

# **WELCOME**

At The Portland Scoliosis and Spinal Surgery Centre, we take great pride in being the only dedicated paediatric and young adult private spinal and scoliosis unit in the UK.

Based at The Portland Hospital, part of HCA Healthcare UK, The Scoliosis and Spinal Surgery Centre is led by four renowned spinal surgeons - Mr Jonathan Lucas, Mr Mark Harris, Mr Stewart Tucker and Mr Thomas Ember, all of whom hold parallel senior clinical consultant posts at Great Ormond Street Hospital and the Evelina London Children's Hospital.

Our surgeons are supported by an expert multidisciplinary team of paediatricians, specialist spinal nurses, physiotherapists, anaesthetists, orthotists and play therapy specialists at The Portland Hospital. Together they offer integrated surgical and non-surgical care for young patients experiencing the full range of spinal problems, from recurring sports and trauma injuries, to congenital and developmental scoliosis and all other paediatric spinal pathologies.



Jane Whitney-Smith Chief Executive Officer The Portland Hospital

If you choose to have surgery to improve your spine and prevent it from getting worse in the future, be assured our dedicated team will be on hand to make you feel as comfortable as possible throughout your stay with us.



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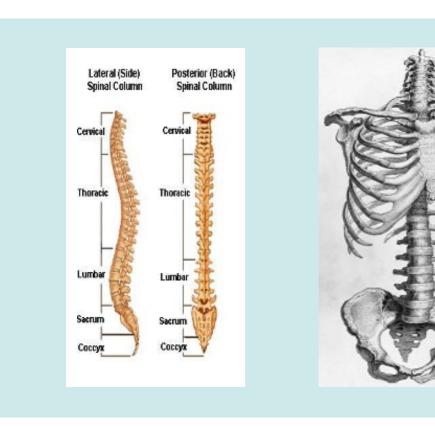
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### **ABOUT SCOLIOSIS**

# The spine

The spine is the strong and flexible central support which holds your head and body upright, allowing your neck and back to bend and twist. The spinal column also protects your spinal cord, which is a collection of nerve tissue that carries messages from your brain to the rest of the body.

The spine extends from the skull down to the pelvis and is made up of 33 individual bones called vertebrae. These vertebrae are stacked on top of each other and form into five groups:



### The structure of the spine is as follows:

- Seven cervical vertebrae in the neck (C1-C7)
- Twelve thoracic vertebrae in the chest (T1-T12)
- Five lumbar vertebrae in the lower back (L1-L5)
- Five fused vertebrae in the sacrum
- Four fused vertebrae in the coccyx

These vertebrae are linked together by a series of mobile joints (facet joints) and discs - soft, gel-like cushions found between each vertebrae that help absorb pressure and keep bones from rubbing against each other.

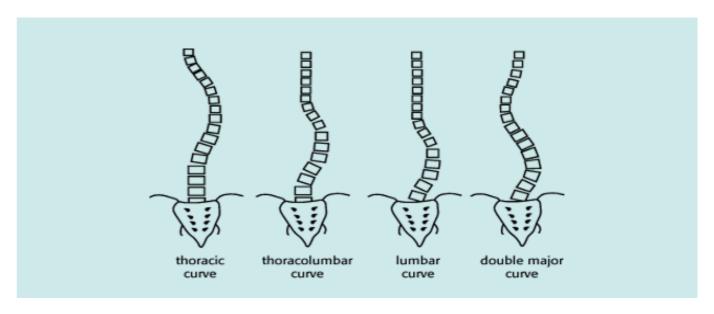
There are also strong ligaments and many sets of muscles around the spine that stabilise the vertebrae and help control movement.

### What is scoliosis?

Scoliosis (from Greek: skolíõsis meaning "crooked") is a lateral (side to side) curvature of the spine which can occur at any time during a child's growth as the vertebrae rotate.

The ribs are attached to the spine and therefore rotation results in the formation of a rib hump which children or parents may notice as asymmetry around the shoulders, back or waist.

# The main types of scoliosis



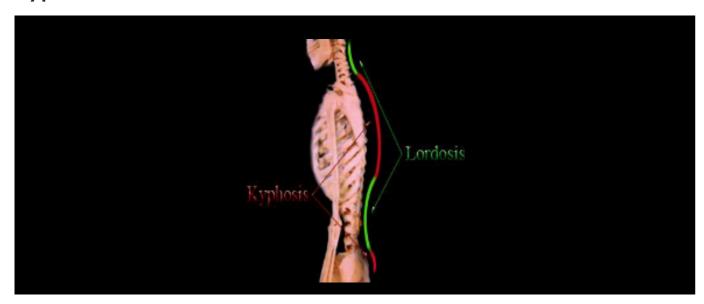
The type of scoliosis diagnosed is dependent on what area of the body the spine is curved towards:

- Thoracic scoliosis spinal curve in the chest area
- Lumbar scoliosis spinal curve in the lower part of the back
- Thoracolumbar scoliosis a curve between the thoracic and lumbar spine
- **Double major curve** a curve in the thoracic and lumbar spine

Your spine may also develop another curve which is known as a 'compensatory curve'. This is your body's attempt to keep you as straight as possible and your head vertically above your pelvis.

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# Kyphosis and lordosis



The spine has an 'S' shape like curve when looking at it from the side, allowing for even distribution of weight. The 'S' shape helps a healthy spine withstand all kinds of stresses. In normal posture the lower back curves into the body as a hollow. This inward curvature is called lordosis. The part of the back that sticks out (most notably the shoulders) is called kyphosis.

### What does this mean?

Kyphosis is defined by an excessive outward curve of the spine and may cause a deformity such as a humpback or hunchback. Lordosis is defined as an excessive inward curve of the spine in which the back may appear swayback, the buttocks more prominent and your posture appears exaggerated.

A scoliosis with additional kyphosis is known as kyphoscoliosis.

### Scheuermann's disease

A common cause of kyphosis is Scheuermann's disease. This is a condition affecting the normal formation and growth of some of the vertebrae in the thoracic or thoracolumbar spine. Many with Scheuermann's disease often also have an excessive lordotic curve in the lumbar spine; this is the body's natural way to compensate for the kyphotic curve above.

Patients suffering with Scheuermann's kyphosis cannot consciously correct their posture and often complain of lower and mid-level back pain. It is more common in boys than girls and commonly occurs in adolescence.

### WHAT CAUSES SCOLIOSIS?

There are four main types of scoliosis in children and young people:

- Idiopathic where the cause is unknown
- **Syndromic** when the curvature is part of a recognised disease pattern
- **Neuromuscular** where the cause is related to a neuromuscular condition which affects the nerves and muscles
- Congenital where the spine does not form properly when a baby develops in the womb

Scoliosis is rarely present at birth but usually develops in the early teenage years (9-15 years of age). It can develop slowly or quickly depending on its cause.

# Idiopathic scoliosis

#### What causes scoliosis?

Idiopathic scoliosis means that in an otherwise healthy person the spine is curved or twisted. The cause of why this occurs is not known. It is not caused by carrying heavy objects (such as heavy school bags on one shoulder), sports or physical activities, poor standing or sleeping postures, or a lack of calcium in the diet, and does not develop as a result of anything the child or parents/carers did or failed to do.

Idiopathic scoliosis accounts for most spinal curvatures (around 70-80%) and can be early onset (before age of 10 years) or late onset (after the age of 10 years). It affects two or three children in every 1000 and it can develop at any time during childhood and adolescence.

It is more common in girls than boys, most commonly occurring at the start of adolescence. There is also a genetic connection of those with a scoliosis having a direct relative with a curve.

### **Symptoms**

The main effect of scoliosis is the alteration in body shape. Some people may feel self-conscious about the alterations to their body shape and it may affect their confidence and perception of their appearance.

In other cases, another person such as a family member notices the curve. It can be distressing for the parents/carers when they see body shape alterations, but these deformities can develop quickly, especially in a growth spurt, and may not be as noticeable under clothes.

