

Idiopathic scoliosis and spinal surgery


A young woman with long brown hair, wearing a light blue denim shirt and light-colored trousers, is sitting on a hospital bed. She is smiling and looking towards a healthcare professional. The healthcare professional, a woman with dark hair wearing a light pink button-down shirt and dark trousers, is standing and holding a folder of papers. She is looking at the young woman and appears to be speaking. The background is a bright, clean hospital room with a window.

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

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This information pack from Great Ormond Street Hospital (GOSH) explains the causes and symptoms of idiopathic scoliosis (curvature of the spine from an unknown cause). Surgery to correct the curvature is the main form of treatment offered at GOSH, so this pack gives details of the assessment process to help decide if spinal surgery is right for your child. It also tells you what to expect when your child comes to GOSH.

What is idiopathic scoliosis?

The spinal column consists of 33 spinal bones (vertebrae) that sit one on top of another from the pelvis to the base of the skull. Each vertebra has a hole through the middle for the spinal cord – this means that the bones protect the cord from injury.

Running off the spinal cord are numerous nerves that reach every part of the body. Muscles, tendons and ligaments are also attached to the spinal column – these support the body to stay upright and allow movement. There is a disc in between each vertebra, which acts as a shock absorber. The spine is naturally curved in three places from front to back.

Scoliosis is a lateral (side to side) curvature of the spine that can occur at any time during a child's growth. The spinal column curved and twists, which in turn rotates the ribcage. Over time, the curvature can progress or worsen, which causes changes to the spine, chest and pelvis and the organs contained within them.

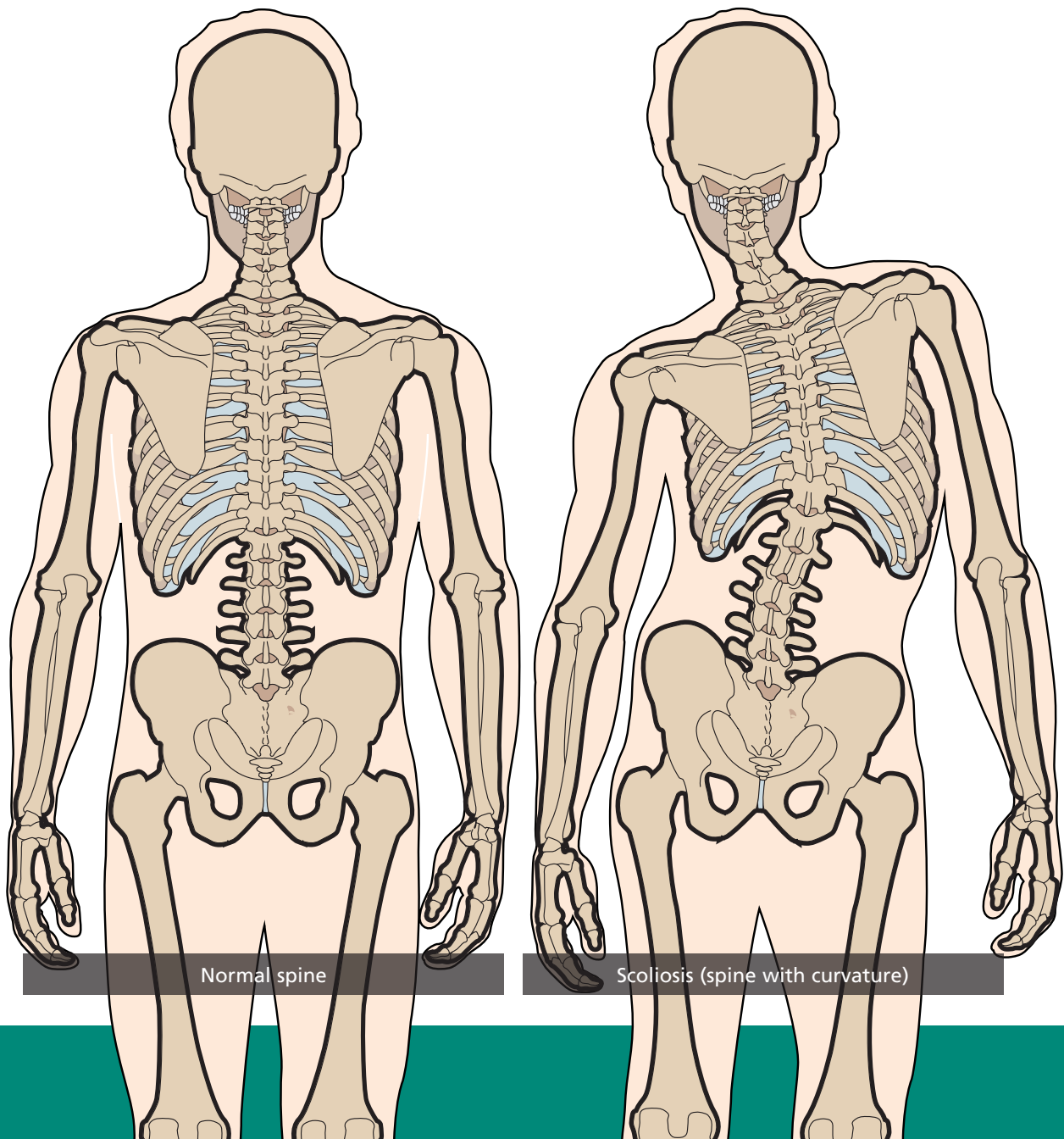
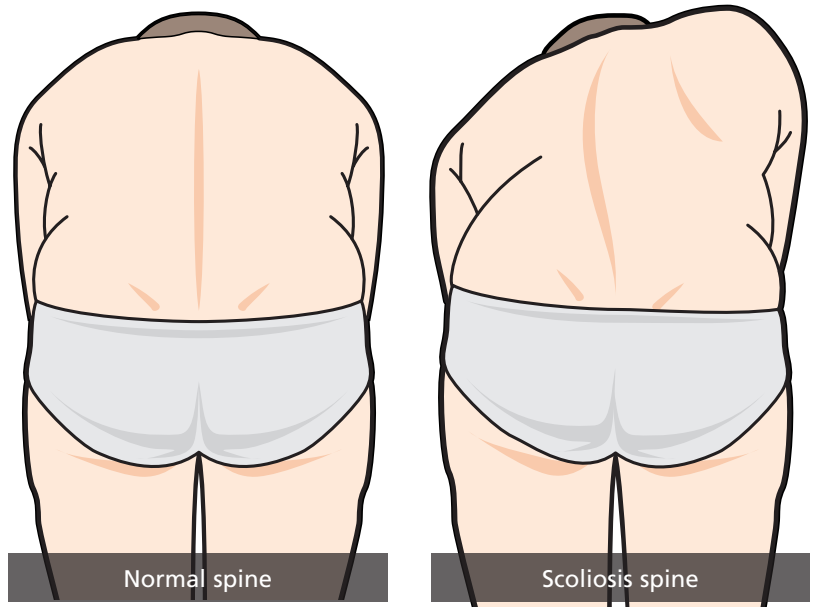
There are several types of scoliosis, but in 80 per cent of cases, the cause is unknown – this is referred to as 'idiopathic' scoliosis. There is no known way of preventing scoliosis.

