

# Having spinal surgery for scoliosis



This information pack from Great Ormond Street Hospital (GOSH) explains about spinal curvature (scoliosis), what causes it and how it can be treated. At GOSH, we use a series of operations to correct the curvature so this information pack tells you about the assessment process that helps you, your family and the spinal team decide if surgery is right for you. The pack also tells you what to expect when you come to GOSH.

Information for young people

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## What is scoliosis?

Your spine is made up of 33 spinal bones (vertebrae) that sit one on top of another from the pelvis bone in your bottom to the base of your skull. It naturally curves in three places from front to back.

Each spinal bone (vertebra) has a hole through the middle for your spinal cord – this means that the bones protect the spinal cord from injury. Running off the spinal cord are numerous nerves that reach every part of your body. Muscles, tendons and ligaments are also attached to the vertebrae – this keeps you upright and allows you to move. There is a 'disc' in between each vertebra, which acts as a shock absorber.

Scoliosis is a lateral (side to side) curvature of the spine that can develop at any point when you are growing. The spinal column curves and twists, which in turn makes your ribcage turn. Over time, this curvature can progress or get worse – this makes your spine, chest and pelvis change and affects the organs inside them as well.

There are several different types of scoliosis but in 80 per cent of children and young people, the doctors do not know what caused the curvature – they call this type 'idiopathic'.

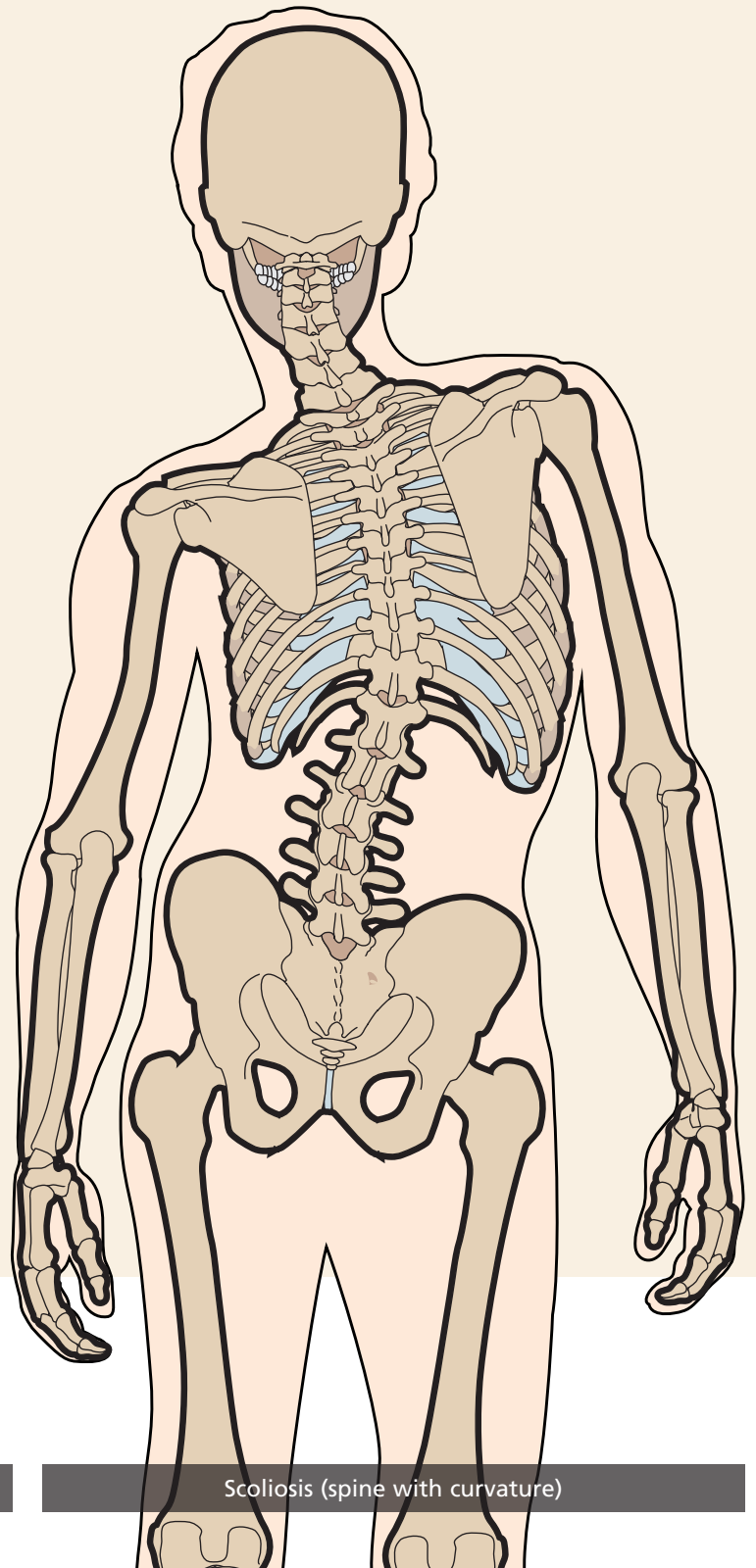
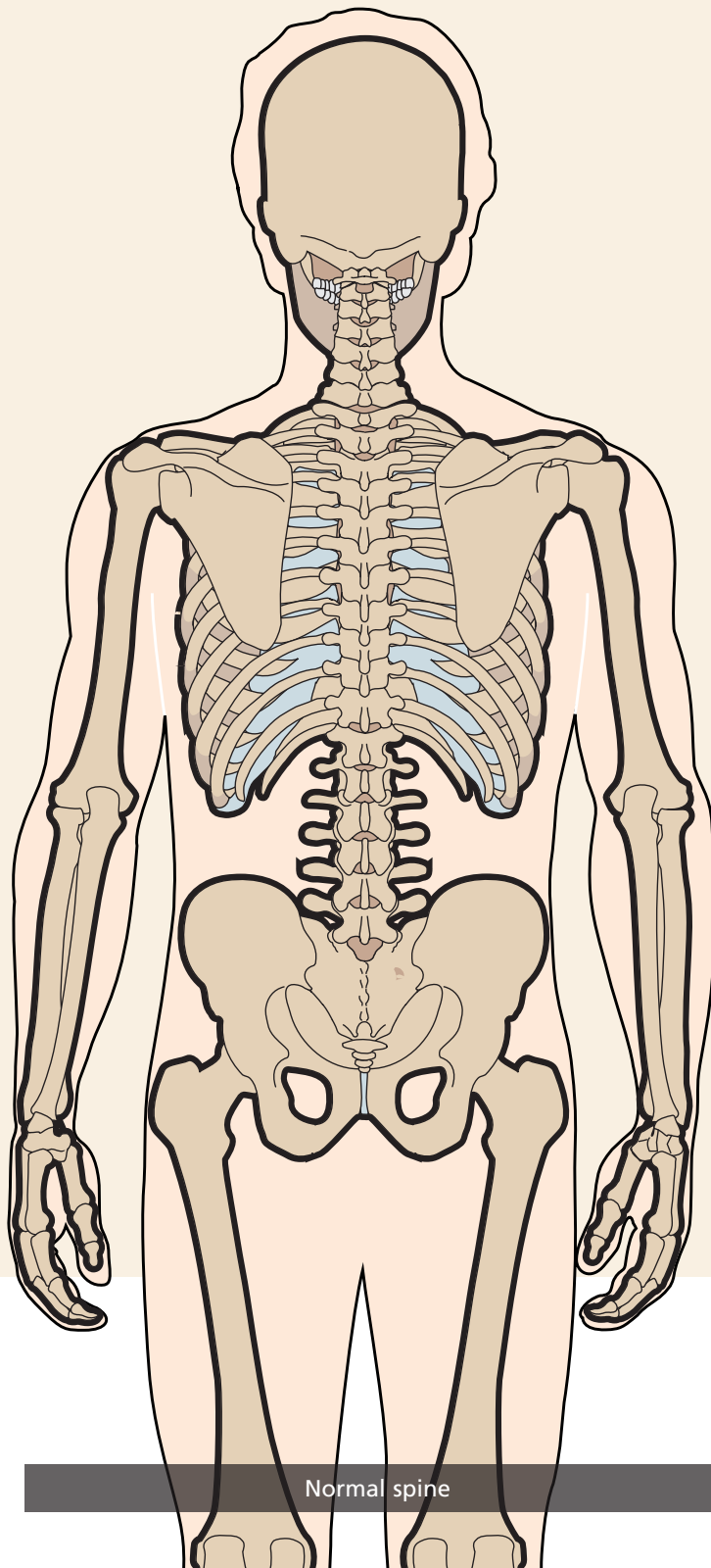
## What is it like to have scoliosis?