#### If the curve is in the chest area you may notice:

- A rib hump/prominent shoulder blade
- One shoulder may be higher than the other
- Asymmetric size or location of the breast
- · Asymmetry of the loin creases with one hip appearing to stick out more from the other

### If the curve is in the lower back you may notice:

- An uneven hip prominence making the waistline appear asymmetrical so clothes do not hang properly
- The patient may lean a little to one side

Scoliosis does not normally present with any other symptoms, including pain. However, the condition may cause back ache during a growth spurt due to structural change.

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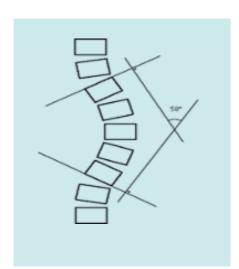
### Are there any restrictions to activities?

Unless specified otherwise, before surgery you can continue with any of your normal activities and exercise as freely as comfort allows. You will not do any damage to your spine or cause any progression to your scoliosis. Your spine is not unstable - just curved.

### How is scoliosis treated?

The aim of surgical treatment is to stop the curve getting worse and to straighten the curve as much as possible (usually achieving about 70% correction).

The choice of treatment depends on your age, the type and severity of the curve, the underlying diagnosis and how well your lungs work.



### What happens with a surgical procedure?

The surgeon will assess the shape of your back through the Adams Forward Bend Test. If a person with scoliosis bends forward with their legs and arms straight, a clear rib bulge will be visible from behind.

The surgeon will assess how the curve is progressing through X- rays of the spine and measuring the Cobb Angle:

- Minor degrees of scoliosis (<20 degrees) may need no treatment but a specialist will regularly monitor the child
- In more moderate forms of scoliosis (20-40 degrees) the use of a spinal brace may be needed (to keep the spine as straight as possible)
- In more severe cases of scoliosis (>50 degrees) spinal surgery may be required

It is difficult to predict which curves will continue to progress and require surgery later, especially if the patient, e.g. your child, is young and skeletally immature.

Your curve may also be described within the King and Lenke Classification. These are useful assessment tools used by Surgeons in categorizing and measuring curves.

# Complementary therapies

There is no reliable evidence to suggest that techniques such as, osteopathy, chiropractics, reflexology or acupuncture make any difference to treating scoliosis.

Curves that are mild to moderate may not increase and those that are progressive will continue to curve regardless of what is done. However, flexibility and increased muscle strength with physiotherapy and exercise can be a helpful factor in recovery.

Some people find muscle relaxing techniques such Pilates, hydrotherapy and massage useful.

### SURGICAL INTERVENTION

Surgery is usually recommended for patients with a curve greater than 40 degrees that is continuing to progress, and curves greater than 50 degrees at skeletal maturity.

The main objectives of surgery are to straighten the spine as much as possible, and maintain correction so that the curve will not continue to progress into adulthood.

This is achieved by fusing the vertebrae along the curvature and then supporting these fused bones with screws and metal rods attached to the spine.

Most surgery is performed posteriorly (down the middle of the back). However some curves (often those that are mainly at the thoracolumbar junctions T12-L1) require anterior surgery, which is performed through an incision on the side of the body.

More rarely, both approaches are required.

Your surgeon will decide which procedure will be the most appropriate for you.

### What happens if I choose not to have the operation?

If your curve is greater than 50 degrees, it is likely to progress as you go into adulthood. This can continue to increase at a rate of 1-2 degrees every year which will eventually lead to a significant deformity.

Some of the severe cases of scoliosis can lead to pain, restriction of breathing, pressure on the heart, and difficulty with physical activities.



### Posterior correction and fusion

This approach involves an incision on the back. Your surgeon will inform you how long your scar will be as this depends on how many vertebrae are involved in the curve.

### **During surgery**

During this method, the muscles are temporarily detached from the spine to allow the surgeon to access the bones. Some facet joints may be removed to provide more flexibility to the curve.

Screws and hooks are inserted into the vertebrae and act as anchors. These anchors are used to pull the curved spine into a straighter position and then they are attached to strong metal rods. The rods maintain the new position of the spine while the bones fuse together over the next 1 to 2 years. Synthetic bone graft is added to the bones to strengthen the fusion and finally the muscles and skin are sutured back into position.





### Anterior correction and fusion

Some curves may be treated anteriorly (although the majority require posterior surgery). In anterior surgery, the incision is from the side.

### **During surgery**

The anterior approach may require the removal of a rib. Using this technique, the diaphragm can be released from the chest wall and spine, enabling your surgeon to get a clear view of the thoracic and lumbar spinal vertebral bodies.

Some discs are removed and this releases the spine. Screws are then placed in the vertebral bodies and the curve is straightened and held in position with a rod.

The fusion of the spine is obtained by the piece of rib that was removed. This bone becomes the bone graft that will create the fusion as it is added to the spaces left by the removal of the discs.





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# Two-stage surgery

In severe cases, two procedures may be required:

- **1.** For patients with a **very stiff curve** (a curve with very little flexibility) it may be necessary to perform two operations usually a week apart:
- Stage 1- **anterior release** (where discs are removed from the spine to loosen up the curve)
- Stage 2 posterior correction and fusion





These may be performed separately with a 1-2 week recovery between stages. In severe cases, traction may be required during the recovery stage to gently stretch out the spine before it is corrected and fused.

- **2**. For patients with **two structural curves** (double major curve) it may also be necessary to perform two operations:
- Stage 1-anterior correction and fusion (to address the lumbar curve)
- Stage 2 **posterior correction and fusion** (to address the thoracic curve)

These operations are usually performed one week apart.

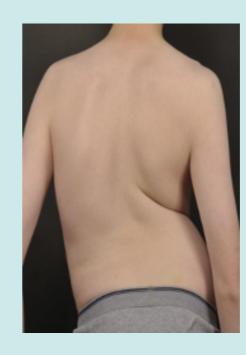




### Before and after scoliosis correction:









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# Correction of kyphosis

The posterior approach is used to treat kyphosis:





#### The wound and scar





6 Weeks after anterior correction

1 year after posterior correction

If you have had the posterior procedure then your scar will be down your back. Your surgeon will tell you how long the scar will be, as this will depend on how far he needs to take the correction and fusion. If your operation is the anterior approach, your scar will be on your side (usually the left side).

# Growing rod system

In young children with scoliosis, fusion may need to be delayed to allow for continued growth. In such cases, growing rods may be used.

If the curve was left untreated until the child was older, the curve may develop into a significantly large deformity that may be too difficult to correct when older. Alternatively if the spine was fused at a young age this would stop growth of the trunk. This can affect lung development and would result in a short body.

### Managing scoliosis

Growing rods control the deformity and gradually straighten the spine while enabling it to grow. This procedure is performed by attaching adjustable rods to the spine.

After the initial operation, the rods need periodic (usually 6 monthly) lengthening over several years. These usually result in a 1-2cm length increase each time. A small incision (approximately 5cm) is made into the middle of the existing scar to adjust the rods.





For the insertion of the growing rods, children usually require a 3-4 day hospital admission but each periodic lengthening surgery is a short operation that usually only requires an overnight stay.

Eventually, usually around the age of 10-12 years old, these children will go on to have the 'definitive spinal fusion' surgery. (By 12 years old the trunk has reached most of its full growth potential).

Children will need to wear a back brace during the programme to help protect the rods.

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#### MAGEC rods

Treatment for early onset scoliosis has progressed greatly over the last decade. Instead of using growing rods that need surgery every six months to lengthen them, we now have the MAGEC rod growing system available as an alternative.

These still allow growth whilst helping to straighten the spine, but work with the use of a magnet to lengthen them. Therefore the lengthening procedures do not require a general anaesthetic and can be performed during a clinic appointment.

One or two MAGEC rods are used depending on the type of curve:





Around three months after insertion of the MAGEC rod(s), a clinic appointment is made for the first lengthening procedure and lengthening procedures occur every three months thereafter.

Within the UK, there is some controversy around the use of MAGEC rods. NHS England requires that prior to the insertion of the MAGEC rod, permission is granted from the UK Medicines and Healthcare Products Regulatory Agency (MHRA). If, after discussing with your child's consultant it is agreed that the MAGEC growing rod system is the best operation for your child's scoliosis, your consultant will obtain the appropriate permission from the MHRA for the procedure for your child.

