Spinal Deformity Team

Chrissy is the Clinical Nurse Specialist for the Scoliosis Service and the contact point for any problems with regards to your treatment.
Tel-01216854397 Ext-55897 Bleep-2717

The Spinal Deformity Team also consists of:

Consultant Spinal Surgeon
Mr David Marks, Mr Jonathan Spilsbury, Mr Adrian Gardner
Mr Johalan Mehta and Mr Matthew Newton Ede

Consultant Anaesthetist
Dr Chandra Bhimrasetty, Dr Tony Sutherland, Dr Connie Blunt
Dr EJ da Silva and Dr Richard Shellard

Nursing and clinic staff
Christina McCaugherty (Clinical Nurse Specialist),
Amy Young (Spinal Pre-Operative Assessment Nurse)
Katy Reese (Spinal research Nurse), Helen Jones (Clinic Sister)
Vicky Walton (Clinic Clerk) Tel-01216854159

Secretarial Team
Sue Jones, Lisa Purcell, Carol Molloy, Sue Yapp and Dominique Campbell
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Useful websites

www.srs.org – Scoliosis Research Society
www.britscoliosissoc.org.us – British Scoliosis Society
www.sauk.org.uk – Scoliosis Association UK
www.ward11.roh.nhs.uk- Ward 11

Infection Control

All staff at The Royal Orthopaedic Hospital takes Infection Prevention seriously. The Trust's clinical policies are built on the World Health Organisation's '5 Moments' campaign which emphasises hand decontamination at the point of care, to prevent transmission of infection between patients.

Patient Advice and Liaison Service (PALS)

If you have concerns or questions or would like to speak to anyone regarding your treatment at the Royal Orthopaedic Hospital please contact the Patient Advice and Liaison Service on 0121 685 4128 or via email on Pals@roh.nhs.uk.

The Royal Orthopaedic Hospital NHS
NHS Foundation Trust

Adolescent Idiopathic Scoliosis

A Guide for Patients & Family

Anterior & Posterior correction

The Royal Orthopaedic Hospital NHS Foundation Trust operates a smoke free policy

What is Adolescent Idiopathic Scoliosis?

So you have been told that you have scoliosis, but now you probably have a lot of questions and this is a guide to hopefully providing you with some answers.

Firstly scoliosis is a twist in the spine which causes the ribs to twist out leading to the development of a rib hump. The adolescent part of the name refers to the age range that this condition is in (age 10 years to 15 years) which is different to infantile or juvenile scoliosis and Idiopathic means no known cause.

The cause however is thought to be related to a rapid upward growth spurt during adolescence, but there is definitely a hereditary association, hence the reason we have asked about any family history of scoliosis.

Adolescent Idiopathic Scoliosis is ten times more common in girls than it is in boys.

What does this mean to me?

As the curve and twist in the spine gets bigger the rib hump increases in size giving hunchback appearances. Sometimes the body is pushed to one side making one hip appear; more prominent than the other or giving you an unequal waist. Scoliosis developing at this age **does not** cause any pressure to your internal organs or cause problems with your heart or breathing.

Is scoliosis painful?

Scoliosis is generally not painful although muscular aches can occur over the rib hump as the scoliosis occurs, however this often settles quickly. If there is significant pain associated with your scoliosis then we will look elsewhere for the cause.

Why did you always ask about my periods?

The spine grows most quickly the year before the start of your periods. If you have started the likelihood of the curve getting significantly worse is smaller than if your periods have not started. This may change the treatment that we suggest. We also need to know the first day of the start of your period for x-ray as you need to be within a 28 day period. If you are not within a 28 day period you will be asked to complete a pregnancy test to ensure that you are able to have your x-ray. Please try and keep a diary of your period's dates as this will be extremely useful.

Why do I have an X-ray at most visits to clinic?

This is important as we can measure the size of your scoliosis and how it changes over time. Unfortunately taking these x-rays takes time and this can mean that your clinic visit is longer than you expect.

Why do I need an MRI scan?

Occasionally scoliosis can be associated with a cyst in the spinal cord or base of the brain. It is important that we know this as if there is a cyst present, it may need treatment that is different to what has already been offered to you or it may change the treatment that we provide for you.

What is ISIS topography scan?

This is a new way of looking at the spine that we are developing currently, to try to cut down on the amount of x-rays that we take. It is a special photograph of the back and allows a computer program to work out the size of the scoliosis from the overall shape of the back. It also gives us and you an idea of what the back looks like. If surgery is undertaken it allows a before and after picture to show you the change from the outside. It does not hurt or is it dangerous in any way.

What is the SRS questionnaire about?

The SRS (Scoliosis Research Society) questionnaire has 30 questions and helps us to understand what bothers you about your scoliosis and by how much. This is very useful information for us and helps us to give you the correct treatment.