Often the first thing you or someone else might notice is that your clothes do not seem to hang right. This is usually because the curvature in your spine is making:

- One shoulder higher than the other
- One shoulder blade is more obvious than the other
- One hip is more obvious than the other, meaning your waistline crosses your body at an angle rather than straight across

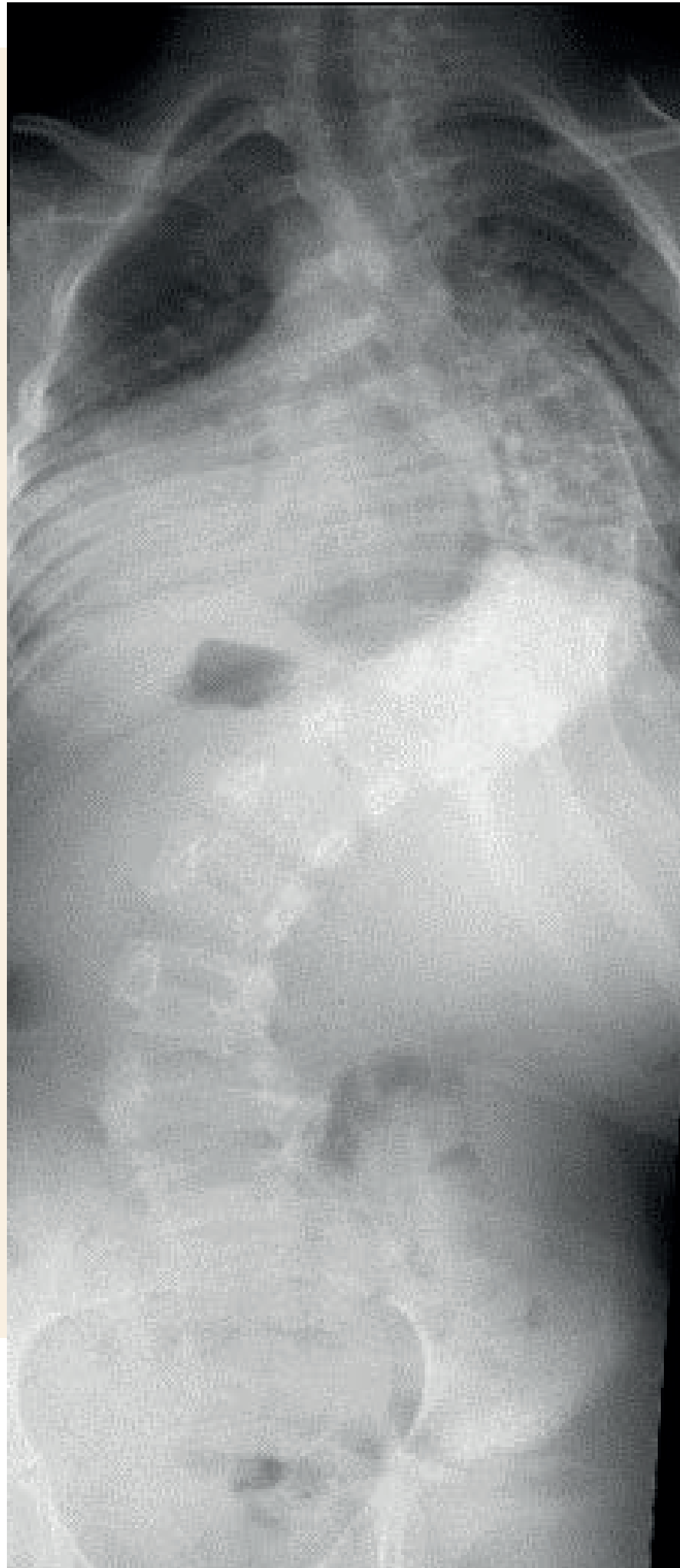
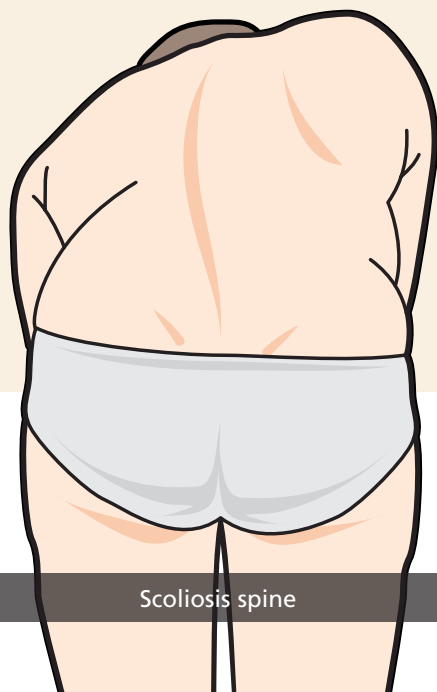
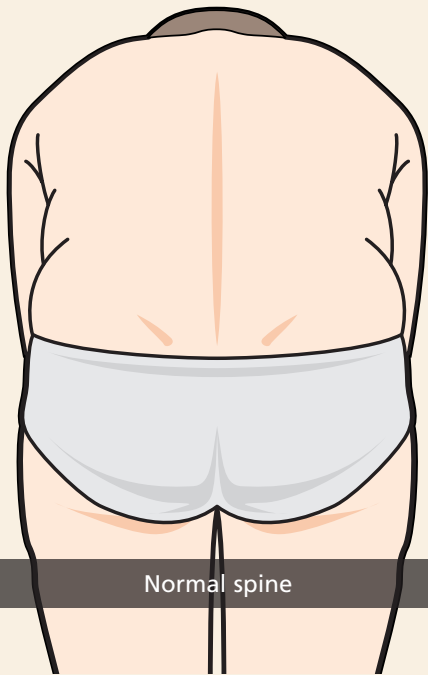
If the curvature gets worse, this can affect how well your organs work. For instance, if your ribcage is twisted, there may not be enough space inside for your lungs to expand fully when you breathe in, which might make you out of breath when you exercise.

Doctors tend to use plain x-rays to work out if you have scoliosis and if so, whether it is getting worse and by how much. Usually, the x-ray machine is positioned in front of you with the camera film behind you.



The x-ray machine sends out x-ray particles which can pass through the body to make an image on the camera film. The particles are unable to pass through dense parts of the body, such as bone. They are bounced back towards the x-ray machine, so that they do not reach the camera film. These areas will look white on the image.