# The MAGEC rod surgery

For surgery to insert the MAGEC growing rods, two small incisions are made at the top and bottom of the back:



The stitches are dissolvable. The scars will never disappear and they do not get smaller as you grow older but they fade with time.

Some people with darker skin can be more prone to keloid which is an overgrowth of scar tissue. This can be further discussed at your consultation.

After the wound has fully healed, at approximately six weeks after surgery, you can start to apply scar reducing ointment to it such as bio oil. It is important that you avoid direct sunlight during the healing process.

# Fusion of the spine

The fusion process usually takes nine months to a year. After the spine has fused it is the bone, not the rods, which hold the spine in place therefore eventually making the rods redundant. However, the rods are generally not removed since it is not necessary.

# Further growth and movement

Ideally spinal fusion is delayed until puberty so you are able to reach your potential height, however if curves are stiff and rapidly progressing then earlier intervention may be required. You will hear terms such as 'skeletally mature' - which means you have reached your potential growth, or 'skeletally immature' - which means you still have more growing to do.

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#### The Risser scale

Your surgeon is able to work out how much growth you are likely to have left by checking the bone formation around your hip bones (pelvis) which is shown within the X-rays taken of your back. This is called the Risser scale. This scale is scored from 0-5, with 0 being the most expected bone growth and 5 being the least.

Children with a **Risser Score** of 0 to 2 are likely to have several more years of bone growth. Once girls have started menstruation there is usually about 18 months more growth.

### After surgery

Fusion stops growth, but after surgery your spine may still continue to grow in the areas that have not been fused. After puberty most growth occurs from the legs. You will also gain height from having a straighter spine.

You do not have much flexibility in your thoracic spine (in the chest) as this is held in place by your ribs. Most of the flexibility in your back is from the lumbar area (lower back). Your surgeon will try to preserve these areas if possible, but if your curve proceeds to this area they will need to be fused.

The flexibility in your back may be reduced post-operatively. This should not affect you too much as a lot of movement such as bending is controlled by the hips.

### Back shape and position

Surgery will not completely straighten your spine. There are several factors which affect how much correction is possible. Your surgeon will discuss this with you. Usually the correction still achieves an acceptable cosmetic improvement.

After spinal surgery it may take 6-12 weeks for your body to adapt to your new shape and your brain to learn a new way to stand and walk. Our physiotherapists will give you exercises to help (see pages 35-36).

### Bracing after surgery

It is rare to need to wear a back brace after surgery. If a brace is needed this is usually for only 3-6 months.

# Will spinal surgery have any effects on later life and work?

The aim of surgery is that you can go on to live a full and normal life. Certain activities will be restricted for a period of time after surgery.

Girls can go on to have normal pregnancies (there may be issues with having an epidural if the fusion is low into the lumbar spine). There should be no problems with choice of career except perhaps if you are interested in joining the armed forces or some areas of the police force.

### Risks of adolescent idiopathic scoliosis surgery

Scoliosis corrective surgery in adolescent idiopathic scoliosis is, in most circumstances, a quality of life intervention. We know that young people with significant curvatures and deformities of the spine do suffer from pain and have an increased risk of disability. Therefore this may impact on other aspects of their life if the curve is not addressed.

However it must be noted that the curvature of the spine in itself is neither life threatening nor lead to paralysis. Therefore any surgical intervention aim is to improve the patient's quality of life and there is no absolute indication to have the surgery.

### Why choose surgery?

Surgery is a choice to try and improve the young person's quality of life for the long term.

There are low risks associated with idiopathic scoliosis corrective surgery, and they can include:

**Paralysis** - the actual risk of paralysis is about one in every 600 surgeries, with loss of function of the lower limbs with:

- Being in a wheelchair with loss of bladder and bowel control
- Loss of sexual function
- During surgery these nerves are monitored to reduce any risk of permanent damage to the spinal cord and nerves.

We use a system called Somatosensory and Motor Evoked Potentials (SSMEPs). This involves small electrical impulses that are given and recorded in the legs and the brain.

If there is a development of slowing of the signals during surgery, this can indicate compromise to the spinal cord or its blood supply and corrective measures can be taken to avoid a permanent injury. However even with this monitoring there is still a very small risk of paralysis developing.

**Uncorrected curvature** - there is a small risk that the curvature is not corrected as much as the patient would wish, and they remain unhappy with how they look after surgery.

In addition there is a small risk of the curve progressing above and below the fixation area of the spine. Not all of the spine is fixed with the rods and screws as one wishes to maintain as much movement as possible. Fixation never goes into the neck and one tries to avoid going into the lumbar spine. If the curve does progress above or below the fixation, then on occasions there may need to be extension of the fixation usually below where it has been fixed in the original operation.

**Wound infection** - with any operation there is a risk of a wound infection. The majority of these infections can be managed with antibiotics. On occasion further surgery is required and very occasionally the metal work needs to be removed. The overall complication rate is less than 5%.

**Bleeding** - loss of blood can be a risk factor and occasionally transfusions of blood are required either during or following this surgery. Usually the blood loss is can usually be kept to a minimum.

We take precautions to ensure you are in optimum health beforehand, and during surgery we use a system called Cell Saver which enables your own blood to be collected and then transfused back to you.

On very rare occasions there can be massive, life threatening blood loss and there have been very rare reports of patients being unable to survive massive blood loss in adolescent idiopathic scoliosis surgery. This complication has not occurred to date at The Portland Hospital.

**Vascular injury** - damage to the large blood vessels around the spine is very rare but can lead to massive blood loss.

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**Spinal fluid leakage** - the nerves are within a sheath called the dura. Very occasionally this sheath can be breached and that leaks cerebrospinal fluid - the fluid that bathes the spine within this sheath. That sheath is repaired at the time of surgery. Very occasionally it can re-leak following the operation and that may require another operation to once again repair the sheath to contain the cerebrospinal fluid. Leakage of cerebrospinal fluid this can lead to headaches.

**Misplaced rods and screws** - the spine is fixed with screws and rods. On occasions the screws can be misplaced and this can lead to pain or indeed neurological deficit or there may be failure of the screws to hold In the bone. This may also be associated with failure of the rods due to breakage. If this occurs then there may need to be further surgery to reposition or replace the screws and rods. This is a relatively rare complication.

**Failure of the bones to fuse** - the objective of the surgery is to improve the shape of the spine and prevent it getting worse In the future. The metalwork holds the spine in position whilst the bone fuses. There is a small risk that the bone fails to fuse. The area where the bone fails to fuse is called a pseudarthrosis. Continued movement in this area leads to strain on the metalwork and metal fatigue which can lead to the rods breaking. If this occurs further surgery is required to get the bone to fuse, and to replace the broken rods. This is a rare complication, affecting less than 5% of patients.

**Intestinal (bowel) obstruction** - correction of the curvature of the spine can lead to temporary constriction of the upper intestine leading to abdominal pain and vomiting. This is called superior mesenteric artery syndrome.

This can naturally be quite uncomfortable, but with supportive measures almost always resolves itself 2-3 days following the procedure and generally no later than 14 days.

Generally following the surgery there is a predisposition to developing constipation, some abdominal distension and discomfort due to slowing down of the function of the bowel and the painkillers that are required to mitigate the discomfort of the surgery. This resolves with time and with appropriate laxatives.

**Deep vein thrombosis** - as with all operations there is a risk of deep vein thrombosis (clots in legs) and pulmonary embolism (clot in the lung).

To help prevent this you will wear TED stockings (compression socks) during your admission and be encouraged to drink a good amount of fluid and to mobilise (when you can) as much as possible. Whilst in hospital, you may also be given a daily anticoagulant medicine which is a small injection to prevent clotting.

**Chest infection** - more common after anterior surgery. This is usually treated with antibiotics and chest physiotherapy. The physiotherapist will teach you breathing exercises, however the most effective treatment is to mobilise.