What happens now my curve has been identified?

This depends on your age and the size of the curve. Small curves in girls who have started their periods are generally observed over time. People with large curves will probably be offered surgery to prevent further worsening of the curve and to improve the overall cosmetic appearance.

What about bracing?

We do not feel that bracing really has a role in this type of scoliosis as there is usually not the growth left in the spine to correct the overall shape with a brace on. Consequently we do not offer braces to the majority of our patients in this situation.

Will I have to have an operation?

No you will not. Scoliosis surgery is for two reasons only:

- To stop the curve getting worse
- To improve the cosmetic appearance of the spine and overall body shape

For many children the only treatment that may be required will be observation of your spine. We will continue to monitor your spine until you are fully grown to ensure that any deterioration is reviewed and addressed. If you have nothing done then the curve will probably increase in size slowly over your lifetime and you may get more back ache in your old age, but that is it. You will be able to do most jobs (not flying a fighter plane though!), play sport, have children and enjoy life.

Can I play sport and do PE with scoliosis?

Yes you can. There may be some activities that you will find more difficult but these should not be avoided. In general there is no reason not to be physically fit and active, your spine and general health will benefit from regular exercise.

Can scoliosis cause paralysis?

It is extremely rare for an untreated scoliosis to cause any problems with the spinal cord function. One of the reasons for doing the MRI is to look for cysts in the spinal cord, which may cause this sort of problem and we can deal with them if necessary.

Before the operation

You will attend pre-operative assessment clinic (POAC) prior to surgery to enable us to assess whether you are fit for anesthesia and surgery. If you have any issues that may delay surgery such as acne to your back, low blood levels, smoking, the use of contraceptive pill, injection or implant then we will offer advice and treatment. You can also highlight specific dates that you are unable to have surgery. You will be expected to have a blood test at this appointment, swabs taken to ensure you do not carry MRSA, urine test and a breathing test called a vitelograph. At this appointment we will try to introduce to the multidisciplinary team members who will help and support you through your operation. The team includes Anesthetist, Pre Operation Assessment Nurse (POAC) nurse, and Clinical nurse specialist, Physiotherapist, Occupational Therapist (OT), Social Worker and Play Specialist. We will fully explain your plan of care for your operation at this appointment. You may have to come back to POAC a number of times if you have any condition that needs to be monitored prior to your surgery such as acne.

Coming into hospital for your operation

You will be expected to come in the day before your operation at around 4pm, you may need to have a blood test and will be seen by the junior doctor to make sure you are fit for surgery. You will also be given the opportunity to visit the High Dependency Unit (HDU) to meet the staff. You will be seen by the consultant and anesthetist prior to your operation to answer any questions and sign a consent form.

Day of the operation

You will be expected to have a shower the morning of your surgery, please do not use hair conditioner on the day of surgery as this prevents monitoring equipment from being attached to your head while you are asleep. You also need to make sure that your hair is completely dry and if you have long hair we recommend loose pigtails or plates. You will be unable to eat or drink after a certain time which we will explain to you fully when you are admitted. If you have any piercing these will need to come out prior to surgery, so please consider this if you are considering having any piercing in the near future. If you have any infections at your piercing site, please notify us as this could cause complications to your operation. You may be prescribed a pre-medication which is medicine that will help relax you prior to going to theatre. A porter, a nurse and 2 parents are able to come to the anesthetic room with you and stay until you are asleep. Your operation may take all day depending on the type of surgery you have, the consultant will let you know.

What shall I bring with me into hospital?

You will need to bring enough clothes and toiletries for your stay. Please bring loose fitting pajamas; vest tops that stretch, nightie, shorts or loose fitting comfortable day clothes. You will need slippers/shoes to mobilise around the ward also. Please bring toiletries including shampoo, conditioner, shower gel, deodorant, and toothbrush and tooth paste. You may also find dry shampoo or detangling spray useful until you are able to have a shower. The use of hair extension glue remover will help to remove the glue that will be used for the cord monitoring during your surgery. Please also think about bringing in a heat pack or hot water bottle as this can help with pain.

Menstruating

In the weeks prior to your surgery we ask if you can refrain from using tampons to ensure that you do not develop Toxic Shock Syndrome (TSS) which would lead to cancellation of your surgery due to infection risk. Please make sure you are aware of the first day of your menstrual cycle. We routinely screen spinal patients for pregnancy on admission to confirm their pregnancy status if outside of 28 days of last period or if sexually active.

Following your surgery it is very likely that you may start your period early therefore we recommended that you bring some sanitary towels with you into hospital. Please do not use tampons for 6 weeks following surgery to prevent TSS and lower risk of infection. You must not be on the contraceptive pill, patch, implant or injection for 6 weeks prior or post-surgery due to increased risk of DVT.

