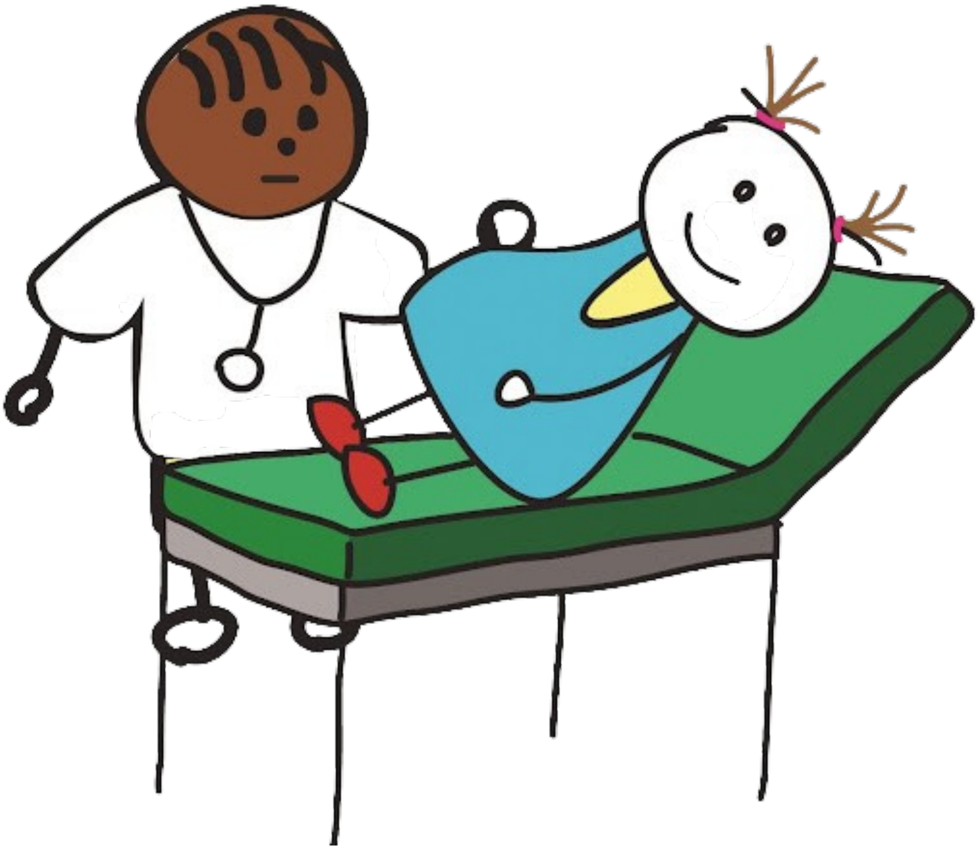
Steps
We don't take walking for granted

Preparing for your child's surgery

Helpful Information from Steps Charity



How This Booklet Might Help

This booklet is designed for parents or caregivers, and there are sections at the end written in a child-friendly tone which you can read together as a family and help you start the conversation with your child. Please note that this is written in the UK and focuses on the system and process in the UK, other countries may have their own specific processes.

Being a parent or caregiver during this time can be tough. There are lots of decisions to make and new information to take in.

Think of this booklet as a guide to prepare for the journey ahead. It won't have all the answers because everyone is different, but importantly, it is here to make sure you are not alone.

If your child is going for surgery related to their legs, hips, knees, or feet, this booklet is for you. It's recommended that the adults read it through first and then you can choose what you want to share with your child, and how you want to share it

There is support, contact and information to help prepare you and your child for their surgery.

What will you find in this booklet?

Contents

Children's section

Remember, there's a whole community here at Steps to help you and your family on this journey!

Reaching Out: Your Steps Family

Sometimes when things are stressful, it helps to talk to someone who understands. At Steps, we have lots of ways to help the whole family. We have a **Family Contact Service**, which means we can connect parents (or adult caregivers) with other families who have been through something similar. They can share advice, be supportive, and give helpful tips.

We also have a supportive group on Facebook where you can discuss your questions and concerns with other parents. It's a safe and friendly place to share your feelings and get support and advice.

If you feel unsure or have questions, adults can call our Steps helpline. You can reach our amazing team at **01925 750271** or via email at **info@steps-charity.org.uk**. Calls are confidential ensuring your worries are addressed privately.

No matter how big or small your concerns are, don't hesitate to contact us, or start by following us on social media. Steps is here to help you!

Top Tip:
Talk to other parents of children with lower limb conditions. Hearing about their experiences can boost your confidence about the future, and you may discover helpful insights.

The Basics: What is Surgery?