What are the signs and symptoms of scoliosis?

Children with scoliosis may have one or more of the following:

- one shoulder is higher than the other
- one shoulder blade is more prominent than the other
- one hip is more prominent than the other, making the waistline appear uneven

In practical terms, this may mean that clothes do not seem to fit well or hang properly. If the curvature worsens, the changing position of the spine, chest and pelvis can affect how well the organs inside work, for instance, if the ribcage is twisted, the lungs may not be able to expand fully, causing breathing problems.



How is scoliosis diagnosed?

Scoliosis, especially when the curvature is severe, may be visibly obvious. In the early stages when the curvature is not so severe, it may only become noticeable when a child bends forwards. Imaging scans, mainly plain x-rays, are used to diagnosis scoliosis, monitor its progress and also measure the effects of treatment.



How is scoliosis treated?

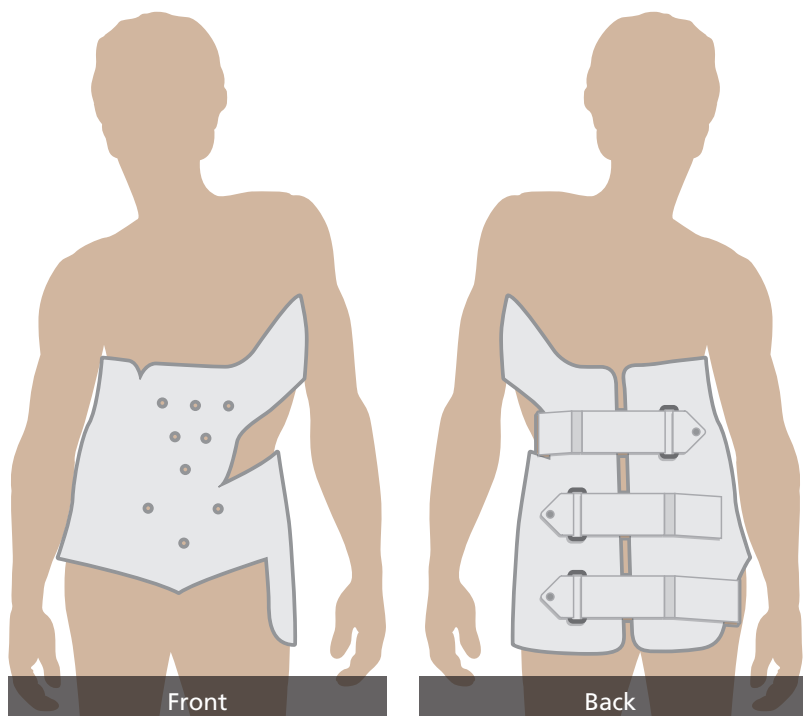
The aim of treatment is to stop the curvature progressing. There are a number of treatment options available – which is most suitable for your child will depend on their age, the severity and type of curve present as well as any other underlying health conditions, if known. The three main types of treatment are:

- Observation
- Bracing
- Surgery

Observation is often the only treatment needed, as most curves do not become more severe. A series of x-rays will be taken each time your child comes for an outpatient appointment. The surgeon will compare these with previous x-rays to see if the curve has progressed.

Bracing is needed if the curve becomes more severe and may help reduce further curvature. A plaster cast of your child's torso will be taken during an outpatient appointment so that the brace is custom-made for your child. Braces should be worn for 23 hours each day, removed only for personal hygiene and activities such as swimming or PE.

Surgical treatment may be needed for severe and/or progressive curvatures. More information about assessment for surgery follows.



The spinal surgery pathway at GOSH

At GOSH, we have developed a pathway for children and young people having spinal surgery. This pathway or outline of your child's plan of care is standardised, but can be adapted where possible to suit your child's needs. Spinal surgery is a complex procedure, so we want you to understand the benefits and risks of the operation so you and your child can make an informed decision about whether to go ahead.

Initial spinal clinic appointment

You will meet:

- A member of the Spinal Surgical Team
- A Spinal Clinical Nurse Specialist (CNS) if available

The aim of this appointment is to have an initial discussion with the team about the procedure proposed for your child, subject to further assessments of their needs. The Spinal CNS will discuss these assessments with you, so that we can plan what level of support you and your child need.

After the initial clinic appointment

Following your child's initial clinic appointment, the Spinal Surgical Team and Spinal CNS will make referrals for further assessments as required. They will explain to you why these assessments are needed. Your child may already have had some of the tests below at another hospital but as we need up to date information about their health, we may need to repeat them at GOSH.

Wherever possible, we will try to build these into the 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

The Clinical Psychologist within the Spinal Surgical Team is available to offer support to children and families at any point on the pathway. This could include support about specific anxieties about the operation, behavioural difficulties or any other emotional need related to your child's health or the proposed operation.

Magnetic Resonance Imaging (MRI) scan

An MRI (magnetic resonance imaging) scan uses a magnetic field rather than x-rays to take pictures of your child's body. The MRI scanner is a hollow machine with a tube running horizontally through its middle.

Your child will lie on a bed that slides into the tube. When your child is in the correct position, the radiographer will move the bed inside the scanner and then go into the control room. The scanner will make a continuous knocking sound throughout the scan, which can be quite loud, but we will give you and your child ear protectors to minimise any discomfort. If your child is watching a DVD, or listening to a CD, this will distract from the noise too.

The radiographer will warn you and your child when a loud noise is due by talking to them through an intercom. When the scan has finished, the radiographer will move the bed out of the scanner and your child can get up and leave. An MRI scan usually lasts between 20 minutes and an hour. This procedure may require sedation or a general anaesthetic which will be discussed with you by the team.

Please watch our podcast (short video film) about having an MRI, available at www.gosh.nhs.uk/medical-conditions/procedures-and-treatments/your-child-is-having-an-mri-scan/video-your-child-is-having-an-mri-scan/ or on the GOSH channel on YouTube™.