Parts of the body containing air, such as the lungs, appear black because the particles pass straight through the lungs onto the camera film. Other areas such as muscle, fat or fluid will look grey. The images are recorded on a computer so a specialist doctor (radiologist) can examine them and write a report.

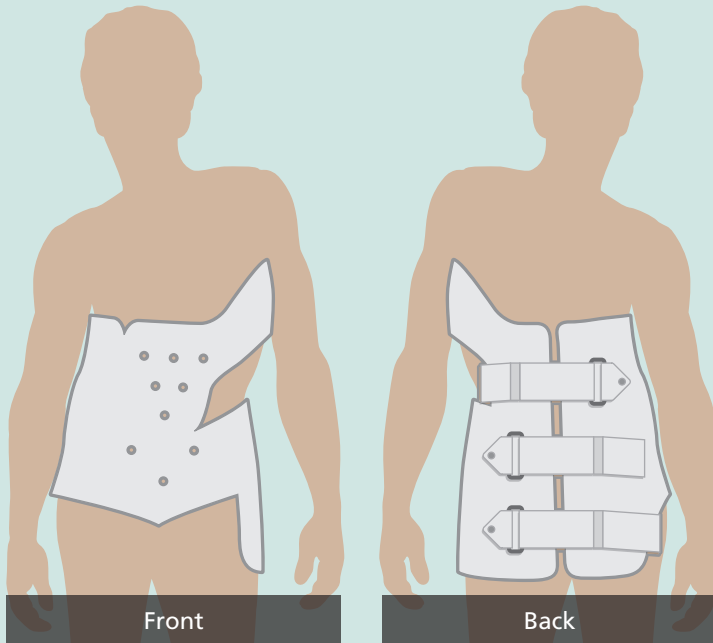




# Can scoliosis be fixed?

The aim of any treatment is to stop the curvature getting worse and straighten your spine as much as possible. There are three main treatment options – the Spinal team will talk to you about the one(s) suitable for you.

- **Observation** – For many young people, this is the only treatment needed as most spinal curves do not get worse over time. They will still need to come to hospital regularly for x-rays so the doctors can compare how much their spine is curving with the previous set of x-rays.
- **Bracing** – This might be suggested if the curvature is getting worse as it can reduce further curvature. Each brace is made-to-measure so you will need to have a plaster cast taken of your chest, which is then used to make the brace. Usually you have to wear the brace for 23 hours a day, only taking it off for a wash or things like games or swimming.



- **Surgery** – This tends to be suggested for the most severe curves or those that are getting much worse. Surgical treatment can be carried in one operation or two separate ones a few years apart – which option is recommended will depend on your age and whether you have stopped growing yet. There are two ways the surgeon can carry out the operation – one is through an incision (cut) on your side and the other is through an incision on your back. One or both of these approaches may be needed to fix metal rods to your spinal bones to straighten them.

At GOSH, most young people have spinal surgery to correct their curvature. This is major and complex surgery so we want to be sure that it is suitable for you and you understand what is involved. We have developed a 'pathway' for spinal surgery, which sets out how we will assess you for surgery and what will happen before, during and after the operation(s).

## Deciding if surgery is suitable for you

At GOSH, we have developed a pathway for children and young people having spinal surgery. This is a standardised plan of care but of course we can adapt it, where possible for your particular needs. Spinal surgery is a complex procedure so we want you to understand the benefits and risks of the operation so you and your family can make an informed decision about whether to go ahead.

### Initial spinal clinic appointment

The first step in the pathway is for you and your parents to meet the Spinal Surgery team – usually one of the surgeons and one of the nurses. The aim of this appointment is to tell you about your options and explain what tests and scans you will need to help us decide on whether to recommend surgery.

### After the initial spinal appointment

We will make any referrals needed so you can have further assessments. Although you may already have had some of these assessments at your local hospital, we may need to do them again so we get up to date information. We will try to build the assessments into your Spinal Investigation Day (described in the next section) but sometimes this is not possible. We will do our best to book them so you have as few journeys to GOSH as possible.

**Psychology** – Having spinal surgery can be a big step so we offer all young people considering it support from our psychology team. They can talk to you about whether the surgery is worrying you, any other challenges in your life and work with you to develop ways of coping.

**MRI scan** – This uses strong magnets rather than x-rays to take pictures of inside your body. The MRI scanner is a hollow machine with tube running through its middle. You will lie on a bed that slides into the tube while the images are taken. It makes a continuous knocking sound during the scan but we will give you headphones to wear and you can watch a film too.

We request a MRI scan to make sure that check the spinal cord is normal.



## Investigation day

The aim of investigation day is to carry out a number of tests so we have a full picture about your health – this will guide us to decision whether surgery is the best and safe option for you. The day will be quite busy but we will give you a timetable of which tests to expect when – here is some information about the tests we usually carry out on investigation day.

- **Height and weight** – We need to know how tall you are and how much you weigh so we can work out how much medicine to give you during and after the operation.
- **Blood tests** – These give us a good picture of your general health as well as specific information such as how long your blood takes to form a clot. Knowing this is important for any major surgery.
- **Lung function test** – These are breathing tests to check how well your lungs and chest muscles are working. The most common type of test is called ‘spirometry’, where you breathe out as hard and fast as possible. We usually give you a few goes to see how well you can do.
- **Heart assessment** – We need to know that your heart is working well enough for the operation and has not been affected by your scoliosis or any other health problems. One test is usually an electrocardiogram (ECG), which involves putting sticky pads on your chest and connecting them to the ECG machine. It produces a ‘heart trace’, showing how your heart is working.
- **Clinical photography** – It is useful to have ‘before’ and ‘after’ pictures so we can see the effect of spinal surgery. You will usually have to undress for the photographs but someone can stay with you when they are taken.
- **X-ray** – These are the same as the ones taken to diagnose scoliosis but it is important to do them again shortly before the operation just in case your curvature has got worse.

You will also have a number of other assessments and appointments during investigation day, usually with the following people:

- **Paediatrician** – These are specialist doctors in child health so review your overall health and take a full history of what symptoms you have and when they developed. They might need to organise some other tests or appointments with other specialist doctors at GOSH – this varies from person to person.

- **Physiotherapist** – Their role is see how you are moving before the operation so they will ask you to do various things such as walk or get up from a chair. They will also check how strong your muscles are and whether you have any breathing problems. The physiotherapists will be the ones to help you get up and about after the operation so they need to have a good idea of what you can usually do.
- **Occupational Therapist** – They will assess your daily living skills, such as how you eat, how you sit at school and whether you have any hobbies. If there are things you find difficult before surgery, the occupational therapist will work with you to find ways of helping so you can get back to your everyday life afterwards.
- **Anaesthetist** – These specialist doctors give you anaesthetic medicine so you do not feel anything or know what is happening during the operation. They also manage pain medicine after the operation when you feel sore. They will talk to you about any previous anaesthetics and how you felt afterwards, as well options for pain relief afterwards.

The spinal surgeons are not usually present at the investigation day, but the spinal clinical nurse specialists will be there so you can ask any questions that have occurred to you before or during investigation day.

## Multidisciplinary team (MDT) meeting

Once you have had all the tests, assessments and appointments during the investigation day, a group of clinicians will meet to review the results as well as whether the benefits of surgery are bigger than the risks. They will also discuss what specific needs you have so we can make arrangements for your stay. The people you met on investigation day will be part of this group, along with the spinal surgeons, as well as others who will be involved in your hospital stay.

