

Caring for your sick child

A GUIDE FOR PARENTS AND CARERS



This book aims to support parents and caregivers of Children’s Health Queensland Hospital and Health Services (CHQ) and was written and developed by psychologists working in various clinical areas (psychology education, oncology and haemophilia services).

If you would like more information or have questions about anything covered in this booklet, please don’t hesitate to ask your child’s treating team.

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This information is provided as general information only and should not be relied upon as professional or medical advice. Professional and medical advice should be sought for particular health concerns or manifestations. Best efforts have been used to develop this information which is considered correct and current in accordance with accepted best practice in Queensland as at the date of production.

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For further information contact Psychology Clinical Educator, CHQ on 07 3310 9444



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Introduction

Caring for a loved one when they are sick is something that most families will go through at some point in their lives.

This can be particularly difficult when a child is sick. This booklet outlines what to expect as the caregiver of a sick child and includes tips to help you and your family cope with the responsibilities and challenges ahead.

Long-term care may be required for a wide range of different conditions. A child may need long-term care if they have health issues such as developmental disabilities, congenital problems, genetic diseases, chronic conditions such as diabetes and cancer, serious mental illness, or accidental injuries causing spinal cord and/or brain injury. In these cases caregivers will need to provide routine healthcare in the home to meet their child's complex health and functional care needs. It is important to remember that parents, grandparents, siblings and other family members can have a supporting role as caregivers. You don't have to do it all alone – it's ok to ask for help if you need it.

PARENTS, GRANDPARENTS AND OTHER FAMILY MEMBERS
CAN HAVE A SUPPORTING ROLE AS CAREGIVERS.
YOU DON'T HAVE TO DO IT ALL ALONE



Your role as a caregiver

As a parent it will usually be up to you to know about the special needs your child might have because of their condition, and to manage them by:

- monitoring your child's condition
- making sure others know how to deal with them
- advocating for your child and their condition
- working with others to provide appropriate boundaries and reinforcements
- preparing a special diet
- arranging/supervising outside services.

As well as navigating the healthcare system on behalf of your child, you will need to help your child keep up with school and support them to stay in touch with their friends and other children as much as possible. It is important that your child doesn't lose all ties with the life they had before they became sick. Staying in touch with their friends and keeping up with school work will help them stay connected to the world outside of hospital visits and home therapy.

We recognise that as a caregiver you provide essential 'front-line health services' and in many cases, play a big part in your child's health recovery journey – you are an extremely important part of your child's care team. Making sure your child sticks to their treatment plan at home supports the complex medical and therapeutic treatments they receive in hospital.

Due to the amount of time you may need to spend helping your child with daily activities (e.g. getting dressed, feeding themselves, giving medication), caregiving can have a significant impact on your life and your family's routine. These added responsibilities can make you stressed and at times this stress can become unmanageable. Caring for a sick child can strain marriages, reduce emotional availability for other children in the family and compromise career goals.

Differences in opinion with spouses or ex-spouses, grandparents and other relatives about the care of a sick or disabled child may cause or intensify painful emotional rifts. This can lead to parents feeling very out of step with their peers whose children are fit and healthy.

Caregivers may experience feelings of loss, or even grief, for developmental milestones that their child misses out on such as high school formals and graduation, learning to drive, intellectual milestones, etc. Isolation from friends and extended family, the loss of more "normal" relationships with your other children and a loss of professional aspirations and retirement plans are also common. This booklet will provide you with information about the adjustment process, what support is available and how you can look after yourself and your family while also caring for a sick child.

YOU ARE AN EXTREMELY IMPORTANT PART OF YOUR CHILD'S
CARE TEAM. MAKING SURE YOUR CHILD STICKS TO THEIR
TREATMENT PLAN AT HOME SUPPORTS THE COMPLEX MEDICAL AND
THERAPEUTIC TREATMENTS THEY RECEIVE IN HOSPITAL.