Surgery is a word which can be used to describe many procedures, both big and small, there are many different types of surgery, including operations. Operations are specific surgical procedures where a skilled surgeon will make careful cuts into the body to fix or remove something which is causing a health issue. Doctors suggest surgery when it is the best available option.

Have you got all the information? – Talking to your doctors

Finding out that your child needs an operation is often a very emotional and stressful time. It is normal to feel overwhelmed at this moment. Take the time you need and talk to friends, family, specialists, or any support services you need to help you ask informed questions to fully understand the operation and processes around it.

The more you know and understand, it can make it easier to mentally and physically prepare for the operation, and will help you communicate with your child. It's important to understand exactly what your child's treatment will be and how it will help them. During a typical visit, the doctor gives you a lot of information all at once, and it can be a bit overwhelming.

To make the most of it, don't be shy about asking questions!

- Make a list of questions or things you want to talk about with the doctor. This way, you won't forget anything.
- Think about bringing a partner or friend along, they can listen and take notes too. After the appointment, you can talk about what you heard and make sure you both understood the options and discussions in the same way. You may have each focused on or picked up on different things.
- If you don't get a handout with written information, ask if they have one.
- If you don't understand something, ask them to explain again.
- If you didn't get to ask all the questions you have, ask for another appointment!

It is part of the doctor's role in your child's care to answer your questions and they don't expect you to know everything, but if you don't ask questions, they will think that you understood.

Important things you might want to ask about:

- What previous experience the doctor has with your child's condition.
- If there are any risks associated with the treatment.
- If there is anything to be aware of after surgery (e.g. difficulties going to the toilet, needing rest, or not going to school).
- If your child will go straight back to the ward after surgery or if they'll be in a special unit.
- If your child will be able to walk straight after the operation, will they be on crutches. If not, then they may be using a chair, for how long?
- If your child will have an anaesthetic and if you will get to talk to the anaesthetist before the operation.
- If there will be a pre-operation hospital visit for you and your child to meet the team and understand what is going to happen on the day of the operation.
- How long your child will be in hospital.
- How will you and your child get home at discharge?
- What care your child will need at home after returning from the hospital.
- What the hospital provides and what you need to organise yourself.
- What help is available for getting equipment that the hospital doesn't provide.
- Will your child have access to an occupational therapist, physiotherapist, and/or psychologist.
- What will the long term impact be into adulthood?

If the answers make you feel unsure or worried, it's okay to ask more questions.

It's also okay to talk to another specialist expert for a second opinion, but before doing this it's worth talking to your current doctor or specialist to see if they can explain things better or clear up any confusion from previous visits.

Cast, prosthetics and walking aids

If your child is going to have a planned amputation or will be wearing a cast or frame after the operation, then ask to see some examples and how they work. This will help you explain to your child but also support you in knowing what to expect.

Again, this is an opportunity to ask any questions, including practical questions about getting around, toileting and sleeping.

- Will your child need adapted clothing and/or a special seat or car seat?
- Will the change affect your child's sleep, hygiene, or toileting?
- Will my child get to see a cast/ leg/ walking aid before the operation?
- How will they learn to use the cast/ leg/ walking aid?
- How long will the cast/ leg/ walking aid last?
- Should I bring nappies to the hospital, or will my child need absorbent pads?
- Can my child personalise the colour or pattern of their cast/ leg/ walking aid, and how?

The doctor may direct you to a different specialist to answer these questions if needed.

Some hospitals have adapted dolls or teddies so they can better demonstrate and explain to children what it will be like. You may be able to find similar toys, or people who are able to make and personalise toys for you to play with at home

Getting Ready

The next section of this booklet looks at the steps you will go through from before attending hospital to after you have returned home from hospital. This aims to support you in understanding the process, so you can identify items that need to be organised before the hospital visit, and to prepare you for talking to your child.

Pre-operation hospital visit

It might be standard, or you might be able to request that the hospital arrange a day visit before your child is admitted for the operation. This may include a few checks and tests or may just be an opportunity for the child to experience the hospital. You will usually get to meet the team that will be looking after them during their stay (nurse, physiotherapist, play specialist etc.)

Your child might have their own questions and can bring along a scrapbook with these questions written down. They can take down the names, jobs, and the role in their care of everyone in the team if they like. They can even draw a nice picture of each member of the care team while you're asking questions.

Here are some questions you can ask the doctors together

- Will I be in a private room, or in a room with other children?
- Can I bring my favourite toy? (the answer will almost always be yes)
- How long will I be staying in hospital?
- Will mummy/ daddy/ carer stay with me? (again, the answer should be yes)
- What food can I eat after my operation?

After the operation

They should also let you know in the pre-operation visit what will happen after the surgery, what you will need, and how to arrange this. This may include things like; how to get a wheelchair, how to arrange regular physiotherapy near home, follow-ups, and planning to return to school.

