

# Limb length difference and limb lengthening

Information for families

**Great Ormond Street Hospital  
for Children NHS Trust**

**This booklet explains about limb lengthening and deformity correction, especially that of the leg, the reasons why it may be needed, and how to keep life as normal as possible during the lengthening process. This booklet gives a rough guide to the process of limb lengthening followed at Great Ormond Street Hospital (GOSH) but the process can vary from child to child and may also differ if the operation is carried out elsewhere. If you have any questions, please ask your consultant.**

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## What are limb length differences?

A difference in the length of the arms or legs can occur for a number of reasons. Usually the shorter limb is abnormal, but this is not always the case, as sometimes the longer limb is the abnormal one.

### Increased limb length

#### Hemihypertrophy

The main cause is a condition called hemihypertrophy, where the sides of the body grow at different rates. Although both the arm and leg on the affected side can increase in length, it often affects only the leg. There can be other problems associated with hemihypertrophy, usually affecting the kidneys, so regular check ups using an ultrasound scan are sometimes needed. In most cases, doctors cannot find the cause for the hemihypertrophy, but it does occur in certain conditions like Klippel-Trenaunay-Weber syndrome. Children with this syndrome (a collection of symptoms) are born

with too many blood vessels, which may show up as birthmarks or enlarged veins. In some children however, the blood vessels are deep in the leg and so are not visible.

#### Neurofibromatosis

This is a rare condition which causes overgrowth in one leg, along with other symptoms like brown freckles or skin lumps, or curvature of the spine.

#### Overgrowth after a fracture

Very rarely, increased limb length can occur after a fracture of the thigh bone or shin bone and may need treatment.

### Decreased limb length

#### Congenital causes

Congenital means 'present at birth'. Some children are born with an underdeveloped or shortened bone, which may be associated with other problems in the limb. We do not know why this happens, but it is likely that it occurs early in pregnancy when the limbs are developing.

## **Growth plate injuries**

The area at the ends of bones where growth takes place are called growth plates. These can be injured or damaged, and as a result the bone can stop growing. If half of the growth plate is damaged, this can result in the bone growing unevenly and becoming deformed.

## **Neurological problems**

Many neurological problems (to do with the brain or spinal cord) cause decreases in limb length. The most common cause is polio, but this is now very rare in the UK due to widespread immunisation against the disease. Other causes include spina bifida and hemiplegia, but the degree of shortening which they cause varies.

## **Olliers Disease**

This is a condition where there are lumps of cartilage (soft tissue that is involved in bone formation) in the bone. This is often associated with a decrease in limb length and deformity, usually affecting one side of the body more than the other.

## **Multiple exostoses**

In this condition, patients have extra lumps on their bones. These can interfere with growth as well as being a nuisance if they get knocked.

## **Other conditions**

### **Club foot (talipes)**

This condition occurs when the foot is bent inwards while the baby is in the womb. The condition does not always result in decreased limb length, but requires treatment usually by manipulation (to move the foot into the correct position) and maintenance of the correct position using splints or plaster casts. If these methods do not work, then surgery may be considered. The limb lengthening process tends only to be used when the club foot returns to its original position despite the operation.

For more information about these disorders, please visit our websites at [www.gosh.nhs.uk](http://www.gosh.nhs.uk) and [www.childrenfirst.nhs.uk](http://www.childrenfirst.nhs.uk).

## What treatment options are there?

The options for treatment for your child tend to depend on how different from each other in length their limbs are expected to be once they stop growing, and whether they will have any associated deformity. There is a choice of treatments, and their aim is to enable your child to live a normal life and carry out activities like walking, running and playing.

Treatment options tend to fall into the following categories:

- No treatment
- Shoe raises
- Shorten the longer leg
- Lengthen the shorter leg
- Amputation and fitting of a prosthesis (artificial limb)

The options for your child will be fully explained to you by their doctors.

If the expected difference in length between the legs is under 3cm, there is either no need for further treatment or an adapted shoe (shoe raise) can be used to lift the shorter leg by a small amount.

If the expected difference is between three and six centimetres, the doctors usually advise slowing down the growth in the longer leg, using an operation called 'epiphysiodesis'. This operation can only work if your child is still growing. For more information about this operation, please see our leaflet *Epiphysiodesis: information for children and young people*. If your child has stopped growing, there is the option of shortening the longer leg by removing a piece of bone. This is quite a serious operation and tends to be used more often to treat adults than children.