Being prepared

Dealing with different health services

Attending a medical/healthcare appointment, whether it's a clinic, scheduled hospital visit or longer stay, can be stressful. Dealing with different health services and knowing what you need to ask your child's doctor/s can be tricky, however there are a few practical steps you can take to make the most of your appointment. It may be helpful to do the following before each of your child's appointments:

- Write down any questions you would like answered by the doctor you are seeing/phoning.
- Make a list of the type of information you need (e.g. information about your child's diagnosis, treatment options, any risks or side effects).
- Take note of any areas where you and your family might be struggling and ask for help (e.g. access to support networks).

It can also be helpful to make a note of who you spoke to at your appointment (doctors, nurses, support agencies, etc). Take down their name and contact number so that you can reach out if you have questions about what you discussed with them later on.

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Medical procedures

Explaining what is going to happen to your child before it happens can help them feel more comfortable and less anxious about the medical procedures they need to have. Here are some simple ways you can help your child cope:

- Talk about the hospital as a cheerful place where doctors and nurses help to make people better.
- Read story books about hospitals to your child.
- Play games where you and your child role play doctors and nurses. For example, “Let’s take teddy to the hospital so the doctor can help him feel better”. You can even act out taking teddy’s pulse or giving him some medicine – if your child is going to have an MRI you might make one out of an old cardboard box and show your child how teddy goes inside.
- Reassure your child that you will be there for them as much as possible, and that they will be coming home eventually.
- Visit the hospital beforehand or use our virtual tour to explore the hospital from home (www.childrens.health.qld.gov.au/qch/about-us/virtual-tour). Showing your child that the hospital is a colourful place with its own playground, Starlight games room, etc. can even help them feel excited to visit.
- Ask your doctor about the treatment they are having so that you can explain to your child what’s going to happen in simple terms they can understand.
- Keep explanations simple about x-rays, blood tests, injections and other treatments they may need, but tell the truth – it’s important they know what to expect (e.g. if the needle might hurt for a second).

Here are some examples of simple explanations (please ask your child's treating team if you would like any other more specific examples):

What is an x-ray?

"An x-ray is like a photo that shows the inside of your body, especially your bones. X-rays show through the soft part of your body easily but they can't go through your bones. It shows the doctor where the injury is in your body and how big it is. An x-ray is very quick and it doesn't hurt at all!"

What is a blood test?

"Your blood can tell doctors a lot about how well your body is working. Sometimes they just need a single drop of blood from a finger prick, but sometimes they will need more blood than that. They will then take blood from your arm, where the veins are bigger and easy to see. Your blood is taken out with a type of needle called a syringe and then put into small tubes, ready to be sent to the lab for testing. Then a scientist in the lab will look at your blood. Don't worry, this will not take a long time. It will feel a little bit like an ant bite and it won't make you weaker."

What is a MRI scan?

"A MRI scanner uses a computer to show pictures of your body but it doesn't use x-rays. It uses radio waves and a magnet. The scanner looks like a tunnel and your whole body goes inside at once. You may have to try your best to stay very still while you're inside, but it won't hurt at all."



Use the space below to write a simple explanation of a medical procedure your child may need. If you need help with this, please check with a member of your child's treating team.

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EXPLAIN IN SIMPLE TERMS WHAT IS GOING TO HAPPEN TO YOUR CHILD BEFORE IT HAPPENS. THIS CAN HELP THEM FEEL LESS ANXIOUS

Getting admitted to hospital

As a parent it is natural to want to make the hospital experience easier for your child and yourself. One way you can do this is to find out as much as you can about the hospital before your child is admitted as an inpatient. On the opposite page is a checklist of things that you may want to consider before a planned admission to hospital.