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



Investigation day

The aim of the investigation day is to ensure that we have as full an understanding of your child's health as possible to make an informed decision whether surgery is the best and safe option. The day is quite busy and runs to a timetable – we will give you a copy when you arrive. The investigation day will involve the following tests:

■ Height and weight

■ Blood tests

■ Lung function

These are breathing tests to see how well your child's lungs and breathing muscles are working. They will be instructed to take a big breath in and then blow out as hard as possible into a tube attached to a computer which has interactive games. The machine records how much air is blown out and how fast. It gives us important information about their airways. The measurements are repeated a few times to obtain the best values possible. Not all children are able to do these tests.

■ Cardiac (heart) assessment

Part of the assessment for spinal surgery involves making sure that your child is well enough to go ahead with the operation. It is important to make that their heart has not been affected as part of the wider problems related to your child's condition. Nearly all children and young people being considered for spinal surgery will have an electrocardiogram (ECG). An ECG measures electrical activity within the heart through sticky sensor pads put on your child's chest. You will be able to stay with your child throughout the scan.

They will need to take off or undo their top and lie on a bed next to the ECG machine. The technician will apply some sticky sensor pads on your child's chest, which they will then connect with wires to the ECG machine. Your child's heart activity will be recorded through the sensors and you will both be able to see the picture on the screen. The results are also printed on a thin strip of paper, which added to your child's medical notes.

■ Clinical photography

It is helpful to have 'before' and 'after' photos of your child. Clinical photography forms part of Medical Illustration based at GOSH. All our photographers are fully qualified and members of the Institute of Medical Illustrators. This means that they have to follow a strict code of conduct and update their skills regularly. Photos are usually taken in our studio but can also be taken in the operating theatre or wards. Please be aware that children may be asked to remove their top.

■ X-ray

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. The images are recorded on a computer so a specialist doctor (radiologist) can examine them and write a report. They are also used to plan surgery both before and during the operation.

People you will meet at investigation day

A number of healthcare professionals are involved in investigation day – they all have a part to play in assessing your child's health and working out whether spinal surgery is a safe option for your child. Please note that the Spinal Surgery team are not present on investigation day. If you have any questions about the pathway, please talk to your Spinal CNS. You will meet:

■ Paediatrician

The General Paediatric Consultant will take a detailed medical history including pregnancy and birth, all past illnesses and operations, immunisations and development and family history. They will also do a comprehensive physical examination to ensure that no medical problems are missed which could increase the risk of the general anaesthetic and spinal surgery. The general paediatric assessment may identify additional investigations which need to be done, for example x-rays or blood tests. Occasionally your child will be referred to other Paediatric Specialists for assessment. All of this is done to make sure that your child is medically fit for spinal surgery.

■ Physiotherapist

The physiotherapist's role is to assess your child's range of movement, muscle strength and reflexes in their arms and legs. They will also look at how they move about (mobilise) and can balance in a standing or sitting position. A physiotherapist will also ask your child if they have any breathing complications. All this information is important to ensure that the spinal surgery does not impact on your child's mobility or function afterwards.

After spinal surgery a physiotherapist will check your child's breathing, show them how to get out of bed, ensure they are safe walking and are able to climb stairs if needed. If you have a local physiotherapist they will be informed of your child's progress during their stay and their current needs on discharge home.

■ Occupational Therapist

An Occupational Therapist (OT) will assess your child's daily living skills both at home, school and in play/hobbies. This will identify potential difficulties that can be problem solved before surgery. This will allow your child to become as independent as possible so that they can go back to normal life after the operation.

■ Anaesthetist

An anaesthetist is the doctor who gives your child the anaesthetic medicine, cares for them during surgery and ensures that their pain relief is managed after the operation. You will first meet an anaesthetist on the investigation day. They will ask some questions about your child and any illnesses they might have, and they will discuss the anaesthetic options with you. They might also talk to you about any risks of the procedure, pain relief and how your child will be looked after afterwards. You can ask the anaesthetist any questions about the anaesthetic, or discuss any worries with them at this time. You will meet the anaesthetist who will look after your child during the operation when you come into hospital. They may ask some more questions and talk about the anaesthetic again. You can also discuss any concerns with them. There are many anaesthetists that work in our hospital, and after your child's procedure there will always be someone available to make sure they are comfortable.

Multi-disciplinary team (MDT) meeting

Once all the tests and assessments have been completed and reported, a group of clinicians will meet to review the proposed benefit and risk of spinal surgery for your child. The people involved in these discussions will include the clinicians you met on investigation day as well as some others who will be involved in your child's inpatient stay. Everyone will review and discuss your child's results to reach agreement about whether your child would benefit from spinal surgery or not. If they agree that your child would benefit, they will review what specific needs your child will have during their inpatient stay, for instance, if they could be admitted on the day of surgery or in advance.

Following this meeting, we will send you a letter stating whether your child is medically fit for surgery and an appointment to come to clinic so you can talk through the results and plan for your child.

- If the letter explains that the team have decided that the risks of surgery outweigh the benefits, the appointment will be with the Spinal Surgery team to discuss this further. If you would prefer to discuss this decision with the team that referred your child for spinal surgery, please let us know.

However, if they were not involved in the multidisciplinary team discussions, we encourage you to meet the Spinal Surgery team first and then see your referring doctor.

- If the letter explains that the team have decided that the benefits of surgery outweigh the risks, the appointment will be with the Spinal Consultant to discuss the operation further and address any queries. At this appointment, we will also ask you to give permission for your child to have the operation by signing a consent form.

Each spinal operation is unique. If you would like to discuss your child's operation further, please contact the Spinal Clinical Nurse Specialist team.

Getting ready for the operation

Once your child has had their 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. If your child is currently taking any type of contraceptive pill please contact one of the spinal clinical nurse specialists.

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 child's 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, this is not an exhaustive list there may be other illnesses that may cause cancellations. Please call the CNS team as soon as possible if your child is experiencing any of the following:

- 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

The morning of surgery

An important part of our daily routine is to keep ourselves clean – this is a major part of preventing infection – your child’s skin is the physical barrier that keeps out germs and bugs. It is also very important that they take good care of their teeth and gums – this too will help reduce their chances of getting an infection.

Any operation or procedure poses a risk of infection – the surgeon will discuss the specific risk to your child, as it depends on the type of operation your child is having. Almost all operations involve breaking the skin in some way – either through an incision (cut), through a cannula (thin plastic tube) placed into a blood vessel, or by having a tube in their mouth (to help them breath during their operation). The risk of infection getting inside the body can be reduced by having clean skin and good mouth care.

Why is it so important to have clean skin before an operation?

