

Cocooned Parents Handbook

*How to survive when your child is in hospital
– a guide for parents, carers and families*

Whether your child is in hospital for a day, weeks, or months. Below are some suggestions to help you navigate this difficult time.

1. Ask Questions – never be afraid to ask questions

Can you explain what that means?

Ask for more information about your child's diagnosis, prognosis and treatment. Start with the doctors and nurses who are caring for your child, if they can't answer all your questions, find out where to go for more information. The more you know and understand about what's going on, the less scared and more reassured you can feel.

Don't rely on Google for information, you're likely to end up misinformed. Trust the people who have the training and the knowledge, and know your child.

How can I be involved in my child's care?

Even if your child is in NICU or PICU, you may still be able to carry out simple tasks like; changing their nappy, washing them, or feeding them. If your child has a feeding tube, nurses will usually be more than happy to show you how to run feeds yourself. These may seem like small things, however they allow you to bond with your child and the benefits to both of you are immeasurable.

Can I hold my child?

It can be very daunting and distressing to see your child covered in tubes, bandages, lines and wires. You may be concerned about hurting them or causing discomfort. If you ask, with a little bit of assistance, you may be able to hold your child.

What am I entitled to?

Being in hospital with a child for an extended period of time can affect families financially. Perhaps there are there discounts for hospital patients for the car park? For the local Laundromat, restaurants or hotel? Is there government assistance available for your situation? Find out or ask someone to find out for you.

2. Look after yourself

This is extremely important. It's very difficult to look after your child, or their siblings, when you are completely emotionally and physically drained.

Eat well; The temptation in this situation is to go for comfort food. Certainly don't deny yourself chocolate and coffee! However you're not going to do yourself any favours eating greasy fast food every night. Try and eat at least one fresh meal a day and keep fresh fruit on hand for snacks. You'll feel much better for it.

Get out; Leave the hospital (you don't need to leave the grounds) just get outside the building. If you can manage a small walk or even participate in one of your usual physical activities like yoga or visiting the gym, you'll be amazed at the difference this can make to your day.

Get some sleep; This is not always possible, especially if you are staying in the hospital with your child. However the lack of sleep can build up, and severely affect your ability to cope and function. If you need to go home or back to the hotel during the day or even at night to get sleep while someone else is with your child, do it. Get some sleep and come back feeling a bit more human.

Take a shower! Often you'll be exhausted, and getting into a shower seems like too much effort. Another very small thing, that can make a world of difference.

Practice mindfulness; Basically, mindfulness helps reduce stress by focusing your attention on the present moment. There are a number of ways you can do this such as meditation, mindfulness colouring books or breathing exercises. Look at the numerous apps and websites available, and find something that works for you.

3. Hope for the best, but be prepared

By this we mean, remain positive, however don't only accept the 'best case scenario' and expect everything to go to plan.

For example, if doctors give your child a recovery time of 2-4 weeks, plan according to 4 weeks or even more. More often than not, your child will be fully recovered even sooner. However sometimes, things don't go according to plan, and if you've only accepted the best-case scenario, you've already made things so much harder on yourself.

4. Trust your instincts

You know your child best, and you are your child's advocate. If you think that something isn't right, persist. Ask for a second opinion, ask for a doctor or specialist from another discipline. Find someone whose opinion you trust, and get the answers you need.

By the same token, is it important to understand that the staff in the hospital are human too. They work long shifts, can be exhausted and have their own worries. It's only natural that they are going to miss things and occasionally forget. In being your child's advocate, sometimes you need to make sure things aren't missed or forgotten about.

5. Ask for and accept help

Ask what help is available *within the hospital*. There are a myriad of staff and facilities on hand to help you, your child and your family; services like physiotherapists, play therapists, lactation consultants, music therapists, social workers, sometimes even financial advisors. There are also facilities available to you like family rooms, laundry rooms, showers and play centres.

Most children's hospitals have *volunteers* who will sit with your child, read them stories or even play games with them. This is fantastic for when you need time to run errands, or take a break and get some fresh air.

Ask *family and friends* for help. This isn't always easy, however more often than not, these people want to help you, they are just unsure of what they can or should do.

Along with this handbook, we've also put together a list of suggestions, of ways that family or friends can help. Print it off or email it to anyone who offers help, share it with your family and friends on social media, or if your child has a scheduled surgery, send out before you go in. By letting them know how they can help, you are more likely to get the help you need.

From our family to yours, we wish you and your child all the very best xx

Karen and Demos

How to help when a friend or family member is caring for a child in hospital

1. Talk to them

Don't worry about whether or not it's a good time to call. If you call and it's not a good time, they won't answer. Leave a message, let them know you're thinking of them. If you can drop by and see them, even better.

Remain positive, however often saying things like "oh they'll be fine" can come across as unfeeling and insensitive, even though this is not your intent. They are, at that moment, living something that can be quite harrowing. Often, all they want to hear is "that's horrible and it really, really sucks". Expletives are welcome too! accompanied by a loving hug (if appropriate).

2. Listen to them

Let them talk about their situation and their child, they may cry and that's ok. If that would make you uncomfortable, send them a message and simply let them know that you're thinking of them. It's important for them to be able to offload, and feel like they have been heard.

3. Make specific offers of help

If you say "is there anything I can do to help?" more often than not, your offer will be kindly rebuffed, however much help they may actually need. The best way to help, is to make specific offers.

If they are away from home, tell them you'll pick up their mail, mow their lawn on the weekend, or look after their dog. Perhaps you can help by organising a roster with other people who also want to help.

If you can drop by the hospital, let them know you'll be there Tuesday night with dinner, some snacks and clean clothes. Perhaps Tuesday night won't work for them, but Wednesday will. By saying what you will do, and when you will do it, you are more likely to be able to provide the help that they need.

4. Don't forget about the siblings

It's a difficult time for the whole family, and siblings of the child in hospital will be just as upset and confused and most likely missing their parents and sibling. If you can, spend some quality time with them and ask them how they are.

5. Take, or send, the parents or carers something

Take them a magazine to flip through, a book, perhaps some slippers, or a clean pair of pyjamas. Think about what things they might need, and make them a little care package. (A list of other suggestions can be found on our website) They will certainly appreciate it.