

# Coping when your child is in hospital; Psychological Support for Your Family

Clinical Psychology Service, Children's Airway and Home  
Ventilation

Information for Patients, Parents and Carers



Advice on managing emotions and coping as a family when your  
child is in hospital or on discharge home

University Hospitals of Leicester  
NHS Trust



*Caring at its best*

# Coping When Your Child is in Hospital

The process of adjusting to a chronic illness in a child and managing the demands of their care will take time and can be a challenge for any family. Your journey to this point is likely to have been scary and traumatic, and may have been an unexpected shock. In these circumstances, most parents will experience some kind of difficulty. You may also find that parents and relatives react differently depending on their personality and past experiences. 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. Perhaps 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 complex medical information that you may not always understand. You may also be required to learn treatments and procedures to care for your child such as changing tracheostomy tubes or suctioning. At times it may feel like you are more of a nurse than a parent, and this is both daunting and challenging. Some parents can feel very torn between wanting to carry out medical care but finding it incredibly hard to do so.

*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 clarity when talking to medical staff. Do not be afraid to ask for information to be repeated or re-explained in a different way. Ask as many questions as you need to.*

## **Practical Worries**

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

*Tip: Ask extended family and friends to help with practical tasks e.g. lifts, shopping etc. Your loved ones may offer to help but may 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. Admissions to PICU and needing surgery can be particularly traumatic, 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 may 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 are having the same thoughts over and over, talk to the Psychologist.*

## **Sadness and 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 may 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 we can share difficult feelings 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

Brothers and sisters can also find it difficult to adjust when a child is poorly. They may have to witness medical procedures and will have to cope with all the changes happening in the family as a result of the illness. The hospital can be a confusing and daunting place; siblings may have lots of worries about what is happening to their brother/sister but they may not always know how to articulate these worries.

Common reactions you might see;

## 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 hospital in a rush.

*Tip: Help siblings to understand by giving them age-appropriate information 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 opportunity to ask questions if they are old enough.*

## Jealousy

Siblings 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 other siblings and take them out for 'treats'. Ask the Play Specialists for ideas to support siblings and involve them in your child's care. If siblings are starting to struggle emotionally, ask the Psychologist for advice as*

# Helping siblings (continued)

## Difficult behavior

Siblings who feel emotionally unsettled may react by expressing themselves through behavior. 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 quiet or more withdrawn than previously.

*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 on them. Speak to the Psychologist about any concerns you have.*

## Top Tips

- ⇒ Involve siblings as much as you can. Bring them to hospital, let them ask questions, help them to feel included.
- ⇒ Keep things 'normal'. Try and keep siblings normal daily routines (school, clubs etc.). Ask extended family and friends to help with practicalities.
- ⇒ 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 recognize how well they are coping or how helpful they are being.
- ⇒ Explain what is happening in honest, straightforward ways that are age appropriate. 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. This will depend on the child's personality, previous life experiences, and developmental stage. 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 may notice behavioural changes in your child e.g. they may become more clingy or even more aggressive with you. It is important to maintain boundaries and keep the same 'rules' in your family about what was acceptable before.

Some children can really struggle with procedural distress e.g. cannula insertions or tracheostomy tube changes. Speak to the Play Specialists about supporting your child with having procedures done.

Children, just like us, are likely to have thoughts and fears about the future and 'what happens next'. They may wonder about whether their friends will still be there for them, what they have missed at school, or whether they can go back to clubs they used to enjoy. They may have questions about their body and how they will look. Try to be honest; give specific facts of things you know to be true, but also share ideas about how things might change. Make sure that you re-visit your explanations over time and as your child gets older.

## 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 Specialists for advice.
- ⇒ Keep some routines and structure when you can. Having similar feeding times, or having regular lessons with the hospital School team can help children to 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/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, or a friend or family member and have some 'breathing space', just as you would at home.
- ⇒ Plan visitors to come in 'shifts' so that your child is not overwhelmed.
- ⇒ Have lots of 'distractions' available. Tablets, favourite toys or books can help when your child is struggling emotionally, but can also just be a welcome reminder of home.
- ⇒ Relax—deep breathing exercise, mindfulness, or simply calming music 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.

# Speaking to the Clinical Psychologist



Working days: Wednesday, Thursday  
every other Friday

Office: Room 7, CDC, ground floor

Telephone: 295 2959

*Dr Vicky Elliott is a Specialist Clinical Psychologist working in the Children's Airway and Home Ventilation Service*

## **What can the Clinical Psychologist offer?**

Advice and support to 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 Psychologist do?**

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 signpost you to other help in the community, or might even come and meet with you as a family at home.

## **How do I speak to the Psychologist?**

Ask any of the Ward staff or members of the Airway and Home Ventilation Team e.g. your Consultant Paediatrician.











## Today's research is tomorrow's care

We all benefit from research. Leicester's Hospitals is a research active Trust so you may find that research is happening when you visit the hospital or your clinic.

If you are interested in finding out how you can become involved in a clinical trial or to find out more about taking part in research, please speak to your clinician or GP.

**If you would like this information in another language or format, please contact the service equality manager on 0116 250 2959**

إذا كنت ترغب في الحصول على هذه المعلومات في شكل أو لغة أخرى ، يرجى الاتصال مع مدير الخدمة للمساواة في 0116 250 2959.

আপনি যদি এই লিফলেটের অনুবাদ - লিখিত বা অডিও টেপ'এ চান, তাহলে অনুগ্রহ করে সার্ভিস ইকুয়ালিটি ম্যানেজার ডেভ বেকার'এর সাথে 0116 250 2959 নাম্বারে যোগাযোগ করুন।

如果您想用另一种语言或格式来显示本资讯，请致电 0116 250 2959 联系“服务平等化经理” (Service Equality Manager)。

જો તમને આ પત્રકાનું લેખિત અથવા ટેપ ઉપર ભાષાંતર જોઈતું હોય તો મહેરબાની કરી સર્વિસ ઇક્વાલિટી મેનેજરનો 0116 250 2959 ઉપર સંપર્ક કરો.

यदि आप को इस लीफलेट का लिखती या टेप पर अनुवाद चाहिए तो कृपया डेव बेकर, सर्विस इक्वालिटी मैनेजर से 0116 250 2959 पर सम्पर्क कीजिए।

Jeżeli chcieliby Państwo otrzymać niniejsze informacje w tłumaczeniu na inny język lub w innej formie, prosimy skontaktować się z Menedżerem ds. równości w dostępie do usług (Service Equality Manager) pod numerem telefonu 0116 250 2959.

ਜੇਕਰ ਤੁਹਾਨੂੰ ਇਸ ਲੀਫਲੈਟ ਦਾ ਲਿਖਤੀ ਜਾਂ ਟੇਪ ਕੀਤਾ ਅਨੁਵਾਦ ਚਾਹੀਦਾ ਹੋਵੇ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਡੇਵ ਬੇਕਰ, ਸਰਵਿਸ ਇਕੁਅਲਿਟੀ ਮੈਨੇਜਰ ਨਾਲ 0116 250 2959 'ਤੇ ਸੰਪਰਕ ਕਰੋ।

Ak by ste chceli dostať túto informáciu v inom jazyku, alebo formáte, kontaktujte prosím manažéra rovnosti služieb na tel. číslo 0116 250 2959.

Haddaad rabto warqadan oo turjuman oo ku duuban cajalad ama qoraal ah fadlan la xirii, Maamulaha Adeegga Sinaanta 0116 250 2959.

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