

0-3 years. Guides for Parents

Guide 2. Going into hospital

Children who are born with, or acquire, a medical condition which affects their appearance, often require medical treatment in hospital or at a clinic. Sometimes these treatments are life-saving and essential. At other times they take place following consultations with health professionals and some difficult decision-making for parents.

Knowing how to prepare your child and yourself for going into hospital can help you both feel less afraid and anxious. This Guide also looks at how you can comfort and continue to care for him in hospital and what to expect when you bring him home.

1 MAKING DECISIONS ABOUT TREATMENT

Making decisions about medical treatment that will change your child's appearance or improve function can be difficult. It is an emotional experience to consider letting a small child, for whom you are responsible, undergo painful procedures or surgery. For many parents of children who have disfigurements, the big question is often, "should we put our child through this?"

Often, this stems from society's beliefs about the importance of appearance and what this means for your child's future, e.g. will school be easier for him, will he be more likely to get a job, or find a partner? The beliefs that we all hold are very much a part of who we are and where we come from. If your child has a disfigurement, these beliefs are challenged on an everyday basis.

Others factors that will influence your decision include the risk involved, the nature of the treatment and the length of time in hospital or spent recovering.

These thoughts can cause you to feel ashamed, guilty, angry, upset, confused and frightened. They are also very natural and are part of the process of making such a hard decision. *Changing Faces* can help parents work through their thoughts and feelings associated with their beliefs around disfigurement. In our experience, this enables parents to feel more in control and able to adjust to the process of decision-making.

Before you make your decision, it's important to gather clear information about the medical treatment proposed for your child by:

- Talking through the procedure and its risks and benefits with your child's consultant. Think about the questions you want to ask beforehand and also take along any information you've gathered from other sources including the Internet.
- Asking for a second opinion if you're feeling unsure.
- Speaking to families who have already had treatment.
- Talking it through with your partner, family and friends.

It's important to feel comfortable with whatever decision you make. There are always doubts associated with any decision and we all make different choices at different points in our lives. If you have any concerns about your decision, speak to the staff at the hospital or to *Changing Faces*.

2 FINDING OUT WHAT TO EXPECT

Before you prepare your child for going into hospital, try to find out as much as possible about the procedures your child will undergo during an appointment with his consultant or from a nurse specialist. The Patient Advice and Liaison Service (PALS) at your local hospital and the websites of many children's hospitals provide information on anaesthetics, magic cream and injections as well as what to expect on a hospital ward.

You also need to prepare your child and yourself for a change in his appearance. Find out what you can expect your child to look like after surgery and how this may change over time by asking hospital staff or other parents whose children have been through a similar experience (see the Guide on *Finding Further Support*).

This will help you to feel calmer when explaining things which, in turn, will reassure him. If you're not sure what to say or you are concerned about how he will react to the news that he is going to have treatment, try to speak to a play therapist or psychologist attached to the medical department responsible for your child's care. They should be able to give you some ideas and support.

It is tricky balancing home and work life when your child needs medical care. You may wish to contact organisations like Contact a Family and Working Families which offer information and support to parents who work.

3 PREPARING YOUR BABY FOR TREATMENT

Babies pick up on changes in their routine, strange hospital environments or alterations in your tone of voice or body language.

When you take your baby to an appointment with a doctor or into hospital, try talking to him calmly. Briefly tell him where he is going, that he will be seeing a doctor who will look at his hands/head/nose and that you will be with him. He may not understand the words but the familiarity and intimacy of your voice will provide reassurance and comfort.

4 PREPARING YOUR TODDLER FOR TREATMENT

As babies grow into toddlers, their ability to communicate and understand increases. Your concerns about the treatment and its impact on your child may leave you feeling scared and anxious. It's important to remember that children will pick up on your feelings and this can make them feel scared too.

What a child imagines is often worse than reality. Talking with them about the treatment they are going to have or about going into hospital can help reduce their anxiety and dispel irrational fears.

Children often worry about everyday things like who is going to care for their pet or toy whilst they are in hospital, who will read them a bedtime story and what their younger sister will do. Common fears about being in hospital include the pain of a procedure, the noise of a machine or thinking that they are in hospital because they've been naughty.

Provide basic information

Young children don't remember things for very long so it is best to start your explanations a few days before they are due to go into hospital and keep it short and simple:

- Talk about the reason for the treatment by saying what may change about their appearance or function, e.g. he will be able to hold a spoon, breathe more easily, do his buttons up with his new fingers or his scars will be less bumpy.
- Explain how the doctor is going to help your child e.g. giving him medicine, making him sleepy, putting bandages on.
- Reassure him that you will be with him in hospital.
- Talk about the hospital and the people who work there.

