

WHAT I NEED TO KNOW ABOUT SCOLIOSIS SURGERY

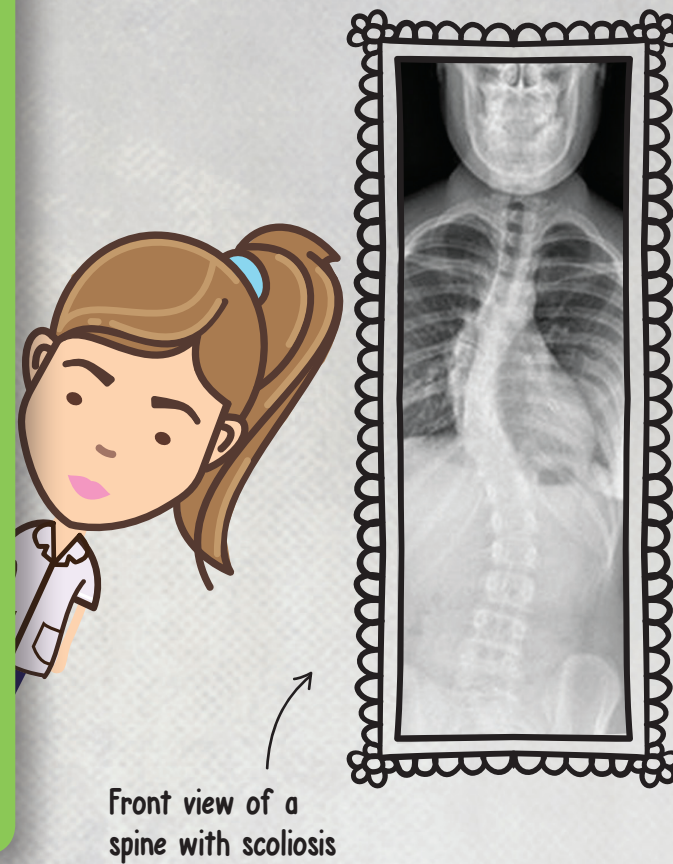
Patient Information



WHAT IS SCOLIOSIS?

When viewed from the front or the back the spine is usually completely straight. The trunk is usually fairly symmetrical and the pelvis bones are level. From the side, there are gentle curves making an S shape to your spine.

A scoliosis means that the spine is curved abnormally when viewed from the front or the back. It can lead to the trunk and shoulders no longer being symmetrical, which can sometimes mean that the shoulders, the head or the pelvis aren't level anymore. The rib cage can also push out on one side so that it becomes prominent - this is known as a rib hump. The severity of the abnormalities can vary between people and can change with time.



SURGERY FOR SCOLIOSIS



In general, surgery is only required if your scoliosis is causing you problems now or may cause you problems in the future. Most people with scoliosis do not have to have surgery. Your surgeon will have discussed alternative treatments to surgery such as pain killers, bracing or monitoring and no surgery. The reason that you have been given this information booklet today is to tell you more about scoliosis surgery itself.

Before offering you an operation the team looking after you will look at the risks and benefits of surgery for you. They will discuss those risks with you to help you make a decision about going ahead with surgery.

The hospital that you have your surgery in should have all of the facilities required to keep you safe before, during and after the operation. Some of those facilities include having the right anaesthetic team. During the operation the anaesthetist will look after you by using lots of special equipment and medication and they will help to control your pain after the operation.

Surgery can only go ahead where intraoperative spinal cord monitoring (IOM) is available as this is essential equipment for the operation. Electrodes are used to monitor your spinal cord. They are placed on your head, arms and legs when you are asleep and they alert the surgeon to any changes in your spinal cord signals during the operation, which reduces the risk of a spinal cord injury (resulting in numbness or weakness) during the operation.

After the operation, you may need to be looked after in a High Dependency or Intensive Care ward for a while. This is to keep a close eye on you and reduce the risk of complications after the operation.

The amount of time that you spend in hospital will vary and this will be discussed with you. As you can expect, you will have to reduce activities for a while to recover from the surgery, the time required will vary depending on the operation that you have had.

WHAT ARE THE BENEFITS OF SURGERY?

Before your surgeon discusses having surgery on your spine you will have come to the clinic quite a few times, had X-rays and an MRI scan to look at your spine in more detail. All of these appointments and scans help the surgeon to understand your condition and what might be the best treatment for you. Your surgeon will also be able to talk you through which of the benefits are most likely to apply to you.

Some people do get very embarrassed about their shape and this is not unusual. If your shape changes make you feel very awkward and worried about your appearance then this is a good reason to discuss surgery. The shape can change as you grow, particularly at the time of growth spurts. Scoliosis surgery usually improves your shape, height, symmetry and posture. It cannot always fully correct this, but the majority of patients do feel improved after surgery.

