Contact details
If you need to contact the doctor please ring his secretary on:
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The specialist nurse is:.................................................................
Contact them on:........................................................................

Your physiotherapist is:.............................................................
Contact them on:........................................................................

Your occupational therapist is:...................................................
Contact them on:........................................................................

Your community nurse is:...........................................................
Contact them on:........................................................................

Feedback
We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS):

Freephone: 0800 183 0204
From a mobile or abroad: 0115 924 9924 ext 65412 or 62301
E-mail: pals@nuh.nhs.uk
Letter: NUH NHS Trust, c/o PALS, Freepost NEA 14614, Nottingham NG7 1BR

www.nuh.nhs.uk

The Trust endeavours to ensure that the information given here is accurate and impartial.

Your external fixator/frame
Information for you and your parents
Paediatric Orthopaedic Department

This document can be provided in different languages and formats. For more information please contact:

Paediatric Orthopaedic Department c/o Ward D34
Nottingham Children’s Hospital
QMC campus
By now you will have had lots of different investigations and talked to the doctors. Now that you have decided to have the external fixator/frame you will meet lots more people. They will tell you more about what will happen.

This leaflet is written specially for you to help you get ready to have your external fixator/frame and help to answer the questions you have.

**What is an external fixator/frame?**

External fixators/frames are used either to make an arm or a leg longer or to correct the position of a foot or an elbow. These pictures show types of fixator that may be used.

You will either have a frame or a bar fixator. The metal around the outside is called the scaffolding or the cage. Its job is to support and look after your leg or arm whilst it is growing or being corrected. It is held on by pins that go through your leg or arm and it cannot fall off.

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**Other questions you may have**

**How long will the fixator/frame be on for?**
The amount of time the fixator/frame is on varies from a few weeks to several months.

**How often do the pinsites have to be cleaned?**
Every day in hospital whilst you are getting used to it but every three to four days at home.

**Can I still go out with my friends?**
Yes! We encourage people to get back to a normal life.

**Can I go swimming?**
Yes. Once all the wounds are healed check with the doctor and the swimming pool. However, if you get an infection then you cannot go swimming.

**What problems might I have?**
- You might get some tingling or numbness in your fingers or toes as the nerves are also being stretched.
- The bone might take longer than normal to grow and become strong.
- Sometimes the fixator/frame needs to be altered if it is not growing into the position that is wanted.
- You may get an infection around the pinsites. This can happen if they get dirty so it is important to only touch them with clean hands. (Signs of an infection are redness, swelling, pain and oozing pus.)

**Will it hurt when my turns are done?**
No, it shouldn’t. Each turn moves your bone only a quarter of a millimetre.

**When can I go back to school?**
As soon as possible. The OT will help you with this.
If the fixator/frame is on your leg, the physiotherapist will give you either some crutches or a walking frame to help you get about. Depending where the fixator/frame is, they will tell you how much weight you can put through your foot. If the fixator/frame is on your leg, you will also need to spend about an hour on your tummy each day to make sure that your hip does not get stiff.

**What is occupational therapy?**
Occupational therapists (OTs) are interested in how you do everyday activities such as washing and dressing, using the toilet, playing and going to school. You will meet an OT at the preparation clinic, where they will talk to you about any worries or questions you have with these activities.

By the time you have your operation, the OT may have already been on visits to see if any help is needed for your return to home or school.

If your operation is to be done on one or both legs you will need a wheelchair, which will be ready for you by the time you have your operation. Depending on your operation it may also be necessary for the OT to make you a splint to protect or support your toes, part of your foot, leg or arm.

By the time you go home, they like to see you doing as much for yourself as possible. The OT can help you do this by providing equipment for you or by practising with you before you leave hospital.

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**Who will look after me and what do they do?**

- **Doctors** – they will do the operation and check on you regularly afterwards.
- **Nurses** – they will look after you before and after your operation.
- **Physiotherapist** – they will teach you exercises and help you to walk
- **Occupational therapist (OT)** – they will help you get back to school and around your house.
- **Anaesthetist** – a doctor who will help you go to sleep and make sure you stay asleep during the operation.
- **Theatre staff** – they will look after you whilst you are having the operation and whilst you are waking up afterwards.
- **X-ray staff** – they will take pictures of your leg or arm.
- **Teachers** – they will do school work with you.
- **Play specialists** – they will give you toys and things to do.
- **Community nurses** – they may help you look after the frame when you get home.
What happens now?

Preparing for surgery
About six to eight weeks before you come into hospital you will be asked to come to a preparation clinic especially for you. You will meet the nurse, the physiotherapist and the occupational therapist. They will explain everything you need to know, what it is like to have an external fixator or frame on and how to look after it. You will be able to look at a frame and photos of other children with fixators/frames on. You will be able to ask all the questions that you have.