So what about an operation then?

This is a way of us changing your shape for ever.
We put rods and screws into the bones of the spine to hold it into its new shape. We then fuse the spine so that the bent but mobile spine becomes a stiff but straighter spine. We never make the spine entirely straight but we are aiming for the best cosmetic result and overall shape that we can get.

It is a big operation that will mean you will need to stay in hospital for 7-10 days and will need to have 6 weeks off school! After you have gone back to school you will not be allowed to do any physical activity for 6 to 9 months so that the bone has time to heal.

Usually a plaster or brace is not required afterwards as your spine is solidly fixed and so you cannot harm yourself or break anything moving around after the surgery.

Anterior and posterior correction involves straightening your spine through your back and chest. This is two operations usually carried out under one general anesthetic. Occasionally it may need to be two separate operations with a week of bed rest in between to rest the spinal cord due to the severity of the curve. Although scars are reasonably long they tend to fade away to thin lines eventually.

You do not grow any more from the spine once it has been operated on. This is because we remove all the growth left by fusing it. However most growth comes from the knees anyway so this will not make too much of a difference to overall height, and the operation which straightens the spine tends to make you taller anyway. You will lose some movement however, but this is mostly in twisting rather than bending which mostly comes from the very low spine and hips.

The metal work does not usually come out as there is no need for it to be taken out. It is made of titanium so it will not set off metal detectors at airports and in shops.

Will I be in pain after the operation?

After the surgery there are many different ways that we deal with the discomfort of the surgery. It is always sore, but pain is not helpful to you or us and we do our best to get your pain at a manageable level. You will probably have an epidural which is a local anaesthetic and pain killer into your spine, you will have a intra pleural line that will numb your chest drain site. We sometimes may give you a morphine PCA, instead of an epidural which is a button to press which gives you strong painkillers when you need them. Occasionally you may require an epidural and a PCA, but it is still important that you take oral pain relief too. We will give you regular tablets such as paracetamol, codeine and oral morphine.

It is really important that you take your medication regularly as prescribed, we have tablets, syrups and some medication are also dispersible. If you do not take your pain relief regularly you will be in more pain as this medication work's on your pain receptors to prevent pain.

We also encourage the use of non-pharmalogical methods of pain relief such as TENS machines, heat packs, hot water bottle, changing position, sitting, walking and also distraction listen to some music, playing a game, reading a book or watching a DVD.

Please try and explain the type of pain that you are experiencing as different pain relief works more effectively on certain types of pain. Common words which are used to describe pain are stabbing, burning, jumping, muscle tightness, shooting and aching.

You will also need to take laxative medication to ensure that you do not become constipated due to the strong painkillers and lack of mobility. You must have your bowels open (have a poo) before discharge home and you may need something called an enema or suppository (This is medication given via your bottom; we will explain this to you in POAC). Please don't

worry if you need some extra help, it does not hurt; it normally works very quickly and makes you feel much better afterwards.

What are the risks of the operation?

All surgery has some risks attached to it. We make every effort to make those risks as small as possible however having a scoliosis operation does come with some risks.

The first risk is infection. There is about a 5% risk of superficial infection requiring antibiotics to settle the wound. The deep infection rate requiring removing metalwork and having another operation is about 1%. Your operation is covered by antibiotics to reduce this risk.

It is important that you have no spots or acne on your back before the operation as these spots are little abscesses and increase the risk of infection. Please notify us as soon as possible if you develop any spots/acne as you may need a course of antibiotic or antibacterial scrub to help clear your skin. If the spots do not clear after a few months you may have to be referred to a dermatologist (specialist in skin conditions) for strong antibiotics. **Any spots on the day of surgery will mean that your operation is cancelled and rescheduled when the spots are treated.**

The second risk is that of the bone not fusing and metalwork subsequently breaking which will require another operation. The risk of this happening is very small in healthy young people, but it significantly increases if you smoke. **We will not perform the operation on someone who smokes. You must quit smoking for 6 weeks prior to surgery ideally longer and refrain from smoking for 1 year after due to risk of poor bone healing and developing a Deep Vein Thrombosis (DVT). Electronic cigarettes also need to be stopped for 6 weeks prior to surgery as these contain nicotine**. Please ask for advice on quitting if you need help as you will be expected to complete a smoking test prior to surgery.

The risk that everybody is really concerned abut is paralysis caused by the surgery. This risk is small and we are obviously very careful about this. We have an early warning system of problems that we use during your operation for posterior surgery, which is called spinal cord monitoring. This is when we can make your spinal cord work during the operation to prove that it is ok. It is not 100% but it is pretty good. You will need to go for a pre-operative test at the Queen Elizabeth hospital for this. Occasionally we also use a wake up test, which is when we lighten the anaesthetic so you can wiggle your toes when we tell you to prove to us all is ok. This does not hurt and you will not remember it afterwards.

