

Planning your rehabilitation

A PRACTICAL GUIDE FOR CHILDREN AND FAMILIES
HAVING LOWER LIMB ORTHOPAEDIC SURGERY FOR
CEREBRAL PALSY

Introduction

This booklet answers some of the questions you may have about rehabilitation after your operation. Other children with cerebral palsy who had lower limb orthopaedic surgery and their families told us what was important for them. We have used that information to help write this booklet.

BEFORE your operation you will have visited the hospital with your family to:

- agree on the goals of your operation
- talk about what the surgeon will do and if there are any risks for you
- talk about how you will be after your operation, and who will help you afterwards and during your recovery

What happens AFTER your operation often depends on whether the goals of your operation are to help you to **keep active** or to help you **be comfortable**. In this booklet:

- 'Keep active' surgery means that the operation aims to improve your walking and your ability to do day-to-day things.
- 'Be comfortable' surgery means that the operation usually aims to make sitting, washing, dressing and toileting easier.

Throughout the booklet there are boxes for you to write about the plans for your recovery and rehabilitation. You can talk about these with your family, your hospital team and the therapy team that you usually see.

There may be lots of people involved after your operation, or just a few, but they are there to support you and your family. You can fill in their names and contact information in the boxes.

1. You and your family



2. Hospital building and healthcare team

- a. Surgeon
- b. Nurses
- c. Hospital physiotherapist
- d. Occupational therapist
- e. Rehab doctor







3. General practitioner

4. Community rehabilitation team

- a. Paediatrician
- b. Physiotherapist(s)

c. Occupational therapist



5. Social worker	
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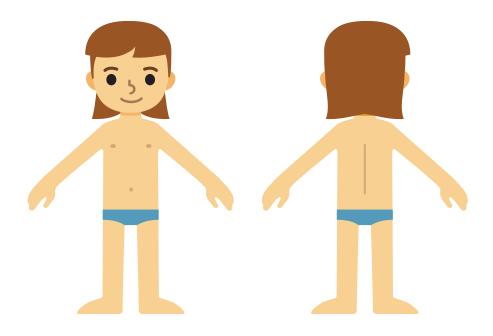




9. 'Others who can help' (psychologist, voluntary agency, equipment hire)

You and your body

You can use the picture below to show where on your body your operation will be



Will I feel tired?

Yes! Having an operation is physically and emotionally tiring. You may also find it more difficult to get to sleep due to pain or getting used to a cast. Hospitals can be noisier than your bedroom at home as the staff will be moving around at night checking on everyone.

Will I have stitches?

After your operation you will have stitches — how many depends on what your operation was. They will be covered with a shower-proof dressing to keep them clean and dry until your skin has healed. This usually takes 10-14 days. Absorbable stitches are normally used which gradually disappear 2-3 weeks after your surgery. Other types of stitches are used for some foot operations and these are usually removed when you have your cast changed three weeks after your operation.

Will I have a cast?

It is common to have a cast after leg operations.

Casts can be made from plaster, plastic or fabric.

Casts made from plaster need to be kept dry and clean so that they do not soften, crack or smell.

They should be checked twice a day to make sure that your skin is not rubbed or hurt. You should never put anything inside your cast. If you have a cast on your foot and ankle you will also have a special 'cast-shoe' so that you can stand when ready.



What I need to know about stitches, casts and splints	

What happens if I am sore?

It is normal to have some pain after an operation. If you have pain you should tell your family or any of your hospital or therapy team. You will be given medicine to help with your pain. Pain medicine works best if taken regularly and before pain becomes very strong. It is a good idea to take pain medicine about 30 minutes before doing things that might cause pain, like getting out of bed, getting dressed or doing exercises.

There can be some side effects with pain medication like:

- Sleepiness
- Constipation
- Itchiness
- Feeling sick
- Mood changes.

These can all be managed or different medication used. You should take all medications that you have been given.

Pain levels can also be affected by having to stay in bed, being worried, infection, tiredness and moving around. Other options to help with pain include:

- Heat
- Ice
- Massage
- Relaxation
- Distractions, like watching TV, playing games or listening to music.

Who can I talk to if I am worried?

You can talk to your family, friends, or any of your hospital or therapy team. It might also be possible to talk to another young person or their family who has had an operation like yours before you have your operation.

"I was scared of falling at the start, but I knew I had to get moving!"

Conor, aged 12





Notes or questions	

Will I be able to get around in my usual way after my operation?