There are also some questions you might want to ask for yourself and your child before the operation and hospital stay.

- Ask if there are restrictions on the type of bedding you can bring to make your child feel comfortable.
- Ask where you can stay while overnight with your child and what bedding you should bring.
- Ask if there is a parent's lounge and what facilities it has or if there are restrictions on when it can be used.

Risks

For you as the parent or caregiver this can be a stressful experience, as the doctor will likely discuss the potential risks and complications of the surgery at this visit. This information is important, the doctors are required to tell you of the risks and cannot strongly encourage surgery, it must be your decision. However, if your doctor or surgeon felt the risks were high, they would recommend against the surgery.

If anything is overwhelming, ask for it to be written down so you can look at it later and ask additional questions

It is worth also remembering that your surgical team will all have a great deal of experience performing this or similar operations. There are lots of procedures and protocols in place, and a big team with specific roles, all designed to make the risks as small as possible.

Even if a complication does occur during surgery, the team are trained to deal with these complications swiftly. Bear in mind that they may not be able to come and inform you immediately of progress, and not all delays are signs of complications.

We have chosen not to include a list of possible complications in this booklet as they are often specific to the operation your child is undergoing and the doctors will ensure you are aware of anything relevant to your specific situation.

Packing for the Hospital

There are so many things to think about in packing and preparing for the hospital stay, we have included a checklist for you in this booklet. It's wise to have everything you can, already packed and ready to go in advance so that you can throw in their favourite toys and get going on the day of the operation.

- Think Bedding

Hospitals can vary greatly in their facilities, so ask some important questions about where you will be staying and what visiting hours are for others. You might find that they offer a sleeping chair or bed but you are expected to bring your own bedding or sleeping bag. Also, think realistically about what you need to try and get the best sleep possible. Do you have a favourite pillow? Would a sleep mask help? Wards are often bright and noisy, it is advisable to pack earplugs even if you don't think you will be comfortable wearing them.

- Think comfortable clothes

You are going to need clothes you can sleep in as well as clothes that you can move around in. Always think about comfortable, easy to wear shoes, it's sensible to make sure they aren't slippy on the floor.

- Think occupying your mind.

There will be times when your child is asleep or in theatre and you may be sat worrying. Pack some things to keep you busy in these quiet moments; books, magazines, a tablet with your favourite show, and some headphones.

- Think Hygiene

Don't forget your toiletries like toothpaste and brush, deodorant, hairbrush. These little things can make you feel better. Take some tissues, and wet wipes. It's also a nice idea to include some face wipes or a flannel and a clean towel so that even if you don't get a full wash, you can feel refreshed.

- Think drinks, food and snacks

Hospital wards often don't allow mugs without lids so get yourself an insulated cup to keep your drinks hot. If you like to add milk then it's a good idea to bring some UHT or dried, as it's not always available. Some wards will only have a kettle so you might also need to bring your favourite tea bag or coffee granules with you. Take some snacks for yourself and food that you can make in the parent's room (most hospitals will only bring food for the patient). Don't forget a plate or bowl and some cutlery to eat from. If there is a fridge, make sure you bring clearly labelled containers with your name and the date on it, so your food won't get mixed up or thrown away. Some hospitals have a strict policy to throw away undated food.

- Think cash

If there is a vending machine, especially if it's the only way to get hot drinks, you might be grateful that you have some change. While many machines now take cards, hospital machines don't always.

- Think mobile

Don't forget the charger for your phone.

- Think health

Don't forget any medication that you might need over the stay.

Packing for the Hospital – Checklist

An itemised checklist to help you prepare for your child's hospital visit

☐ **Medications**

Bring your child's current prescriptions and medication.

☐ **Letters**

Any relevant hospital letters

☐ **Toiletries**

Including toothbrush and toothpaste. Any other care products they need to clean with and daily things like baby wipes and nappies. If they are having a cast, it can be beneficial to bring some highly absorbent pads (such as Tena), you can ask your doctor about this.

☐ **Toys and activities**

Favourite toys and gadgets to play with, colouring books and washable pens, bedtime story books. Don't forget a few 'quiet toys' for nighttime and a few 'pocket-sized toys' that can be taken with you when you both need to leave the ward, like waiting to go into surgery.

☐ **Flannel**

Bring a couple of clean flannels, these can be dipped in clean water and used to dampen sore lips when the child is fasting / 'nil by mouth' (see the section on Fasting below).

☐ Snacks

Bring some of their favourites that do not need refrigeration and that you can keep hidden while they are fasting. You may also want to pack a microwavable meal for shortly after their operation or if you know they are fussy eaters and won't enjoy hospital meals.

☐ Bedding and comforters

If you want to bring specific pillows and blankets for your child It is worth checking with the ward if it is suitable, but if your child struggles to sleep without a specific comforter or toy, then it is worth bringing it and highlighting this to ward staff.