After the meeting, when everyone is agreed, we will send you and your parents a letter outlining what was discussed and an appointment to discuss the recommendations.

- If the letter explains that the risk of surgery is greater than the benefits, the appointment will be with the spinal surgery team to discuss what happens next.
- If the letter explains that the benefits of surgery are greater than the risks, the appointment will be with the surgeon to learn more about the operation itself and answer any questions.

# Getting ready for the operation

Once you have had your appointment with the spinal surgeon, you will have a rough date of when the operation is likely to happen, so you can start to get ready. We will send you an admission letter telling you when the operation is booked – it will also tell you where to come on the day and when. If you have any questions about the admission, you can call the number on the letter or one of the spinal clinical nurse specialists.

Some medicines can affect how you recover after surgery, so please make sure we know about everything you take regularly, including vitamins or complementary medicines whether they are prescribed by a doctor or bought over the counter. For instance, if you are on the pill, you will usually need to stop taking it two weeks before the operation.

Smoking can affect how your bone heals so we advise everyone who smokes to stop before the operation.

Please tell us if you are a smoker – we may be able to help you with quitting aids such as patches.

## Cancellations

When we have scheduled the operation, we will do everything we can to keep it. However, sometimes emergencies happen which may mean we have to postpone your operation. We realise that this can be hard, especially if you have started to get ready, but we would rather reschedule than risk you coming to GOSH but having to go home straightaway.

Some illnesses may increase the usual risk of anaesthesia so we may feel it is safer to postpone your operation until you are feeling better.

- Coughs and colds
- High temperature
- Streaming nose
- Wheezy cough
- Chest infections
- Receiving treatment for the cough or cold from your family doctor (GP) or pharmacist
- Chicken pox and shingles
- Diarrhoea and/or vomiting

Within 48 hours of the planned operation

- Eye conditions
- Coloured ooze in the days in leading up to the operation
- Hand, foot and mouth disease
- Measles
- Taking antibiotics
- Urinary Tract Infections (UTIs)
- Head lice

## Checklist

Tick things off on the checklist below to make sure you remember everything.

### ■ What to do

- Inform your school about the operation date
- Decide which parent will stay with you in hospital
- Read this booklet again and write down any questions
- Make sure you understand about fasting
- Work out how you are going to travel to GOSH
- Arrange for work to take with you while you are in hospital
- Make sure you have enough of your regular medicines
- Stop taking certain medicines as advised by the team
- Start to pack your clothes and wash things for your stay
- Do not drink any alcohol or smoke or vape
- Take off any nail extensions or acrylics
- Call the ward if you are ill just before admission
- Call the ward if you have been in contact with someone ill
- Have a shower or bath and wash your hair
- Take off any nail varnish (fingers and toes)
- Take out any piercings or replace with plastic bar

### When

- As soon as you know the date
- As soon as you know the date
- As soon as you know the date
- As soon as you know the date
- 2 weeks before admission
- 2 weeks before admission
- 2 weeks before admission
- 2 weeks before admission
- 1 week before admission
- 1 week before admission
- 1 week before admission
- 2 days before admission
- 2 days before admission
- Night before admission
- Night before admission
- Night before admission



## Why having a bath or shower is important

Your skin is the physical barrier that keeps out germs and bugs so keeping it clean should be an important part of your daily routine. Any operation or procedure carries a risk of infection - either through an incision (cut), through a cannula (thin, plastic tube inserted into a vein) or tube into your mouth (to help you breathe during the operation). If your skin is dirty, the germs are more likely to get inside your body and cause problems.

Having a thorough wash before an operation can reduce this risk. You do not need to use a special soap, but make sure you wash all the areas on the diagram thoroughly – these are often dark and moist so a great place for bugs to grow. If you have a skin condition, use your usual soap-substitute but do not put any moisturiser or emollient on afterwards.

Your teeth and gums are also an important defence against infection. You should always clean your teeth twice a day with fluoride toothpaste. On the morning of the operation, clean your teeth as usual but do not use mouthwash or swallow any water or toothpaste.

## Jewellery, piercings and nail varnish

Jewellery and piercings can get caught in the monitoring devices used during operations so you should take them out before you come to hospital. If you are worried that the hole may close up you can replace it with a plastic bar just for while you are in hospital. Remember, we cannot take any responsibility for any loss of or damage to your possessions while in hospital so leave your expensive jewellery at home.

Our anaesthetists look at your nail colour to judge how you are reacting to the anaesthetic so nail varnish can stop them doing this safely. We always advise take off any nail varnish or false nails before you come to hospital – this applies to your fingers and toes.

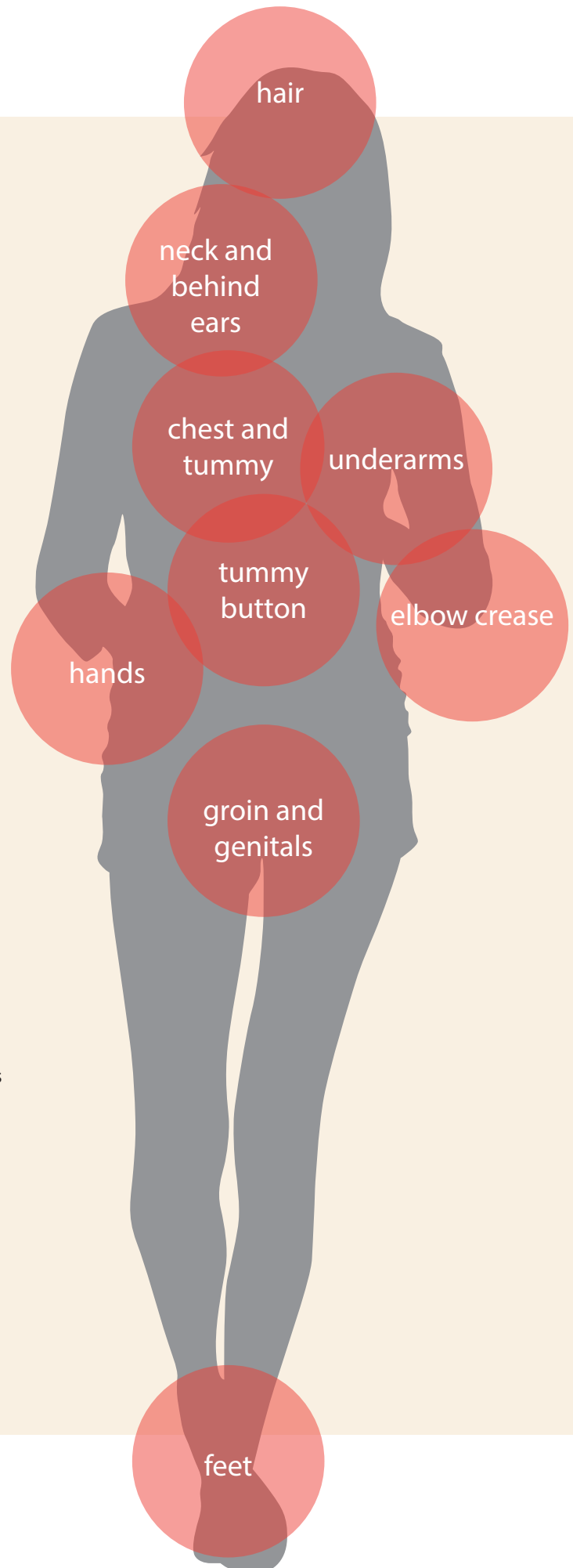
You should also remove any weaves or hair extensions before the operation – these also get in the way of the monitoring machines we use to check your spinal cord and nerves.