After some operations you can get moving again straight away in your usual way. For other operations you will need extra help. For example, you may need crutches or a walker to get moving. You will be encouraged to do this quickly and carefully after your operation by your surgeon and therapists. If you are not allowed to lean fully on your operated leg(s) for a while then you might need equipment to help change position and/or a wheelchair. You might also think about staying on one level of your home until you are stronger to avoid having to go up and down stairs. If you normally use a wheelchair then you may (or may not) need some changes to your wheelchair.

Moving around after my operation



Will I be able to go to the toilet as usual?

If you have to be careful about how you stand, or if you need to stay in bed for a while after your operation, then going to the toilet may be trickier than usual. You may have a catheter for a few days after your operation. You may also need extra help from your family or might borrow some equipment to make toileting easier, like a commode or a bedpan, or a hoist to help with transfers. This will only be for a short time and you will soon be back to your usual way of doing things.

How will I get washed?

It is important that you do not get your stitches or cast wet so you may need to change how you get washed until your wounds have healed and your cast is removed. This might mean having a sponge wash for a few weeks or being careful to cover your cast properly and be safe with transfers in the bathroom/shower. You can borrow equipment like shower chairs or a bath bench if needed.

Equipment I might need



Will I be able to wear my usual clothes?

You will have a hospital gown for the first couple of days, but can soon wear your usual clothes. Skirts, dresses, and shorts or track pants in a bigger size are all good options. If you have a cast/brace that has a bar between your legs you will need to modify your underwear so that it can fasten at the sides.



"Getting showered was tricky — my mum got soaked."

James, aged 9



Getting home

How long will I be in hospital?

This depends on what operation you are having. With some operations you can get home on the same day. For other operations you may have to stay in hospital for a week or more.

Who helps with planning to get home?

After your operation the team in the hospital, including your doctors, nurses, physiotherapists, occupational therapists and social workers, will talk with you and your family about getting home. They will contact your usual therapy team if you need extra help after your surgery such as extra physio sessions or the loan of a wheelchair or other equipment.

Moving around might be more difficult after your operation. If this is the case, the physiotherapist will talk to you about how you can manage this and the occupational therapist will make sure you have a safe way to go to the toilet, have a wash and get in and out of the car. Sometimes a therapist may visit you at home before your operation to help plan how you will manage after your surgery.

I will be in hospital for _____ days

Will my family need to pay for any equipment or treatment?

There is usually no cost to your family for your surgery, hospital stay or your prescribed rehabilitation after your operation. However, this depends on your individual circumstances and your hospital. You should discuss this with your hospital team before your operation. There may be costs to hire equipment, or if you and your family decide to pay for extra therapy, or if your parents take some time off work.



How will I get home?

Most people can get home from hospital the same way that they got there. The hospital therapists will show you how to get in and out of your car. Hospital transport may be arranged if your casts are too long for your family car. The hospital occupational therapists will be able to advise you on an appropriate car seat, if needed. You might also have to fit a folding wheelchair into your car boot if this is needed after your surgery.



How will I get around my home?

If you normally use a wheelchair then you will most likely be able to get around the same as usual. If you normally walk around your home you may have to use a wheelchair or walking aid for a while before getting back to your usual way of getting around. Your hospital and therapy team will plan for this with you and your family.

Notes or questions about getting home

School

Will I miss a lot of school?

This will depend on:

- your operation
- whether you can travel to school in your usual way after your operation
- if you have a lot of pain, and
- whether you need any extra equipment or support to return to school.

After a relatively simple operation you can be back at school after a few days. If you have a more complex operation you may have to miss some school to attend extra physiotherapy for up to a year after your operation. School work can be sent home for you to complete.



"You don't realise how tough it is going to be afterwards, but you have to keep going or it will all have been for nothing."

Sarah, aged 16

Will I need extra help or equipment when I go back to school?

Your hospital team will be able to advise you about any equipment or support that you might need after your operation. This will vary depending on your operation. You may need mobility equipment such as a wheelchair or walker, or assistance with toileting, or help in the classroom for a short time. Your parents should talk to school staff about this several months before your operation so that any necessary changes can be planned.

Back to school plans

Recovery and rehabilitation

How long until I am back to my usual activity?

This varies depending on your operation. If your operation was to help you **be comfortable**, and you normally use a wheelchair to move around, your activity and care needs should be back to usual by 6 months. **Be comfortable** operations usually help with sitting and making activities like washing, dressing and toileting easier.