For a full guide to the Queensland Children's Hospital visit our website, or download the welcome book from www.childrens.health.qld.gov.au/wp-content/uploads/PDF/lcch/welcome-lcch-book.pdf



- Will you need to arrange accommodation close by?**
Find out more about accommodation at www.childrens.health.qld.gov.au/qch/visiting-staying/accommodation
- Can you stay with your child in their room if they are admitted?**
Find out more about staying overnight at www.childrens.health.qld.gov.au/qch/visiting-staying/staying-as-inpatient
- What facilities (e.g. kitchenettes, parent lounges, outdoor spaces) are available in the hospital?**
Find out more about the facilities at www.childrens.health.qld.gov.au/qch/visiting-staying/hospital-facilities
- Do you have other children who will need to be looked after while you are at the hospital? Do you need to organise for relatives or friends to look after the rest of the family?**
- What type of clothes are you and your child going to need while you are in hospital?** Some hospital areas tend to be colder than others so it's a good idea to bring something warm just in case.
- How are you and your child going to keep yourselves entertained?**
Bringing a few books, an iPad, toys, etc. can be a good idea. Remember that for the comfort of those around you, noise will have to be kept to a minimum during the night.
- Does your child need to fast (not eat or drink anything) before they come to the hospital?** Remember not to give any food or drink to your child without your doctor's permission if they are on restricted food intake.
- Try to familiarise yourself with your ward (e.g. times of doctor's consultation, when meals are served) as much as possible before admission.** Find out more about meal times and purchasing food vouchers at www.childrens.health.qld.gov.au/qch/visiting-staying/parent-and-carer-meal-vouchers



Helping your child cope

When you are at the hospital the following ideas can make things run smoothly and help your child feel more comfortable:

- Bring their favourite toy or blanket (no matter how scruffy) and soother or bottle (if used).
- Tell the nurses and doctors special names your child may have for food, the potty, etc. You can use the whiteboard in your child's room to note these things down for hospital staff to see.
- Be involved with the everyday care of your child – it can be scary seeing so many new people every day, so having you there with them can make them feel less anxious about this.
- Do your best to explain what is going to happen during examinations and injections etc. by asking your doctor/nurse beforehand or asking them to explain as they go.
- Your child will really need you before and after an operation – be there to comfort them.
- Reassurance and lots of love is often the most important medicine.
- Encourage your child to talk to and make friends with the other children and get involved in hospital activities e.g. in the Starlight Express Room and other events at the hospital. Find out about events happening in the hospital on the Children's Health Queensland website www.childrens.health.qld.gov.au/events/category/qch-events
- Call home regularly so that your child can keep in touch with their siblings and other relatives, family pet, etc.

Looking after yourself

Remember to look after yourself. It is important that you take regular breaks and get enough rest. Although it might be difficult to be away from your child's bedside, it's OK to take a break and recharge every once in a while. Below are some tips to help make taking these important breaks easier:

- Always tell your child that you are taking a little break, going for a walk, getting a cup of coffee, etc.
- Let your child know when you will be back, and return when you say you will to stop them from getting worried.
- Organise for friends and relatives to visit so that it doesn't always fall to you to be at the bedside. Find out about visiting hours at the hospital at www.childrens.health.qld.gov.au/qch/visiting-staying/visiting-hours



Parental anxiety

We know having a sick child, whether it is an acute or chronic condition, is difficult. Apart from dealing with the fear and stress that can follow an initial diagnosis, you also have to manage the day-to-day anxiety you may have about your child's health, medications and medical procedures. Feeling anxious and worrying about your child's illness is normal, however excessive fear and anxiety can have a negative effect on your wellbeing. Questions that parents often ask are, "Can my anxiety cause my kids to have anxiety?" or "Can anxiety be catching?" As it turns out, parents and children can influence each others' anxious behaviours. The good news is that you can help reduce your child's anxiety by changing your behaviour, using effective coping skills and being a role model for them.

