

Curves in the spine

Information for patients, families and carers



We've written this booklet as a guide to scoliosis and hyperkyphosis, two kinds of curve in the spine. We hope it will help to answer some of your questions about treatment and surgery for curves in the spine in children and young people.

Our specialist children's spinal team will be caring for you and your child. We work closely with other doctors, nurses and physiotherapists who all have specialist experience in caring for children.

We also help family members and carers to understand their child's spinal condition and care, so that they can be involved in decisions about their child's treatment.

Scoliosis

Scoliosis is a sideways curve of the spine that can happen along any part of the back. It can also cause a twist, which makes the ribs more prominent on one side. While this can happen at any time during a child's growth, it is often caused by fast growth spurts during puberty.

There are three different kinds of scoliosis:

Idiopathic scoliosis

'Idiopathic scoliosis' is a curving (or 'curvature') of the spine that has no known cause. It's the most common type of scoliosis, accounting for 80% of cases. Idiopathic scoliosis affects 1 in 2000 people and is more common in females than males.

Neuromuscular scoliosis

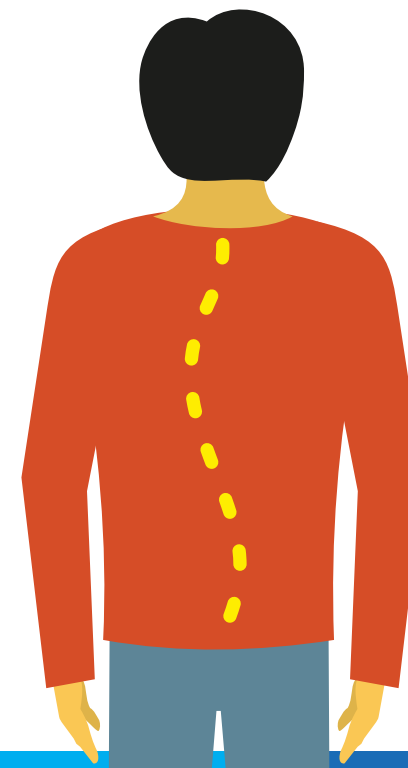
'Neuromuscular scoliosis' is a curving of the spine in a child who has a neuromuscular condition. It's the second most common type of scoliosis we treat.

These curves tend to get worse during growth spurts. Children who use wheelchairs tend to have more pronounced curves, which may make sitting uncomfortable.

Congenital scoliosis

'Congenital scoliosis' is a curving of the spine caused by an abnormal bone shape or structure. It's relatively uncommon and at present the cause is unknown. Each case of congenital scoliosis is different; some cases are unlikely to get worse but some can change suddenly when the child grows.

Children with congenital scoliosis can also have problems with their bladder, kidneys and heart. This is because these organs develop at the same time as the spine. When we assess their scoliosis we may need to do an ultrasound scan and MRI scan. We will discuss this with you at the clinic.



Hyperkyphosis

Hyperkyphosis is an exaggerated forward curve of the spine, which is sometimes associated with Scheuermann's disease (wedging of the spine bones). This usually happens during puberty and is more common in males than females. Hyperkyphosis can sometimes cause pain but this pain usually settles with time.



Treating scoliosis and hyperkyphosis

We create a treatment plan for each individual child based on the size of their spinal curve and the likelihood of it progressing. There are three options for treatment:

Observation

The spinal team will take x-rays at the clinic while your child is still growing to monitor the curve. This may be the only treatment your child needs.

Bracing

We sometimes use braces to help slow or stop a curve progressing in a young child's spine. If your child's doctor decides this is an appropriate treatment option, they will discuss this with you at the clinic. Unfortunately, braces can't correct existing curves in the spine and they often can't prevent a curve from progressing eventually. It's important that your child follows their doctor's instructions and wears the brace as directed.



Surgery

We may discuss the possibility of surgery with you. Surgery can stop the progression of the curve and improve its appearance. It can help a child with breathing, sitting up and using their arms. We may need to assess your child's breathing and heart, and do some scans, such as MRI scans, before we operate.

Spinal surgery for children

Spinal surgery for children can involve a range of different procedures, depending on the child's age.