In addition to the surgical incision, it is likely that your child will have one or more cannulas inserted into a vein or a drainage tube from the operation site. Some children also need to have a urinary catheter (thin plastic tube placed into the bladder). All of these give germs a route inside the body. If the skin around them is dirty, the germs are more likely to travel through the cannula or drain. Having a thorough wash before an operation can reduce this risk.

Spinal wound infections can occur, they are normally managed with the patient going back to theatre for a wound washout. Long term antibiotics are prescribed and in some cases the possibility of metalwork being removed. This is why we would like to emphasise the importance of skin hygiene prior to the operation.

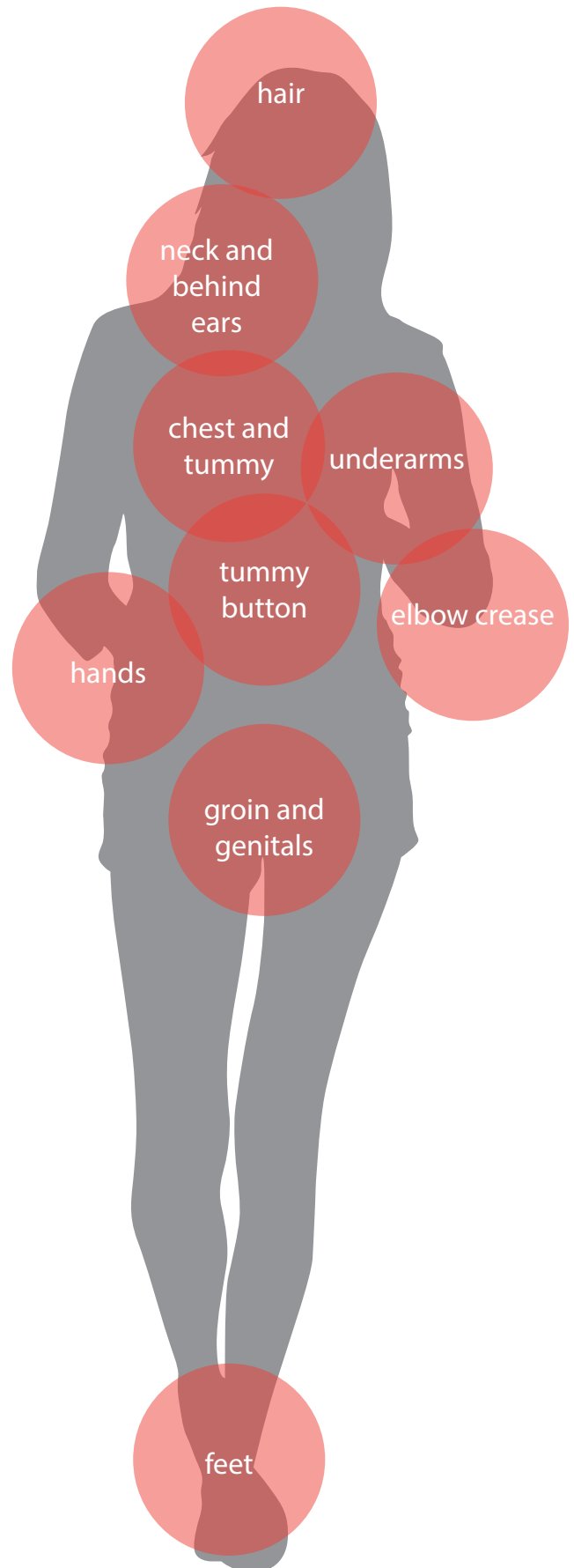
If your child suffers from acne please contact the CNS team prior to your operation date.

Does it matter whether my child has a bath or a shower?

No, either is fine. What is important is that your child uses liquid soap and a clean sponge or flannel to clean the skin. Having a bubble bath or just standing under the shower is not enough to remove germs. Afterwards, your child should dry themselves thoroughly with a clean towel. Damp skin can encourage bugs to grow. Wherever possible, your child should have their own towel that is not used by any other member of the family.

Does my child have to use special soap?

No. It is just as effective to use plain family soap but children often find liquid soap easier to use. However, if your child has an existing infection on their skin you may be given a different soap to use. Your clinical team will talk to you about this.



Which parts of the body does my child need to wash?

Your child should wash every part of their body thoroughly. The diagram below shows the areas to concentrate on particularly.

Should my child wash their hair too?

Yes. When you have washed your child's hair, please do not apply any gel, spray or oil as this could make the hair dirty again. If you suspect that your child has head lice, please warn us before the operation. We would prefer you to treat the head lice using a bug busting comb or treatment mousse before you come to GOSH. Your community pharmacist (chemist) can advise you about treatment methods available.

Why is good mouth care important?

Your mouth is important for eating, drinking, speech and breathing but it is also another defence against infection. Having a clean mouth and healthy gums can stop germs travelling inside the body.

If your child has teeth, they should clean them twice a day with fluoride toothpaste. On the morning of surgery, you should clean their teeth as usual, but not use mouthwash or swallow any water or toothpaste.

If your child does not have any teeth, you should check their mouth for any signs of infection, such as white spots, breaks in their gums or sore patches. If you find any of these signs, please tell your clinical team.

My child has a skin condition – should they still have a wash?

You should be able to follow your usual washing routine, as the soap-substitutes you use should be able to remove germs from the skin. If possible, on the morning of surgery, do not re-apply any ointments or emollients after washing. If you have any concerns about your child's skin condition, please talk to your dermatologist (specialist skin doctor).

Your child will be asked to wash the morning of surgery on the ward then asked to put on their hospital gown. Failure to do so may result in a delay or cancellation to your child's surgery.

Is there anything else we need to do?

It is important that your child does not have any nail varnish on their nails before the operation. Our anaesthetists use nail colour as an indicator of how your child is reacting to the anaesthetic so it is important that they can see your child's nails clearly. We also advise keeping your child's nails short so that they are easier to keep clean. Short nails will also stop any

skin damage if they are itchy after the procedure.

All wigs, weaves and hair extensions must be removed before surgery as it obstructs the spinal cord monitoring which is needed to carry out the spinal operation. All false nails and false eye lashes are an infection risk and need to be removed before admission.

Admission for surgery

Your child will be admitted either the day before the operation or on the day itself. You may have to come directly to the spinal ward – Sky Ward – or to Nightingale, the same day admissions unit. Your admission letter will clearly state when and where your child should come to be admitted. Information about both wards is available on our website at www.gosh.nhs.uk/parents-and-visitors/coming-hospital/ward-and-admissions-information.

It is important that your child does not eat or drink anything for a few hours before the anaesthetic. This is called 'fasting' or 'nil by mouth'. Fasting reduces the risk of stomach contents entering the lungs during and after the procedure.

