



Spinal surgery at GOSH

At Great Ormond Street Hospital (GOSH), we have developed a pathway for children and young people having spinal surgery. Spinal surgery is a complex procedure, so we want you to understand the benefits and risks of the operation so you can make an informed decision about whether to go ahead. This information sheet explains what will happen from your child's initial clinic appointment through to discharge, which clinicians you may meet and what to expect. This pathway or outline of your child's plan of care is standardised, but can be adapted to suit your child's needs.

The pathway will be coordinated by one of our Spinal Clinical Nurse Specialists (Spinal CNS). Throughout the process, they are available to provide information, advice and support as well as answering any questions you or your child have at any point. You can call them on 020 7813 8238 from Monday to Friday from 8am to 6pm.

Initial clinic appointment	2
Spinal clinic	2
Combined Neuromuscular/Spinal clinic	2
After the initial clinic appointment	2
Psychology	2
Magnetic Resonance Imaging (MRI) scan	2
Sleep study	3
Cardiac assessment	3
Investigation day	3
Multi-disciplinary team meeting	5
Admission for surgery	5
During your stay	6
Going home	6
Getting about	7
Wound care	7
Washing	7
Sports	7
School	7
Follow up appointment	7
Useful numbers	7



Initial clinic appointment

Spinal clinic

You will meet:

- A member of the Spinal Surgical Team
- 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.

Combined Neuromuscular/Spinal clinic

You will meet:

- A neuromuscular consultant
- A Spinal Orthopaedic consultant
- Muscle Clinical Nurse Specialist (CNS)
- Spinal Clinical Nurse Specialist (CNS) if available
- Spinal team clinical psychologist

The aim of this appointment is to assess the spinal deformity for severity and progression, and to discuss how best it can be treated, depending on the underlying neuromuscular disorder.

If spinal surgery is considered, we will discuss the indications and best timing for surgery, the benefits and risks and alternative management, if any. This will include the initial discussion about the proposed spinal surgical procedure and a plan for assessment of risks because of their underlying neuromuscular condition. If there is anxiety about spinal surgery or there is a pre-existing emotional or behavioural difficulty in association with their neuromuscular disorder, this will be flagged up for psychology support.

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. 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. 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.



Sleep study

If your child has a known respiratory condition or one that affects breathing in some way, we may request a sleep study. A sleep study is a test to see what happens to your child's body when they are asleep. It involves an overnight stay in hospital and it is essential that one parent or carer is able to stay overnight with their child. Initial results may be available the following day but a full analysis will be sent to the team before the multi-disciplinary team meeting.

More information about sleep study tests is available at www.gosh.nhs.uk/medical-information/procedures-and-treatments/sleep-study.

Cardiac 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 tests to make sure that their heart is working as it should. These will involve heart scans including an Echocardiogram (Echo) to look at blood flow through the heart, an electrocardiogram (ECG) to look at your child's heart rhythm. The ECHO and ECG are normally carried out on the investigation day. Information about ECHO is available at www.gosh.nhs.uk/medical-information/procedures-and-treatments/echocardiograms/ and ECG at www.gosh.nhs.uk/medical-information/procedures-and-treatments/electrocardiograms/

Some children need a specialised Cardiac MRI scan to check their heart function. This will usually have to be scheduled as a separate appointment. Information about Cardiac MRI scans is available at www.gosh.nhs.uk/medical-information/procedures-and-treatments/cardiac-mri-scan-without-sedation-or-anaesthetic/ If your child is having a cardiac MRI, you will be asked to attend an outpatients appointment to discuss the results of this.

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

■ **ECHO/ECG** – An ECHO is only necessary for some patients.

■ **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.

■ **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. You will be asked to sign a consent form for this.

■ **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.

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.

If your child is a wheelchair user their seating system will be assessed so plans for seating post-surgery can be put in place.

Following the investigation day, the team will contact your local services to negotiate the equipment and services required to manage your child's are back at home. Following the spinal surgery, an OT will assess your child's moving and handling, seating and positioning needs again so they can return to their normal daily routines.

■ **Anaesthetist** – An Anaesthetist is the doctor 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 procedure there will always be someone available to make sure you are comfortable.

■ **Respiratory doctor** (if your child has an underlying respiratory condition – As the lungs are near the spine, they will be affected by the surgery and it is therefore important to ensure your child's respiratory function ('how well they breathe') is as good as possible beforehand. The respiratory doctor will carry out a full assessment including a detailed respiratory



history, clinical examination, a lung function ('blowing test') and a chest X-ray.