Spinal surgery for young children

For younger children we can use a method of surgery in which we insert metal rods into their back. This helps to prevent the curve getting worse. The rods are fixed at the top and bottom of the spine but can slide apart in the middle to allow them to grow. There are different ways we can do this, which we'll discuss with you at the clinic.

Spinal fusion

An older child can have a spinal fusion, which is an operation to join or fuse some of the bones of the spine. This helps to straighten the curve and prevent it getting worse. It may not completely correct the curve.

In the operation, the surgeon will insert rods into the child's back and put a bone graft (a small piece of bone from elsewhere in the spine) over the top.

There are three ways that we can do this, depending on the child's overall medical condition, the amount of curve in their back, and the type and flexibility of the curve:

- **posterior spinal fusion:** surgery to the back of the spine through an incision (surgical cut) along the child's back. This is the most common method.
- **anterior spinal fusion:** surgery to the front part of the spine through an incision in the child's side.
- **anterior and posterior spinal fusion:** surgery to both the front and back parts of the spine. Sometimes when the curve is stiff we have to release the front of the spine to make it more flexible before we do the correction at the back.

We won't be able to get the spine perfectly straight after the operation but we hope to get the curve so small that no one else would notice it. If the curve in your child's spine is very stiff, we may not be able to get the spine as straight as we would like to, but this is unusual.

Before your child's operation

Once we have decided that surgery is the best form of treatment for your child, it may take several months to arrange a date for their operation.

When this has been arranged, we will send you some information through the post.

You will receive:

- a letter with the date of your child's pre-assessment appointment
- an 'admission' letter with the date of your child's operation (the scheduled date may be within a few weeks of when you receive the letter)
- an information leaflet about Southampton Children's Hospital services, which will tell you what to bring with you to hospital

Occasionally, operations have to be rescheduled due to circumstances outside our control.

Once you have received your admission letter we recommend that you contact:

- your child's occupational therapist (OT) as your child may need extra equipment for a short time to make life easier when they come home from hospital
- your child's physiotherapist
- your child's school
- your community wheelchair services team, if your child uses a wheelchair (it may need to be adapted after their operation)
- your child's social worker (if they have one)

Staying healthy before the operation

It's important that your child stays fit and active before their operation. Encourage them to carry on with all their normal activities and let us know if they develop any infections or new illnesses close to the operation.

We may recommend that your child starts taking iron supplements approximately six weeks before their operation. This can help to build up their blood stores so that they are less likely to need a blood transfusion and can recover more quickly.

If we have recommended iron supplements for your child, you can ask your GP or high street pharmacist for more information.

If your child is taking any medication that can affect blood clotting, such as the oral contraceptive pill, they should stop taking this at least six weeks before their operation if possible. Speak to their consultant if they are unable to stop taking their medication for any reason (such as very heavy periods or the possibility of becoming pregnant). For advice about how to stop taking medications or about alternative forms of contraception please see your GP.

Your child's pre-assessment appointment

Your child will have their pre-assessment appointment at the ward one week before their operation. The appointment will last for four or five hours. This allows us to carry out routine investigations to make sure your child is ready for their operation:

- **x-rays:** We may do some special x-rays so that the surgeon can see how flexible your child's curve is and decide which procedure is best for them. Sometimes these x-rays give us new information which helps us to adjust the plans for the operation. We will discuss this with you and your child at the appointment.

- **blood test:** Your child will have a blood test with our expert children's blood test team. We use local anaesthetic creams or sprays to help numb the area before taking a small sample of blood.
- **consent:** The surgeon will discuss the operation in detail with you and your child and answer your questions. As a parent or carer, you will then be asked to sign a consent form. Your child can also sign it if they wish.
- **anaesthetic review:** A specialist doctor will tell you and your child about having a general anaesthetic (medicine to make your child sleep) for the operation. They will explain about 'nil by mouth' times when your child mustn't eat anything, and also about pain relief.

The pre-assessment appointment is also an opportunity for you to meet the staff involved with your child's care and ask them questions. You may like to write down any questions beforehand and bring this with you to the appointment.

The day before the operation

Your child will need to come into hospital the day before the operation. Please remember to bring in any regular medications, clearly labelled with your child's name.