You will be informed the night before the procedure of the time that your child should be 'nil by mouth' – in other words, have nothing to eat or drink before the anaesthetic. .

It is equally important to keep giving your child food and drink until those times to ensure they remain well-hydrated and get adequate nutrition. This may involve waking your child in the night to give them a drink which we recommend.

When you arrive on the ward, a nurse or doctor will check that nothing has changed with your child's condition and general health since the investigation day. If your child is admitted to Sky Ward on the day before the operation, we will explain the fasting times to you.

Some procedures carry a risk to unborn babies. These procedures include some (but not all) x-rays, scans and operations. The NHS Commissioning Board Special Health Authority and the National Institute for Health and Care Excellence (NICE) have said we have to check all girls aged 12 or older who are having any of these procedures to see if they are pregnant.

All girls 12 years and over require a routine pregnancy test. We have to test girls even if they tell us they are not sexually active or have not yet had their first period. It is possible for a girl to get pregnant before it is evident that she has started her periods. More information regarding testing can be found at www.gosh.nhs.uk/medicalinformation/procedures-and-treatments/routine-pregnancy-testing-before-treatment.

Once this has been completed, your child will need to change into a theatre gown and surgical stockings, before getting on a

theatre trolley ready to go to theatre. They will have a heated blanket to keep warm. Two people can come to theatre but will need to leave as soon as your child is under anaesthetic. You will be taken back to Sky Ward to wait – or you can wait elsewhere if you prefer but please make sure we have your current mobile phone numbers.

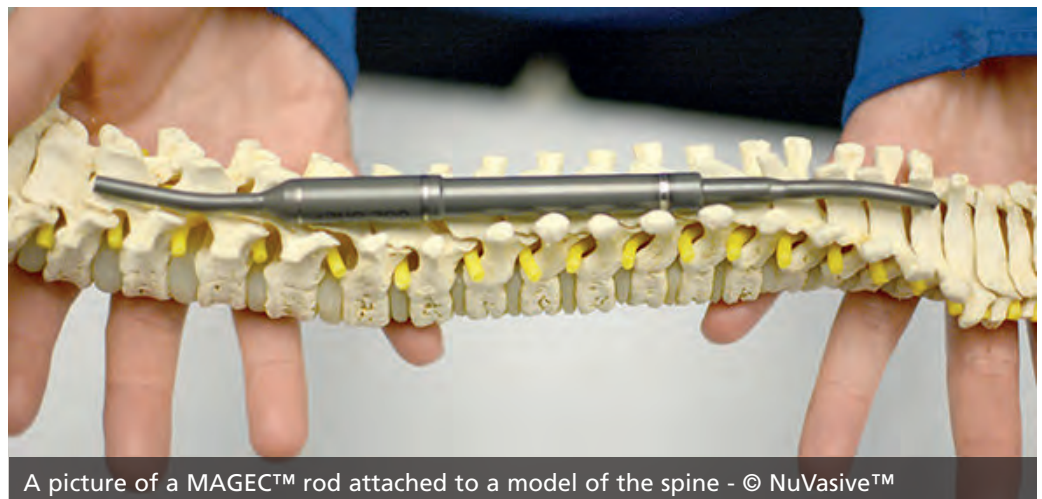
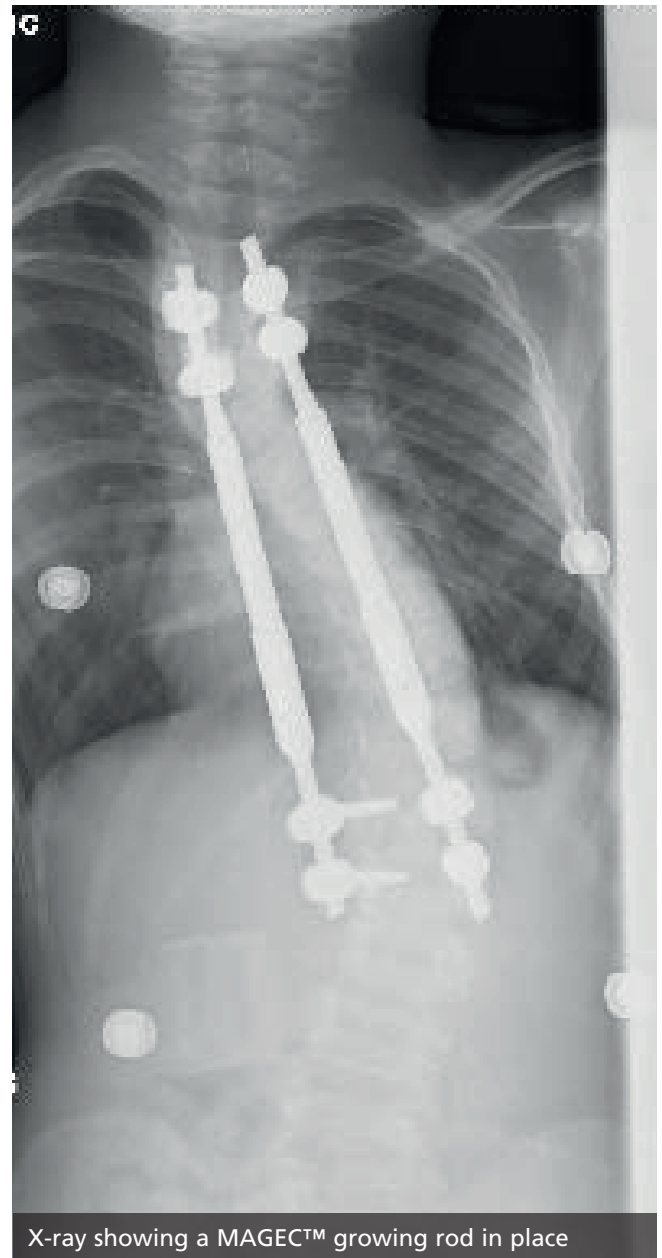
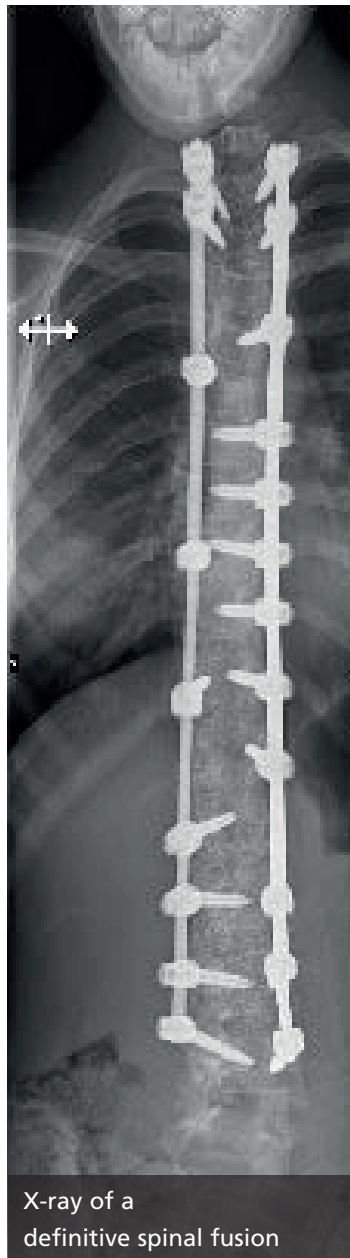
What does the operation involve?