☐ Clothes

Comfortable socks and sleepwear, in a baggy size so it can fit over casts. If your child is getting a hip spica cast, special adjusted clothing can be purchased. Visit the Steps website for more advice on this.

☐ Surprises

It's also a nice idea to prepare a few 'surprises' they didn't know you were bringing, for moments when you feel they need an extra bit of distraction with things such as activity books, surprise toys, drawings or messages from friends and families, video clips of nursery staff saying, "good luck" or anything else you think might cheer them up.

☐ And your bag!

Including your phone charger.

It's easy to forget about yourself in all the planning and prepping. Think of it like putting your oxygen mask on first, the better prepared and comfortable you are the more support you can give to your child

Going into Hospital

Usually, your child will be admitted into hospital on the same day that surgery is scheduled to occur. To be 'admitted' to the hospital just means that a bed is assigned to you and often involves lots of forms being completed. As a parent or caregiver, you will be asked to complete a consent form.

You will likely meet the surgical team and be walked through what will happen and what to expect. You must be honest with the doctor about how your child has been over the last few days and if they have been unwell.

The doctors may have scheduled some final pre-operation tests or detailed X-rays to help inform the surgery and if this is the case, they will explain these tests to you.

Did You Know?

Doing your own research can help you prepare better for how your hospital operates, and what options are suitable for your child's condition and age.

You might want to know more about: baby X-rays, X-rays while menstruating, orthopaedic hospitals.

Fasting

Fasting, or nil by mouth, is a critical part of the operation preparations, and you must ensure that your child does not drink or eat ANYTHING! That includes any food, even snacks, and any drinks, even water.
This will often be the 24 hours before the operation, but ask your doctor how long your child will have to fast.

This can be a challenging part for parents so it is important everyone understands why this is so critical:

The anaesthetic will cause all the muscles in the body to relax, which means that any liquid or solids in the stomach can leak out and up towards the lungs. This can have an immediate impact on the child's breathing during the operation but can also lead to long-term lung issues.
Having an empty stomach means this will not happen.

To help your child out, do not eat or drink around them and encourage others to do the same. Find out when the mealtimes are on the ward and find a toy area, or separate space you can take them to during this time.

A clean and damp flannel can be used to moisten the lips, but it must be well rung out and the child should not suck on the flannel as this will let fluid enter the stomach.

This can be a great time for maximum distraction techniques, pull some exciting toys or videos out of your surprise bag.

Anaesthesia

Anaesthetics are used to put patients to sleep and ensure they do not feel pain during the operation. Pain is felt in the body when a nerve sends messages to your brain. Think of stubbing your toe, the nerves will send a message to your brain telling you where the pain is and what it feels like. The anaesthetic works to stop this signal, and so the pain is not felt. It also causes muscles of the body to relax, so that the surgeon has better access to the area they are working on.

Many parents explain the effect of the anaesthetic to their children using terms like 'magic sleep', so deep they will not remember anything. It allows the doctors to do the surgery without them waking up or feeling anything. You will usually be allowed to stay with your child until they are asleep, but it's worth asking the surgery team to be sure.

The anaesthetist will see your child before the operation, to assess them and plan for the operation. The anaesthetist is a specialist whose whole job is to monitor and administer the correct dose of anaesthetic, specific to the needs of each individual patient. So, they are very skilled at their job.

There are two main ways that an anaesthetic will be administered (given) to children.

- Masks

  A mask is placed over the nose and mouth and the child is asked to breathe in and out and count to ten in their head. Before they get to ten, they will be asleep.

- Injection

  A numbing cream will usually be used on their hand. Once the hand is numb, a cannula (a tube 'line in') is inserted which will administer the anaesthetic. They should not feel any pain due to the numbing cream.

Anaesthesia is very well researched and safe but do take the opportunity to ask any questions or voice any worries that you have, either with your child present or separately. If you miss the opportunity with the anaesthetist, then ask your nurses what to expect.

You might ask:

- Can I be in the room when they have the anaesthetic?
- Which type of anaesthetic will they get?
- How long do they have to fast for before the operation?
- Can I come into the recovery room as soon as the operation is over?

If your child is very anxious the anaesthetist may prescribe a mild sedative before the operation to help calm them.

When your child goes into the operating theatre

This is the moment that can be the most challenging for a parent, you will be waiting in the ward or another room while the operation takes place. This can feel like a very long wait with little updates until the operation is completed.

Everyone is different in how they cope with the emotions and stress of a child going into surgery, but it is important that you have taken time to acknowledge your emotions and identify the coping strategies that work best for you and your family. It's perfectly normal to feel anxious, it's normal to feel panicked, and it's normal to cry. But it is important to think about how you share your burden with others to lighten the load, as well as what your child sees.