Being prepared for medical procedures means that you can help your child cope better – when you know what's going on you can offer reassurance and comfort your child throughout the process. Where possible, you are encouraged to be there with your child while a procedure is taking place. Having you in the room with them can reduce pain-related distress for your child. Make sure you discuss this with your child's treating team beforehand to check it is possible. You can also talk to their treating team about how to help your child cope in different situations/during different types of procedures. It's best to talk about this in private (away from your child) so that they don't become distressed.

YOUR HEALTH AND WELLBEING MATTERS TOO.
REMEMBER TO LOOK AFTER YOURSELF!

Managing your child's anxiety

Reduce anxious talk

Children are great listeners, so while you might think you are having a private conversation with another adult, your child could be tuned in to every word. It is important to process your anxious thoughts with another adult who can listen and help you work through them. It's also important to remember that kids will often fill in any blanks on their own when they hear small snippets of information that may seem scary to them. Children can pick up on their parents' fears and worries, and often internalise this kind of thinking – so make sure that you have these more serious and detailed conversations away from your child.

Use healthy coping skills

When children see their parents using healthy coping skills to manage stress and anxiety, they learn how to cope with their triggers and stressors as well. Some healthy coping skills include:

- Practice deep breathing together with your child. Breath in for four counts (in–1, 2, 3, 4), hold the breath for four counts (hold–1, 2, 3, 4) and breath out for four counts (out–1, 2, 3, 4). You can practice this together every day.
- Use a mindfulness app to relax e.g. *Smiling Mind*. You can search for this in the *App Store* or *Google Play*.
- Do activities together (e.g. reading story books, drawing, cooking).
- Encourage your child to take up journaling to write their feelings down.
- Create a family worry box. Writing down the things that are troubling you may help you to feel a little bit better. You can then put each worry in the box and discuss what you've written down with your psychologist or your child's treating team at your next appointment.

Learning to identify your triggers and find coping skills that work for you not only helps you manage your anxious thought cycle, it also teaches your kids that they can learn to cope with life's ups and downs as well.



Psychological therapy

Your child's psychological health is just as important as their physical health. It may not always be easy to tell when a child is struggling with their emotions, but noticing the signs and asking for help early is important for their long-term mental health.

Any psychological treatment your child receives should work in partnership with their medical treatment. Psychologists work closely with the medical team to make sure your child's emotional, behavioural and developmental needs are being met as they recover. Please let your nurse or doctor know if you feel like your child needs to see a psychologist.

A psychologist will work closely with you as a parent to provide the best care possible for your child. A paediatric psychologist can help your child and family to:

- cope with, and understand an illness
- manage emotional pain
- deal with stress, anxiety, depression, grief, trauma and other psychosocial needs.

We use a range of evidence-based therapies and techniques depending on your child's age and comfort level. Their treatment will be tailored to suit their individual needs.

Introducing your child to psychological therapy

Understandably, children may wonder why they are seeing a psychologist. Even if your child doesn't ask, seems like they aren't curious, or acts as if they don't care, you can be sure they are wondering about it. Following are some guidelines for how you can help your child understand why they are seeing a psychologist and how it will help them.

Think about it from your child's perspective

It is important to reassure your child that therapy is not a punishment for their behaviour and that they are not going to therapy to 'be fixed.' Children often assume that this is the reason they are going to therapy, which can make them defensive or leave them feeling worse about themselves.

Take some time to think about the difficulties that led you to seek psychological help for your child, as well as what this might say about your child's needs. It may help to look back on conversations you have had with your child about their concerns and the difficulties they are having.

Try to introduce therapy from the perspective of your child's needs. For example, if your child is having trouble managing/controlling their emotions, it is not helpful to say, "You are going to see a psychologist to help you have less temper tantrums". A more helpful way to put this would be to say, "I know that when you get upset it feels awful inside, and then you feel really bad about yourself afterwards. I know that is really hard for you. Maybe the psychologist can help you understand those very big feelings so that you know how to take care of yourself when you have those big-feeling moments." The emphasis is not on your child's upsetting behaviour, but rather, on their needs.