EXAMPLE

- Today we are going to the hospital. A lot of doctors will want to look at you. They are the doctors who look after your eyes and head.
- We will come back to the hospital next week. You will be staying in a bed of your very own for a couple of nights. There will be other children next to you. One of us will be there with you. They have a bed next to yours where Mummy or Daddy can stay.
- The doctors are going to make your head bigger. They will give you some medicine to help you sleep. When you wake up you will be sore. Mummy will be there with you.
- When you go to hospital the doctors will give you medicine so that you can sleep. While you are asleep they will make you a new thumb. It seems strange but they will use your toe to do this. When you wake up you may feel sore and tired. The nurse can give you something to make it less sore. Your fingers will be bandaged up for some time. It will take time to get used to your new thumb and to not having a toe. The staff at the hospital and Mummy and Daddy will be there to help you.

Address your child's particular fears

Your child may have particular worries or fears which they aren't able to share when you are explaining about going into hospital. These may come out at other times, such as when you are reading a bedtime story or playing together. Don't worry too much about this but if you do pick up on particular fears, e.g. having an injection or going to sleep, then simply repeat your explanations in a reassuring manner. Having an injection can be scary for all of us, so one way which you can alleviate the worries is to be honest and say that it will hurt a little bit but only for a moment and that Mummy or Daddy will be there.

Stories, playing and drawing

Use story books about children in hospital to help your child express his feelings and know what to expect. See the list in the Resources section at the end of this Guide.

Draw a picture of what is going to happen at the hospital or doctors. Ask your child to explain what is going on in the picture. Let him lead the conversation. Ask questions that start with 'when', 'what', 'where' and 'how' so you can gauge how much he understands about what is going to happen and what he is thinking or feeling. You may have to re-explain some things as a way of reassuring your child and allaying his fears.

Let your child play at dressing-up with a doctor's kit and a sick teddy so that he can practise what is going to happen, express any fears and feel more in control.

Some hospitals (especially children's hospitals or regional hospitals) have play specialists who can help prepare a child for a procedure. Playing like this allows a child to familiarise himself with the equipment (thermometers, oxygen masks, magic anaesthetic cream) and the hospital environment.

Familiarise your child with the hospital or ward

Some hospitals allow you to take your child to visit beforehand so you can both meet the people who work there and have a chance to practise what is going to happen.

Packing to go to hospital

The last step of preparation is packing bags and getting ready to go. Children, particularly toddlers with greater independence, will feel more in control if they can decide what to take with them, like a favourite toy.

5 CARING FOR YOUR CHILD IN HOSPITAL

Reassuring your child

Babies under eight months of age usually adapt quickly to a new environment and can be easily comforted by parents and hospital staff. Toddlers are often scared by new environments or new people and may experience more difficulties in settling than babies. They are also used to exploring the world and asserting their needs as they become more independent. Being in hospital can limit these new found skills.

Crying, refusing to eat, withdrawing or throwing tantrums can be construed as misbehaviour but are actually natural responses to being in hospital. Let your child show his feelings through crying or screaming if he needs to. Let him know you understand that he is scared, angry or upset and that you will be there with him.

It's important that you also have someone to share your feelings with such as family, friends or the hospital staff. By looking after yourself, you will have the emotional and physical energy to give your best to your child. Try taking a break, give yourself time to talk with a friend or to share a meal with your partner.

You may find some procedures difficult to watch. If you feel your anxiety will rub off on your child, ask someone your child likes and trusts to stay with him instead.

Immediately after treatment

It is a great relief when your child returns to the ward after surgery but you may find yourself shocked by what he looks like, by the medical apparatus (e.g. trachea, drips, sedation) or the care he needs.

Adjusting to a change in your child's appearance can cause a mix of emotions even if it has been explained before the surgery. You may have to take a second look at your child to check that it is really him. You have come to love and know your child the way he looks and it is normal to experience feelings of shock, loss and sadness at such changes. Your child may also feel sad at having "lost" his mole or special mark.

Remember that how your child first looks after surgery or treatment is not the way he will look after his face or body has healed.

Sometimes treatment means a child may find it difficult to move freely or use his voice. This can make it hard to determine how he is feeling or what he needs and you may be unable to respond to his normal needs, e.g. feeding, nappy changing, close contact, play. You can still comfort and reassure your child even though you may not be able to cuddle and hug him as normal.

- Touch: Hold his hand and caress his foot or forehead.
- Voice: Talk softly and lovingly to him, tell him you want to hold him close.
- Presence: Let him know that you are there and love him.

Continue to offer explanations about what he is experiencing even if you're not sure he can hear you.

- You cannot talk because the doctor put a tube in your throat to help you breathe.
- It is normal to feel sick after an operation. It does not last for too long. You should start to feel better later today / tomorrow. Daddy will be here with you.

