

Resilience in hospital

by parents who have done it before

Sometimes people with Down syndrome have serious health conditions that require an extended stay in hospital. This can be a stressful time for patients and families but there are ways to build resilience and manage that stress. If you do find yourself with an extended stay in hospital consider some of these excellent tips from families who have been there before.

Get to know the social worker and Nursing Unit Manager

The social worker is there for more than just counselling. Ask for assistance with:

- eligible Centrelink payments
- Victorian Patient Transport Assistance Scheme
- NDIS
- parking discounts, petrol, food and transport options
- connections to support organisations
- accommodation options closer to the hospital if the patient is in ICU or additional family need to stay nearby.

While staying in hospital you can be exposed to a range of traumas and medical emergencies. If this upsets you or it is a trigger for you, speak to nursing staff to get the support you need.

Before leaving hospital ask for help to organise logistics:

- paperwork sorted and signed for work leave
- Centrelink info
- prescriptions and equipment
- review appointments, outpatient appointments, hospital in home visits/community visits, therapy for rehab, referrals, and reports.

The room

Try to make it a cosy place and personalise the space for an extended stay: bring pictures, messages from friends, a special quilt or blanket, a special toy to cuddle that is washable.

Pack your own creature comforts from home including lots of changes of clothes, toiletries and your own pillow.

Pack the essential technology and activities to keep boredom at bay, such as iPad, portable wifi, headphones, chargers, DVDs etc, puzzles games etc.

Take any communication aids you may need. Anything your child might need to use to communicate if someone else is watching them for a period of time.

An 'About Me' book is good to take in so the nurses and staff get to know your child and have something to talk to them about.

Does your child usually have a sensory diet or sensory processing disorder? Take in things that they may need to help calm and settle them.

A diary to write down which medications were given including time and dosage and to record anything unusual that happens with the patient including temperature and oxygen saturation changes. Record things the doctors and nurses say. This is useful if conditions decline and you can answer questions that may be asked.

Be present with your child: hold their hand, talk to them, sit with them and sing to them.

Family and friends

Accept offers of help:

- meals for during your stay and when returning home
- gardening, cleaning, washing clothes etc
- driving in to the hospital and looking after other kids at home
- SAY YES!

Be clear with visitors about when they can come and when they can't. Have a notebook for visitors to write messages in.

Initiate interactions with friends. Some may not know what to do or say. Time can go quickly and some may need you to reach out to them.

Visiting pets. If your child likes animals see if your hospital has a visiting pets program. Some hospitals allow you to bring your own pet in.

If your child is at school, see if you can arrange a Skype session with the class if they are up to it or a card from the class.

Resources and equipment

If expressing breast milk or tube feeding, bring all your own equipment and cleaning equipment. Don't expect they will have this available.

Wash your clothes at the hospital. Take washing powder and a peg circle to hang on a door.

Online grocery shopping and delivery if needed for home and get takeaway delivered to the hospital if needed. An esky with ice is useful for storing food too.

Get stocked up with towels, sheets and toys from the nursing staff before a weekend as these run low and may not be restocked till Monday.

Order everything on the menu available for the patient to ensure a stock of snacks and sandwiches if money is getting tight.

Respite and relaxation

The floor can be a space to play if you put down a blanket or foam mats. Bring in a bouncer or see if there is a Tumbleform chair that can be borrowed for younger children.

Ask the staff about resources that can be borrowed.

- Does the ward have a games cupboard?
- Is there a playroom or a play therapist?
- Are there balls or is there play equipment that can go outside?
- Is there a library that you can borrow from?
- Are there musical instruments or art supplies that can be borrowed?
- Is there an art or music therapist?

Therapists are trained to work with people to do a lot more than just preventing boredom or providing a distraction. They can help with reducing anxiety and stress, improving relationships, improving outlook, processing emotions and experiences as well.

Ask for opportunities to get outside in the fresh air where possible or organise a day's leave if medically stable.

If you normally attend a group that's important to you and your child is stable, see if someone can stay with your child so you can go.

Reach out to other parents in the hospital for coffee or a chat.

You are not alone.

Thank you to the parents who shared their experience to compile this article.

Join the Voice team

We are looking for volunteers to join the *Voice* editorial team. Writing and editing experience is not essential but always welcome. As long as you are passionate about Down syndrome, we would love to have you on the team. *Voice* is published three times a year and the team meets via phone conference once or twice per issue to discuss the content, to share information and follow up on story ideas. You might like to take on the role of book reviewer or digital reviewer or you may have a skill or connections that you would like to share with our community.

We would love to hear from you!
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