Pre-admission clinic
This happens on a Wednesday one or two weeks before you have your operation. At this clinic you will see different people including:

- Mr Lawniczak, who will ask your mum or dad to sign a form saying you can have the operation.
- Nurses who will fill in lots of paperwork about you.
- The ward doctor, who will make sure that you are healthy enough to have the operation.

You will also have any x-rays, blood tests or photos that are needed. If you have any questions to ask the physiotherapist or occupational therapist we can also contact them.

How might I feel about the fixator/frame?

Having a fixator/frame on your arm or leg may change the way you feel about your body. You may also be asked lots of questions about it and may be teased by other children. This is usually because they don't understand what is happening to you. Talking about your fixator/frame and explaining why you have it usually helps. If teasing is a real problem then tell your teachers or parents and they can help.

Your treatment will also take a long time and you will have to wear your fixator/frame for several months so you may get frustrated and bored. Again it is important to talk about this with your family, even your brothers and sisters. You can also talk to the staff at the hospital about this if you want to.

What is physiotherapy?
The physiotherapist is the person who helps you to move your leg or arm and also teaches you to walk if the fixator/frame is on your leg. You will first meet her/him at the special preparation clinic.

Once you have had your fixator/frame put on, they will teach you exercises to make sure that your leg or arm does not get stiff and also to make sure that the muscles do not get weak. It is important that you do these exercises every day.

(continued over page)
You may have a shower seven to ten days after your operation. The dressings should be removed before you go in the shower and afterwards each pinsite must be cleaned as described. You cannot have a bath whilst you have your fixator/frame on.

If your pinsites become red, swollen or painful or are oozing a thick, discoloured fluid or pus you may have a pinsite infection (straw coloured fluid oozing from a pinsite is normal). It is very important that this is treated as soon as possible to prevent it from getting worse. Your GP will prescribe some antibiotic medicine/tablets to treat this. If the infection gets worse, you may need to come and stay in hospital for a few days to have antibiotics through a drip in your hand. You will also need to clean any pinsites that are infected once a day until the infection has gone.

One of the community nurses will be in contact and may visit you whilst you have your fixator/frame on. They will arrange any more supplies of equipment needed to do your pinsite care.

What happens when I come into hospital?
You will be asked to come to the hospital on the Friday morning. Remember that you are not allowed to have anything to eat or drink from a certain time that you will be told.

The last bits of the paperwork about you will be filled in. The nurse will also take your temperature and your heart rate (pulse). The anaesthetist will come and see you and talk about how he will help you sleep during the operation.

You will have your operation on that day. It normally takes about two hours but because you will be asleep it will seem like no time at all for you.

What happens in my operation?
While you are sleeping the fixator or frame will be put on your arm or leg. If it is to lengthen your arm or leg, the surgeon will cut a bone so that it will be able to grow.

When the operation is finished, you will wake up in a room called the recovery room. You will not be able to see your frame because it will be covered in bandages.

You will stay in the recovery room until you are properly awake and then the nurse and your mum or dad will come and get you to take you back to D34.
What happens after my operation?

- You can have something to eat and drink as soon as you feel like it.

- You will have a ‘drip’ that gives you medicine to stop your arm or leg hurting through a small plastic tube in your hand. You will also be allowed to have other medicine to stop the pain, either as tablets or syrup.

- The nurses will regularly take your temperature, heart rate and breathing rate. They will also check your fingers or toes of the arm or leg you have the fixator/frame on.

- You can go to the toilet using a special bottle or bed pan until you are able to get to the toilet yourself. You will also have a wash in bed until you can get to the bathroom. You will not be able to have a bath while your frame is on but you can have a shower once your wounds have healed.

How do I look after the pinsites?

Pinsites are where the wires/pins of the fixator/frame go into your leg or arm. Looking after your pinsites will start the first day after your operation and will continue the whole time you have your fixator/frame on. This is a very important part of your treatment and must be done to stop you getting pain and infection in the pinsites.

To start with you may find that cleaning your pinsites is painful but the pain usually settles down as time goes on. The nurses will do it to start with and will teach your parents how to carry on once you go home. You may even be able to help once you get used to it being done.

On the first day after your operation the bandages around your fixator/frame will be taken off. There will also be dressings around your pinsites. On the second day these will be removed and all your pinsites will be cleaned. You will be given painkillers before this is done and you may also need to have some special gas (medicine) to breathe to help you relax whilst they are being cleaned. You will probably only need to have this the first one or two times.