#### Other complications:

- There can be complications with the way that the patient is positioned for the surgery.
- There is a very small risk of blindness.
- There can be some stretching of the nerves to the arms, leading to some tingling and numbness and on rare occasions weakness to the hands. This almost inevitably resolves within 3-4 days following the operation.
- Very rarely a swelling of the calf called compartment syndrome can occur. This requires an operation to release the pressure within the calf of the lower leg.
- There are general anaesthetic risks with all operations and your anaesthetist will discuss these with you. Please also see the separate anaesthetic information sheet which will be given to you at your pre-admission clinic appointment.

Overall the risks of corrective surgery for adolescent idiopathic scoliosis deformity are low, however those risks can never be made zero unfortunately.

At The Portland Hospital we do absolutely everything that we can in order to reduce the risks of this occurring. Your surgeon will go through in detail with you the exact type of operation you are having and the risks of that surgery with you such that you can then ask any specific questions that concern you.

### WHAT HAPPENS BEFORE SURGERY?

### MRI scan

All patients having spinal surgery need a whole spine MRI scan (Magnetic Resonance Imaging). This allows your surgeon to ensure there are no other causes of the scoliosis and that the spinal cord is normal.

MRI is an advanced technology that allows the radiologist to see your internal organs, blood vessels, muscles, joints and more.

### During your scan

You may be able to have a friend or family member stay in the room with you during your scan. MRI scanners can make a loud knocking noise. You may be given earplugs or headphones to wear so you can listen to music or even watch some DVDs. It is important that you are as comfortable as possible during a scan, because you must lie very still to avoid blurring the images. A spine scan lasts 30-60 minutes.

Very rarely the MRI scan can show a syrinx (a fluid filled cavity within the spinal cord) which is often the result of a Chiari malformation. In these cases, your surgeon will refer you to a neurosurgeon for further assessment and review before commencing spinal surgery.

### CT scan

Occasionally, your surgeon may also require a CT (Computerised Tomography) scan to further assess the spine. This scan uses X-rays to produce a 3D image of the spine and is useful for surgical planning. The scan only takes a few minutes.

### Pre-assessment clinic

You will need to attend a pre-assessment clinic which is normally arranged 4-6 weeks before your planned admission date.

The appointment is co-ordinated by spinal Clinical Nurse Specialists, and during the clinic appointment you will meet your surgeon, physiotherapist and anaesthetist. You will likely also meet other members of the team who will be caring for you during your stay. As well as these introductions, our team will carry out a series of tests to ensure you are fit and able to undergo your planned surgery.

At your pre-assessment clinic you will meet the following specialists:

### Your surgeon

- Your surgeon will look at your X-rays and examine your back. They will be able to tell you what type of
  operation you will need to achieve the best correction of your curve. They will discuss the risks of surgery with
  you, and if you are a parent attending with your child you will be asked to sign a consent form to say that you
  are happy to proceed.
- We will discuss your health and past medical history. The doctor will examine you to ensure you are fit for surgery. It is important you tell the doctor and nurse about any allergies to medicines, food or plasters you may have.
- It is also important you tell the doctor about any regular medicines you may already be taking and if you have had any recent infections or poor health.
- Females on the contraceptive pill will need to stop taking it six weeks prior to surgery to limit the risk of blood clots. Please ask your doctor for more information.

#### Your anaesthetist

The anaesthetist is the doctor who will put you to sleep for the operation using various anaesthetic drugs. They will discuss this with you and your parents and ask about any previous anaesthetics you have had. They will also explain how we will manage the pain you will have in the immediate period following the surgery.

### The physiotherapist

The physiotherapists will also introduce themselves to you and discuss with you a plan for after your operation. They will assess how you are currently walking and give you tips on how you will be able to comfortably move around after your surgery.

They have the important job of helping you get up and walk after your operation as well as ensuring that your chest and lungs are working well by giving you breathing exercises.

# The tests you will need to have done in pre-assessment clinic are:

### Spinal X-rays

We will take several X-rays of your spine from the front and the side, while you are bending to the left and then to the right, and also a view of you bending over. This last image may be slightly uncomfortable for you as it requires you to get into a position that bends back your curve to straighten it out.

These X-rays are very important as they will enable your surgeon to decide the best surgical approach for you and how much correction of the curve can be achieved.

### Medical photography

We will take photos of your back from different standing and bending positions. This will enable us to see the effect your scoliosis has on the shape of your body. About 3-6 months after surgery we will repeat these pictures to compare the difference before and after.

### ECG (Electrocardiogram)

This is a painless procedure in which 10 sticky pads are placed over your chest and connected to a machine that shows a trace of the electrical activity in your heart.

#### Lung function test

For this test, the physiotherapist will ask you to breathe out via a mouthpiece into a handheld device. This will then give a reading which informs the team how well your lungs are working.

#### **Blood tests**

We will need to do some blood tests to ensure you are fit for surgery. These tests look at what blood group you are, to see if you have a low number of red blood cells (anaemia), to check how long it takes for your blood to clot and to check your liver and kidneys are working properly. Before a blood test we will put on numbing cream if necessary.

If your iron level is low, we will prescribe some oral iron for you to continue until you come in for your operation. We also have an information booklet about increasing the iron intake in your diet which we advise you do before surgery. This precaution is taken to help prevent the risk of you requiring a blood transfusion during or after surgery.

Occasionally we have to make referrals to haematologists to further explore some of your blood results, such as; low iron levels and clotting abnormalities. These may require further appointments with these specialists to ensure we have everything safely in place for surgery.

#### MRSA swabs – nose and groin

We will take some skin swabs (using a cotton bud) to ensure you are free from any skin infections. We will also check the skin on your back to check it is free from any broken down areas or spots which may put you at risk of a wound infection. If you suffer from acne on your back we may refer you to dermatology or liaise with your GP to prescribe treatment, such as oral antibiotics, before surgery.

#### Observations

We will record your weight to inform how much medicine we can give you, and height so we can see how much you grow after surgery. We also take your blood pressure and temperature, record your heart and breathing rate and monitor how much oxygen you have in your blood.

### The Portland spinal multidisciplinary team meeting (MDT)

The information we gather during your pre-assessment is vital to ensure we know we are offering you the right operation and that it is safe to proceed with surgery. This information (clinical history, examination findings, blood test results, X-ray and MRI images) is then collated and discussed in a spinal multidisciplinary meeting.

A group of independent surgeons with input from anaesthetics, paediatric medicine, radiology, physiotherapy, and specialist nurses will review your case and discuss the relative risks and benefits of the plan for surgery. Patients and family do not attend this meeting. Assuming there is a consensus on the plan the MDT will approve the decision to offer surgery.

Occasionally the MDT will suggest alternative approaches to manage your spine and if this is the case then your surgeon will explain the reasons for considering each of the options.

# Preparation at home before surgery

There is little preparation needed at home as by the time you are discharged from hospital you will be walking around comfortably and be able to walk up and down stairs. It is however important that you sleep on a standard bed, ideally not a bunk bed or a cabin bed as this may initially be difficult for you to get in and out of.

Also it will be helpful to inform your school and let them know about your operation. They can start plan things for you whilst you are away and co-ordinate your studies/exams around your admission and recovery. They may also be able to arrange some home tuition whilst you are off school.

You may want to consider how you get to and from school as initially public transport in rush hour may be too much for you. There is a letter for school on page 42 and the physiotherapist will discuss with you how to make your return to school easier.

It is important that you are in optimum health before your operation. If you are unwell on the day of your admission or a few days before please contact us as it may be best to postpone your surgery.

Please contact the ward, the Orthopaedic Nurse Specialist or admissions if you think you have been exposed to an infection such as chicken pox, or have developed any of the following symptoms:

- Temperature
- Cough
- Cold
- Vomiting
- Diarrhoea

If you are due to have any immunisations around the time of surgery, we advise that you do not have these for at least two weeks either side of your operation.

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### **ADMISSION TO HOSPITAL**

You will be in hospital for approximately 3-5 days and be admitted to our paediatric surgical ward the day before your operation. This is to ensure we have plenty of time to settle you in and repeat or perform any tests that might be required.