## Fasting times

We will call you and your parents the night before admission to check you are well and talk to you about 'fasting times' before the anaesthetic. We will tell you the last time you can have anything to eat or drink – it is important you do this as it reduces the risk of stomach contents entering the lungs during and after the anaesthetic. However, we also recommend that you keep eating and drinking until these times – this will help stop you feeling dehydrated and hungry after the operation. It might be an idea to set your alarm to have a last drink during the night.

## Regular medications

We should have a record of which medicines you are taking on a regular basis so will tell you which ones you should carry on taking before the operation. In general, we advise taking medicines on the day of surgery but adjusting the time you take them so you do not have anything to drink after your fasting times.



# Coming to GOSH for the operation

Your admission letter will tell you what time to come to GOSH and where you should go – some young people can come straight to Nightingale Ward at GOSH on the morning of the operation but others may need to come to Sky Ward the day the operation. Information about both wards is available on our website at [www.gosh.nhs.uk/parents-and-visitors/coming-hospital/ward-and-admissions-information](http://www.gosh.nhs.uk/parents-and-visitors/coming-hospital/ward-and-admissions-information)

When you arrive on the ward, a nurse or doctor will check that nothing has changed with your general health since the investigation day. They will take some observations of your temperature, pulse, breathing and heart rate and record them on our computer system.

Girls aged 12 or older – We will ask you to give a small sample of urine (wee) so that we can carry out a pregnancy test. We have to do this even if you tell us have not started your periods or having sex as some operations could harm an unborn baby. This has to be a fresh sample – please do not bother to bring one in from home.

We will ask you to have another wash on the morning of surgery and then put on your hospital gown. Please do this when we ask as it could delay your surgery or even lead to us cancelling it if you are late.

## How will I have the anaesthetic?

When you see the anaesthetist before the operation, they will tell you about the options for the anaesthetic – usually this is given as an injection into a cannula on the back of your hand or as a gas to breathe in through a mask. Both your parents (or another grown up) will be able to go with you to the anaesthetic room and stay with you until you are asleep under anaesthetic. They will then leave to wait elsewhere until the operation is over. Once you are under anaesthetic, the anaesthetist will closely monitor your blood pressure, pulse, temperature and breathing throughout the operation, ensuring that you are safe and fully asleep. ensuring that you are safe and fully asleep.

## What does the operation involve?

The spinal surgeon will have described the operation to you at your last appointment but here is a quick reminder. There are two main ways the surgeon will access your spine:

- **Anterior** – through an incision (cut) at the side of your chest wall
- **Posterior** – through an incision down your back

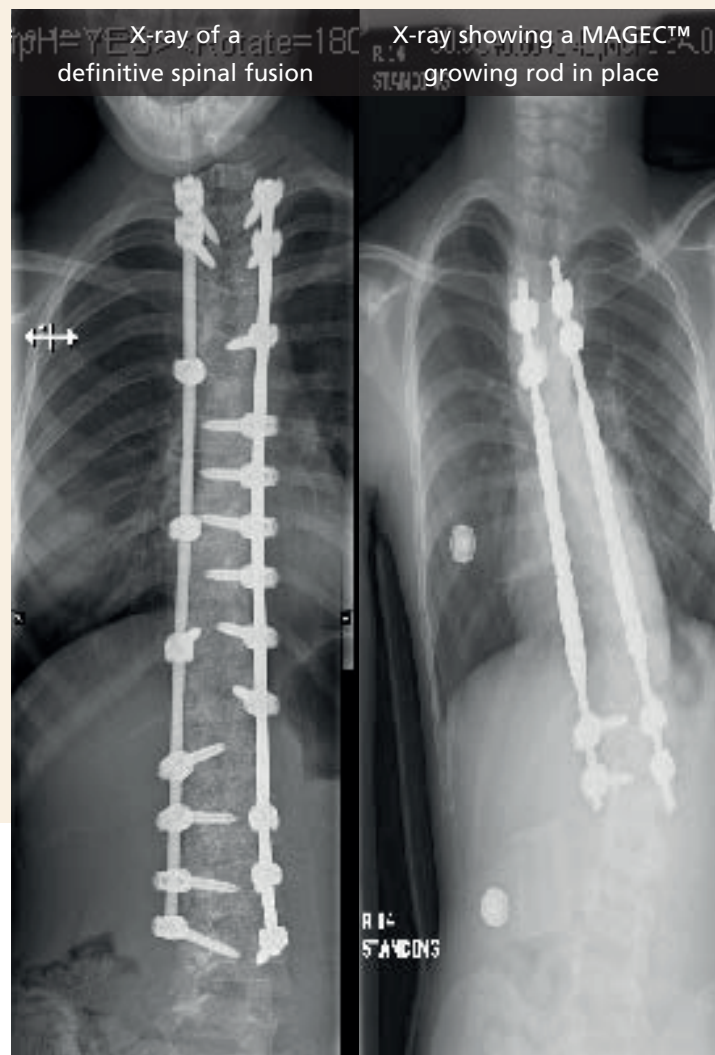
Occasionally, the surgeon may have to do incisions in both places.

The surgeon will fuse some of the bones together in your spine and hold them in place using 'growth rods'. We use two types at GOSH:

- Magnetic growth rods (known as MAGEC™) – generally used in younger people who are still growing
- Traditional growth rods – used for more severe curves or older people who are near their adult height

When the surgeon is happy with the position of the growth rods, they will close the incision and put a number of dressings over the area.

You will usually be away from the ward for three to six hours but you will probably feel sleepy for a while afterwards.



## Could anything go wrong?

All operations have some level of risk which in many cases increases if the operation is complex, like spinal surgery. The reason we carry out so many tests and assessments during investigation day is to identify potential risks to help you decide whether to go ahead or not. Spinal surgery carries some specific risks – the surgeon will have discussed these with you previously and explained which might apply to you, but here is a short reminder.

- All anaesthetics carry some risk, but these are usually small and short-term. They include: feeling disorientated or emotional on waking up, feeling sick, and having a sore throat. More rarely it is possible to cause damage to a lip or a tooth, to have breathing problems during the operation or after, or to have an allergic reaction. In some situations there may be additional risks - your anaesthetist will discuss these with you, and consider how any existing health conditions you have might alter your risks.
- Infection is a risk with any operation but you will have antibiotics during and after the operation to reduce the chance of any problems. The nurses will also check the operation site regularly – if there are serious concerns, you may have to go back to the operating theatre for further treatment.
- There are a number of large blood vessels near your spine which could be damaged during surgery, which could lead to severe bleeding needing a transfusion. There is a small chance of damage to the spinal cord or nerves running from it with any type of spinal surgery. If it occurs, it could cause weakness or paralysis affecting the legs and/or problems with bladder and bowel control. The surgeons monitor the spinal cord throughout the operation to reduce the chance of this happening.
- There is always a risk that the operation will not work to correct your curve enough, sometimes if the growth rods break or do not work as expected. This does not happen very often but will usually involve further surgery.

If you have any questions about the risks of surgery, talk to the surgeon and clinical nurse specialist.

## Transfer to the recovery area

When the operation is over, you will be transferred to the recovery room. This is a large room in the operating theatre suite where you wake up from the anaesthetic. When you are starting to wake up, the team will call your parents to the recovery room. They can sit with you while you gradually wake up, holding your hand and talking to you. Our recovery nurses look after each person until they are fully awake and comfortable enough to return to the ward.