In preparation for this, the Steps community or professional counselling might help. But you can also talk to your medical team about coping strategies for both you and for your child. If you can, find time to practise these strategies before the operation day, both by yourself and with your child. This will make it easier to use them when you feel overwhelmed.

Top Tip:
It is highly likely that if your child sees you are very fearful of the operation, that they too will be fearful. To address this, it is worth considering what points you are most fearful of, and if you need more information to clarify the risks. Also find a coping strategy that you can use when things get overwhelming.

Some recommended strategies include:

- Deep breathing, controlled deep breaths in and out, counting to 2 and then 4, trying to slow the breathing.
- Visualisation (thinking) about a happy place or fun time (this can include using audio or visual recordings).
- Singing, making music or listening to music (you may need headphones in hospital).
- Instant distractions for adults. This might be your favourite soap opera or podcast, for children this might be bubbles or playing "I-Spy".

Returning from Theatre

Once the operation is complete, depending on hospital policy, you may be allowed in the recovery room with your child, to be with them when they wake up.

Waking up

Remember they will be heavily sedated, so might be grumpy or sleepy and won't remember much or might not feel that any time has passed. They may feel sick, or be sick, this is due to the anaesthetic and should pass quite quickly.

The more reassuring and calm you can be at this point, the better for your child to help them during this confusing period of waking up groggy. Your familiar voice, with familiar words like a story you read often, or a song you sing together can help to soothe them.

Once they are more awake, they will usually be moved back to the ward.

Did You Know?

Post-anaesthetic Delirium or Emergence Delirium (ED) is a relatively uncommon and 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 reawaken, unaware of the incident having taken place. If you are worried about this please talk to your clinical team.

Catheter

A catheter is a small tube inserted into the body to empty the bladder and the urine is captured in a bag. Due to the anaesthetic impact on the muscles, it is likely that your child will be using a catheter for at least 24 hours following surgery, if not longer. The nurses should help you empty the bag and when removal is appropriate, they will do this.

Breaking the Fast

At first, your child will be allowed small sips of water, but once they are fully awake they will be able to eat normally. Hospital meal times can be strict, and it is sensible to have packed something for them to eat after the operation (remember they will have fasted before the operation, and this will be their first food for some time).

Pain Relief

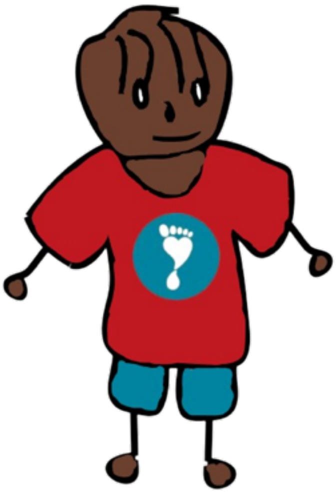
While in hospital the ward staff will manage their medicine and pain relief, but you can ask for a copy of the pain relief schedule and help the staff ensure that relief is administered in line with it.

There is likely to be medication scheduled overnight, and this might involve waking your child. It is important to help nurses with this, as pain is easier to treat before it gets too much. This is preferable to the child waking up in pain and having to wait for medication to be available for administration.

Going home

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 experiences any pain or discomfort whilst at home. Please follow the instructions on the labels for how much to give, and how often.

Be realistic about your child feeling pain. An operation has changed something in the body and the surgery site needs to heal. They may feel stiff from not moving in bed, may catch a limb and pull a tender spot, or the pain relief may start to wear off. It may also be very emotional for them to find they are moving differently. Talk with the medical team about what is likely to cause pain, recommended strategies to cope with this pain, or distraction techniques suitable for your child's age, and practise them at home. Consider new hobbies that they can try when they get home, things they have not tried before and where they can invite friends to take part as this may help them cope with changes.



However, if you find your child is in pain and the medication is not working sufficiently, or as discussed with the doctor, 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 if they are able to do so.

Transport

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.

Once Home

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 that they will provide in your discharge booklet, if you have any questions or worries. The hospital will also usually organise for your child's GP to supply you with any necessary additional equipment.

Back to Daily Life

After the emotions of the hospital, feelings can rise to the surface as you get home and find things have changed. If you can prepare in advance for the week or so after you come back from hospital, it can reduce your mental workload when you come home. For example, having frozen or pre prepared meals ready, having agreed who can visit and when, having suitable clothes and equipment in place for your child.

School

Your child will need time to recover, and some time off school is expected. How long your child needs before returning to school will be guided by the doctor, they will be able to estimate how much recovery time your child will need and what additional needs they may have on returning to school. You can then discuss this with the head teacher and the SENDCO (Special Educational Needs and Disability Coordinator) and agree on a return-to-school plan.