On your admission we will check you are well by taking your blood pressure and temperature and monitoring your heart and breathing rates and the oxygen levels in your blood. We will also recheck your weight. We will ask you to provide us with a sample of your urine so we can test that you do not have any infections, and also in all girls above the age of 12 years old we have to do a pregnancy test.

#### Additional assessments

Your surgeon and anaesthetist will also see and assess you to ensure all is ready for the next day. You will be seen by the Pain Nurse Specialist who will explain and show you equipment on how we ensure you are comfortable after your operation.

You will need to have another blood test. As mentioned before, in case you were to need a blood transfusion during or after surgery we need to ensure that we have the correct blood for you, and so we need to confirm this match through two blood tests (the first sample will have been taken at pre-assessment clinic).

#### Unit visits

During this day you will also be able to visit our Paediatric Intensive Care Unit and Post-operative Care Recovery Unit as this is where you will wake after surgery. As it is a different setting to the ward we hope this will give you an opportunity to ask any questions you have.

### Before you go to bed

Before you go to bed we will give you Octenisan antibacterial wash to shower in. This is part of our infection control methods and ensures you are clean for surgery (see Infection Control Leaflet).

# On the morning of surgery

There may be two patients having spinal surgery on the same day. In this case, the first patient will go down to theatre from 7.30-8.00am and the second patient will go down when the first operation is finished, usually after midday. We will inform you the day before your operation when you will be going down so we can best prepare you.

### Your preparation

Prior to your procedure, you will be asked to do the following:

- Not eat six hours before or drink anything two hours before
- Get up and begin to get ready about 90 minutes before your operation
- You will need to have your shower and if you have long hair, it is a good idea to put it in two plaits with a centre parting as this will stop it getting tangled and stuck on dressings.
- You will be asked to put on a theatre gown and some anti-embolism stockings (these help speed up blood flow to prevent clotting while you are not mobilising).

Your bed will be remade with clean sheets. Your nurse will then put some of the numbing cream on your hands - this is so you will not feel anything when the anaesthetist uses a needle to insert a small plastic tube into a vein in your hand so you can have the anaesthetic medicine to put you to sleep.

#### Going to theatre

When the operating theatre is ready, a porter will come to collect you and you will be wheeled on your bed with your parent(s)/carer and nurse to the anaesthetic room.

The only thing that happens while you are awake is that the anaesthetist will wipe the numbing cream off and insert the small plastic tube (called a cannula) into your hand. The anaesthetist uses the cannula to give you the medicine that will put you to sleep. Your parent(s)/carer can stay with you until you are asleep.

### **During surgery**

Spinal surgery can take a long time. Even though the surgery itself is often only 2-4 hours, the whole process will be longer due to the preparation in the anaesthetic room.

For your parents it will seem like a long time that you are in theatre. Your parent(s)/carer do not have to stay on the ward but wherever they go they must be contactable and ensure we have a correct mobile number.

When your operation is finished, the Surgeon will come and talk to your parent(s)/carer and then the Nurse will take them to the Paediatric Intensive Care Unit or Post-Operative Care Recovery so they can be with you as you wake up.

### Bed space on PICU:



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### Paediatric Intensive Care Unit (PICU)

The PICU at The Portland Hospital has nine beds and cares for patients from birth to 18 years old. It is located on the 6th floor.

On the day of your operation you will be admitted to one of our wards. On this day there will be an opportunity for you to come and visit Intensive Care, so that you can see were you are going to be after your operation. We will try to answer all your questions and show you some of the machinery, such as the monitors that may be used to help you recover from your operation. We hope this will put your mind at rest and prepare you for a different environment when you wake up. We will also have some pictures available if you would like to see them that show you what happens in Intensive care.

We will not see you the day of your operation until later in the afternoon when the theatre staff transfer you to the PICU. As soon as we have you settled in we will call the ward to let them know your progress and parent/s or guardians can come to visit you.

The length of your stay in Intensive Care cannot be predicted, but in general most children go back to the ward that evening or the following day. You will be discharged to the ward when you are stable and have your pain under control.

There is nothing specific that you will need for your stay on Intensive Care but here are a few recommendations:

- Wash bag with toothbrush/toothpaste/deodorant/face wipes
- Glasses if you wear them
- Ipod/Nintendo DS/Portable DVD player
- Pyjamas/nightgown (easy to get on and off)
- Socks

# Additional information for parents/guardians:

- **Visiting times:** Our current visiting rules allow one parent to stay with their child once they are back on the ward from the PICU. If another family member also wants to visit, they need to please call the ward in advance and arrange a suitable time with the manager of the ward. Please note they will only be allowed to visit for one hour and will be unable to visit daily.
- **Infection control:** Please could you wash your hands each time you enter the ward. Coats and bags need to be removed and placed in the lockers provided in the hand washing area outside of PICU. Please finally gel your hands on entering and exiting the unit.

Parents can stay for the first night whilst your child is on the ward. If your child goes to the PICU, you will need to find other accommodation whilst they remain there. When your child is back on the ward, one parent can come back and stay with them again. The ward manager can also arrange one-hour visits with other family members.

If you have any questions during your stay at The Portland, please ask any one of our clinical or support staff who will be happy to speak with you. We would rather answer questions than have you worry about things.

### **AFTER SURGERY**

You will be transferred to the Intensive Care Unit where you will be lying on your back on the bed. When you wake up there will be a special tube in your mouth that is helping you breathe. When you are fully awake and the doctors are happy with your breathing and your heart, the tube is taken out and you are able to breathe as normal again. You might need a little oxygen to help with your breathing at first, which can be given to you using a face mask or by a short tube that allows oxygen to go up your nose.

The doctors and nurses will be regularly checking and observing you, such as taking your blood pressure, temperature and asking you to wriggle your toes and move your legs.

#### Your recovery

When you wake up you will find that a few tubes and lines have been put in while you were asleep. Initially you will have some intravenous (into a vein) drips delivering fluids directly into the bloodstream.

You will also be given antibiotics to reduce the risk of any problems with your operation site. You may also have a tube through your nose into your stomach to stop you 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. These lines are only in place for a short time and are used to monitor you and make sure you are comfortable and safe. These will be explained to you further during your pre-assessment clinic.

### Seeing your family

Initially after surgery your family may notice that your face might be a little swollen and your eyes are puffy. This can be the result of being positioned on your front for so long during the operation and is only temporary.

You will have to lie quite flat for about 12 hours after your operation to let the wound settle and then the nurses will help you turn and move around to a position that is comfortable.

You can usually start to gradually drink and eat soon after the operation when you are fully awake. Sometimes you can feel sick after an operation but we can give you some special medicine to help.

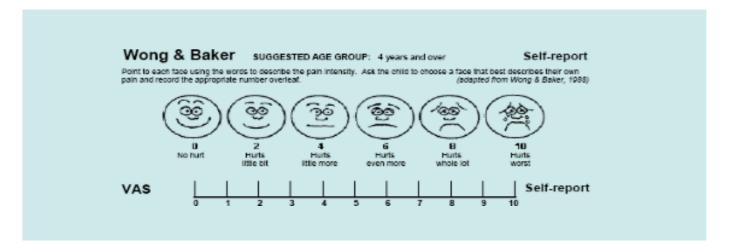
# Pain management



You may be worried that after big surgery like this you will be in pain. The first day after surgery you will be carefully monitored and encouraged to eat and drink. The physiotherapist will also come to see you in the morning and afternoon to assess your movement and to help you sit or stand up and walk, depending on how you are feeling. You will be given regular pain relief medication including Morphine, Diclofenac and Paracetamol. Some special pain relief medicine is given by a machine with a button.