Spinal Fusion:

There are two main approaches to spinal surgery: anterior, where the surgical approach is through an incision (cut) at the side of the chest wall, and posterior, where the approach is through an incision on the back. One or both of these approaches may be needed. The surgery may be done in one or two stages, and on average will take three to six hours. The bones in the affected part of the spine are fused together and held in place with one or two metal rods.

Insertion of Growing Rods:

In younger children, a growth rod is often inserted to allow the spine to grow as the child grows. There are a few different types of growing rods available. The ones that are more commonly used at GOSH are MAGEC™ rods and traditional growing rods, both of which are inserted during this operation. These will be lengthened several times as your child grows and may need replacing. When there has been enough growth, your child will have a 'definitive spinal fusion' operation. Which type of rod is used depends on your child's spinal condition – not all curves are suitable for MAGEC™ rods – so the decision is made by the spinal surgeon.



Are there any risks?

All operations carry some degree of risk, and spinal surgery is associated with some specific risks. Your surgeon will discuss these fully with you and explain which are most applicable to your child. The aim of the investigation day is to identify these risks before the operation to help you decide whether surgery is suitable and safe for your child.

Having an anaesthetic does not usually cause any problems, but the anaesthetist will discuss how your child's existing condition may affect the anaesthetic used and side effects afterwards. Damage to the large blood vessels around the spine is rare but can result in serious blood loss.

Infection can be a risk with any surgery, but your child will have antibiotics to reduce the chance of any problems with the operation site. The nurses will also check the operation site regularly. In rare cases, further visits to the operating theatre to wash out the wound might be needed.

There is a small chance of damage to the spinal cord or nerves running from it with any spinal surgery. If damage occurs, it could result in weakness of the legs or paralysis, bladder and/or bowel dysfunction. The spinal cord is monitored throughout the operation to minimise this risk.

The aim of this operation is to fuse the spine so if this does not occur, the rods and/or screws inserted to support the spine may break requiring further surgery. Finally, there is a small chance that the surgery may not work as expected, for instance if the rods fail or do not straighten the spine sufficiently. If this happens, the surgery may need to be repeated.

What happens afterwards?

Spinal surgery takes several hours and following the procedure, children return to the High Dependency Unit (HDU) on Sky Ward. All young people having spinal surgery need close monitoring afterwards and this is why they are admitted to HDU. This is a self-contained four-bedded bay on Sky Ward. There is 24 hour visiting for parents but you will not be able to stay at the bedside. We will ensure you have hospital accommodation on site so you are able to get some rest and visit your child as wish.

Most children leave HDU and finish their recovery on Sky Ward before being discharged home. In some cases, only one night in HDU is needed after an operation, but in others, particularly after complex or major surgery, children may need to stay a number of nights in HDU. Each day, the ward team will assess each child in the HDU to review whether they still need closer monitoring or whether they could be transferred to the main ward. Occasionally, children may be transferred from the HDU to our Paediatric Intensive Care Unit (PICU) if they become unwell or require more help with their breathing, for instance.

Your child will be made comfortable with a pain relief infusion. Initially your child will have an intravenous (into a vein) drip delivering antibiotics and fluids directly into the bloodstream. They may also have a tube through the nose into their stomach to stop them being sick. There may also be a drain from the chest wound to collect fluid, as well as a catheter into the bladder to drain urine.

As your child recovers, these tubes will be removed and your child will be able to start eating and drinking again. Three days after the operation, the clinical nurse specialist will check the wound underneath your child's dressing. If the wound is clean and dry and there is no sign of infection, the intravenous antibiotics will be stopped. When your child is starting to recover, they will have an x-ray to check the position of the metalwork.

During their stay following your child's operation, in addition to all the routine care, they will be visited by a member of staff from the Surgical Site Infection Surveillance (SSIS Team). A surveillance officer will collect information about your child's surgery and progress. If there are any issues these will be discussed with your surgical team and the infection control team as necessary.

Your child's operation site

The operation site will be covered in SteriStrips®, which are sticky paper dressings. These keep the edges of the operation site together so it can heal well.

We put a 'honeycomb' dressing over the top of the SteriStrips®. This is a padding 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.

Following initial recovery, most children will stay on Sky Ward until they go home. Each day, children will be seen by the physiotherapist and other professionals who will help them with their recovery. It is essential that children move once able following surgery and as directed by the physiotherapist.

Your child may need to wear a spinal brace to support the spine as it heals. The orthotist will make a plaster cast of your child's spinal area and the brace is custom-made from this for your child. The surgeon will advise whether it is possible to remove the brace for short periods of time, for example to have a shower.



SteriStrips® closing the operation site



Honeycomb dressing over the top of the SteriStrips®

Looking after your child's skin during their stay

Sometimes, for a variety of reasons, people who are unwell develop pressure ulcers. They can be very painful and can lead to complications. Most people think that pressure ulcers only affect older people, but this is not true.

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.

How can we prevent pressure ulcers?

The first thing we will do is look closely at your child's skin as soon as they are admitted. We use an assessment form that helps us measure how active your child is, whether they are able to tell us of any discomfort, whether their blood circulation is good and whether they are in nappies or pads. If we decide that your child is 'at risk', this does not mean that they will definitely develop a pressure ulcer. It just alerts us to put special equipment and nursing care in place to stop one developing.

If your child is 'at risk'

There are a variety of things we can do to reduce the chance of a pressure sore developing. We will discuss our plans with you as soon as we have identified your child as 'at risk' of developing a pressure sore. Basic details of what care might involve include:

- **Turning and repositioning** – This helps relieve pressure on specific parts of the body. We might turn your child over or reposition their arms and legs. We aim to move your child every two hours or more frequently if needed. There will be times when moving your child is not an option, but we will explain if this is the case.