When you arrive, please register at ward G3. We will complete some paperwork with you and then show you and your child around the ward.

We will also take you to visit our neurophysiology team who specialise in brain and nerve connections. We'll do a spinal cord monitoring (toe twitching) test with your child to make sure all their nerves are working as they should be before the operation.

On the day of the operation

Your child can eat normally up until the day of their operation. If they are having overnight gastrostomy feeds (food through a tube) we will stop this six hours before the operation. On the day itself, they can drink water up until two hours before the operation.

Your child will need to remove any make-up, metal jewellery and nail varnish for their operation.

As a parent or carer, you can come with your child to the operating theatre waiting room, and one parent or carer can be with them while they are given their anaesthetic medicine. Once they are asleep, you can then wait on the ward or go to Ronald McDonald House, our accommodation for parents and carers of children in hospital. You can leave the hospital during the operation but you must stay within a 20 minute drive.

After the operation

Your child will wake up either in the recovery room outside the operating theatre or in the paediatric intensive care unit (PICU). This will depend on what surgery they have had and how their general health is. You will be able to see your child soon after they wake up.

When your child wakes up they will see lots of machines like computers around them. These help us to make sure that they are well. The machines will sometimes beep and make other noises but that doesn't mean anything is wrong. Your child may also be given oxygen through a face mask or prongs that sit inside their nose.

When your child wakes up they may have some or all of the following tubes:

- **central line:** a tube in the neck to give them medicine
- **cannula:** a small tube into the arm or hand to give them pain relief, anti-sickness medicines and fluid until they feel like drinking

- **epidural catheter:** a very small tube into the back giving them pain relief
- **urethral catheter:** a small tube into the bladder to drain away urine
- **drain:** a tube into the chest and/or wound to remove fluid from the operation site

Pain relief

The pain team will visit your child after the operation and on a regular basis throughout their stay in hospital. They will make sure your child has the pain relief they need to be as comfortable as possible. They can also give you guidance about pain relief when you go home.

On the ward

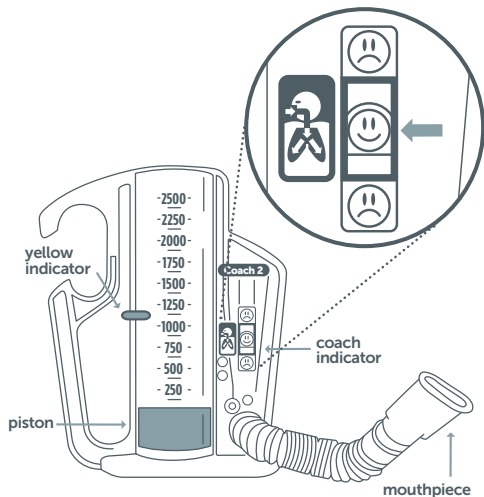
Most patients stay in hospital for five to seven days after their operation. We will monitor your child throughout their stay and gradually remove the tubes.

Physiotherapy

Your child's back will ache after surgery but moving around will help. We'll encourage them to move as soon as possible. The physiotherapists (muscle and movement specialists) will visit to check their chest and to teach them some exercises for breathing and moving in bed. This will progress to sitting on the edge of the bed and taking a few steps if they are able to.

Breathing exercises

Your child will need to take deep breaths and cough every hour when they're awake so that they don't get a chest infection. We'll give them an "incentive spirometer" (a special measuring box to breathe into) to help them practise their deep breathing.

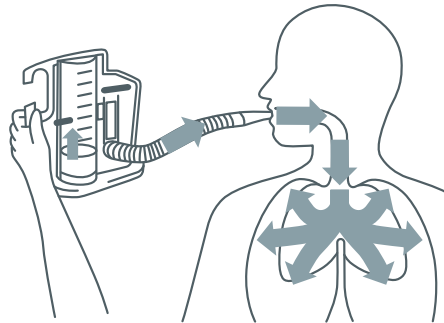


Incentive spirometer

Exercise 1:

Using the incentive spirometer, take a slow, deep breath in through the mouthpiece. The yellow disc should move up. Try to get it above 500mls. Make sure you keep the small yellow ball in the middle smiley face.

Repeat this exercise five times.