If you have an operation to help you **keep active**, and walking is your usual way of getting around, it may take a year or more for you to recover fully, that is to say, to get back to your pre-operation movement and then to improve. You may continue to improve your motor function and walking into the second year after your operation.

Will I need rehabilitation or other therapy?

With **be comfortable** operations the combination of surgery, medication, orthotics and equipment all work together. Often there is not 'active' rehabilitation for this type of surgery.

If walking is your usual way of getting around and you have surgery to help you **keep active**, you will have an 'active' rehabilitation programme. You will work on improving your range and quality of movement, muscle strength and regaining and improving your function and independence. This is a big commitment for you and your family. Your rehabilitation programme will be guided by your physiotherapist, orthopaedic surgeon and rehabilitation physician.



Ouestions about your rehabilitation programme

Your hospital team will discuss your likely rehabilitation needs before your operation with you and your family. How often, how long, types of activity/exercise, and progression of activities depend on the type of surgery undertaken and the individual child and family. Therapy is usually more intensive during the first three to six months. Depending on your operation and needs, you may come back into hospital for a short period of intense rehabilitation. You will have exercises and activities to do at home as well. Your therapy programme will be challenging but should be fun as well as hard work!

What equipment might I need?

You may need some extra equipment to help you in the days and weeks immediately after your operation. Equipment such as wheelchairs, walking aids, commodes, hoists and transfer boards are often needed in the short term. You may also need new orthotics or splints. Your hospital and therapy teams will help you plan in advance for any equipment that may be needed after your operation.



When do I go back to the surgeon for a check-up?

This depends on your operation but usually you will be reviewed before you leave hospital, and then at three weeks, six weeks, three months and one year after your operation. Your therapy team will contact the hospital team with any queries, and you can also contact the hospital, your doctor or any member of your therapy team in between if you have any concerns.

How will I deal with the challenges of surgery and rehabilitation?

Having an operation is a big decision but you will have time to discuss it with your family, friends and hospital and therapy teams. If walking is your usual way of getting around, and your operation aims to help you **keep active**, you will have to commit to a rehabilitation programme. In the beginning it will be harder than usual to move around and you may need help from new equipment and other people. It can be difficult to accept changes (even for a short time) but knowing the timeframe for your recovery and making realistic goals will help to keep you motivated. Looking after your diet, getting enough sleep and taking the medicine you need will keep your body well prepared for rehabilitation. Talk to your family and healthcare team about any concerns and your progress. Talking to other people who have been through a similar operation may also help.

My rehab plan (more writing space available on pages 17–19)		

What happens when things don't go to plan?

All surgery has risks and benefits and these will be discussed in depth before your operation. It is important to seek **urgent** medical help if any of the following happens:

- Your wound site becomes red, itchy, hot tender or oozing. Your wound site is the place on your body where the operation was done.
- Your pain is severe and cannot be eased by medication or any other means.
- You develop pain, swelling, redness or tenderness in your calf.
- Your **skin** has developed redness that does not disappear within an hour of relieving pressure; you have areas of skin breakdown or open sores.
- You develop a temperature over 38°C.
- You have pain or burning when you go to the toilet; or a severe sore throat; or tummy pains, vomiting and/or diarrhoea; or chest pain and/or shortness of breath.
- You develop unusual headaches or tingling, weakness or numbness in your legs that doesn't go away after you change positions.

Issues with casts and splints that you should call your doctor or hospital about are:

- swelling, tightness, numbness, tingling, burning or severe pain inside or below the cast that is not improved by elevation, rest or medication.
- severe pain and difficulty when moving your toes.
- · cold or discoloured (pale or mottled) toes.
- a new stain seeping through the cast or the cast smelling very bad.
- the cast is cracked, broken or loose, or anything falls inside it.

If you have an active rehabilitation programme it is important to set realistic short, medium and long term goals so that you can monitor your progress. Sometimes you may have muscle pain or joint stiffness but these will be managed within your rehabilitation programme and should not affect the long term outcome of your operation.

The information within this leaflet is meant for general guidance only.

The illustrations are provided as a prompt for discussion about your child's needs following their operation and do not constitute medical advice. Each child and family is different, so each operation and recovery is different. Please follow any additional advice given by your hospital and therapy teams.

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Notes	

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Major project contributors





Centre of Research Excellence in Cerebral Palsy

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