Each pinsite will be cleaned using special bits of gauze or cotton buds which have been soaked in salty water. The metal pins must also be cleaned and dried if they are obviously dirty.

Once this has been done, square dressings soaked in an antiseptic solution will be put around each pinsite. When you are in hospital your pinsites will be cleaned each day but when you go home they need to be done only every three to four days. You must not pick at your pinsites and they must only be cleaned by somebody who has very clean hands.

(continued overleaf)
What can I wear over my fixator/frame?

Depending on where your fixator/frame is and how big it is, you may not be able to wear your normal clothes. This means that you will have to alter your clothes so that they fit over your fixator/frame. If you have a fixator/frame on your foot or leg your pants/boxer shorts may need to be cut at the side and then held together with Velcro or poppers. Your trousers will also need to be altered in the same way, although you can get some tracksuit trousers to fit over the fixator/frame, especially those with poppers or zips down the side of the legs. You will be helped to get dressed whilst you are in hospital and the nurses will talk about how to fit clothes over your frame.

If the fixator/frame is on your arm then you may be able to fit baggy T-shirts over it. Otherwise tops and jumpers will need to be altered and fitted with Velcro or ties.

Some children like to keep their fixator/frame covered all the time. This can easily be done by putting elastic at both ends of a pillow case to make a tube of material that can be worn over the fixator/frame. The OTs may also be able to provide a cover for your frame.

We do try to make sure that there aren’t any sharp edges or wires on the fixator/frame but mattresses, chairs and settees should be protected to stop damage, as should car seats. You can use a rug to do this. It may also be worth taking something to protect furniture if visiting friends/relatives.

The next few days

The physiotherapist will come and see you and teach you the exercises that you will need to do whilst you have your fixator/frame on.

Over the next few days they will help you to get out of bed. If you have the fixator/frame on your leg, they will teach you to use crutches or a frame and also to get up and down stairs. (Read more about the physiotherapy on page 13).

Usually on the second day after your operation the drip that gives medicine to help with your pain, will be switched off and the plastic tube will be taken out of your hand. You will still be able to have the tablets or liquid medicine if you still have some pain. On the same day your nurse will start to clean your pinsites. (You can read more about this on page 11.)

The occupational therapist may need to make a special shoe for you if the fixator/frame is on your leg. This will protect your foot when you put it down on the floor and also stop it from getting too ticklish. (Read more about the occupational therapist on page 14.)

Before you go home the doctor may come and teach you how to turn the bits on the frame that will make it move to lengthen or correct the shape of your leg or arm. There are also teachers who work on the ward and whilst you are in hospital they will give you school work to do.
**Will it hurt?**

When you wake up after your operation you will be in the recovery room. You will be looked after by nurses (wearing pyjamas!) and once you are properly awake your ward nurse and mum or dad or carer will collect you and take you back to the ward.

You can have something to eat and drink when you are back on the ward, as long as you are not feeling sick. Fluid may be given to you through the plastic tube (drip) in your hand or arm if you don’t feel like eating or drinking.

The anaesthetist will have given you painkillers in theatre to make sure you are comfortable when you wake up. You will also have a drip to give you painkillers all the time. For young children the nurses will be able to give you an extra dose of this painkiller when you need it by pushing a button. If you are older, you will be able to push the button yourself. Parents are NOT allowed to push the button for their child.

This painkilling drip will be used for two to three days and will stop when you are feeling more comfortable and not needing to push the button as often.

After your operation you will also be given pain killing liquid medicine or tablets to swallow. These will be given to you regularly for the first few days and then only when you need them. This means you need to tell the nurse if you have any pain. By the time you go home you will not be needing painkillers as often. You can keep taking them when you need to but do not take ibuprofen regularly – only have this if you are feeling really sore.

**What about eating?**

You may find that you are not as hungry as before your operation. This will be because you are not as active as normal, but it is important to keep eating as your body will need more of some foods to help it grow strong and heal. Try to eat more meat, fish, cheese, eggs, yoghurts and milk.

Some children also find it difficult to have a poo after their operation. Eating fruit and vegetables and drinking lots of water and fruit juice will help with this. If it continues to be a problem you may need to get some medicine from your GP to help.

**When can I go home?**

You will be able to go home about seven days after you have had the operation. Before you can go home you need to be able to:

- go to the toilet on your own
- manage your wheelchair if you have one
- do all your exercises and walk with crutches/walking frame (if your fixator/frame is on your leg)

Either you or your parents also need to be able to:

- do the ‘turns’
- clean the pinsites

When you are ready to go home, you will be given an appointment to come and see Mr Lawniczak. To begin with, these appointments will be every week but then he will see you less often.