If the expected difference is more than six centimetres and shortening the longer leg is not an option, the doctors will usually advise leg lengthening. This booklet explains about this process later.

If the difference in leg length is large and there are associated deformities, amputation (removal of part of the leg) may be the best option. However, this is only considered in the most severe cases.

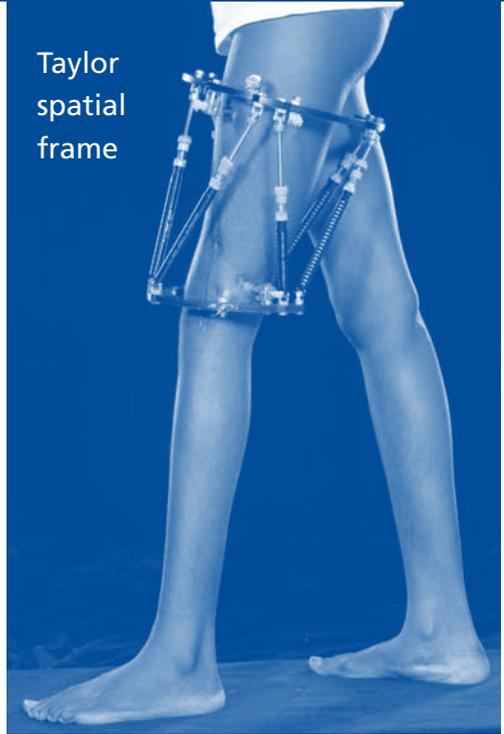
## What is leg lengthening?

Leg lengthening is a process that takes advantage of bone's ability to heal itself by generating more bone. An operation is carried out during which your child's leg is broken, and then, while supported by a frame or a fixator, their leg is stretched. This allows extra bone to form in the gap between the broken ends of the bone, and this grows stronger over time so that it can support your child's weight fully.

The two types of frame most commonly used at GOSH are the Ilizarov and Taylor spatial frames, which were both named after the doctors who invented them. The frames consist of several circular rings, that go around your child's leg and are attached to their bone using thin wires or pins.

The Ilizarov rings are made of stainless steel or carbon fibre and are connected to one another by bars (rods) which contain a nut or screw which is used to gradually increase the distance between the cut ends of the bone. If your child's leg or foot needs to be straightened as well as

Taylor spatial frame



lengthened, the rings will contain hinges as well, so that the position of their leg or foot can be adjusted over time. There is a picture of an Ilizarov frame on page 9.

The rings on a Taylor spatial frame are made of aluminium and are connected by six struts. Computer software produces a programme which tells you how much to turn each strut every day to gain the length and any straightening your child needs.

Sometimes a third type of fixator called an Orthofix® fixator is used. This consists of a strong bar attached to the leg by screws. It is sometimes used when there is not enough room to attach the Ilizarov or Taylor spatial frames.

### **The pre-admission clinic**

We will invite you and your child to a pre-admission clinic about four to six weeks before their proposed operation date. This is an opportunity to discuss the treatment with the surgeon, the physio-therapist and the psychologist. We aim to explain the treatment, the risks and complications and answer any of your questions. It is important that you all understand the process of treatment as this makes it more likely to succeed. There are various practical matters which need to be discussed like getting a wheelchair for your child to use for a while after the operation. They will be encouraged to walk as much as possible, but a wheelchair can make it easier for you to get out and about. Arranging physiotherapy in your local area, and schooling will also need to be planned.

## **The operation to fit the frame**

Your child will usually be admitted to hospital one day before their operation, so that special X-rays can be taken to help plan their operation. He or she will also see the physiotherapist to learn how to walk using crutches, which they will need to do for a while after their operation. You and your child will also meet the nurses and other members of the team and become settled into the ward routine. You will probably be familiar with the treatment plan by this time, but if you have any questions, please ask.

### **What happens before the operation?**

You will already have received information about how to prepare your child for the operation in the Welcome to our hospital booklet and your child's admission letter.

The doctors will explain about the operation in more detail, discuss any worries you may have and ask you to sign a consent form giving permission for your child to have

the operation. Another doctor will also visit you to explain about the anaesthetic.

If your child has any medical problems, particularly allergies and constipation, please tell the doctors about these. Please also bring in any medicines your child is currently taking.

### **What does the operation involve?**

Your child will be given a general anaesthetic (medicine which puts them very deeply to sleep) for the operation, which lasts between four and six hours.

