



Steps

We don't take walking for granted

Preparing for Your Child's Surgery



The Parents' Guide





Introduction

This booklet is aimed at parents of a child with a complex lower limb condition who will be undergoing surgery on their leg, hip, knee or feet.



This publication can't tell you everything you need to know, nor how your child will react - but we do hope it will help you to reassure your child. It's also intended to show that practical help, specialist medical information, emotional support and links to other sources of information are all available, if needed. This will help you be more prepared for the road ahead and have information to hand so that you can ask informed questions about your child's care, treatment and prognosis. Further publications and fact sheets are available: offering support and advice to schools and other care providers; giving support to older children and teenagers; and on the specific treatments and challenges associated with individual conditions.

Support when you need it

Being able to contact someone who knows what you are going through can often be the biggest help when facing an uncertain situation. Our Family Contact service can put you in touch with others who have shared a similar experience.

Our Online Forum and Steps Charity Worldwide Facebook Pages (both public and closed groups) are full of inspirational stories and are a

fantastic resource for those who are coping with a child with complex lower limb conditions. You can also share your problems and solutions to everyday challenges.

No matter how big or small your concern, our helpline team are available to offer an expert ear and support in complete confidence. Telephone [01925 750271](tel:01925750271) or email info@steps-charity.org.uk

Communicating with doctors

It's important to understand exactly what your child's treatment will be and how it will help your child. Preparing in advance a list of questions or topics that you want to discuss at your hospital appointments, will make it more likely that everything is covered.

Don't be afraid to ask questions! Parents often get given a lot of information in a short amount of time during a typical visit. If you are not given a handout with the information written down, ask for one, or take notes and ask questions about things you don't understand. If you don't ask any questions, your doctor will assume that you understand everything!

Another way to ensure you really grasp what's going on during the appointment is to bring a partner or friend along who can serve as another set of ears and make notes. If there are two of you there, you're more likely to get a balanced perspective and you can discuss what you heard afterwards.

Key questions to ask may concern: the consultant's experience with your child's condition; risks associated with the operation; any difficulties following surgery, such as problems

with going to the loo, getting around at school or car travel. Can your child weight bear after the surgery? Will they be able to use crutches or is a wheelchair needed? What equipment does the hospital provide and what will you have to arrange for yourself? What help may be available to access equipment that the hospital doesn't provide? What after care will you need to provide on your return home? Will your child have access to an Occupational Therapist? After surgery, will they return straight to the ward or will they be on the high dependency unit?

If you feel uneasy about the answers and would like to consult with another expert about your child's treatment plan, you may ask for a second (or further) opinion. However, it is advisable to first discuss this with your existing consultant and GP in case they wish to clarify any points not fully understood at previous consultations.

School and other considerations

Other wider questions that will need addressing may be around possible eligibility for child disability living allowance, discussing absences from work with your employer, and addressing any issues around school attendance with the Head Teacher and school SENDCO (Special Educational Needs and Disability Coordinator).

Depending on the personal care required following surgery, it may be possible for your child to attend school normally with basic support. However, your school may lack the resources to help with issues such as toileting. If practical, a grandparent, aunt or uncle could also arrange for some annual leave during the recovery period and make themselves available to help with school attendance. Any such arrangements must be discussed with the school well in advance, as adults attending a school setting will need a DBS check through their local council.

Some absence from school is inevitable and careful planning of school work will minimise disruption to your child's education. Activities with your child's friends at home, such as craft, film and homework days will help to keep your child connected with their peers and education. Discuss your situation with other parents at school and make arrangements for joint activities on your child's return home from hospital.



Talking with your child

It goes without saying that you will be worried about telling your child that they are going to have surgery. It can be tempting to keep your child 'in the dark' about the procedure for as long as possible, to try and protect them.



However, children cope incredibly well, as long as they are not taken by surprise. Your child will respond well to an honest and straightforward explanation of their treatment, with lots of opportunities to ask their own questions and involve themselves in their own care. The more honest you are, the less likely it is that your child's imagination will start inventing outcomes that are scarier than the truth.