- **Special 'air' mattress** – These are different to regular bed mattresses and also relieve pressure on your child's skin. Again, there are circumstances where an air mattress is not suitable, but we will explain this to you.
- **Protective dressings** – These can help to protect the skin and act as an extra layer of padding between the skin and a device or the bed. They can also help protect from rubbing and you will be given advice on how to use them.
- **Nappy and pad changing** – If your child uses nappies or pads, we will change them more frequently than usual to prevent any moisture building up on your child's skin. We also use creams and sprays to protect against moisture and nappy rash.
- **Aqueous cream** – We use this instead of soap when we wash your child, as it is moisturising but not greasy. It is particularly useful if your child develops nappy rash, as it is non-irritating. If you use specific products to wash your child, please tell us about them and bring in a supply if you want to continue to use them.
- **Barrier cream or spray** – This helps protect the skin against urine, faeces and sweat and comes as a cream or a spray.

If your child develops a sore area, we will ask our Tissue Viability team to review it. They will suggest how to treat the sore area, which could involve special dressings that encourage healing. Very rarely, the area may need a surgical procedure to help it heal and we would make a referral to our Plastic Surgery team to advise on this.

How you can help us

Please tell us if your child has a history of pressure ulcers. At GOSH, we practise 'family centred care', which means that we like you to continue caring for your child in hospital in the same way you do at home if you feel able. When you are washing and dressing your child, you can help us by looking closely at your child's skin and telling us about any changes to your child's skin.

You can also help us when we are turning or repositioning your child, helping us with moving them and telling us about favourite sleeping positions, for instance. Creased or rumpled bed sheets can rub so please straighten them if they become messed up when moving your child.

Please encourage your child to move if they are able, as this will reduce the risk of pressure sores. A good balanced diet and hydrating fluids are especially important for those at risk of developing a pressure ulcer. If your child is on special feeds or under the care of a dietitian, please let their team know.

Going home

Your child is likely to be in hospital for five to seven days, although in a few cases, a child may need to stay longer for medical reasons. Your child will also need to meet certain goals before discharge, which we will explain. For instance, we would expect children to be eating, drinking and weeing as usual, to have had a bowel movement (had a poo), walk around the ward and up and down a flight of stairs and have a post-operative whole spine x-ray. Ward staff will arrange transport home for one parent and your child.

When your child is ready to go home, you should expect to receive a discharge summary. The discharge summary acts as a record of what happened during your child's hospital stay, what medications have been prescribed, and details of any follow-up appointments or any further treatment required at GOSH. Your family doctor (GP) and referring hospital will also receive a copy of the discharge summary to inform them that your child has gone home and to explain any care or support you may need.

If you did not receive your child's discharge summary when you left the unit, please wait five working days, if it does not arrive then please call the unit your child was admitted to and speak to one of the members of the team.

Looking after your child at home

We may arrange for your local children's community nurse to visit to check your child's wound or, if your child is mobile, you will need to make an appointment with your practice nurse at your family doctor (GP) surgery. In the meantime, if you notice any of the following, you must contact clinical nurse specialists at GOSH for advice:

- Redness
- Swelling
- Oozing
- Pain
- Tenderness

To enable our Surgical Site Infection Surveillance (SSIS) team to monitor your child's wound following discharge, we need your help so we will telephone you at home to ask about your child's wound. This will usually be about 30 days after your child's operation.

When we telephone you, we will ask the following question:

■ Has your child's wound healed without any problems?

If it has, we will not need to ask you any further questions.

However, if problems have developed, we will carry on to ask:

- Whether you reported the problem to your child's surgical team at GOSH
- Whether the wound has been red
- Whether it has felt hot
- Whether it has oozed clear fluid
- Whether it has leaked pus (yellow or green fluid)
- Whether the wound has broken open
- Which, if any, healthcare professionals you have seen about the wound
- Whether they took any samples from the wound for testing
- Whether your child has been given any medicine
- Whether your child has been admitted to another hospital

Everyone at GOSH is committed to the prevention of infections following surgery. An infection following surgery is an unpleasant experience. To help us understand why infections develop and prevent them we need to ensure we know about any that occur.

Being in hospital can disrupt a child's normal day-to-day routine, so it can take some time to get life back to normal. We encourage your child to be as active as possible (avoiding sports as explained below) but they may still feel tired. Your child has had a big operation and it will take some time to recover fully.








When you lift your child, make sure they are supported under the buttocks and around the back. Avoid lifting your child under the arms. Please be mindful of your back as well when lifting or moving your child.









We will give you a week's supply of pain relief medicines to take home. After this, you will need to get a repeat prescription from your family doctor (GP). It may be wise to order this as soon as you get home just in case delays occur.









When your child's operation site has been clean and dry for 10 days, they can have a shower, which puts less strain on the back than a bath. If you do not have a shower, your child should continue to strip wash until after the follow up appointment. Do not let the operation site soak until it has healed completely.

Up and about

The ward physiotherapists will have started to help your child get up and move about before going home so you should carry on as they showed you. If they gave your child any stretches or exercises to do, make sure they 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 your child can and cannot do but as a rough guide:

Activity	Timescale after surgery			
	6 to 12 weeks	3 to 6 months	6 to 12 months	1 year
Walking 	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
Yoga or pilates 	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
Swimming 	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
Cycling 	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
Dancing 	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
Gym 	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
Jogging 	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

Activity	Timescale after surgery			
	6 to 12 weeks	3 to 6 months	6 to 12 months	1 year
Table tennis or badminton 	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
Tennis or squash 	None	Begin by patting a ball on the spot, gradually increasing duration Avoid excessive twisting No overarm serving	Increase duration and movement	No restrictions
Netball or basketball 	None	Practise your ball skills with gentle throwing and catching drills	Start pivoting or changing direction Increase your speed	Competitive match play allowed
Athletics 	None	See jogging Otherwise no other athletics	Re-start running events	Re-start jumping and throwing events
Hockey 	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
Football 	None	On the spot kicking and stopping the ball, dribbling No tackling	Increase speed and power when kicking the ball	Competitive match play allowed
Rugby 	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
Golf 	None	Pitch and putt or crazy golf only	Gentle golf swing	

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

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

Back to school

Your child will be well enough to return to school four to six weeks after the operation. While your child is away, try to keep in touch with the school, for instance, inviting school friends to visit or arranging for course work to be sent home.

When your child is ready to go back to school, we suggest they return part-time until ready for a full school day. Heavy lifting, including school bags and books weighing more than 1 to 2kg, is not allowed for about six months after the operation. Talk to your child's teacher or special educational needs and disabilities coordinator (SENDCo) about this and other adjustments to the school day.

Your child will not be able to do PE or contact sports for at least three months following surgery. They should also miss swimming for six months afterwards, although gentle hydrotherapy may be possible after the follow up appointment. Please talk to your consultant about any sports your child wants to re-start following surgery.