There is then the risk of any operation such as bleeding, sore throat and the need for further surgery at some point in the future. You may need a blood transfusion but we try to avoid this by recycling your own blood during and after the operation. **If for any reason you are on the contraceptive pill, injection or implant this can increase your risks of DVT and needs to be stopped 6 weeks before surgery and seek other forms of contraception if sexually active.**

What happens after the surgery?

You will be in the High Dependency Unit (HDU) for 2-4 night following surgery depending on how long you require a chest drain. This is a tube used to help keep the lung expanded post-surgery and drain away any excess fluid. When you wake up following your surgery the surgeon will ask you to move your arms and legs to ensure everything is working ok. The anaesthetist will then commence your epidural to numb your back, a interpleural line to numb the chest drain site, a morphine Patient Controlled Analgesia (PCA) pump, fluid running into a tube in your hand called a venflon or cannula, possible wound drain and a tube in your bladder called a catheter so you do not need to worry about going to the toilet. You will also have an arterial or Picc line inserted while you are asleep and these tubes enable us to get blood without having to use a needle.

There are a lot of machines for making sure you are ok, these machines are quite noisy but please don't worry. You may need to use a special breathing machine called Bi-pap. This machine can take a little while to get used to as it helps assist with your breathing by pushing air into your lungs (feels like air blowing in your face). Please try and relax and breath with the machine and before you know it you will forget it's there. You will be able to eat and drink straight away after your surgery but some patients do feel sick after their anaesthetic so we can give you medicine to help with this.

The day after your operation the physiotherapist will come and help you try to sit on the edge of the bed and hopefully stand up if you are well enough. It is also really important than you complete deep breathing exercises the physio will show you how use an incentive spirometer (a plastic tube you blow in). This will prevent you developing a chest infection and you should use the spirometer two hourly at least during the day. Initially you will find

it difficult to move on your own so we may use a special sheet called a slide sheet to help assist you. It is really important that you roll and change position frequently as this will stop you developing pressure sores to your body and help with your pain. The quicker you start moving after your operation the easier it will be.

Over the next 4- 5 days we will take you off some of the monitoring machines and gradually we will slowly remove your fluid, epidural, intrapleural line catheter and cannula. Once the chest drain is able to be removed you will return to ward 11. Each day your movement will improve and you will be expected to sit out for longer periods, complete deep breathing exercises and move more frequently. If you do not comply you are at risk of developing a chest infection and will need to stay in hospital for a longer time. If you are a wheelchair user we will gradually increase the amount of time that you are able to sit out in your chair and ensure that your wheelchair is suitable with your new position.

You will be able to take a shower to get the glue out of your hair from the cord monitoring and we will change your wound dressing for a nice clean one. When we do your dressing change you are more than welcome to have a photo taken so you can see what your scar looks like. You will need to have your bowels open prior to discharge. You should be eating and drinking a healthy balanced diet which will aid a faster recovery and help your wound to heal.

You will need to be able to get in and out of bed with minimal assistance, walk the length of the ward and successfully walk up and down the stairs before the physios will be happy for you to be discharged home.

We will take a final x-ray of your back and chest, if the surgeon is happy you will be allowed to go home. We will provide you with medication to take at home and spare waterproof dressings in case you require a shower. The occupational therapist will make sure that you also have any equipment that you may need to help with your independence prior to going home. You must not have a bath until you have attended a wound check at 2 weeks following your surgery in the clinic and the nurse has stated that the wound is healed. The wound usually has dissolvable sutures which do not need to be removed. **If you have any concerns about your wound you must contact the ward or clinic as the wound will need to be reviewed at the hospital as soon as possible**.

You will see us again in clinic at about 6 weeks following the surgery for review and then again at 6 months, 1 year and 2 years after surgery. If you are a wheelchair user you will require a wheelchair assessment 6 week post operatively to ensure chair is correct for your new shape.
You will need to avoid all real physical activity for between 6 to 9 months following the surgery to allow the bones to fuse properly. In the short term following the operation you will tire easily and need to rest regularly. However you must make sure that you continue to mobilise and sit out for good periods once you get home during your 6 weeks off school.
And finally Spinal surgery is a big operation. Please try and stay positive and remember the best place for you to recovery is at home.

Information Governance

The team of healthcare professionals caring for you keep records about your health and the care you receive from the NHS. This is important to help ensure that you receive the best possible care from us.

There is a separate leaflet available for you entitled ‘Ensuring your information stays confidential’. This guide explains:

- What information we collect
- Why we collect it and how it is used
- How it is protected
- How to see your information
- Your rights.

If you would like a copy of this leaflet or require a copy in another language or format please contact the Patient Advice and Liaison Service Officer on 0121 685 4128.

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