation providing advice, guidance and support to families raising children with a disability and or additional needs. Kalparrin's [in-hospital support program](#) 🌟📍 can be of value to you as an outpatient, emergency or unexpected admission.

## If you have a planned hospital admission to PCH:



- PCH provides some information on their website as to on what to do to prepare before, during and after a visit to hospital. You can also download [A Guide to PCH](#).
- If you or your child is going to PCH for a planned operation or for a medical reason, you will generally be provided with an admission letter with special instructions about your admission.
- If you have private health insurance, you will be contacted by a [Private Patient Liaison](#) a week before your appointment to ensure that a doctor of your choice is available.
  - When you come in for an operation, you will need to provide information to the hospital. This may include information on Allergies, Medication, and Dietary requirements.
  - Read the information on [what to expect and some tips](#) so you can be prepared prior to your visit.
  - After a planned admission you may be discharged and receive nursing care at home by a home visiting service team. A hospital in the home service (HITH) and Post-Acute Care (PAC) service is provided to assist your child recover at home in familiar surroundings. You can read more on the HITH and PAC in our DSA fact sheets or click [here](#).
  - The hospital may also ask you to come back post admission for an [outpatient appointment](#) to monitor your child's condition.



## Prolonged hospital stays due to complications or complex care

Children generally recover quickly and if admitted to [an inpatient ward](#) usually have a relatively short hospital stay. Parents and carers can stay with their child in bedside accommodation or at a purpose-built facility Ronald McDonald House if they reside more than 100kms away.

When your child's medical condition results in unforeseen complications, is more severe or complex a longer hospital stay may be necessary. During this time in hospital, your child's care might involve several specialists (heart, respiratory and diabetes team).

Children with Down Syndrome do not necessarily present with symptoms as children without Down Syndrome would. You can make medical staff aware of this using information provided by [Down Syndrome Australia](#) or the [My Voice My Health Web App](#).



Sometimes this can be overwhelming for a parent and the advice you may receive might appear different or contradictory.

### In such cases it might be valuable for you to know that:

- Doctor and nurses may change on a weekly basis, so you may not always see the same person.
- There may be different doctors on the weekend and less cover and support than on weekdays
- You can ask for a multidisciplinary team meeting (doctors from different specialties) to discuss the complexities related to your child's care. Speak to your Nurse Coordinator in charge of the ward.
- You will no doubt have many questions about your child's care, and it is OK to ask questions.
- You can **escalate your concerns** 🌟📢 if you feel your child's condition is getting worse and you feel you have not been heard.
- If you feel strongly about something related to your child's care and feel the need to speak up, you have the right to respectfully speak up.
- You can ask for an **Advocate** 🌟📢 from the Health Consumer Council to help you speak about your concerns and defend your **rights**. 🌟📢
- If you do want to provide feedback there are many avenues depending on what it is
  - **Compliments and Complaints to PCH** 🌟📢
  - Share your experience via an independent body: **Care Opinion**. 🌟📢

Having your child in hospital can be a challenging. You can develop resilience if you know how to access the right supports. Learning from other parents who have been in such situation can be helpful.

**Resilience in Hospital** 🌟📢 is a helpful DSA resource .

Once discharged you will be sent home and will be back under the care of your General Practitioner (GP). It is good practice to see your GP on a regular basis if you are concerned.

The **My Health Matters** 🌟📢 resource can be helpful for communicating with health providers, particularly if your child has communicating difficulties.



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## Disclaimer

The information in this resource is general in nature and does not constitute advice. Down Syndrome Western Australia will not be held responsible for any decisions made as a result of using this information. The contents of the resource do not constitute medical and legal advice and should not be relied on as such.

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