If you are in pain is important that you tell your parent(s)/carer and your Nurse. There is always something we can do to help, so please do not suffer in silence but let us know how you are feeling. We have specialists such as the anaesthetists who will regularly assess you and ensure you receive the right amount of medicine. We also use a pain score from 0-10 (0=no pain up to 10=very bad pain) for you to let us know how we can best help you:

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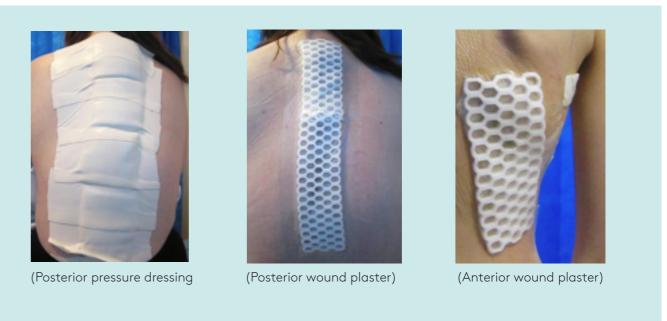
#### Holistic care

Our physiotherapists will be advising you on breathing exercises (this is especially important if you have had anterior surgery), sitting you up in bed, helping you to get yourself comfortable and encouraging you to start rolling from side to side. As well as medication, the nurses and physiotherapists can help you to be more comfortable by teaching breathing exercises and encouraging gentle movement. They will help you change position regularly and you will be supported with pillows and can use the electric bed controls.

**Day 1-2** - From the morning of the first day after your operation, you will be assisted to get out of bed by the physiotherapist. They will teach you a specific technique called a "log roll", which will make getting out of bed easier. You will then sit on the edge of the bed and if your pain and dizziness is manageable, you will be encouraged to stand and take a few steps with the nurse and physiotherapist assisting you. They will then help you back to bed and return in the afternoon (if it is a weekday), to repeat the process again.

**Day 2-3** - most of your lines and tubes will have been removed. You will be able to have a wash and get into your own clothes. Loose, button up clothes such as pyjamas or tracksuits are recommended, as you do not lift your arms over your head to get them on and off. You can wear a bra as soon as you feel comfortable

We will also review your wound dressing around this time. This just involves gently removing the sticky pressure dressing. Underneath is a lighter dressing which looks like a large plaster. If this is dry and intact we will leave this in place:



We will do some check blood tests to make sure that your red blood cell count is ok and that you are not anaemic. Again we will use the numbing cream so you will not feel anything.

Over the next few days you will continue to build up your sitting and walking tolerance. We will gradually get you walking longer distances and then ensure you can safely walk up and down stairs.

Usually by the third or fourth day after your operation we will take some X-rays of your back. This is usually very exciting as you can see what your back looked like before and after your operation. We can give you copies of these pictures.

# Going home

Before you go home we will need to ensure:

- Your pain is well controlled
- You are eating and drinking good amounts
- You are passing urine and passing flatus
- Your wound is dry
- The surgeon is happy with your x-ray
- You are mobilising well: independently getting in and out of bed/chairs and able to walk up and down stairs
- We aim for discharge home on day three, four or five

# Physical activites after surgery

Until your surgeon says otherwise, the only activity we would like you to partake in is walking. You can discuss further activity at each follow-up appointment but generally non-contact sports can be commenced within 6 to 12 weeks.

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# Physiotherapy at home

You will not routinely require follow up physiotherapy once you go home. It is important for you to steadily build up your walking and sitting tolerance. Some specific exercises to help your recovery will be explained before you go home and are show below.

# **Physiotherapy Exercises and Tasks**



### Lying or sitting:

Bend and straighten your ankles.

Repeat 15 times.



### Sitting or standing:

Turn your head to one side until you feel a stretch. Hold approx 5 seconds. Repeat on the other side.

Repeat 5 times.



### Sitting or standing:

Tilt your head towards one shoulder until you feel the stretch on the opposite side. Hold approx 5 seconds. Repeat on the other side.

Repeat 5 times.



### Sitting or standing with your fingers on your shoulders:

Lift arms up to shoulder height.

Repeat 5 times.



### Sitting or standing:

Bend your elbows and bring them up to shoulder level.

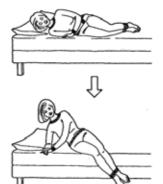
Repeat 5 times.



### Lying or sitting:

Bring your shoulder back and down.

Repeat 5 times.



#### Get out of bed:

Bend one knee, roll onto your side and lower one leg at a time over the side of bed, use your arms/upper body to push up into the sitting position.

#### Get into bed

Sit on the side and lower your body using your arms while lifting the legs at the same time.

### Top tip:

When you roll over in bed, always bend your knees and try to keep them in line with your back to avoid twisting.

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# Physiotherapy Plan

### DAY 1

We will start by having a listen to your chest and breathing.

We will check the range of movement and strength in your legs and run through all the exercises shown on the previous page.

We will help you to perform a log roll and sit up on the edge of the bed.

We will help you to stand and take a few steps on the spot if your pain and dizziness is manageable.

#### DAY 2

We encourage you to take a more active role in your log rolling and moving into sitting – don't worry, we will continue to help if you need.

We will help you stand and walk around your bed-space and sit out in a chair.

We will encourage you to spend time sitting in your chair throughout the day, for example to eat your meals.

#### DAY 3

We will keep increasing your walking distance, and will walk around the ward. It is very common to feel a little "wobbly" initially but this will improve the more you mobilise. This is also the chance for us to measure you to see how much you have grown.

We will practice going up and down stairs.

We encourage you to practice your walking with the nursing staff or your family and friends throughout the day.

### DAY 4

We want you to be doing most tasks and walking as independently as possible – we will come and review you to practice if you still need it.

Keep practicing walking on the ward to improve your confidence and balance.

Remember to keep practising your exercises to help prevent any stiffness, and to improve your strength and endurance.

#### Checklist for going home:

- I can get in and out of bed by myself
- I can 'sit to stand' from the chair and bed by myself
- I can walk as far as I need to for home, by myself
- I can climb up and down the stairs by myself (with or without a handrail)
- I understand and can complete my exercises by myself and I am happy to continue these at home.

### FOLLOW UP AND REVIEW AFTER SURGERY

### **Outpatient appointments**

If you require a back brace after surgery, you will be measured for the brace before you go home or be booked into orthotic clinic once you have been discharged. The brace is then ready to be fitted and collected 1-2 weeks after the initial appointment.

Your post-surgery follow-up appointments will be at:

- 2-3 weeks
- 3 months
- 6 months
- 1 year

#### Follow-up care

You will continue to receive follow-up care until around two years after surgery, or until you have fully grown and your surgeon is satisfied that everything is well.

During these appointments you will have an X-ray and see the surgeon/senior spinal consultant.

If you have any questions or concerns before or after these appointments, please do not hesitate to contact the Orthopaedic Nurse Specialist or a member of the team. We do not want you to worry at home and are more than happy to offer advice over the phone or see you sooner in clinic for review if needed.

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# GUIDELINES FOR ACTIVITY AND FOLLOW-UP FOLLOWING SPINAL SURGERY

### Discharge from hospital - two weeks post-surgery

**Wound care** - your dressing will be clean and dry before you go home. We will give you some spare dressings to stick over the top of the existing dressing in case it comes loose but advise that you leave the dressing intact.

An appointment will be made for you with the practice nurse at your GP practice for wound review about 10 days after surgery – you can also see an orthopaedic nurse specialist at The Portland Hospital. A letter will be sent to the practice nurse explaining instructions. At this appointment the practice nurse will remove the steristrips (paper stitches). The practice nurse will continue to dress the wound until it is dry, and give you a supply of dressings will be given to you when you go home. The wound is usually healed after 14 days and then the dressing can be left off and air allowed to get to it.

It is important to look at and assess the wound for any signs of infection. These may include:

- Redness
- Open areas
- Oozing
- Increased pain and tenderness around the site

Your back incision may be numb for 4-6 months. It is also quite normal for the incision site to be sensitive to touch and feel tingly. This usually lasts for several months whilst the tiny nerves that would have been cut during surgery regenerate.

**Stitches** - all stitches are dissolvable but if a chest drain has been inserted (for patients who have had the anterior approach) there will be a stitch inserted to secure the drain exit site. This will need to be removed by the Practice Nurse about 10 days after the drain was removed.

**Follow-up outpatient appointment -** Your initial follow-up appointments with your consultant will be approximately four weeks after your surgery.