Exercise 2:

Wrap your arms around your chest (use a towel or pillow if needed) and let your arms help you have a strong cough. Coughing may be a little sore, but holding your chest like this will help. Try to cough up any phlegm and spit it out.

Repeat these two breathing exercises three times.

Bed exercises

Exercise 1:

Wiggle your toes.

Exercise 2:

Point your foot away and then turn it up towards you. Repeat this exercise five times.



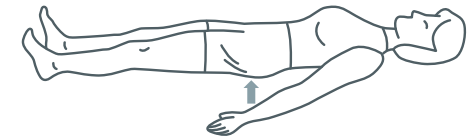
Exercise 3:

Bend one knee so that your leg makes a triangle shape pointing upwards and your foot is flat on the bed. Push your foot down into the bed and hold for five seconds. Repeat this exercise five times with each leg.



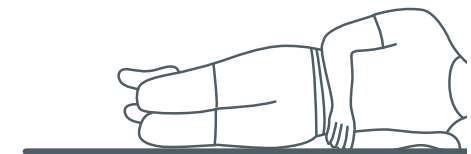
Exercise 4:

Squeeze your bottom together and hold for five seconds. Repeat this exercise five times.



Exercise 5:

Lie on your back and bend your knees. Roll onto your side, trying to keep your shoulders, back and hips in a line.



When your child goes home

If your child usually walks, we'll make sure they are able to go up and down stairs safely before they go home.

If your child usually uses a wheelchair, we'll make sure they are able to sit comfortably in their chair before they go home.

Our occupational therapist will assess the wheelchair and see if it needs adapting for your child to sit comfortably. They may need a temporary wheelchair due to the change in the shape of their body. While they're in hospital we will use hoists to help them move around.

As they become more comfortable we will gradually increase the amount of time they spend in the chair. We'll also take an x-ray of their spine to make sure that they're ready to go home.

When you leave hospital, we'll give you the details of our email and telephone advice services so that you can contact us if you have any concerns.

About 10 days after the operation, your child will need to visit the nurse at your GP surgery to have their wound checked. Sometimes

there are suture (stitch) knots that need trimming. If your child may need a hoist to move around, let your GP surgery know when you arrange your appointment. Some GP surgeries don't have hoist facilities so they may need to organise a home visit for you.

Your child will have a review at our outpatients clinic about three months after the operation and another review about a year after the operation. They may also need to see the physiotherapy team again.

If your child has neuromuscular scoliosis we may refer them for a special physiotherapy programme, which may include hydrotherapy (physiotherapy in water). It can take up to 12 weeks for a child to get back to the level of mobility they had before the operation.

Your child can start using bio oil on the wound as soon as it has healed. For the first year after the operation, your child should keep their wound covered and use sun block all over (as always) when they are out in the sunshine.

Everyday routines

Encourage your child to return to a normal daily pattern as soon as possible. It's best to sleep at night, be active during the day

and avoid lying in bed for daytime rests. Remind them to move around regularly so that they're not sitting still for long periods.

Where possible, they should try to carry out their normal routines independently (such as washing and dressing). Bending at the hips and knees will help them when picking objects up off the floor.

Your child can return to school when they feel able to. It usually takes four to six weeks for a child to feel ready. It may be easier to do half days to start with.

Exercise and activities

If your child uses a wheelchair, slowly increase the time they spend in it. They may need to take regular breaks out of the chair for several weeks.

If your child is able to walk, they can increase their walking one day at a time. Start with a five minute walk and then add another five minutes to the walk each day, until they are able to walk for at least an hour.

Your child can carry on with activities such as jogging, dancing and cycling on a static exercise bike as soon as they feel able to. They can also start swimming again once their wounds have healed.

After your child has had their three month review at the outpatient clinic

they can return to moderate and high contact sports such as netball, rugby, football and hockey.

After 9 to 12 months, they can take part in high speed impact activities such as roller coaster rides and skiing.

Risks of surgery

It's very unlikely that problems will occur during spinal surgery but, as with all operations, there are possible complications.