This may be adapted as needed once your child is out of the hospital. It may be possible for your child to attend school normally with basic support. However, your school may lack the resources needed for issues such as toileting.

Discuss the options with your school. It may be suitable for a member of the family to attend school and help with issues while the child recovers. This has to be agreed clearly with the school as any adult entering a school setting will need a local council DBS (Disclosure and Barring Service) check. This can take a week or two so should be organised in advance.

Also discuss with the school whether an 'at home' work plan is suitable to minimise any negative impact on your child's education.

For playtime games and physical education lessons, they may need a gradual return, discuss with their teachers and doctors, encourage alternatives that mean your child is still included in activities with their peer group.

Socialising and activities

There are lots of activities that your child can do at home with the family. They can also invite their friends to visit and have an arts and craft afternoon, a movie evening, or a homework group dinner. This will help keep your child connected with their peer-group and will help encourage ongoing participation in education. Some of these 'play dates' can be arranged in advance.

Also, consider your own need to socialise and for time out, other parents can be very supportive, helping with school runs for siblings, or adult conversation over a cup of tea or coffee while the children play or are at school.

Time Off Work

If you are in full-time work, you will need time off to attend hospital and to stay at home with your child before they return to school, nursery or activities.

If you or another member of the family is going to support your child at school, they will also need to arrange time off for this.

Talk to your work and arrange the time off that you need, and how to manage this if additional time off is needed. It may be tempting to agree to do some work from home but be aware of the mental and emotional load that you are under, especially in the first few days back home.

Eligibility for Allowances

This may not be a priority, but the additional needs of your child, especially if long-term, will carry additional costs. The Steps community may have advice on this, or you can contact the Citizen's Advice Bureau for more support on benefits.

Talking with your child

Now you've read this booklet and hopefully asked all the questions you need to ask, are you ready to talk with your child?

The words surgery and operation can feel like very scary things to talk to children about, so It is normal for adults to worry about how they will communicate this. It's not uncommon for parents and caregivers to think about keeping everything secret, hoping this will protect their child. But Steps has seen that kids are braver and more resilient than adults realise, and making the surgery a surprise can often cause more distress as they are not given the chance to ask questions.

Taking the time to explain the operation gives your child time to understand the surgery and ask any questions they might have. The more honest and clear you can be, the less the child's imagination will fill in the blanks with a scary scenario.

Top Tip:
Consider getting a scrap book for your child. It may help them express their emotions. They can draw in this and document their journey

It helps if you are as prepared as possible, so that your fear doesn't make your child scared. As a parent or caregiver, learning all you can about your child's condition, from clinicians and the Steps network, can help you prepare for difficult questions. You can also find advice from other families on the tricky questions they were asked.

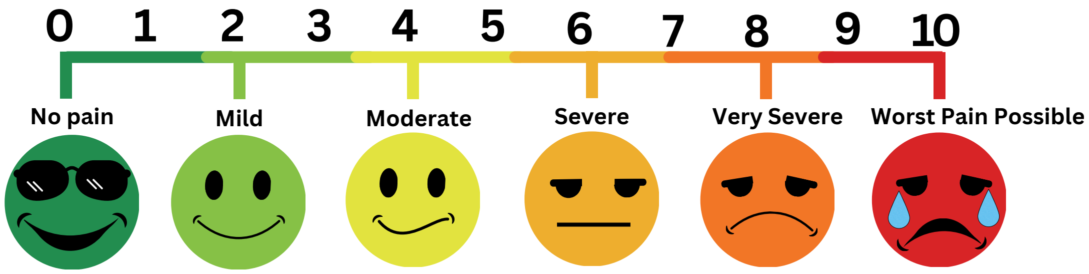
Children thrive on practical information, so having talked with the consultant about what the day of the operation will look like will mean you can explain it clearly to your child. There will usually be some specialists working with you on the day of the operation, like a play specialist and, sometimes, a psychologist. These people are there to help you make your child comfortable and distract them with toys and games.

Choose Your Words

The words you choose can also help. You know your child best and know what they may and may not understand. There is nothing wrong with practising what you are going to say in advance, to ensure you feel confident about how you will present it to your child in a way they can udnerstand.

When it comes to discussing painful parts of the process, or elements you think will cause them to worry, consider the following:

- How much detail you want to give (you may want to adjust this depending on your child's reaction to initial information.)
- Choosing language that is gentle and 'neutral' but suitable for your child's level of understanding and maturity; For example, "the surgeon will make an opening" rather than "the surgeon will cut", or "It will sting" rather than "it will be painful".
- Avoid lying, it is very tempting to comfort a child by saying that there will be no pain, this may stop them from worrying but will mean the pain comes as a bigger shock.
- Try using the visual pain chart (below) to help your child understand their pain. In the weeks leading up to the operation, when they bump their head or graze a knee, they can use the image to tell you how painful they find it. This will help them communicate clearly to you and the hospital team when they are in pain and help inform the pain relief needed.