Follow up appointment

Your child's follow up appointment will be arranged for around six weeks after discharge – they will have an x-ray followed by an appointment with the consultant. You and your child will be able to come to this appointment by public transport. After this appointment, we will arrange further appointments as decided by your consultant. Most children are completely discharged from the Spinal Surgery team one year after the operation.

Lengthening of growth rods

As your child grows, they will need to come back to GOSH to have the growth rods holding their spine straight lengthened.

Your child will have regular outpatient appointments with the Advanced Nurse Practitioner for Spinal Surgery to lengthen the MAGEC™ rods using an external remote control approximately every three months. The lengthening process does not require any anaesthesia, sedation or pain relief.

If your child had traditional growth rods, they will need to return to GOSH every six months or so for a series of minor operations. Lengthening is carried out through a small incision on the back and is carried out as a day case. Your child will spend the night after the procedure in the Patient Hotel in Weston House. They will have to come back to the ward to have their wound checked but will then be able to return home.

What is the long-term outlook for children who have had spinal surgery?

Once your child has had a posterior spinal fusion the aim is for your child to require no further spinal surgery for the rest of their lives. A posterior spinal fusion will stop spinal growth, but growth may continue in the areas that have not been fused. After puberty most of the growth occurs from the legs. They will be followed up for two years after the operation.

In terms of the future for your children, girls can go onto having normal pregnancies. It is important that the doctors are aware of your child's surgery, especially how low the fusion goes so it does not interfere with an epidural. There are few limitations with choice of career apart from if your child is interested in the armed forces or police force – we would recommend contacting the employer before applying.

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.

My daughter's scoliosis journey

Like all parents, my children are my world. I have three children and when there is something wrong with any of them, whether emotionally or physically, it has an effect. The journey I'm about to tell you about involves Ella, my youngest.

Ella is 13 years old and although she is full of life and has a smile that wins the hearts of those around her, she struggles on various levels both socially and emotionally. With a diagnosis of ASD, ADHD and severe learning difficulties, the family have had to adapt to the very different way of thinking that makes Ella, Ella.

When Ella was eight years old, she was diagnosed with scoliosis and has been under the care of GOSH ever since. After regular monitoring over the years, her scoliosis deteriorated and it was agreed that she would be placed on the surgery waiting list.

This now made everything feel very real and it's from this point that my 'mummy worrying' (as the kids call it) kicked off, not only about the surgery itself, but also about how we were going to prepare Ella and how would she ever cope with the enormity of what lay ahead.

When Ella was placed on the waiting list, I entered this period of needing to know a date for surgery. Not only so I could start preparing Ella, but also so that I had a timescale to work towards. This was an unsettling time because we were very much in limbo. After six months of being on the waiting list, we received a date for the Investigation Day. It was from this point that things started to move quite quickly.

The Investigation Day is designed to reduce the number of visits for the patient, and all the necessary tests and required medical history is gathered in one day. It was during this appointment

that we met key members of the team. The day itself was incredibly informative and helpful for Ella because she was able to meet the people who would be involved throughout her stay and beyond. As Ella is very visual and needs lots of reassurance, Loren was kind enough to spend time with her, showing her around Sky Ward and explaining the procedures that lay ahead. Ella was able to see first-hand where she would be staying and have all her questions and concerns answered!

Surgery day came around so quickly in the end! We arrived at Great Ormond Street on time, which is rare for us because we are late for most things! We were greeted by Loren and Rachel who were now familiar faces to Ella. It's the little touches like this that help Ella the most. She was swiftly prepped for theatre and before we knew it, we were accompanying her down to the anaesthetic room. Giving Ella a kiss goodbye after she was asleep was probably one of the hardest things I have ever done. I never usually let my guard down but inside, my heart was breaking.

Arriving at GOSH



The wait was long, very long. We did not know what to do with ourselves. All the risks associated with the surgery were going around my mind and knowing that we had given consent, made everything so much harder. Eventually, the call came to say that she was out of theatre. I couldn't wait to see her, to check that our Ella was still Ella. But then, the fear of seeing her for the first time set in. What would she look like? How much pain would she be in? How long would it be before she was back to her smiley self again? So many questions. Loren had promised to be there for when she woke up and sure enough, she was. At that moment in time, Loren was our familiar face and despite Ella being disorientated from the anaesthetic and her face very swollen, we felt reassured that everything was normal. She was moved to HDU where she received the care and attention she required to control her pain and was able to sleep during the early stages in her recovery. The Physio team came around the following morning and encouraged her to sit up. She was not in a good way at this stage but bless her heart, she did everything she was asked to do. They talked her through every process, and in return, gained her trust. She worked hard to impress them! That afternoon, they arrived back at her

bedside and announced that they would try to get Ella on her feet. At the time, I thought... 'good luck with that one'! Anyway, with careful manoeuvring, a calming manner and lots of reassurances, Ella did just that! Now, this did bring a few tears to my eyes I can tell you (and in public too!), because not only was my brave girl on her feet less than 24 hours post-surgery, but she had gained a few inches in height!

The following days were a mix of good days and bad days. Ella struggled on several levels, but the nursing team were amazing and helped her to help herself. Gradually, as the days went by she grew stronger and more confident with the feeling she was experiencing in her back. It was then time to prepare for the return home to continue her recovery. This was an event in itself because it was by ambulance, complete with 'blue & twos'! Ella absolutely loved this attention, even if it did zap her energy! The first few days at home were tough. As she was still being quite sick, she had stopped eating and drinking altogether, and was losing weight by the day. There were days when she just didn't have the energy to walk as part of her physio and I tended to know when to encourage and when to allow her time to rest. After about a week of more bad days

than good days, she suddenly turned the corner in her recovery, and literally went from strength to strength.

Within four weeks of surgery, she decided that she wanted to return to school part time. We worked alongside the school to ensure that she was kept safe. I couldn't help but feel that this was a little too soon, but we have been guided by Ella throughout this journey, so why would we stop her now?! By allowing her back to school, she was able to regain some much-needed normality and routine back in her life, which she relies on.

We are now five months post-surgery and I can honestly say, I am in awe of what Ella has achieved in a very short space of time. I will be eternally grateful to her Consultant and the team of professionals who have all had a hand in her recovery.

If your child is about to embark on the same journey, please be kind to yourself, always be honest with your child and remember, that your child WILL come through this. Children have the most amazing positivity when they need it, and with the fantastic support from all at GOSH, and having you beside them, they will be a lot more resilient than you will ever give them credit for. Good luck.

By Kate (Ella's proud Mummy)



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 or call their helpline on 020 8964 1166.

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