Make sure you learn all you can about the condition and the treatment, so you are prepared to answer those difficult questions at bedtime, when there is no one else there to offer an explanation. Try to prepare simple, understandable answers to any questions that may come up. Speaking to your medical team, child psychologist or other parents who

have experienced a similar thing will help you with your answers. Some sample responses are detailed across;

'Sometimes bones don't grow how they should'

'Sometimes we have one leg that is different to the other. This can make it harder to walk and run'

'The doctors at the hospital can help your hip grow to make it easier for you to join in with your friends'

'Your special foot just needs a little extra help to get you up and running'

Preparing your child

As a parent, you know best how your child reacts to different situations and how much information they will be able to handle. Your hospital will have a play specialist and perhaps a psychologist, to help prepare your child in advance and help with distraction strategies while awaiting surgery or having an uncomfortable procedure. For very young children (3-6 years) it is best to prepare them a few days in advance of surgery, explaining that the hospital is a safe place with friendly nurses and lots of toys. It is important to take as much opportunity as you can to talk to your child about their feelings but don't assume that silence means they understand. Encourage them to communicate by drawing and keep a scrap book, where you can write down their questions and keep their drawings, to help them become involved in the process. The scrap

book will be useful to help explain the procedure to school friends on your child's return to class and will record the process for your child to look back at.

It's advisable to prepare older children (over 7 years) about a week in advance. You can prepare your child after the pre-assessment clinic, but go over this again about a week before admission. Allow your child the opportunity to ask questions and express concerns and answer honestly, in language they can understand. Asking open ended questions such as "What are you wondering about your operation?" is a useful way to help your child open up.

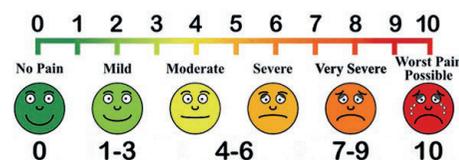


Discussing their concerns

If your child is worried about body image, help them to understand what their leg will look like during and after the treatment and what any equipment/ devices/ casts will be like. There are many blogs and social media sites that show other children's journeys, but pick your resources carefully and never leave your child unattended on the computer. Using a calm and quiet time to draw pictures and read stories about going into hospital can be helpful; choose the amount of detail you give according to your child's reactions.

You could describe certain sensations as "warm" rather than "burning" or "hot". You might say that things might feel "a bit stinging" rather than "sore" or 'painful'.

Never tell your child something will not hurt if it will. It may be useful to practice using a pain chart when your child grazes a knee or accidentally hurts themselves in the weeks before the operation, so they can get used to grading their discomfort. This will help you and your medical team assess their pain relief needs.



Talk to your medical team about coping strategies for painful or unsettling procedures, as they work better if you practice beforehand. These include: deep breathing; thinking about a happy or fun time; singing; counting backwards from 10; hand squeezing; listening to music and distracting with toys or bubbles.

Planning for hospital

Make a plan for going into hospital: decide what favourite treats, toys and books you are going to take and agree what DVD's you can watch together. Reading books with characters who attend hospital or playing 'doctor' with your child, using a doctor's bag and cuddly toys to role play, will make the experience less scary.

If your child is undergoing a planned amputation, playing with adapted dolls or toys can help to prepare them emotionally. Introducing them to different types of prosthetics and allowing them to choose colours or designs will help them feel included in the process. A further publication 'Families Preparing for an Amputation' is available from the Steps website and discusses other aspects of the process.

Your hospital may arrange a visit before your child is admitted. Reassure your child that you'll remain with them during their stay and explain what being in hospital will be like. Tell them whether they'll be sharing a ward with other children or in their own room and explain that they can bring some special things from their bedroom at home. During this visit,



your child will probably get a chance to meet some of the nurses, physios and other members of staff who will be involved in their care and rehabilitation. Encourage them to bring their scrapbook with them and ask any prepared questions they may have been thinking about.

It may be useful to prepare a 'surprise bag' or rucksack of small toys, games, activity books and messages/ drawings from friends and family to take along to hospital. Short film clips from teachers and peers sending 'good luck' and 'get well soon' messages may be a nice distraction from nerves or hunger during fasting while waiting for long periods on the ward.



Going into hospital

Going into hospital for surgery with your child can be one of the most stressful experiences you go through as a parent. Hospitals vary on the level of facilities they provide for parents with children so it's worth checking beforehand what you need to bring and what is allowed. Most hospitals will have a parents' room with a fridge, kettle, toaster and microwave and some comfortable seating. Make sure any food you bring in is in labelled containers with the date as hospital staff will discard any unlabelled and undated food.

We have compiled a Going into Hospital checklist, which lists some items you and your child might want to bring into hospital to make your stay more comfortable.

You and your child are likely to attend a pre-admission clinic a few weeks before their proposed operation date. This is an opportunity to discuss the treatment with the consultant, the physiotherapist and possibly a child psychologist; you'll discuss all aspects of the treatment and any risks and complications. You should also hear about practical matters,

such as how to get a wheelchair, arranging physiotherapy close to your home, supplies of any dressings or other essentials, and planning a return to school.