## The high dependency unit on Sky Ward

Once you have recovered enough to leave the recovery room, you will be transferred to the high dependency unit (HDU) on Sky Ward. All young people having spinal surgery need close monitoring for a night or two, which is best delivered in the HDU area. Occasionally, some people may be transferred to our Paediatric Intensive Care Unit (PICU) if they become unwell or need more help with breathing, for instance.

The nurses will continue to take observations of your temperature, pulse, breathing and heart rate regularly, to begin with as often as every 15 minutes. As you start to recover, this will happen less often until you are having observations every four hours or so.

You will have a drip (intravenous infusion) into the vein delivering antibiotics, pain relief and fluids directly into your bloodstream. You may also have a tube going up your nose, down your throat into your stomach – this will stop you feeling sick until you feel like eating and drinking. You may also have a drain – this will drain off any fluid that collects around the operation site – and a catheter into your bladder to drain off your wee until you are up and about.

Your parents are allowed to stay as late as they would like on High Dependency Unit – but they will not be allowed to sleep at the bedside. Parents will be given a bedroom nearby and will be able to come to the HDU whenever you would like to see them.



## Your operation site

Immediately after the operation, the incision will be covered in SteriStrips®, which are strong paper stitches that hold the sides of the wound together. These usually stay in place for a week or two before they start to peel off the skin. If they are still in place after two weeks, please peel them off gently.

We put a 'honeycomb' dressing over the top of the SteriStrips®. This is a padded dressing with see-through holes so that the nurses can check your child's operation site without

removing the dressing. It protects the operation site from infection and is waterproof so will not come off in the shower but is easy to remove as the site heals.

On top of both of these dressings is a pressure dressing – we will usually remove this three days after the operation. If there has been any oozing after the operation, the nurses will change the honeycomb dressing at this point.



SteriStrips® closing the operation site



Honeycomb dressing over the top of the SteriStrips®



Pressure dressing

# Getting ready for discharge

## Transferring to the main ward

As you start to feel better, the drips, drains and catheters will be removed and you will be able to eat and drink again. The physiotherapist will visit you to help you to sit and stand after the operation – you will probably feel quite wobbly for a day or two but this will improve.

Three days after the operation, the clinical nurse specialist will check your operation site underneath the dressings. If the wound is clean and dry and there is no sign of infection, the antibiotic drip will be removed. You will also be visited by the Surgical Site Infection Surveillance (SSIS) team. They will collect information about your operation and progress. You will also have an x-ray to check the position of the growth rods.

## Looking after your skin during your stay

Sometimes, for a variety of reasons, people who are unwell develop pressure ulcers. They can be very painful and can lead to complications. Pressure ulcers (also known as bed sores) happen when there is constant pressure on an area of skin because a person is not able to move or change position.

They can also form when there is friction against the skin, for instance, rubbing on a bed sheet. Moisture can also make it more likely for a sore area to start. Areas that can be affected in children include: the back of the head, ears, heels, elbows, base of the spine and the nappy area. Some medical devices, such as nasogastric tubes, splints and CPAP masks, can also cause pressure ulcers.

When a pressure ulcer is first developing, the area can just look a bit bruised. In light-skinned people, the area might look reddened. In darker-skinned people, the area might look darker or purple, blue or violet in colour. The skin might seem shinier than usual and feel 'stretched'. As a sore area develops, the skin might swell, develop blisters or crack. In the worst cases, the skin breaks down to form a deep wound.

You can help reduce the chance of a pressure ulcer developing by:

- Turning and moving position
- Checking your skin regularly
- Straightening your bed sheets
- Eating and drinking healthily

If any part of your skin feels sore, please tell your nurse immediately – we can call another team to look at your skin if needed and they can advise of other forms of treatments.

You are likely to be in hospital for five to seven days – young people with other health conditions might need to stay a few days more if they are taking longer to recover. We will set certain goals for you to achieve before you can go home – we will work these out for each person according to their abilities before the operation but they usually include the following:

- Eating and drinking
- Passing urine (weeing)
- Passing faeces (pooing)
- Controlling your pain with regular medications
- Walk around the ward
- Go up and down a flight of stairs

When you are ready to go home, we will give you a discharge summary, which acts as a record of what happened during your stay, which medications you have been prescribed and what follow up care or treatment you will need. If the summary is not ready for when you go home, we will post it to you. We will also send a copy to your family doctor (GP) and local hospital.

We will arrange hospital transport to take you and one adult home.

# Getting better at home

Being in hospital can disrupt your usual routine so it can take some time to get back to normal. We encourage you to be as active as possible but make sure you have a rest when you feel tired. You might find sleeping in your own bed again difficult but this will improve in a few days.

## Pain relief

You will probably need to carry on taking pain relief medicines for a week or two after you get home. We will give you enough for one week but then you will need to get a repeat prescription from your family doctor. Make sure you order this in plenty of time just in case there are delays at the pharmacy.

## Looking after your operation site





You will need to carry on looking after the operation site when you get home and have it checked – this might be done by your community nursing team or your family doctor surgery. If you notice any of the following, call the clinical nurse specialists for advice:

- Redness
- Swelling
- Oozing
- Pain
- Tenderness

## Up and about

The ward physiotherapists will have started to help you get up and move about before you came home so you should carry on as they showed you. If they gave you any stretches or exercises to do, make sure you do them as advised.

The physio team have developed a programme of 'graded return to activity' following spinal surgery – they will talk to you about what you can and cannot do but as a rough guide:

Timescale after surgery				
Activity	6 to 12 weeks	3 to 6 months	6 to 12 months	1 year
<b>Walking</b> 	Aim for about 3km each day on a flat surface/pavement only	Gradually increase the distance Start walking up and down hills	As normal	As normal
<b>Yoga or pilates</b> 	Basic exercises such as pelvic tilts, leg slides and lunges	Shoulder stability exercises	Specific core stability exercises such as bridging, four point kneeling	Advance to exercises like table top
<b>Swimming</b> 	None	Build up slowly Focus on front crawl or breast stroke No jumping or diving into the pool	Jumping into the pool from side allowed	Diving from higher height into pool is allowed Return to butterfly stroke
<b>Cycling</b> 	At 6 weeks, use static bike with no resistance	Start outdoor cycling – on level and even ground for short distances (4 km or so)	Build up distance and speed slowly Start cycling up and down hills (not mountain biking)	Off road mountain biking is allowed Can commence BMX cycling









You can gently peel off the honeycomb dressing after three days. The SteriStrips® will gradually start to fall off but you should peel off any that are left after two weeks. Your community team or practice nurse may remove them or you can gently peel them off after this time. The operation site will still look quite red at this point – this is not usually a worry, but do call the ward if you are concerned.

When your operation site has been clean and dry for 10 days, you can have a shower. When you are drying yourself afterwards, pat the skin around your operation site dry rather than rub it. If do not have access to a shower, we suggest you carry on strip washing until after the follow up appointment. This will put less strain on your back.

You do not need to put any creams or lotions over the area as it usually heals better without but do keep an eye on clothing that could rub the area, such as bra straps or zips. A soft piece of gauze could stop any rubbing.

The Surgical Site Infection Surveillance (SSIS) team will call you about 30 days after your operation to ask how your operation site is healing, whether there have been any problems and what treatment you have received.