Pain control - you will be given pain relief medicines to take home with you, such as:

- Paracetamol
- Diclofenac
- Ibuprofen
- Codeine Phosphate

Your consultant will explain dosages to you and answer any questions you have about your medicines. If necessary, you can get a repeat prescription from your family doctor (GP). They will have been informed about your surgery.

**Holistic care** - a lot of the discomfort you may experience is often to do with muscle aches, especially around the shoulders and lower back area as you get used to your new shape. Other techniques which may also help include regular position changes, gentle massage, stretching exercises and the use of hot or cold pack.

**Bathing** - when your operation site is clean and dry, about seven days after surgery, you can have a shower. A shower is preferable because it puts less strain on the back than getting in and out of a bath. Do not let the operation site soak until it has healed completely.

**Toileting** - you may find that you are a little constipated initially after your operation. You will be discharged home with laxatives (usually Movicol, Lactulose and/or Senna). The constipation should settle once your diet and routine has returned to normality and you are taking less medicines.

We advise that you continue to take the laxatives until they are no longer required. If the problem persists contact

your surgeon or spinal Clinical Nurse Specialist on 07936 363 235.

**Eating and drinking** - it is important that you drink good amounts of fluid and eat a balanced diet. This will help you build up your strength and promote healing of your wound. Increasing the iron in your diet will help make you less tired. If your iron level was a little low before you were discharged, we will send you home with some oral iron supplement for you to have for about 4-6 weeks after surgery.

**Rest and activity** - you will probably feel some degree of tiredness for the first few weeks after surgery but this is normal. Being in hospital can disrupt your normal day-to-day routine so it can take some time to get back to normal activities once home, especially following a big operation. It is important that, although you may feel tired, you continue to do little and often throughout the day-spend time changing positions between lying, walking and sitting to help rebuild your stamina.

When sitting, it is good to have a supported chair with back and sides instead of perching on a stool or sitting on the floor. Overly soft and low sofas may be more challenging to get on and off initially, but pillows and cushions are great for helping to get you comfortable in a position.

For parents of smaller children following spinal surgery - when you lift your child, make sure he or she is supported under the buttocks and around the back. Avoid lifting your child under the arms.

**Bracing** - very occasionally a brace is needed postoperatively. Your surgeon will discuss this as required, but to emphasise, it is very rarely needed.

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### 1-4 weeks post-surgery

- Once the wound is completely dry, you can shower as normal, you will usually had a shower before leaving hospital.
- Keep working on sitting tolerance throughout the day for longer periods to help prepare you for going back to school.

# 4-6 weeks post-surgery

- You should aim to return to school part time at 4 or so weeks and full time by 6 weeks. Whilst you are away try to keep in touch with the school, for instance, inviting school friends to visit and arranging for course work to be sent home. We recommend starting back at school around four weeks post surgery on a part-time basis, building up to full-time hours over the next two weeks. Most people like to start with half days and increase from there. You should be able to return to PE at approximately 3 months (see table of activities below).
- Having two copies of textbooks (one for home and one for school) will save having to carry them back and forth. If more books are required you will need help, may be a friend, to take them from class to class.
- In addition, having a locker at school may be helpful to store books during the day. You may also need to stand up and stretch during lessons if you have been sitting for a while. It may also be advisable to ask to leave classes slightly earlier to avoid the crowds at class changeover time. We advise that you sit in a supported chair and avoid perching on stools, such as used during science classes, and avoid sitting on the floor.
- Talk to your teacher or Special Educational Needs Coordinator (SENCo) about dealing with these issues. A letter explaining all this is on page 40. Please give this to your teacher and school nurse. (There is a separate letter for children undergoing the growing rod programme and for those requiring two-stage surgery these can be given to you at pre-admission clinic).
- You will have a follow-up appointment four weeks after your operation. Your surgeon will review you and your wound to ensure all is healing well.

# 6-12 weeks post-surgery

• You should be back at school for full days after approximately six weeks. No PE at this stage. Increased exercise through walking longer distances will improve your overall stamina.

# 3 months post-surgery

- Follow-up appointment with your consultant and an X-ray of the spine on arrival
- Steadily increase your physical activities swimming can usually be commenced at this stage and you can
  partake in gentle PE but no contact sports.

If you have any queries about what activities you should or should not be doing, please contact our physiotherapists or orthopaedic nurse specialist.

# 1 year post-surgery

- Follow-up appointment with your consultant and X-ray of the spine on arrival.
- Most children can return to full normal activities at one year post-surgery. Please discuss activities of interest with your surgeon.
- Your consultant will follow-up your progress with your for a minimum of two years following your operation.

### General guidelines

- Build up exercise tolerance steadily following surgery, particularly with increased amounts of walking.
- Avoid carrying heavy books and objects for the first six to eight weeks and try and make arrangements at school to help with this.
- · Avoid excessive bending, twisting, jerking and jumping movements in the first 8 weeks post-surgery.
- Once you can sit comfortably for around 20-30 minutes at a time, you can travel in a car with breaks as needed. This should be between two to four weeks.
- You can travel in an aeroplane when you can sit comfortably for around 20-30 minutes. You can take regular breaks to stand and walk during the flight. It may be best to wait at least 6-8 weeks after surgery before taking a longer flight as your metal screws and rods may set off detectors please don't worry as we will give you a patient card on discharge to prove you recently had spinal surgery.

Once permitted to, swimming is one of the best exercises you can do to strengthen your muscles.

One year post-surgery, you should be able to resume all of your normal activities. Remember that you will not have been very active for some time so gradually build up your ability and tolerance - see activity chart below.

### In case of emergency

Please notify our Spinal Clinical Nurse Specialist and/or your surgeon, GP or The Portland Hospital immediately if you experience any of the following problems:

- Fever or chills
- Any signs of wound infection such as the site looking red or inflamed, or if it feels hotter than the surrounding skin.
- If there is any breakdown or oozing from the wound
- Increase in pain
- Numbness, tingling or increased weakness in your arms or legs
- Changes in bowel or bladder control

Contact the spinal team at The Portland Hospital if you have any concerns or would like further advice.

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Activity	4 to 12 weeks	3 to 6 months	6 to 12 months	1 year
Walking	Aim for about 2+ km each day on a flat surface/pavement only	By 3 months should be walking normally and as far as you like	As normal	As normal
Yoga or pilates	Basic exercises such as pelvic tilts, leg slides and lunges	Build up to normal	As normal – there may be some limitations due to flexibility	As normal
Swimming	May start gentle swimming at about 8-12 weeks	Build up slowly	As normal	As normal
		Focus on front crawl or breast stroke		
		No jumping or diving into the pool		
Cycling	Start cycling at 6 weeks – static bike preferably. At 3 months, start normal cycling outside.	Build up normal cycling	As normal, including mountain bike and BMX.	As normal
	May start gentle dancing at 8 to 12 weeks.	Ballet – barre work and build up	Re-start higher energy dance for all forms listed	As normal
Dancing		Tap – very low level and building to normal.		
		Jazz/Modern/Street dance – as above		
		Build up types gently		
Gym	Exercises prescribed by ward and clinic physiotherapist	Start on a cross trainer, treadmill, exercise bike, or light weights for weight lifting.	Build up duration slowly	As normal
Jogging	May start gently at 8-12 weeks.	Build up the distance jogged over the next few months	May use rowing machine	As normal
Table tennis or badminton	Start at 8 – 12 weeks	Build up as symptoms allow.	As normal	No restrictions
Tennis or squash	None	Begin by patting a ball on the spot, gradually increasing duration. Gently build up to serving at 6–12 weeks.	Should almost be back to normal.	No restrictions
Netball or basketball	Gentle practice at 8 – 12 weeks	Practice your ball skills with throwing, catching drills and aim to return to matches at 4 to 6 months	Build up to lobs	As normal
Athletics	At 8–12 weeks, may start gentle jogging normally	Build up running and fitness training	9 to 12 weeks near normal	Re-start jumping and throwing events