The surgeon will position the rings of the fixator around your child's leg and attach the wires or screws to the bone using small incisions (cuts). She or he will then make a larger incision (cut) to access the leg bone or bones of the foot. This is then cut between the rings so that the lengthening process and deformity correction can begin.

### **What are the risks of the operation?**

All the doctors who perform this operation have had lots of experience and the chance of any complications is low.

All surgery carries a small risk of bleeding and infection during or after the operation. Every anaesthetic also carries a risk of complications, but this is very small. Your child's anaesthetist is a very experienced doctor who is trained to deal with any complications. After an anaesthetic some children may feel sick and vomit. They may have a headache, sore throat or feel dizzy. These side effects do not usually last long and are not severe.

There is a small risk of nerve injury during the operation which may result in numbness or weakness, but this is usually temporary.

## What happens after the operation?

After the operation, your child will recover from the anaesthetic in the recovery room. When your child is more awake, he or she will be moved back to the ward.

Your child will need to rest in bed for one or two days after the operation. Their leg will be a bit uncomfortable for the first few days, so the doctors and nurses will make sure that your child has enough pain relief. After 24 hours, the nurses will clean the pin sites (where the wires or screws enter the skin) which can be uncomfortable at first but will become easier with time.

About three days after the operation, the physiotherapist will take your child to the physiotherapy gym, where she or he will teach your child the exercises needed to strengthen their leg. They will also teach your child how to walk safely with crutches.

## How long will treatment take?

It is difficult to predict exactly how long your child will have to wear the frame because this depends on the severity of your child's condition and how well the bone forms. As a rough guide, treatment takes a month for every centimetre of lengthening needed. So, if the difference is five centimetres, then the treatment will take about five months.



## Problems with the leg lengthening process

There can be many problems with leg lengthening but the most common ones are pin site infections, muscle contractures and pain. These are explained below, and it is a good idea to know about them and what to do if they occur.

Pin site infections are common, despite rigorous cleaning, because the wounds give a direct entry point to germs. If infections are not treated in time, the lengthening process may need to be stopped, and the infection could spread to the bone (osteomyelitis). Please see the section on pin site infections for further information.

Muscle contractures occur when muscles crossing joints come under increasing tension as your child's leg is lengthened. Your child will be given a resting splint, which supports their leg or foot, and they should use it as instructed, particularly at night.



Your child may feel pain as their leg lengthens due to the nerves and veins stretching along with the bone. You should watch out for signs of this happening, like your child complaining of tingling, pins and needles, or reduced blood supply to the foot which can make it cold. If these things happen, you should inform the doctor and slow down or stop the lengthening process (at this stage, called 'distraction' as explained later). Regular pain relief should be enough to deal with any pain, but alternatives are available if this is not sufficient.

## Getting used to the frame

### Pin site care

This is a vital aspect of the leg lengthening process as it keeps the pin sites clean and reduces the risk of infection. For the first few days after the operation, while the pin sites are oozing, you or your child will need to clean them once a day. Once the pin sites have stopped oozing, they will need cleaning once a week.



The nurses on the ward will teach you and your child how to clean the pin sites. You may feel that this is an awful lot to learn but we will make sure you are confident before you go home.

### Pin site infections

■ When you are cleaning the pin sites, you should check for any signs of infection. These are:

- Pain
- Redness
- Soreness
- Oozing

If you notice any signs of infection, clean the pin sites twice a day until it clears up and contact the hospital for further advice. If the infection does not clear up, a course of antibiotics may be needed.

### Distraction

This is the process by which the cut ends of the bone are separated and gradually pulled apart. It usually starts about five to ten days after the operation. You will be shown how much to turn the nut using two spanners or 'clicker' or strut before you leave hospital. The

adjustments are made between one and four times a day, which leads to a total of around 1mm separation per day. Distraction is not painful for your child, as the amount of separation is very small.

Your child will have regular X-rays to check that the amount of distraction is correct and that new bone material is forming between the cut ends of the bone. The amount you turn the nuts or struts may be changed according to the results of these X-rays. For example, if the bone is slow to form, the distraction may be reduced.

## Clinic appointments

A vital part of the lengthening process is the regular clinic appointments every two weeks, to check on your child's progress. During the lengthening process, he or she will see the doctor and physiotherapist for a check up and have regular X-rays taken. The clinic appointments are held every second and fourth Friday morning, with a swimming session around lunchtime if your child wants to

take part. The clinics can be quite long so it is a good idea to bring a drink, a snack and something to do or read!