Timescale after surgery				
Activity	6 to 12 weeks	3 to 6 months	6 to 12 months	1 year
<b>Dancing</b> 	None	Ballet – barre work only with no rotation at all Tap – very low level with no jumping Jazz/Modern/Street dance – as above Build up all types gently	Re-start higher energy dance for all forms listed Build up duration slowly	All forms – Return to full activity as able
<b>Gym</b> 	Exercises prescribed by ward and clinic physiotherapist	Start on a cross trainer or exercise bike using your legs only with very low resistance	Start on a treadmill, rowing machine or cross trainer using your arms with slow speed and low resistance With all CV based equipment, gently build up resistance and speed	Re-start with weight machines
<b>Jogging</b> 	None	Build up the distance jogged over the next few months Avoid inclines or uneven ground	Practise changing direction and/or speed Commence gentle inclines or uneven ground	As comfortable with no restrictions
<b>Table tennis or badminton</b> 	None	Stand on the spot and only do gentle underarm hits of the ball or shuttlecock, gradually increasing duration Avoid excessive twisting	Increase duration and movement	No restrictions
<b>Tennis or squash</b> 	None	Begin by patting a ball on the spot, gradually increasing duration Avoid excessive twisting No overarm serving	Increase duration and movement	No restrictions
<b>Netball or basketball</b> 	None	Practise your ball skills with gentle throwing and catching drills	Start pivoting or changing direction Increase your speed	Competitive match play allowed
<b>Athletics</b> 	None	See jogging Otherwise no other athletics	Re-start running events	Re-start jumping and throwing events
<b>Hockey</b> 	None	Practise your ball skills with dribbling, gentle stopping and pushing drills but no sweeping passes	Start turning direction and running	Competitive match play and return to sweep pass allowed
<b>Football</b> 	None	On the spot kicking and stopping the ball, dribbling No tackling	Increase speed and power when kicking the ball	Competitive match play allowed
<b>Rugby</b> 	None	Throwing and catching skills as comfort allows Emphasis on gentle pass with limitations in rotation	Increase speed and amount of throwing action Commence agility work but with no contact	Restart tackling

Timescale after surgery				
Activity	6 to 12 weeks	3 to 6 months	6 to 12 months	1 year
<b>Golf</b> 	None	Pitch and putt or crazy golf only	Gentle golf swing	
<b>Climbing wall</b> 	None	Begin shoulder stability exercises	Continue strengthening exercises	Begin on easy indoor climbing wall
<b>Volleyball</b> 	None	None	Practise gentle ball skills – passing and gentle serve with soft ball	Re-start full activity
<b>Karate or judo</b> 	None	None	None	Re-start full activity
<b>Horseriding</b> 	None	None	None	Re-start full activity
<b>Water sports</b> 	None	None	None	Re-start full activity
<b>Skiing or snow boarding</b> 	None	None	None	Re-start full activity
<b>Theme park rides</b> 	None	None	None	Re-start full activity
<b>Not advised</b>	Bungee jumping 	Gymnastics or acrobatics 	Trampolining 	

If your favourite sport or activity is not on this list, please discuss with the physio to ensure you are safe.

## Back to school

While you are away from school, try to keep up with schoolwork – this should have been arranged before the operation – as well as keeping in touch with friends. We usually suggest you go back to school or college four to six weeks after your operation.

It might be easier to do short hours for a while until you feel ready for a full day. Talk to your teacher or Special Educational Needs and Disability Coordinator (SENDCo) about planning your return to school and gradual build-up of time to a full day.

When you start back at school, do not carry a heavy bag – keep it weighing less than 2kg (an average bag of sugar). We suggest using a rucksack so any weight is spread evenly over both shoulders.

It might also be a good idea to see if you can have a little more time to move between lessons – perhaps leaving five minutes early. This could be especially helpful if corridors and stairwells get crowded so you could get bumped.

You will not be allowed to do any PE or contact sports for at least three months after the operation. You should not swim for six months either, although you may be able to do gentle hydrotherapy after your follow up appointment.

## Follow up appointment

We will ask you to come back to GOSH around six weeks after you have gone home – this is to have an x-ray and then meet the consultant to discuss how you are recovering. This is a good opportunity to ask questions so why not bring a list?

At this point in your recovery, you should be back to full movement with little or no need for pain relief. You should be able to come to the appointment on public transport but please telephone the number on the appointment letter if you have any questions.

# Growth rod lengthening

Unless you had a one-stage operation, you will need to come back to GOSH every so often to have the growth rods in your spine lengthened as you grow taller. The method of lengthening the growth rod depends on the type of growth rod the surgeon used.

- **MAGEC™ magnetic growth rods** – You will have appointments every three months or so with the Advanced Nurse Practitioner for Spinal Surgery. She will use a remote control to lengthen the growth rods – as the rods are increased in length very slowly, you will not need an anaesthetic or any pain relief.
- **Traditional growth rods** – You will come back to GOSH every six months or so for a series of minor operations to make the growth rods slightly longer. The surgeon will make a small incision on your back – wherever possible in the same area as your original operation – and lengthen the rods directly. This is done as a day case, but you will spend the night afterwards in the Patient Hotel before a check-up the following morning before you go back home.

The Spinal Surgery team will have given you a rough idea of how long the lengthening will continue before the final operation.

## What is my long-term outlook?

Spinal surgery is successful in the majority of cases, with straightening of the curve improving the position of the shoulder blade and improving the levels of the hips, shoulders and waist. Back pain is also improved.

Once you have had a posterior spinal fusion the aim is for you to require no further spinal surgery for the rest of your life. The surgery will stop spinal growth, but it may continue to grow in the areas that have not been fused. After puberty, most of height comes from your legs growing. You will be followed up for two years after the operation.

In terms of the future, girls can go onto having normal pregnancies. However, we encourage you to talk to your midwife and doctor about your spinal fusion and which bones are fused, mainly so that any epidural injections given during childbirth do not interfere.

There are no limitations with your choice of career but please bear in mind if you are interested in the armed forces or police force or similar careers there may be some limitations that you will have consider.



## Ella's journey on the spinal pathway

Hello, my name is Ella and I am 13 years old. When I was eight years old I was told I had a wiggly spine, so I had to start going for check-ups on my back. It got worse and worse every six months so I had to have an operation. Then I met the anaesthetist and he told me he would be at my side throughout the surgery. This made me feel really happy and comforted. The bed was really cosy and warm and I felt like I was in a hotel.

When I woke up I felt really tired and really uncomfortable. What I really wanted the most was my mum because she was there every step of the way. I slept most of the first night.

I hope you have learned a lot about me and I hope you get better soon. Good luck, you'll do great and if you ever feel down, please read this back to yourself.

