

3-11 years. Guides for Parents

Guide 2. Going into hospital

Children who are born with a medical condition which affects their appearance can often require ongoing medical treatment during their school years. Other children may acquire a visible difference during their childhood that needs 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 your child whilst he is having treatment, help him adjust to a changed appearance and support him to go back to school.

1 MAKING DIFFICULT 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 your child 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.
- Talking it through with your child.

Your child may have his own views about whether he wants to have treatment or not. You may not believe that he is old enough to make the final decision but it can help him to talk it through with you. His reasons for wanting or not wanting treatment may highlight his own beliefs, fears, concerns or wishes. If you believe he should have some part in decision making, let him know exactly what he can make the decision on. It may be limited to whether he has the treatment now or during the holidays or he may be the one to decide whether he wants a reconstructed ear, a prosthetic or to keep his little ear.

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 PREPARING YOUR CHILD FOR TREATMENT

Explaining to your child

Many parents naturally find it distressing to talk through the ins and outs of medical treatment and instinctively want to avoid conversations that may upset their child. From the time you make your decision to being admitted for treatment, it's important to provide your child with simple explanations, as it is often the anticipation and the "not knowing" that makes children feel anxious or scared. Talking with him will reduce his anxiety in the long run, dispel his irrational fears and aid his ability to cope with treatment.

Like all children, he has most likely already picked up on bits of information from adult conversations, TV or other friends who have been in hospital. Children can mix up these different bits of information so keep checking his understanding even if he has been in hospital before. It can be useful to use analogies that he will be familiar with, e.g.

"The doctors are going to look inside your head and fit your bones together like a jigsaw puzzle."

"You know how when you fall over and cut yourself in the playground it can bleed and hurt a bit? Well, your body is just like a clever machine and makes new blood all the time and it will do the same thing when you're in hospital."

Children's common fears can also include the pain of an injection or a procedure, how they may look afterwards, the sports day they are missing out on or fitting back in with their friends at school.

- Start by asking your child what worries them about going into hospital as what a child imagines is often worse than reality, e.g. waking up during the operation.
- Talk about the reason for the treatment by saying what may change about his appearance or function, e.g. he will be able to walk more easily, his jaw will be wider or his scars will be flatter.
- Talk about what your child is expecting to look like after treatment and speak with doctors who may be able to show you both pictures of other children they have treated both before and after.
- 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.

- If you don't know the answer say, "I don't know but we can ask the doctor together."
- Talk about the hospital and the people who work there.

EXAMPLE for younger child

- When we go into hospital, the nurse will put a clever thing in your arm that looks like a tiny tube so she can give you medicine to make you feel sleepy. It feels a bit like the injection that we had at the doctor's last week, so it will only hurt for a moment. After this, you will be asleep for a nap so the doctor can look after your scars. When you wake up, you will be in a big green bed and there will be other children next to you. You might feel a bit sleepy or sore on your face and hands but I will be there with you. If anything hurts, just tell me and the nurse can give you some medicine to make it better. The people at the hospital are very nice and they even have a bed next to yours where Mummy or Daddy can stay.

A child who has ongoing treatment or who is older may be more aware of what is going to happen and may need more information to allay his curiosity and anxieties.

EXAMPLE for older child

- We wanted to chat with you about what is going to happen when we go into hospital next week. When we go in, the nurse will show you where your bed is and we can sort out your books and games and stuff. The nurse will come and show us downstairs to where they are going to do your eye operation. She'll put that small tube in your arm - like the one we saw on the hospital visit- so it will hurt a bit. Then the nurse will give you an anaesthetic to make you fall asleep for a couple of hours while the doctor puts in extra bone under your eyes. When you wake up, you'll probably feel a bit groggy. It shouldn't hurt but if it does, just tell us and the nurse can give you some pain medicine. We want to make sure you understand what will happen so please ask us any questions.

Books and drawing

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

Draw a picture of what is going to happen at the hospital or doctors. Let him lead the conversation and 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.

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 with the equipment.

Let him choose

The last step of preparation is packing bags and getting ready to go. Children will feel more in control if they can decide what to take with them, like a favourite book or a gameboy, or certain clothing, like a baseball cap or his trainers. You can also talk about

how he wants to keep in touch with his friends, when he would like them to visit and what he wants you to tell them. You could even let him take his mobile phone in (switched off, of course) so that he can pick up his messages once he is allowed to walk around the hospital grounds.

3 CARING FOR YOUR CHILD IN HOSPITAL

Reassuring your child

Children can react in different ways to being in hospital. Some may withdraw, others may be tearful or aggressive but these are natural responses to being in hospital. Let your child know that it's OK to feel this way, that you will be with him and that he won't feel like this for long.

It's also important that you have someone to share your feelings with such as a family member, friend or the hospital staff so that you can reassure your child through your own calmness. If you find some procedures difficult to watch and are worried that your anxiety will rub off on your child, ask someone else who he trusts to be there instead.

By looking after yourself, you will have the emotional and physical energy to give your best to your child. Take breaks by talking to a friend, sharing a meal with your partner or asking someone close to your child to stay with him for a while.

Immediately after treatment

It is a great relief when your child returns to the ward after surgery but you may be 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. It helps to tell yourself that the way your child first looks after surgery or treatment is not the way he will look after he has healed.