Once the lengthening process has finished, but while your child is still wearing the frame, he or she will need to attend clinic appointments every four to six weeks, again for a check up to see that the bone is hardening properly.



## Physiotherapy

It is very important that your child does regular physiotherapy while the frame is on their leg and also for some months after it has been removed. This will help restore any joint movement lost or muscle weakness which has developed while the lengthening takes place. Many of the exercises aim to help your child use their leg normally so he or she will be encouraged to put weight on it when walking and be as active as possible as this helps bone formation.

We will make arrangements for your child to see a local children's physiotherapist in your area once

they go home. The hospital physiotherapists will make sure that your local physiotherapist is up to date with your child's progress during the lengthening process.

## Getting about

Although we would like your child to walk as much as possible, this is often not easy as the frame is quite awkward and heavy, especially until your child gets used to it. To help you get out and about as a family, we will arrange for your child to borrow a wheelchair from your local wheelchair centre or the Red Cross.



## Frequently asked questions

### What sort of support can I expect when I get home?

Your child will have visits from the community physiotherapist, and also from a community nurse if needed. Please remember that you can call the ward at anytime, on the number at the end of this booklet, if you have any questions or worries

### Where do I get equipment and supplies?

Ward staff will organise for your child's family doctor (GP) to supply you with the cleaning equipment. We will also arrange for loan of a wheelchair or crutches. If you have any problems getting hold of supplies, please call the ward for advice.

### Where do I get any medicines?

We will give you a prescription for codeine and paracetamol before you go home. You should collect this from the pharmacy. We do not recommend that your child takes

painkillers like Ibuprofen, unless recommended by your consultant. If your child has muscle spasms, diazepam, a tranquilliser and muscle relaxant, is helpful in relieving these. You should discuss this with your child's family doctor (GP).

### What about showering and bathing?

Your child can shower and bath as usual during the lengthening process. If your child has a bath, it may be easier to sit on a bath board and it is important that the frame is showered clean afterwards. A shower may be better, as it is easier for your child to get in and out of a shower than a bath.

### What about clothing?

You may worry about what clothes your child will be able to wear during the lengthening process. He or she will be able to wear 'normal' clothes, but they will have to be baggier than usual to accommodate the frame. It can also help to unpick the side seam on trousers and underwear and fasten it using Velcro<sup>®</sup>, poppers or a zip.

## **What about food?**

Your child should eat a balanced diet during the lengthening process, particularly including lots of food containing calcium. If your child drinks milk, this is the best way to get plenty of calcium, but many other foods contain calcium too. Please ask to see a dietitian if you are worried or have questions.

## **Will my child be able to go to school?**

We recommend that, where possible, your child returns to school during the lengthening process. If staff at their school have any questions or worries, they should contact the physiotherapist for advice.

## **What about swimming or PE?**

We like children to be as active as possible during the lengthening process. Swimming is a great activity as it gives good all-round exercise. We hold swimming sessions at the hospital following clinic appointments, so please ask the physiotherapist for details. If your child enjoys a particular sport or

activity and feels able to take part while wearing the frame, please ask their doctor or physiotherapist if this is safe. Some of the children we treat here have continued to play football and other sports while wearing their frame!

## **Will we be entitled to any extra benefits?**

While your child has the frame, he or she will need more care than usual, so you may be entitled to Disability Living Allowance. Your child's social worker can advise you about claiming this.

## **Can we go on holiday?**

There is no reason why you cannot go on holiday, as long as your child does not miss any clinic appointments. There should be no restrictions on flying, although it may be helpful to ask for a seat with extra leg room so your child is more comfortable. If you are planning a holiday, please contact your child's consultant or physiotherapist to discuss any special instructions for while you are away.

## **How are we all going to feel?**

Your child (and you and the rest of your family) may feel fed up with the leg lengthening process from time to time. The following are problems that may occur, but do not expect them as not every family is affected in the same way. If you are bothered by any of these, call the ward staff as they may be able to arrange a meeting with one of our psychologists who will be able to give you ideas of how to cope.

### **Sibling rivalry**

Your other children may get annoyed with the amount of attention their brother or sister is getting. Having 'special time' with your other children may help. If relatives and friends seem to focus on your child going through the leg lengthening process and pay less attention to your other children, you could ask them to treat all your children equally. Having as much attention paid to your other children will make them feel a bit happier.