Your respiratory doctor will ask about your child's history of respiratory problems focusing on respiratory infections and any longer term respiratory symptoms such as cough, breathlessness or asthma that are present. Additional tests such as a sleep study may be required to help get a more comprehensive picture of respiratory function, for instance, if your child already uses a ventilator

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.

Multi-disciplinary team 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 outlining the discussions and a copy of the test results along with 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.

Information about spinal surgery

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

Further information about scoliosis, is available from the Scoliosis Association – call them on 020 8964 1166 or visit their website at www.sauk.org.uk. Information about treatment using magnetic growth rods is available from the manufacturer's website at www.ellipse-tech.com/magec-patients

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 Puffin the same day admissions unit. Your admission letter will clearly state when and where your child should come to be admitted.

Information on Puffin Ward can be found at www.gosh.nhs.uk/parents-and-visitors/coming-to-hospital/ward-and-admissions-information/puffin-ward/ and about Sky Ward at www.gosh.nhs.uk/parents-and-visitors/coming-to-hospital/ward-and-admissions-information/sky-ward/.

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. Fasting times are provided in your admissions letter - in broad terms, this is six hours for food (including milk), four hours for breast feeding and two hours for clear fluids before the procedure.

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. All girls 12 years and over require a routine pregnancy test, more information regarding testing can be found at www.gosh.nhs.uk/medical-information/procedures-and-treatments/routine-pregnancy-testing-before-treatment.

Once this has been completed, your child will need to change into a theatre gown ready to go to theatre. 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.

Spinal surgery takes several hours and following the procedure, children either return to the High Dependency Unit on Sky Ward or to the Paediatric Intensive Care Unit (PICU) – we will have told you which before the operation. All young people having spinal surgery need close monitoring afterwards and this is why they are admitted to HDU or PICU. Both units offer 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. All children who go to PICU will spend some time in HDU once they are well enough.

Information about PICU is available at www.gosh.nhs.uk/parents-and-visitors/coming-to-hospital/ward-and-admissions-information/paediatric-intensive-care-unit-picu.

During your child's stay

Following initial recovery, most children will stay on Sky Ward until they go home. Recovery from spinal surgery usually takes between five and ten days. Each day, children will be seen by the physiotherapist and other professionals who will help them with their recovery. Your child will also need to meet certain goals before discharge, which we will explain. It is essential that children move once able following surgery and as directed by the physiotherapist.

All children receive pain relief tailored to their needs. Pain relief is usually given into a vein (intravenously or IV) at the start, changing to medicines taken by mouth (orally) when your child feels like eating and drinking again.

We will check your child's spinal wound three days after surgery – if it is clean and dry, their antibiotics will be stopped at this point.

Going home

Once your child has recovered well, the staff on the ward will arrange your discharge home. We will give you advice on pain relief and any necessary medication. All children go home by stretcher ambulance following spinal surgery. There will only be room for one parent in the ambulance.

When you get home, there are a few guidelines about your child's activity which we will explain fully.



Getting about

- We strongly encourage normal activity, including using stairs.
- Walking for up to two miles a day is also encouraged.
- Your child should continue to do the exercises taught by the physiotherapist.
- If your child was a wheelchair user before the operation, the physiotherapists and occupational therapists will discuss and plan mobilisation and time spent sitting.

Wound care

- Your child should have their wound checked by your family doctor (GP), practice nurse or community children's nurse, around a week after discharge.
- If the wound is healing well, it will no longer need a dressing and your child can have a shower.

Washing

- Your child can have a shower when their wound is dry. Bathing is not encouraged until after the follow up appointment.

Sports

- Full contact sport can be resumed from six months to a year after surgery – please discuss with your consultant.
- No swimming for three to six months. Hydrotherapy can sometimes be started after the follow up appointment but please check with your child's consultant.

School

- Your child will be able to go back to school after the follow up appointment.
- Some children may need to return to school gradually, for instance, attending morning or afternoon lessons only for the first few weeks.
- For the first three months, we advise that they leave lessons a few minutes early or late to avoid getting rushed and banged into between lessons.
- They should also avoid carrying a heavy (1-2kg) school bag or get a friend to help.

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. If your child is a wheelchair user or public transport is not suitable, please discuss this with the team so that transport can be provided if needed.

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.

Useful numbers

Spinal CNS – 020 7813 8238

Monday to Friday from 8am to 6pm

Appointment queries – 020 7813 8235

Monday to Friday from 8.30am to 4.30pm