

# Coping when your child is in hospital - psychological support for your family

Clinical Psychology Service  
Children's Chronic Illness  
Information for Patients, Parents & Carers

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## Introduction

The process of coming to terms with a chronic illness in a child and managing the demands of their care will take time and can be a challenge for any family. Getting to this point is likely to have been scary and possibly an unexpected shock. In these circumstances, most parents will experience some kind of difficulty. Everyone, including friends and relatives can react differently depending on their own situation. This leaflet outlines some common emotional difficulties and suggests some strategies that may help.

## Common feelings and struggles

### Knowing how to cope:

Lots of parents tell us that although they are managing day to day activities, and perhaps hear other people describe them as "coping well", it often does not feel this way. Maybe you feel like you are 'going through the motions' in a situation that feels completely unreal.

### Learning new and difficult things:

You will be faced with lots of new and difficult medical information that you may not always understand. You might also need to learn treatments and procedures to care for your child, such as changing tracheostomy tubes, calculating carbohydrate to insulin ratios, or using an EpiPen. At times it may feel like you are more of a nurse than a parent, and this can be upsetting and challenging. Some parents can feel very torn between wanting to carry out medical care but finding it incredibly hard to do so.

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or call 111 for non-emergency medical advice**

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To give feedback about this information sheet, contact [InformationForPatients@uhl-tr.nhs.uk](mailto:InformationForPatients@uhl-tr.nhs.uk)

**Tip** - Be honest with the medical team about how much you feel able to do. Allow yourself some 'slips' and know that there may be days when you feel overwhelmed. Ask for clear explanations when talking to medical staff. Do not be afraid to ask for information to be repeated or explained in a different way. Ask as many questions as you need to.

### **Practical worries:**

Most parents will have worries about finances, absence from work, and difficulties with managing time e.g. when there are other children to care for, or perhaps you also care for elderly relatives. Some families also experience worries about housing and finding equipment.

**Tip** - Ask extended family and friends to help with practical tasks e.g. getting a lift, shopping etc. Your loved ones may offer to help but might not know how best to do this, so give them specific jobs that will make your life easier.

### **Managing crises and uncertainty:**

At times it may feel like you are on a rollercoaster that never seems to stop. Admission to the Children's Intensive Care Unit (CICU) or needing surgery can be particularly upsetting, but often these feelings come after the crisis has happened and there is more time to think. If emotions run high, you may find that there is more tension between family members. You might also find yourself in conflict with medical staff at times.

**Tip** - When you're struggling, let people know. If you notice yourself getting more emotional or angry, talk it through with those closest to you. If you are finding it hard to forget upsetting events, or you have the same thoughts over and over, talk to the psychologist.

### **Sadness and a feeling of loss:**

There is likely to have been a lot of change in your family life and in your role as a parent. It can feel hard to maintain some of the independence you had before and you may feel less confident as a result. You might feel as if you have 'lost' the child you had before, which can be very upsetting. Lots of parents also feel guilty and this can be hard to talk about. Tiredness and exhaustion also contribute to how emotional we feel.

**Tip** - Be kind to yourself and give yourself permission to be upset sometimes; this is completely normal. Encourage talking within your family and introduce the idea that difficult feelings can be shared with each other in safe ways. The psychologist can help you with this, and is available to talk to both on and off the ward.

## Helping siblings - common reactions you might see

Brothers and sisters can also find it difficult to adjust when a child is poorly. They may have to see medical procedures and cope with all the changes happening in the family as a result of the illness. The hospital can be a confusing and scary place. Siblings may have lots of worries about what is happening to their brother or sister, but they may not know how to talk about them.

### Worries:

Brothers and sisters need to make sense of what is happening to their sibling and what the implications may be. They might worry that they will catch the illness too, or that other people in the family may become unwell. They might worry about something happening to you, particularly if they have seen you worried or disappearing off to the hospital in a rush.

**Tip** - Help siblings to understand by giving them information that is right for their age about what is happening and what is likely to happen. Play specialists in the hospital can help with this. Include siblings and give them the chance to ask questions if they are old enough.

### Jealousy:

Brothers and sisters may feel upset that their poorly sibling is getting more attention than usual. They are likely to feel this way even if they understand why the extra attention is needed. Every child needs attention, and so these feelings cannot be helped.

**Tip** - Try to make time (however small) to spend on your own with the other children e.g. go to the canteen and have a chat about their day. Ask extended family to check-in on siblings and involve them in your child's care. Ask the play specialist for ideas to support siblings and involving them in your child's care. If siblings are starting to struggle emotionally ask the psychologist for advice, as they may be able to help them too.