### **Body image**

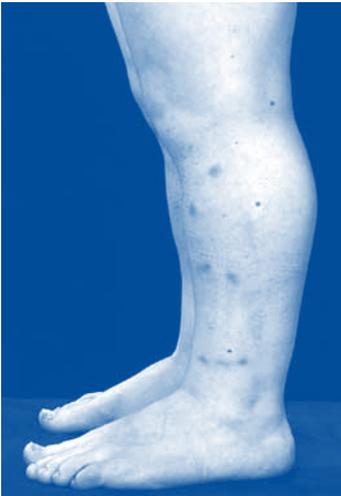
Children may feel self conscious about their frame. Talking to other people in the same situation can help so contact the support organisations for advice.

### **Mood swings and 'down' periods**

It is entirely natural for your child to have periods where they are fed up with the frame and the leg lengthening process. In our experience, it helps to keep things as normal as possible at home, although we realise this can be hard. If you or your child are feeling very 'down', please talk to the ward staff as there are lots of things we can do to help. We can arrange a session with the psychologist or we can arrange for your child to have a short stay on the ward to get things back on track.

## When the correct length has been achieved

Your child will have regular X-rays to check how their leg lengthening is progressing. When the correct length has been reached, their doctors will tell you. However, this does not mean that the frame can be removed immediately. Doctors will only recommend removing the frame when they are sure that the bone is strong enough to support your child's weight during any activity. It can take several months for the bone to strengthen enough, during which time your child will continue to wear the frame. If the frame is removed before this happens, there is a risk that their bone could fracture.



## Removing the frame

When X-rays show that your child's bone has strengthened enough, the frame will be removed. This is done in a short operation using general anaesthetic. Children sometimes want to keep the frame or the wires as a souvenir. This is not possible, but sometimes we can give him or her one of the pins to keep!

Once the frame has been removed, your child will need further physiotherapy to strengthen his or her leg muscles and to get movement back in any stiff joints. This is particularly important if the joint has been immobile for a while. The physiotherapy will need to continue for several months at home too. Your child will also have to use crutches until their leg has strengthened, and their physiotherapist will help them with this.

If your child had other problems with the leg that needed correcting, he or she may need to have their leg in plaster for a while. Their doctors will tell you if this is likely to happen.

## When it is all over

### Scars

Once the frame has been removed, your child's leg will have quite a lot of small scars from the wires, but also from the operation site where the bone was cut. Sometimes, these scars do not heal properly and restrict movement. If you are worried, please talk to their doctor.

Your child may also dislike the look of these scars, and there are plenty of options for making them less visible. These include silicone gel, steroid injections or plastic surgery. Another alternative which covers up the scars rather than removing them is cosmetic camouflage. For more information about this option, please see our leaflet *Cosmetic camouflage: information for families*.

### Future long term problems

There is a risk that the new bone will break when the frame is removed so your child will only be allowed to put some of their weight on their leg and must use crutches for the first six weeks. Your child will continue to have physiotherapy and hydrotherapy during this time to build up their muscles and help get the joint moving again.

If your child breaks their leg in future, it will be treated in the usual way by your local hospital. If the doctors want to speak to someone at GOSH, your child's consultant will be able to give advice over the telephone.

Your child's knee may continue to feel stiff, despite all the physiotherapy. If he or she continues to have problems once the lengthening process has finished, please call us to discuss this further.

## Support organisation

### STEPS

Warrington Lane, Lymm, Cheshire WA13 0SA

Helpline 0871 717 0044 Mon-Fri, 9.30am to 4pm

Email: [info@steps-charity.org.uk](mailto:info@steps-charity.org.uk)

Website: [www.steps-charity.org.uk](http://www.steps-charity.org.uk)

## Notes

**If you have any questions at any time during the lengthening process, please call Sky Ward on 020 7829 8807.**

## Useful details

Your child's name: \_\_\_\_\_

GOSH number: \_\_\_\_\_

Great Ormond Street Hospital (GOSH): \_\_\_\_\_ 020 7405 9200

GOSH (Emergency): \_\_\_\_\_

Sky Ward: \_\_\_\_\_ 020 7829 8807

Physiotherapist \_\_\_\_\_

Other information: \_\_\_\_\_

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[www.goshfamilies.nhs.uk](http://www.goshfamilies.nhs.uk)

[www.childrenfirst.nhs.uk](http://www.childrenfirst.nhs.uk)