Here are examples which Steps has found useful before:

- "Sometimes we have one leg that is different from the other and that can make it harder to walk. In your leg the big bone has grown differently on the left side.
- It needs some help from the doctors to make it better, so it doesn't hurt when you walk. The doctors at the hospital need to go inside your leg and put some metal rods in which will help it grow nice and straight.
- You will have to wear a special frame for a little while, but by the summer holidays you will be able to take it off and see your new strong leg."

Maturity Matters

Of course, how mature your child is can affect their understanding and concept of time. Toddlers often will not need more than a few days' notice, so they can understand it is happening the day after tomorrow. Then repeat this the day before and the day of surgery. It's best to explain that the hospital is a safe place with friendly nurses and lots of toys. But also think about what your child is used to and the stimulus they often react to and prepare them for the new experiences in hospital, such as bright lights, lots of people etc.

For slightly older / more mature children who are used to asking questions and like role-play games, giving them information at least a week before the surgery date gives them time not only to ask questions, but also to explore the option of 'roleplaying' the hospital visit.

For children with a maturity over about 7 years old they are likely to need more time to talk to you and process the information about the surgery. They may have more complex questions than a younger child and it is recommended that they are kept updated about the surgery dates and decisions.

Things to think about: children have active and curious minds, and bedtime is often a time when all the questions come up, it will be just you and them and the perfect time to put their fears to rest.

Roleplaying and demonstration

Many children learn through doing, demonstration and play.

- Find some shows (DVD / streaming / download) that show a character going to a hospital.
- Find a book with characters who attend hospital to read together.
- Play 'hospitals' with your child, taking turns to be different characters. You can use teddy as a patient and show your child how they will be looked after. If they are going to have a gas anaesthetic, you can use a funnel and tube to demonstrate on teddy how the anaesthetic works.
- If your child is going to have a walking device, prosthetic limb, or cast consider finding a doll, teddy or book character that uses this device. This can help a child understand what they will look like after the operation, how this might affect their movement, and will normalise it for them.

We have listed some of our favourite shows and books about having an operation in the links at the end of this booklet, but please check their suitability for your child's age and understanding before viewing with them as some are more appropriate than others

Listen to Their Responses

Not all children will know how to react to the news of their surgery, and many will take a little time to consider what their thoughts and fears are about an operation.

If your child is worried about body image, help them to understand what their body/ 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.

If your child is less able to express themselves verbally, allow calm and quiet drawing sessions, ask them to draw themselves in hospital, then ask if they can talk through the picture. This can help you to spot things they are unsure or fearful of which they may not otherwise discuss.

If they have been present in the clinical session where you were given the information, then they might have lots of questions that you can't answer yet. You can agree to write them all down for the next visit.

The rest of this booklet is written in a friendly style, aimed at children, to help you explain the process to your child, or so you can read sections which are suitable and relevant together.

So, you're going to visit the hospital. – children's section

So, by now you probably know that you are going to visit a hospital. This might be your first time or your one-thousandth time, but this time the doctors are going to make an opening to look under your skin where you have been having pain or problems.

They might mention it after a special clinic visit but will go over everything again a week before you go to the hospital. Your parents will ask if you have any questions or things you want to talk about. They'll be honest and use words you can understand. They might ask, "What are you wondering about your operation?" That's a fancy way of saying, "What's on your mind?"

If you've never been to a hospital, it is a big building filled with lots of people, and lots of doctors and nurses. You, and whoever is going with you, should go to a special part of it that has toys in it and a friendly person called a surgeon, this is the doctor who will work on fixing part of your body.

The surgeon should talk to you for a little bit, and then when they are ready you might have to change into some clothes, like hospital pyjamas and get into a hospital bed. Then you should be taken on a bed with wheels, to a room with bright lights overhead. Then they will make sure you can go to sleep before the operation.

All the grownups in your life (parents, carers, doctors, and nurses etc.,) want to help you understand what is going to happen and get you ready for your visit.

What's it Like in the Hospital

Have you ever been to a hospital before, maybe to visit someone else or to see a doctor? Have you ever seen a hospital on TV or in a book? Maybe you have a toy that is a doctor or a nurse?

Don't worry if the answer is no, you can do that now. There are TV shows that show your favourite characters going into hospital and coming home afterwards.