PSYCHOLOGICAL HEALTH IS JUST AS IMPORTANT AS PHYSICAL HEALTH.
IT MAY NOT ALWAYS BE EASY TO TELL WHEN A CHILD IS STRUGGLING,
BUT NOTICING THE SIGNS AND ASKING FOR HELP EARLY IS IMPORTANT



Explain that therapy is for the benefit of the whole family

Children often think that they are going to therapy because they are the problem. You can explain that parents also need help to learn how to understand their child and give them what they need. Try to be enthusiastic when talking about this with your child – show them that you are interested in learning and growing as well. It's important that your child doesn't feel like you are being burdened by the task at hand.

Children may already have a hard time with the fact that their parents hold most of the power in the parent-child relationship. Hearing you acknowledge that you would like to continue to grow as a parent can be a relief to your child and help them feel like you are in it together.

Remind your child (and yourself) that we all need help

If your child feels badly about having to see a psychologist you can remind them that all children need helpers as they grow up – be it parents, other family members, friends, teachers, coaches, spiritual guides, etc. Their psychologist is just another one of these helpers.

You can also remind your child that you need helpers as well. Be a role model for your child by taking an interest in your own internal experiences and what they mean. When parents show emotional awareness by self-reflecting and self-regulating their emotions, children begin to learn these skills for themselves. These skills can become part of your entire family's philosophy. Valuing internal experiences, not just managing external behaviours, helps family members feel like they are understood and can lead to stronger relationships and more family unity.

Make sure your child knows that you support them

Understandably, you may have mixed feelings about bringing your child to hospital for treatment. You may feel frustrated, scared, or worried about your child, or be anxious to see immediate results. You may also feel a sense of helplessness when your child goes into the treatment room with their therapist while you wait outside for them. These feelings are normal, and most parents will feel this way at some stage throughout their child's healthcare journey.

It is also common for parents to disagree with each other about whether they need to bring their child to the hospital for treatment. This is why it's important for you to monitor and work through your reactions and disagreements in an adult context. Children are keen observers and will take cues from you as to how they should feel about their treatment. If you are supportive and encouraging of your child's treatment, your child will feel like they have permission and freedom to engage with it wholeheartedly.



Caregiving

Taking care of a sick child can be a profoundly rewarding experience, however it also comes with its fair share of challenges. The demands of taking care of the physical, medical and emotional needs of a child with a medical condition can stretch the resources of any caregiver. With most of your time and attention being focused on your sick child's needs it is easy to lose sight of how important it is for you to take care of your own needs.

If you notice that you are experiencing any of the signs listed below you may need to start taking better care of yourself:

- being exhausted – physically and emotionally
- changes in your appetite and sleep patterns
- withdrawal from social activities
- increased anxiety
- heightened emotions (excessive crying or irritability)
- decreased emotions (feeling empty or unconcerned).

For you to provide your child with the best care possible, you need to take care of yourself. Some simple ways you can incorporate self-care into your life are:

- take a break – you should not have to feel as if you must stay at your child's bedside every minute of the day
- go for a walk, get a coffee or go outside for some fresh air
- read a book
- watch a movie or tv show
- take a power nap
- get a good night's sleep (this can improve your mood and help you cope)
- eat well (try to eat a balanced diet)
- exercise (two to three lots of ten-minutes a day is recommended)
- seek emotional support when you need it so that you don't feel isolated
- reach out for practical support when you need it e.g. transport, housework, respite.

Remember, you should not feel guilty about taking time for yourself to do these things. Being a caregiver to a sick child can be incredibly demanding and you deserve to take a break sometimes. You will be able to care for your child much better if you look after your own wellbeing too.



My child's team members

Lead doctor

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Lead nurse in the ward

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Psychologist

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Physiotherapist

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Speech pathologist

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Social worker

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Occupational therapist

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Other important people

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Questions to ask/notes

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