By Ella



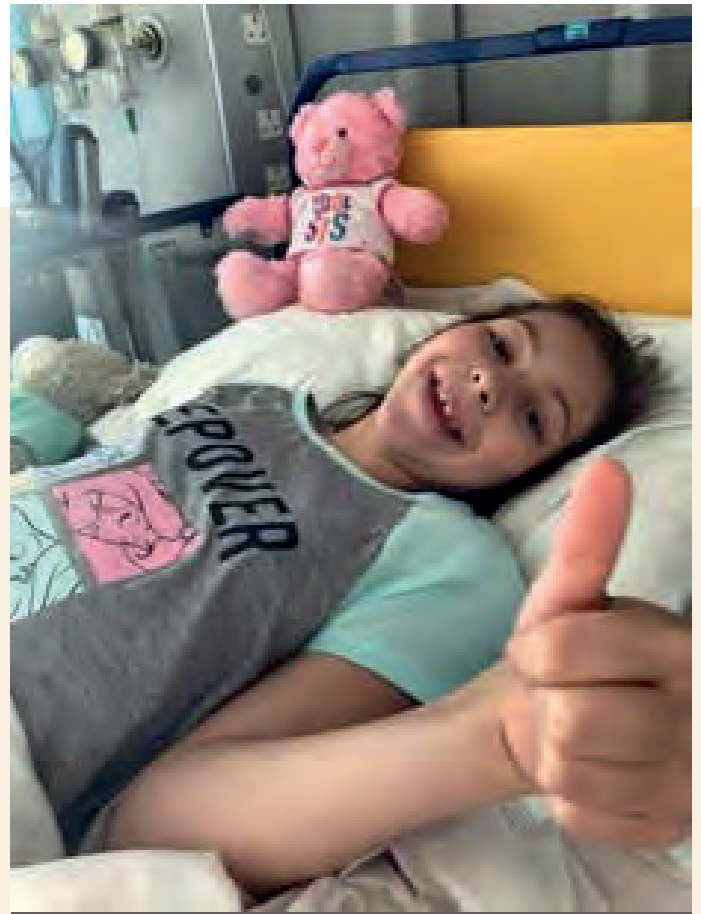
This is me at the Investigation day - I had lots of tests and then had to wait to hear when my operation would be happening.



This is me before I went down to the theatre. I felt really nervous and scared because this was a big operation for me.



Then in the afternoon, they came round again and asked me if I would stand up - it felt really strange.



There were good days and bad days and everyone was lovely to me. The hospital was not as bad as I thought it would be but I really wanted to be at home.



The following morning, the physios came round and asked me to sit up. I felt a bit dizzy because it was my very first time sitting up after the operation.



This is me just over two weeks after my operation. I felt good, I had a straight spine and since then I've been doing really well.



# Lewis' spinal journey

Lewis had anterior and posterior spinal fusion

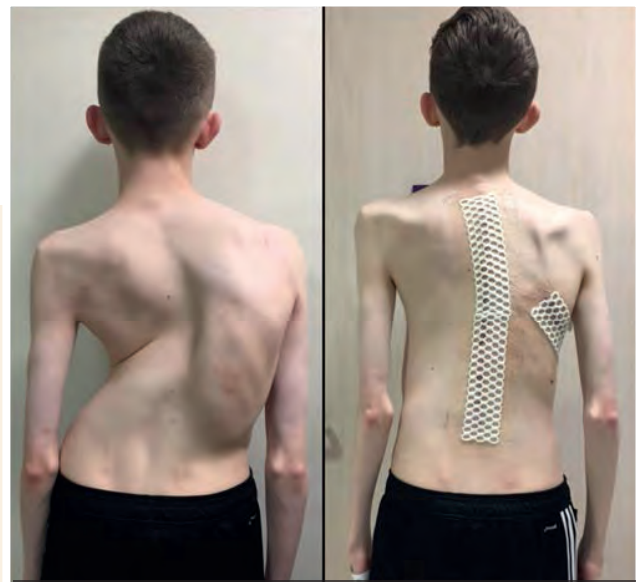
My name is Lewis, I'm 17 years old and I'm from the UK. As a kid I was always happy and always smiling, loving and living life to its full potential.

Starting down at the very bottom, weighing around one hundred and twelve pounds with a curve of one hundred and ten degrees, I was broke – physically, mentally and emotionally.

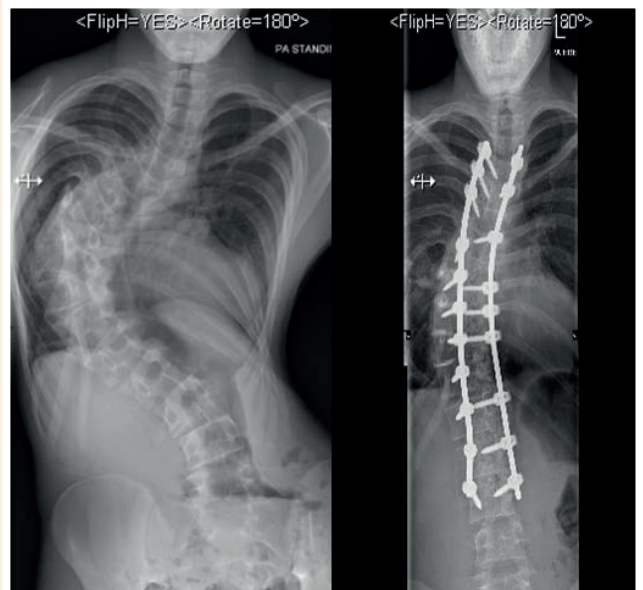
I couldn't bear the sight of my body – I was that little 15 year old Lewis that was deeply shy and insecure. There would be times when I wouldn't go out but just play Xbox for up 13 hours per day without a single break, my depression building up to the point of eruption bursting into tears about the situation.

There would be times when I would retreat to my bedroom away from civilisation; I remember spending a lot of time off of school because of the pain, which would frequently occur throughout each day. There are no words to describe what scoliosis did to me. All of which I hid from my family and acted as best I could like I was fine.

Sometime had passed by and GOSH had been in contact with my parents about the situation and the plan of action because of the stage my back was in. I just remember thinking to myself it's finally here and the time has come but this time I wasn't going to let my back



Lewis before and after the operation



Lewis before and after the operation



Lewis, his mum, Loren and Mr Tucker





Lewis having his temperature taken



Lewis, up and about



Wound dressings and drains

anchor me down. This time I was impenetrable and I was not going to be beaten, not now, not ever, motivation was what I needed and the cavalry had arrived. I was ready to go to work and bring that image which I had always dreamed of to life.

A few days later we spent a night in London, spending time together and resting before my operation, going around London shopping, which was nice taking my mind off of the task ahead.

The next morning had arrived and it was the big day – most of it was a blur but the second I stepped into that hospital gown, it all came to life; step by step, leap by leap, strolling down to theatre I was hungry for a change. Lying on that hospital bed was the single best decision I have ever made.

I would describe my encounter with scoliosis to be the most challenging experience of my life but there are many more benefits to the surgery than what the surgeon even tells you such as: improving your confidence, changing your mindset, bringing you closer to your family, strengthening you as a person and much more.

Big thanks to the most amazing hospital staff in the world, not only did they bring my vision to life but they also made me and my mum feel welcome throughout the month I was there. They provided me with world class treatment that you can't get access to anywhere else in the world.



Lewis and his lunch



For me, Great Ormond Street will always be with me whether I'm a mile away or at the other side of the world. They will always have a special place in my heart, from the cleaners of the rooms to the very surgeon himself - my love for those people will never die and I'm sure you will say the same when you reach the other side. Never be frightened to ask any questions that might be troubling you. It's best to go in to your operation with everything answered, rather than left for you to wonder about.

I hope my story has both helped and inspired you, so you have the confidence to do just as I did.

Best wishes, Lewis

Feeling good



Lewis standing tall and proud

Going home







**Edel Broomfield (Spinal Advanced Nurse Practitioner), Stacey Lambourne (Spinal Clinical Nurse Specialist), Sarah Lowery (Spinal Pathway Co-Ordinator), Loren Wailes (Spinal Nurse Practitioner) and Lucy Howlett (Spinal Clinical Nurse Specialist).**

## Further information and support

If you have any questions, please call the Clinical Nurse Specialists for Spinal Surgery on 020 7813 8238.

The Scoliosis Association offers support and advice to anyone affected by scoliosis. Visit their website at [www.sauk.org.uk](http://www.sauk.org.uk) or call their helpline on 020 8964 1166.

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Information for children