Talk to the team treating your child about anything you think is important. Inform staff of any special words your child uses – how they ask go to the toilet – and any special things that calm them down if they are upset. You may also wish to discuss any specific religious needs your child may have.

The operation

Usually, admission to hospital occurs the day of surgery and may allow for detailed x rays to help plan the operation. This is another opportunity to discuss any worries you may have and the return home. You may also have a chance to practice things such as toileting and walking on crutches, if required.

You will meet your surgical team to sign the consent form and to discuss the operation, the anaesthetic procedure and any other underlying health conditions that may have a bearing on the procedure or aftercare. You'll have been asked to bring any current medication with you. If your child is ill or has a temperature, it's important to tell your medical team.



Going to theatre

Having an anaesthetic is often the biggest concern for both you and your child and is a difficult concept to explain. You may like to describe it as a 'magic sleep' that is so deep they will not see, hear, feel or remember anything. Depending on their age, explain the process as starting with the magic cream that will make their hand all numb, ready for the dream injection or there could be a face mask of sleepy gas to help. Practicing this process with a teddy as part of your role play will stop it being scary

and alien. Reassure them that you will stay with them, that they will not be aware of the surgery taking place and that you will be there as soon as they wake up.

The anaesthetist will see your child before the process to assess them and plan for the operation. You and your child will be able to ask any questions you may have and your child may be given a mild sedative to help calm them if they are very anxious.

It's perfectly normal to feel anxious about your child going to theatre and having an anaesthetic. It is also normal to have a good cry, but try not to do this in front of your child if you can. Anaesthesia is a very safe procedure - but do talk to the doctors and nurses on the ward about any specific concerns you have. Most hospitals allow parents in the anaesthetic room so that you can reassure your child whilst they are going to sleep. The nurses on the ward will tell you what to expect and explain how long your child will need to go without food.

Fasting is a critical part of preparation for surgery. It may seem mean, especially if your child is

thirsty, but avoid giving food and fluid, no matter how persistent or upset your child gets. Anaesthesia causes the body's muscles to relax and any food or drink in the stomach can leak out. This can affect the breathing and may even lead to long term lung problems. Avoid eating or drinking in front of your child while they are fasting. If your child is 'Nil by Mouth' during ward mealtimes, remove them to a play area and distract them with toys and books. Now may be a good time to produce something exciting from the 'Surprise Backpack'. A clean damp flannel may be used to moisten your child's lips, but ensure it is well wrung out to avoid any fluid entering the stomach.

What are the risks of surgery?

Your surgical team will all have a great deal of experience performing similar operations and the chances of anything going wrong are very small. All surgery and anaesthesia involves some risk, such as bleeding

or infection, but your medical team are trained to deal with complications swiftly and competently. Other risks include nerve damage causing weakness/ numbness, but this is extremely rare and usually temporary.

Returning from theatre

Waiting for your child to come back from theatre can feel like for ever. You will be told when your child is ready to return to the ward. In some hospitals, you may be allowed into the recovery room to be with your child when they wake up. Remember, they'll still be heavily sedated from the anaesthetic, so won't remember much. On waking, your child may feel

- or be - sick, due to the effects of the anaesthetic: although unpleasant, this should be short lived. Try to be calm and reassuring. The sound of your voice will help them to settle; softly singing a favourite song may help to soothe them. When your child is more awake, he or she will be moved back to the ward.

Most patients recover very quickly. They will only be allowed to sip small amounts of water to begin with, but as soon as they are fully awake they will be able to eat normally.

Post anaesthetic delirium or Emergence delirium (ED) is a relatively uncommon short lived state of increased distress and disassociation following anaesthetic. It is much more likely to occur in children between two and five years old, but can happen at any age. It can be very upsetting to watch and the child may seem completely disassociated or 'out of it'; thrash about, scream and cry and is unlikely to respond to usual consoling

methods. While distressing for parents, a child will usually fall asleep again following the event and will re-awake, unaware of the incident having taken place.

It is likely that your child will be using a catheter for at least 24 hours following surgery, if not slightly longer.



Pain relief

Good pain management is one of the most important things you can do for your child following surgery. Ask for a copy of your child's pain relief schedule and help hospital staff to ensure that relief is administered in line with it. This is especially important at night when your child needs to be given medication and the temptation is to let them sleep: it may mean nursing staff rousing your child gently in order to administer it. It is much easier to manage pain proactively, rather than trying to administer relief when they are already distressed and have started to hurt.

When you are discharged from hospital you may be given a prescription or some pain relief medication to take home with you. These are given just in case your child may experience any pain or discomfort whilst at home. Please follow the instructions on the labels for how much to give, and how often. If you find your child is in pain and the medication is not working sufficiently, then please contact your GP or hospital for advice. It may help to make a chart, so that your child can share responsibility for administering any medications.

