

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

Paediatric Psychology Service
Children's Chronic Illness

Information for Patients, Parents & Carers

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Introduction

The process of coming to terms with a long-term illness in a child and managing the demands of their care will take time. It 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 have some kind of difficulty. Everyone, including friends and relatives, can react differently depending on their own situation. This leaflet outlines some common emotional problems 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. You may 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, working out carbohydrate to insulin ratios, or using an EpiPen. At times it may feel like you are more of a nurse than a parent. This can be upsetting and challenging. Some parents can feel very torn between wanting to carry out medical care but finding it very hard to do so.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact 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 for example, when there are other children to care for, or you may also care for elderly relatives. Some families also have worries about housing and finding equipment.

Tip: Ask extended family and friends to help with practical tasks such as getting a lift, shopping and so on. 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 very upsetting. 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 are struggling, let people know.
- If you see 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 psychology team.

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 keep some of the independence you had before. You may feel less confident as a result. You might feel as if you have 'lost' the child you had before. This can be very upsetting. Lots of parents also feel guilty and this can be hard to talk about. Tiredness and exhaustion can also affect how emotional we feel.

Tip:

- Be kind to yourself. Give yourself permission to be upset sometimes. This is completely normal.
- Encourage talking within your family. Introduce the idea that difficult feelings can be shared in safe ways. The psychologist can help you with this. They are 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 for example, 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. They may start to become 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, but it is important to acknowledge how hard it can be for them. Speak to the psychology team 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. They will depend on their personality, previous experiences and stage of development. Younger children may take things very literally. This 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 for example, they may become more clingy, or even more aggressive with you. It is important to keep boundaries and the same rules that your family had before, about what is acceptable.

Some children can really struggle with distress caused by medical procedures for example, 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
- Will they 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. As your child gets older, make 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.
- Do not 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. 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. They 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 psychology team for advice.

Asking for help

What can the Paediatric Psychology service offer?

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

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

What will the Psychology team do?

A clinician from the Paediatric Psychology team may come and talk to you on the ward. They may possibly arrange further meetings with you in a different room in the hospital. This might be Psychologist, Psychological Practitioner, Family Therapist, Psychiatrist, or Specialist Nurse. They 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 Paediatric Psychology team?

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

Contact details

Paediatric Psychology Service:

Artemis House

Westcotes House Site

Westcotes Drive

Leicester LE3 0QU

Telephone: 0116 295 2959