Sometimes treatment means a child may find it difficult to move freely or use his voice to communicate his needs. It's important to continue to reassure your child as he comes around and starts to be more aware of where he is and how he is feeling:

- **Voice:** Reassure him that he is waking up now and that the operation is over. Talk to him about how he may be feeling drowsy or a little sore or may feel bandages on his face but that everything is fine and he is doing really well. Try distracting him by talking about the things he will be able to do once he is up and about.
- **Touch:** Try holding his hand or touching his cheek or forehead to let him know you are there and to distract him from the other parts of his body that may feel sore.
- **Squeezing:** If your child can't communicate with his voice, try asking them to squeeze your hand in response to questions, e.g. "Are you thirsty?"

- Presence: Try standing or sitting close to the bed as just being nearby provides comfort and security for children.

Continue to offer explanations about what he is experiencing even if you're not sure he is very aware of what is going on, e.g. "You cannot talk right now because the doctors put a tube in your throat to help you breathe." or "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. I will stay with you."

Exploring the change to his appearance

When he is feeling a bit brighter, think about exploring the change to his appearance with him. You can start to do this at the hospital and continue at home when you have some quiet, uninterrupted time together.

Start to talk to him before any dressings come off. Children often have unrealistic expectations of how they may look after medical treatment, and it's best to prepare your child by talking about how at first he may have swelling, redness, bruising or stitches. Reassure him by reminding him that how his face or part of his body will look different when it has settled down.

- "Your jaw is bandaged up but I can see that it has changed shape and looks a bit wider than before. Can you feel how it's changed?"
- "Once the dressings come off, your skin may look red and swollen, but in a couple of weeks, you'll see that your scars look flatter."
- "Your eyes are covered now but I can see they are a bit bruised around the edges. When the bandages come off, they may look a bit black and blue and you will see some stitches, but they will all be gone in a few weeks and your eyes will look smaller than before."

Once the dressings are off, most children will want to use a mirror to see the changes in their appearance. Wait until your child suggests it, as the longer you wait the more his features will have settled down but if he does want to look, then it's important to let him.

Often children are surprised by the way they look after treatment so be prepared for some shock or disappointment, even if this is only temporary. Your child may look at his face after reconstructive surgery and think –"I know it is me but I just look so different." They may have expected immediate changes or hoped for much more than was realistic.

Get him talking about how it looks and how it feels both to you and to him:

- "Your right side looks a bit swollen, but I can see that the skin on your cheek looks more like the skin on your forehead now. The colour's the same and it feels the same. What do you think?"
- "Can you see how your mouth has changed shape? The bone from your hip in your gum. Now your new teeth can come through."

If the treatment has been to improve function, get your child to explore the new things he can do by asking him questions:

- "Can you see that poster over there without moving your head?"
- "What do you think you'll be able to do with your new hand?"

It is also important to talk about the things that haven't changed:

- "Abdul is coming in later. Do you want me to disappear for a bit so you can watch TV together?"
- "Let's play one more round of that game you love- I bet you'll beat me again."

Returning to a normal routine

For children who have disfigurements, returning to a normal routine as soon as possible in hospital 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. "What film do you want to watch?"
- Encourage him to socialise with other children on the ward as well as yourself.
- Give him news from home, e.g. "Your team won the match! 3-0. They all said they would be glad to have you back for the next match."
- Encourage him to keep in touch with friends via texts, phone calls or visits.

4 GOING HOME

When you bring your child home, he may need to rest more and may not be able to walk, eat, or move around as he generally does. To stop him feeling left out, encourage him to engage in normal activities, e.g. playing, watching TV, computer games, having his mates around, doing his school work, as much as he can. Take time to notice the improvements he is making and praise his achievements.

Keep exploring the change to his appearance together by using 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:

5 BACK TO SCHOOL

It will take time for a child who has undergone treatment to settle back into school so it's important to encourage him to progress and reintegrate at a pace that suits him, rather than expecting him to be just the way he was before.

Share information between the hospital staff and the teaching staff to let the school know what your child's specific needs are or how to best support them. Also, ask if the hospital has outreach workers who can offer information and support to your child and the school.

It is vital for all staff members – including administrative, ground and catering staff – to understand about your child's condition – what has changed, stayed the same and what he can do or not do. They also need to know what to say or do when somebody stares, makes a comment or asks a question about your child's appearance so that everyone is saying the same thing.

- "John was in an accident. He was burnt on his arms and legs. His skin looks red and lumpy where he got burnt. He will have to wear something called a pressure garment on his arm to help the scars heal. He would love to play footie but his legs are stiff and

still a bit sore so he will only manage a couple of minutes at a time. John may not want to talk much about this so please don't pester him about it."

- "Peter has had surgery on his hands. He wants to be at school so that he doesn't miss out but he will not be able to write until his hand heals. He will have a support assistant to write for him and help at meal times. He still wants you to join him for lunch though!"

You can also let your child's school or nursery know about *Changing Faces'* work in schools which provides training, information and advice for teachers in early years settings through to 16+ education.

You can also contact *Changing Faces* yourself if you are concerned about how your child is settling back at school after treatment.

6 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 to you 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.

7 HELPFUL RESOURCES

Children's story books

In Hospital by Daphne Butler
 The Twins go to Hospital by Francine Pascal
 At the Hospital (People Who Help Us) by Deborah Chancellor
 Hospital Sticker Activity Book by Cathy Beylon
 Going into Hospital by Anne Civardi.
 I don't want to go to Hospital by Toni Ross
 Miffy in Hospital by Dick Bruna
 Separations – Hospital by Janine Amos
 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

The Hospital Highway Code by Diana Kimpton
People at Work in a Children's Hospital by Deborah Fox.

Letterbox Library offers a selection of books on child health and disability.
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