Going home

Many hospitals will arrange transport home for your child if using their usual car seat is impractical. Any specific needs for transporting your child should be addressed before you go home and this is one of the topics that will be discussed with your hospital team.

Your child may have visits from the community physiotherapist or community nurse if needed: there may also be regular clinic appointments. Please remember that you can call the treating ward, on the number they will provide to in your discharge booklet, if you have any questions or worries. The hospital will also organise for your child's GP to supply you with any necessary additional equipment.



Beyond this booklet - support when you need it

Our Family Contact support service can put you in touch with others with shared experience. All our Family Contacts are interviewed and given training before they engage with a family. However, there are many online condition specific support groups for parents, providing a forum for sharing ideas and consulting other parents on day to day questions. Although none of the external groups are linked to Steps, we understand the need for parents to communicate with each other on a larger condition specific platform.

[Steps Charity Worldwide \(Steps Charity's own open Facebook group, sharing stories and news on lower limb conditions\)](#)

[Steps Charity Worldwide \(Closed Facebook Group - Steps Charity's own, managed FB Page acting as a forum for those affected by lower limb conditions to communicate in confidence\)](#)

Please note, external websites are not associated with Steps and Steps are not responsible for their content

Other Sources of help

There are many websites that offer guidance on everything, from benefits applications to equipment funds and advice from specialist nurses. Below are some of these sites:

<http://www.nhs.uk/conditions/pregnancy-and-baby/pages/going-to-hospital.aspx> is a useful NHS guide about attending hospital with a child, including a video

<http://www.bbc.co.uk/cbeebies/grownups/helping-your-child-prepare-for-an-operation> is a useful CEBEEBIES site about going to hospital and a 'Get well soon' app with songs about different procedures.

www.newlifecharity.co.uk is offering equipment grants and access to specialist nurses

www.cafamily.org.uk is advice on benefit applications and all aspects of caring for a disabled child

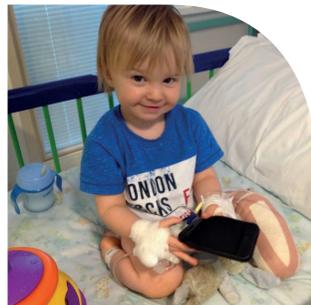
www.citizensadvice.org.uk is advice on benefit application and other topics such as discrimination and taking time off work to care for your child

www.gov.uk/government/publications/equality-act-2010-advice-for-schools is a guide for schools to avoid disability discrimination and help children back into school setting

Paddington Bear goes to the hospital – published by Harper Collins

Going to the Hospital: Miniature Edition (Usborne First Experiences)

The following website provides information about the role of play in medical settings www.nahps.org.uk.



Questions for your consultant

How long does surgery last?

What anaesthetic is needed?

Will there be a cast/brace/bandage?

Is there pain after and how is it managed?

Going into hospital checklist

Things to take into hospital

Hospitals vary on what facilities they provide for parents and children so it is worth checking beforehand what you need to bring and what is allowed. We have listed below some items for you and your child to take into hospital to help make your stay more comfortable.

FOR YOU

- Books, ipods, magazines – something to keep you occupied
- Comfortable clothes and shoes and don't forget your PJs and slippers!
- Ask about Sleeping bag, duvet and pillows as they may not be provided
- Toiletries, towels, tissues, wet wipes
- Food and snacks (inc tea, coffee and dried milk) – just in case there is no access to a fridge
- Insulated cup with lid – hot drinks without lids are not usually allowed on the wards
- Plate/bowl and cutlery
- Eye masks and earplugs as the ward can be noisy and bright even at night

- Plenty of change for payphone/ car parking/TV tokens
- Mobile phone and charger
- Any medication you may need yourself

FOR YOUR CHILD

- 'Surprise bag'
- Any medication your child takes
- Any relevant hospital letters
- Favourite toys, comforter and books (incl quiet toys to entertain your child at night)
- Clean flannel (for dampening dry lips when nil by mouth)
- Toiletries
- Colouring books, paper, washable pens, pencils, crayons

- Blankets and pillows or pillow case to make your child more comfortable (check with the ward if some of your child's own bedding is acceptable)
- Food and snacks - anything which does not require refrigeration eg. Raisins, jars, rice crackers (but keep well hidden while your child is fasting)
- Baby wipes, cotton wool and toiletries
- Clothes, socks and nightwear (in baggier sizes to fit over any casts/ equipment)
- Tena Pads to use inside a cast (if required)



Notes

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steps-charity.org.uk

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We don't take
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granted...