### Difficult behaviour:

Siblings who feel upset may react by expressing themselves through their behaviour. You might notice changes in how they behave or perform at school, or they may start becoming more challenging or demanding at home. Some siblings might even become withdrawn or quieter than before.

**Remember** - Try not to take these changes personally. Most siblings cope very well with unexpected change, however it is important to acknowledge how hard it can be for them. Speak to the psychologist about any concerns you have.

## Top tips to help support siblings:

- Involve siblings as much as you can. Bring them to hospital, let them ask questions and help them to feel included.
- Keep things normal. Try and keep the normal daily routines (school, clubs etc.) for siblings. Ask extended family and friends to help with practicalities if needed.
- Listen and allow them to feel. Show siblings that you understand that they feel upset, angry, jealous, or worried. Show them these are normal feelings.
- Try and find some special time to spend with siblings and acknowledge how well they are coping or how helpful they are being.
- Explain what is happening in honest, straightforward ways that are right for their age. Siblings will worry more if they are kept in the dark.
- Ask visitors to bring a small gift for young siblings, as well as the poorly child. Involve them in conversations with visitors and make sure **every** child is talked about.

## How to support your poorly child

Children will learn about illness through the world around them, making sense of people's experiences and reactions to form their own ideas and beliefs. These beliefs will be individual to each child and depend on their personality, previous experiences and stage of development. Younger children may take things very literally which can lead to misunderstanding.

Children can become frightened or worried if they do not understand what is happening or if things happen suddenly, without chance to prepare. You might notice a change in your child's behaviour e.g. they may become more clingy, or even more aggressive with you. It is important to keep boundaries and maintain the same rules that your family had before, about what is acceptable.

Some children can really struggle with distress caused by medical procedures e.g. blood tests, accessing a port-a-cath, changing of a tracheostomy tube. Speak to the play specialist about supporting your child when procedures are being done.

Just like us, children are likely to have thoughts and fears about the future and about what will happen next. They may wonder whether their friends will still be there for them, what they have missed at school, or whether they will be able to go back to clubs and activities they used to enjoy. They may have questions about their body and how they will look.

Try to be honest and give specific facts about things you know to be true, but also share ideas about how things might change. Do this regularly over time and as your child gets older, making sure to change your explanations if needed as their understanding gets better.

## Top tips for supporting your poorly child:

- Explain things more than once in a way they will understand. Pictures and drawings can be helpful, as can story books. Ask the play specialist for advice.
- Keep some routine and structure where you can. Having meals at their normal time, or regular lessons with the hospital school team, can help children feel normal.
- Don't leave worries unanswered; talk about things and share feelings with each other. It is OK to be worried or feel sad sometimes.
- Show affection in ways that are normal to your family. Touch can be powerful in reminding each other we care.
- Find your own language. Developing a shared language for naming complex conditions, medicines and equipment, can help you to talk about them as a family.
- Take breaks. If your child is struggling with feelings of anger or frustration and you are finding this hard to respond to, take a break. Swap with your partner, friend or family member, and have some breathing space just as you would at home.
- Arrange for visitors to come in shifts, so that visits are not too much for your child.
- Have lots of distractions available. Tablet computer, favourite toys or books can help when your child is struggling emotionally, and can also be a nice reminder of home.
- Relax with deep breathing exercises, mindfulness, or simply calming music. This might help all of you manage your anxiety. Regularly practicing these techniques can help at times of stress. Ask the play specialist or the psychologist for advice.

## Asking for help

### What can the clinical psychologist offer?

Advice and support for young people, their families and siblings around coping with and adjusting to being in hospital.

Psychological interventions to help with anxiety, low mood, anger, guilt and other difficult feelings.

### What will the clinical psychologist do?

The clinical psychologist will come and talk to you on the ward and possibly arrange further meetings with you in a different room in the hospital. The psychologist might tell you about help in the community, or possibly even come and meet with you as a family at home.

### How do I speak to the clinical psychologist?

Ask any member of your medical team such as your consultant paediatrician or specialist nurse, or any of the ward staff.

## Contact details

Clinical Psychology Team / Paediatric Psychology Service:

Artemis House

Westcotes House Site

Westcotes Drive

Leicester LE3 0QU

**Telephone:** 0116 295 2959

If you have any questions, write them down here to remind you what to ask when you speak to your child's nurse or consultant, or the clinical psychologist:

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اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔  
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો.

ਜੇ ਤਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

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