- **Infection:** Surface wound infections occur in approximately 2 to 4% of patients. These infections usually improve after a week of taking antibiotics. Deeper infections, which occur in less than 1% of patients, may need to be treated with further operations.
- **Bleeding:** During a big operation like spinal surgery, patients can lose blood and some may need to have a blood transfusion. We use special medications and anaesthetic techniques to prevent this, and have dramatically lowered the number of people who need blood transfusions after their operations. We can also use special machines and drains to receive the blood a patient loses and feed it back into their system. With these measures in place, only 1% of patients will need to have a blood transfusion.

- **Numbness and nerve damage:** One common side effect of spinal surgery is numbness in the thigh after the operation. This isn't a sign of major nerve damage and usually gets better very quickly. In some rare cases, patients notice pain, decreased feeling and weakness in part of their legs after the operation. The wound may feel a bit tingly after surgery and then feel numb for many months. This can be due to bruising around the nerves. It usually gets better within a few months after the operation, but for some people the nerves never fully recover.
- **Persistent pain:** After spinal surgery some patients may have pain that lasts. This could be caused by an infection, by problems with the metal rods inserted during the operation or by the spine not fusing fully. Sometimes the cause is unclear. Patients with persistent pain may need a course of physiotherapy or further surgery.
- **Paralysis:** The risk of paralysis is extremely low, affecting less than 0.03% of patients having routine scoliosis surgery. During the operation, while your child is asleep, we will use special equipment to monitor their nerves throughout the surgery. If the nerves and spinal cord will be at risk, we may not be able to straighten the spine as much as we would like to.
- **Further operations:** After their spinal surgery, some patients develop another curve or have problems with the metal rods that were inserted. Approximately 5% of people will need another operation after spinal surgery.

Looking ahead

Pregnancy

Having spinal surgery shouldn't affect a woman's chance of becoming pregnant, carrying a baby or delivering a baby normally in the future. However, we would recommend waiting for at least a year after the operation before becoming pregnant, as spinal surgery patients need to have follow-up x-rays during this time. Back pain during pregnancy is common and normal. There is some evidence to suggest that women who have had a spinal problem of any nature may have more back pain during pregnancy. However, if they return to normal fitness after delivering the baby their back pain tends to disappear.

Women who have had scoliosis surgery can have an epidural or spinal block for pain relief during child birth as long as it is placed below their surgical scar. This is because the fusion or metalwork from the operation will be behind the scar. The obstetrician (specialist pregnancy doctor) or midwife may need to check with the spinal team before giving a pregnant woman this pain relief.

A healthy lifestyle for the future

After your child has recovered from their spinal surgery, we hope they will lead a full and active lifestyle. If they use a wheelchair we aim for them to be comfortable enough to spend all day in it and participate fully in any activity they choose.

Most adults who have had scoliosis surgery as a child don't go on to have related issues or clinical problems as an adult. Sometimes people who have had spinal surgery develop problems with their spine many years later but this is unusual. Speak to your child's GP if you are concerned.

We run spinal clinics specialising in adult scoliosis. Ask your nurse or your GP if you'd like to find out more.

For all of us, if we stay fit, active and healthy, we're less likely to have problems with our spines. People who don't do much physical movement (due to working at a desk or long periods of studying for example) tend to have worse problems with back pain than people who are fit and active.

Contact us

If you have any questions or concerns, you can contact us using the details below:

Consultant spinal surgeons:

Mr Evan Davies, Mr Chris Dare and Mr Steve McGillion

Paediatric consultant

anaesthetists: Dr Ollie Ross, Dr Gareth Jones, Dr Erica Dibb-Fuller, Dr Andrew Baldock and Dr Paul Sutherland

Email: childrens.spinal@uhs.nhs.uk

Secretary: **023 8120 5173**

Children's spinal nurse specialists:

Katie Webber and Jo Newman

Email: childrens.spinal@uhs.nhs.uk

Telephone: **023 8120 3729**

Mobile: **07826 892351**

G3 Ward

Telephone: **023 8120 6486**

Find out more about coming into hospital

For further information about getting ready to come into hospital while you wait for your child's admission letter, visit our website www.uhs.nhs.uk/childrenshospital and download the children's services booklet.

If you need a translation of this document, an interpreter or a version in large print, Braille or on audiotape, please telephone **023 8120 4688** for help.