Activity	4 to 12 weeks	3 to 6 months	6 to 12 months	1 year
Hockey	Start ball skillset at 8 to 12 weeks	Practice your ball skills with dribbling, gentle stopping and pushing drills but no sweeping passes	Build up to normal and competitive matches	Competitive match play and return to sweep pass allowed
Football	Start gentle ball skillset at 8 to 12 weeks	Increase practice	Re-start running and throwing events	Competitive match play allowed
Rugby	None	Throwing and catching skills as comfort allows Emphasis on gentle pass with limitations in rotation	Re-start jumping at 6–9 months.	Restart tackling – one should consider if one wants to consider further rugby
Golf	At 8 to 12 weeks start gentle hitting of ball	Build up gently – by 6 months should be back to almost normal	Start team training and matches 9 to 12 months.	As normal
Climbing wall	None	Begin shoulder stability exercises, pull ups and gentle climbing at 6 months	Build up to start matches at 6–12 months	As normal
Volleyball	None	Start practicing gentle ball skills – passing and gentle serve with soft ball	Increase speed and amount of throwing action	Re-start normal activity
Karate or judo	None	None	Commence agility work but with no contact	
Horseriding	None	Return to gentle riding	As normal	As normal
Water sports	None	Build up gently	Build up as symptoms allow	As normal
Skiing or snow boarding	None	Start gentle skiing	Start matches	As normal
Theme park rides	None	Able to restart	As normal	Re-start full activity
Not advised	Bungee jumping	Gymnastics or acrobatics	Trampolining	Full contact sports e.g. American football and Rugby

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### **GET IN TOUCH**

Hospital Switchboard: +44 (0) 20 7580 4400

Pre-Admissions Team: +44 (0) 20 7390 6032

Pre-Assessment Team: +44 (0) 20 7390 6228

Orthopaedic Nurse Specialist: +44 (0) 20 7390 6553

Therapy Department: +44 (0) 20 7390 6553

Paediatric Intensive Care Unit: +44 (0) 20 7390 8214

Outpatient Enquiry Line: +44 (0) 20 7390 8020

# Parents' accommodation & parking

The parent who will be staying can stay with their child in their allocated room in the ward for the first night of their admission. For the consecutive nights whilst your child is in PICU, please note you will have to find alternative accommodation (we have a discount with Holiday Inn just across the road). Once your child is out of PICU and back on the ward, one parent can stay with their child in the room for the duration of their stay.

### Alternative accommodation

The Holiday Inn, located just across the road from The Portland Hospital, offer discounts to parents and families with loved ones who are being treated at The Portland – please speak with our team who will be happy to help arrange this discount for you.

Please contact the below details to book a stay or find out more:

T: +44 871 942 9111

E: reservations@hiregentspark.co.uk

Holiday Inn London - Regent's Park Carburton Street London, W1W 5EE

### Other useful websites

Spine Health: www.spine-health.com

Support 4 Scoliosis: www.support4scoliosis.co.uk

Kids Health - Nemours Foundation: www.kidshealth.org/kidhealth\_problems/bone/scolio.html

### Alanna's youtube address:

www.youtube.com/user/littlemissgiggle94

### References

Marieb E.N (1995) Human Anatomy and Physiology , 3rd Edition, The Benjamin/Cummings Publishing Company. Inc, California, USA

Waley and Wong (1995) Children's Nursing London, Mosby

www.pediatric-orthopedics.com/Treatments/Kyphosis\_Lordosis/kyphosis\_lordosis.html

http://en.wikipedia.org/wiki/Scoliosis http://www.sauk.org.uk

# **Patient Story**

### A life-changing procedure

When Hattie first felt her back hurting in March 2019, her parents didn't immediately think it was anything serious. However a scan in October showed a significant curvature of Hattie's spine.

Diagnosing her with scoliosis, Hattie's paediatrician referred her for further investigation and a consultation at The Portland Hospital, with consultant orthopaedic and spine surgeon Mr Jonathan Lucas.

### **Visiting The Portland**

After the initial appointment and MRI scan with Mr Lucas it was clear that the scoliosis was severe and would require surgery to correct and control it. Hattie and her parents were invited to visit The Portland twice beforehand in preparation.

The first of these occasions was with the physiotherapy team who spent time showing Hattie how to loosen her muscles. At the pre-operative assessment two weeks before the procedure, The Portland nursing team took her on a welcome tour of the hospital. Hattie's mum said "the team were so welcoming and lovely, they became like Hattie's adopted family."

### Preparing for surgery

Hattie and her family arrived at The Portland the day before Hattie's surgery. Once Hattie was settled in her room "Mr Lucas popped by to visit and talk about the procedure in more detail - before leaving to Hattie to rest whilst watching her favourite programme 'Friends'.

### The day of the operation

On the morning of Hattie's operation, Mr Lucas visited her room to say hello and ensure Hattie felt as comfortable as possible. Shortly afterwards Claire the anaesthetist escorted the family to the lower ground floor to give Hattie her anaesthetic.

Hattie remained brave the whole time ahead of surgery, and whilst her mother and father were understandably nervous, they were ecstatic when they returned to The Portland later in the day. "Clinical Nurse Specialists Sue and Lisa were there to welcome us, before Mr Lucas wandered in to say the operation had gone even better than expected and Hattie was already wiggling her feet and toes - I was so relieved I burst into tears!"

#### The day after surgery

Hattie remained in hospital for the next four days to help with her recovery. During this time Mr Lucas visited her every morning and informed the family that post-operation Hattie had grown 9cm - a huge increase on the expected 3cm.

In fact, the day after the operation Hattie's immediate progress was impressive enough that Mr Lucas felt she was ready to move from her bed in the Paediatric Intensive Care Unit (PICU) to sitting up in her temporary wheelchair, with the promise of chocolate ice cream as a treat if she could manage some gentle arm-assisted movements, neck turns and shoulder rolls with the help of physiotherapist Maria.

As they had done from the very beginning The Portland staff helped put the family's mind at ease. Russ, Hattie's father, gratefully reminisces, "Hattie was transferred back to the ward mid-afternoon. Two of the staff from the PICU popped down to visit and said that everyone was already missing Hattie and us - it was so sweet!"

#### Hattie's post-operative recovery

The remaining three days in The Portland were a case of slowly recovering, as the extent of the procedure and pain relief medication Hattie was on naturally made her feel a little sick occasionally.

When Mr Lucas removed Hattie's dressings two days after the operation he was very pleased, and once Hattie had finished her cornflakes Claire helped Hattie with her physio - which this time around included walking back and forth from her bed to the nurses' station.

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### Family time and Hattie's positive influence

Despite recovering from major surgery herself, Hattie was also helping other young patients. Russ said "Sue and Lisa asked her if she would be a mentor to other children as she had such a positive mindset. She talked to two other children who had undergone the same surgery." A lovely surprise for Hattie on day three of her recovery was the visit of her younger sister Libby, who was so pleased to see her big sister she'd made a special certificate of bravery for her.

### Getting ready to go home

After a much needed lie in, on Hattie's final morning in hospital the family were overjoyed when they saw Hattie's post-operative X-rays. Anna, Hattie's mum said "seeing how straight her spine has become was amazing! Maria came again helped Hattie with stair-based physio and gave some invaluable advice on caring for Hattie at home. I got really emotional and cried when she said goodbye!"

There was one more pleasant surprise from The Portland's nursing team. "Sue and Lisa came to shower Hattie and provided some spare dressings and advice. They measured her and we found she'd gained 9cm growing from 5'1" to over 5'4"!"

### New lease of life and looking ahead

Since arriving home, Hattie now has so much confidence in herself and was able to go surfing without experiencing any pain whatsoever. Her next plan is to ride a rollercoaster.

Hattie loves her scar too. Russ said "It shows the journey of what she's been through and says it's her best attribute. She even has it as her profile picture on her Facebook page."







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Notes	Notes

# Our group







The Harley Street Clinic

The Lister Hospital

London Bridge Hospital

The Portland Hospital

The Princess Grace Hospital

The Wellington Hospital

The Christie Private Care

**GP Services** 

HCA UK at University College Hospital

HCA UK at The Wilmslow Hospital

Leaders in Oncology Care

020 7580 4400 theportlandhospital.com

The Portland Scoliosis & Spinal Surgery Centre part of HCAHealthcare UK