Helping your child adjust to changes in his appearance

When he is feeling a brighter, think about exploring the change to his appearance with him but take things at your child's pace:

1. Talk to him about the differences, e.g. "before the operation you had a hole in your lip. Now the hole has disappeared and a small red mark is there."
2. Talk about the similarities e.g. "Ruan is coming in later. Do you still want to read Thomas the Tank Engine together like you do at home?"
3. Get your child to explore the new things he can do. Ask him questions e.g. "I can see that your hand has a new finger. It's going to work much better now. What do you think you'll be able to do with your hand?"
4. If the change in appearance is on your child's body, he will notice it straightaway - often because it hurts! Ask him how it feels. He might say it feels 'funny' or 'ouch'. Then, it is useful for you to describe how it looks in his language, e.g. "Ben had a red mark on his leg. Now he's got some new skin to make his leg better."
5. If the change is on your child's face, it is unlikely that he will have seen the differences to his face. Even so, ask him what it feels like and how he thinks his face may look. Then describe how his face looks in his language e.g. "your cheek is a bit big at the moment. It must feel funny. Your strawberry used to be red and now it is pink."

Research shows that it is best not to show your child his face in a mirror until he is nearly recovered or the swelling has gone because his face may change dramatically as his features settle. Wait until you get home if you can.

For children who have disfigurements, returning to a normal routine as soon as possible and mixing with other children and adults can speed up their recovery and the adjustment to the change in their appearance or function. The things you can do to aid this include:

- Give him a choice wherever you can – e.g. “Would you like apple or orange juice?” or “Do you want to watch Bob the Builder or Teletubbies?”
- Encourage him to play with other children as well as yourself.
- Give him news from home - e.g. “Said went to school today and is going to soccer this afternoon. When he comes in later, we can ask him if he won.”

6 GOING HOME

It's important to keep exploring the change to his appearance by talking, playing and reading stories together – when he is feeling up to it.

If the change is to his face, use a mirror to point out each of his features in turn, commenting on the ways that he is similar to how he was before and how he is similar to you or your partner. When you are speaking about his visible difference, speak about how it looks and how it feels both to you and to him:

“You have brown eyes. I loved your big brown eyes when you were born. They are just like Daddy’s. Your lip looks different than it did before you went to see the doctor. It was long and wonky. Now, your lip is smaller and has a red bump at the end. Can you feel the bump too? I like the colour red.”

7 CHANGES IN BEHAVIOUR

You may notice that your child’s behaviour changes after you bring him home from hospital. He may be more clingy, distant or fearful. If he had started to walk before going into hospital, you may find that he returns to crawling or just wanting to sit on your lap. Or he may have started eating solids but now wants his bottle again.

If this behaviour is not a result of the treatment, e.g. his legs or throat may be sore, then it is likely to be a normal response to feelings of vulnerability known as regression. With your love, comfort, presence and normal daily activities, these feelings of vulnerability will fade away. It can take some months though so be patient and encourage your child rather than forcing change or being angry.

Young children can also remember being in hospital long after it took place. He may recall a toy he played with or the pictures on the wall of the ward. These memories can pop up in conversation at strange times. It can help to briefly explain things when this happens so that he can make sense of why he went to hospital.

8 DELAYS IN DEVELOPMENT

Hospitalisation early on in a baby’s life can result in delayed development. The stress of early treatment, the body’s focus on healing and the likely interruptions to a normal routine may result in a baby learning to talk or walk later than one would expect.

If you are concerned about your child’s development, seek advice from his health visitor, paediatrician or consultant. If your baby is young, a ‘wait and see’ approach may be taken. If your child is older and concerns remain, he may be offered further assessments and support.

9 SIBLINGS

Many of the ideas about preparing your child for treatment can also be used for your other children to allay their fears. Use simple explanations about the treatment their brother is going to have, let them know when they can visit, who will be looking after them and when you will be home. Ask them to explain what they think is happening so that you can correct any misconceptions and give them a chance to express their feelings.

Reading books about hospital, giving them choices, e.g. when they can visit their brother or sister, and sending taped messages, cards and pictures can also be reassuring.

When you get home, sit down together as a family and explain to all your children about what happened in the hospital, what has changed about their brother or sister's appearance and why it has changed, e.g. so he can close his eye or so that he can smile on the left side of his face. Encourage everyone to think about how they could easily explain this change to other people.

It can also help to give your other children lots of compliments, hugs and positive feedback on what they are doing so that they know they are important to you too.

10 USEFUL RESOURCES

Children's books

Going into hospital by Anne Civardi
 I don't want to go to Hospital by Toni Ross
 Miffy in Hospital by Dick Bruna
 Tomorrow I will feel Better by Rien Broere
 Topsy and Tim go to Hospital by Jean and Gareth Adamson
 When I went to Hospital by Juliet Bawden

Letterbox Library has a great selection of books too. www.letterboxlibrary.com

Information for parents

You and Your Child in Hospital by Margaret Carter. (Methuen)

www.babyandkids.co.uk/Health/Hospital.asp
www.childrenfirst.nhs.uk
www.actionforsickchildren.org

Please note the following websites are based on the system of healthcare in the USA:

http://kidshealth.org/parent/system/doctor/dr_visits.html
http://kidshealth.org/parent/system/surgery/hosp_surgery.html

Working Families Tel: (020) 7253 7243 Legal Helpline: 0800 013 0313. Email: office@workingfamilies.org.uk Web: www.workingfamilies.org.uk