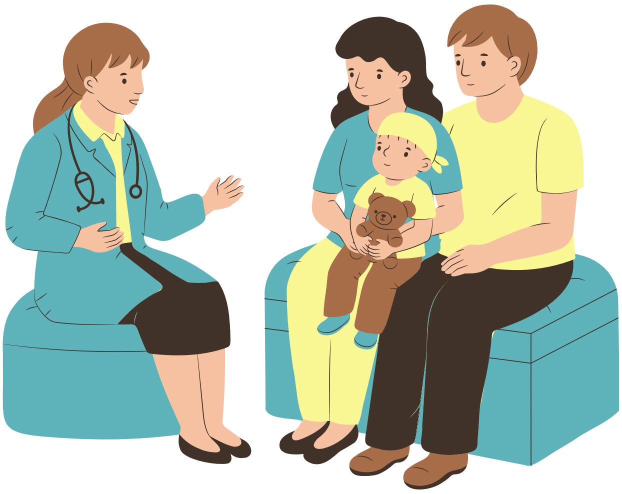
You can also play hospitals with your teddies, and your favourite grown-up can show you what it is like visiting a hospital.

When you go into hospital for your operation, there will be a big group of grown-ups looking after you, you can talk to them all, write down their names and make a picture if you like. They are all there to help you and answer any questions you have. You can work with your grown-up to think of questions you might like to ask them.

On the day of your operation, your grown-up (parent or caregiver) comes with you into hospital. When you get to the hospital, the nurses should tell you which bed is yours. Here you can unpack your things, your mummy/ daddy/ carer will have packed some nice comfy sleep clothes for you. You might have a few tests, these should be like tests you have had before, like an X-ray. Your grown-up can tell you more about what should happen while you're in hospital and when you get home.

Tell me how you are feeling

Maybe after your mummy or daddy, caregiver, or doctor has told you about the operation you have lots of thoughts and questions. Ask them! We grown-ups don't have all the answers, but we can do our best to explain.



If, for example you are feeling worried about what you might look like while you are having treatment, then we can talk about it together. Would you like to see pictures of other kids who have had the same treatment and hear their stories? If so then your grown-ups can find some suitable resources on social media, or through the Steps charity.

Worrying about your body is completely normal, and it's good to talk about any worries you have, but remember the treatment is going to help you.

Sometimes it can be difficult to say everything you are thinking, so how about drawing it? If you can, find a quiet time to draw what you are thinking about your own hospital visit wi. You can read a book about going to the hospital and play a game where you pretend to be the doctors or patients.

If you are really lucky there might be a doll or a teddy bear that you can play with which looks like it has had the same operation that you are going to have.

Beyond this Booklet

Steps understand that all this information cannot replace support and advice from other people who are going through, or who have been through the same experience. We can help you get the benefit of that experience too:
Visit **www.stepsworldwide.org** for more info

- Family Contact Service (confidential)

Connecting parents (or adult caregivers) with other families who have been through something similar. Enquire via our helpline **01925 750271** or email **info@steps-charity.org.uk**. All our Family Contacts are interviewed and given training before they engage with a family, providing a forum for sharing ideas and consulting other parents on day-to-day questions.

- Facebook discussion groups (private)

There are two pages for members to join
Steps Charity Worldwide - Support Group for Parents
Steps Charity Worldwide - Support Group for Adults

- Helpline (confidential)

Call **01925 750271** with any questions you have or email **info@steps-charity.org.uk**.

- Social media

Steps is active on X (**@Steps_Charity**), Instagram (**@StepsCharityWorldwide**) and on YouTube (**StepsCharity**)

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

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Steps Charity Worldwide Groups:
Steps Charity Worldwide - Support Group for Parents
Steps Charity Worldwide - Support Group for Adults

steps
We don't take walking for granted

The Leading Charity for Lower Limb Conditions

Our favorite links

Parents always check the suitability of a resource for your child before sharing it with them*

These resources look at hospitals, operations, and feelings, but there are lots of toys and books that look at limb difference and wearing a prosthetic limb or cast.

Books:

- Paddington goes to hospital
- Peppa Goes to Hospital: My First Storybook
- People who help us: At The Hospital
- Your Little Sleep: An illustrated storybook for children having an operation or scan under general anaesthesia
- Ruby's Worry: A Big Bright Feelings Book
- In My Heart: A Book of Feelings

Video

- A Little Deep Sleep - a Family Guide to Anaesthetics (Youtube)
- Surgery Day for Little Casey! (Youtube)
- Operation Ouch!

There are lots of toy brands that now offer toys with walking aids, wheelchairs, casts, or prosthetic limbs. Some small business may make a toy to order that can be made specifically for your child.

Contributors

This booklet was last reviewed in February 2024, With special thanks to contributors: The Steps Team, Walk:Enabled, Steps Volunteer Clinicians, researchers, and families. Special thanks go to families who submitted photos allowing their use in this resource.

Disclaimer

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