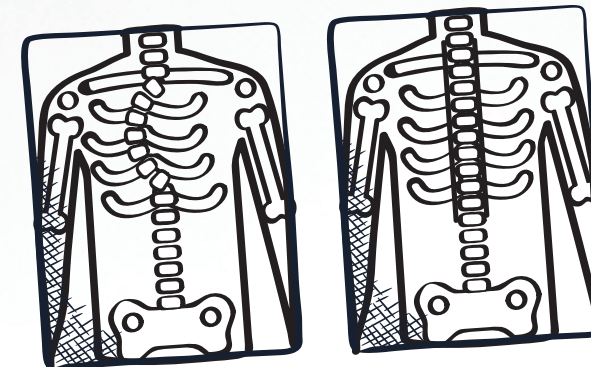
Scoliosis can affect the way that your spine moves and works. This can cause aches and pains. Although surgery is never guaranteed to improve pain, it can sometimes achieve this by realigning your spine and fusing the spine.

If it is felt necessary to operate at a younger age, the advantage of surgery is to reduce the chance of a severe scoliosis later on in life. It also is felt to improve the development and function of your lungs.

Scoliosis that has started as a child or teenager can go on to cause wear and tear changes in the spine later in life resulting in pain or pressure on nerves. Scoliosis surgery may reduce the chance of this happening by realigning your spine. Unfortunately, we have not been able to prove this yet and there is still a possibility of needing treatment later on in life even after scoliosis surgery.

Scoliosis that starts later in life is usually because of wear and tear on the spine and this can cause pain and pressure on nerves. The aim of surgery in this situation is to relieve the nerve root pressure and to fuse the worn parts of your spine. This should improve nerve pain and hopefully some back pain as well.

The surgeon looks at each person's condition as an individual story and using their experience and knowledge will make a plan according to what they feel is the best treatment for you.



SPINAL SURGERY AIMS TO:

1. Prevent your curve from getting worse
2. Decrease your curve, which improves the appearance of your spine and back and improves your posture
3. Improve the space for your lungs to let them work better



WHAT ARE THE RISKS?

The risks of undergoing surgery are low. Scoliosis surgery has been happening for a long time and has continued to improve. This means that this sort of surgery is tried and tested and so the risks are well controlled.



THINGS TO EXPECT

STIFFNESS

All scoliosis surgery is done by using rods and screws or other implants attached to the bones in your spine. We do not use flexible rods, so you will have a stiffer spine after the surgery. That means you won't bend through your back as easily, although your hips and the rest of your spine will still allow you to move easily for every-day life.

If you are very keen on sports you need to talk this through with your surgeon. In general most people get used to the stiff feeling and it feels normal by 3-6 months in most cases.

SCARS

Scoliosis surgery is an open procedure and is performed by making an opening in your skin which will leave you with a scar. Sometimes the scars are long and on the side of your trunk as well as on your back. Sometimes they may be just in the middle of your back. Ask your surgeon what the scar will be like and how long it will be. Most scars heal as a faint straight line. Occasionally they can become raised or widened depending on how your body heals.

POSSIBLE RISKS

Although a lot of care is taken when you have an operation, things can happen that we don't want to happen. This is a list of some of the things that we warn you about with scoliosis surgery.

NOT LOOKING BETTER

One of the reasons you may have surgery is to improve your shape and how your body looks. Most people (80-90%) that have surgery feel a definite improvement in their shape. Sometimes what you are left with is not as good as you thought it would be. Sometimes you may feel there is no improvement at all. Your surgeon will usually be able to give you an idea of how much better your shape may get. It is important for you to realise that getting back to being completely straight is not always possible. Sometimes your surgeon will advise that leaving some curvature is less risky and will plan your surgery that way. Early on after surgery it is not unusual to still be asymmetrical due to swelling, your body and muscles getting used to a new shape. This will improve over weeks.

GETTING WORSE WITH TIME

If you are very young when you have surgery or if your surgery is on a very short part of your spine your curve could get worse over time. Older adult patients that have scoliosis surgery can also be left with shape changes after some time. Often this can be dealt with by considering more operations if you and your surgeon feel it is necessary.

LEAK OF SPINE FLUID (CSF LEAK)

Very occasionally (2% of the time) you can get a leakage of spine fluid from around the nerve roots at the time of the operation. This can sometimes result in your wound oozing, headaches and a slight increased risk of infection. It is not known to cause long term problems and can be dealt with usually at the time of the operation. It may need you to remain on the bed for a few days after the operation. If things don't settle, it may require another operation, but this is rare.

POSSIBLE RISKS

NUMBNESS OR WEAKNESS (NERVE OR SPINAL CORD DAMAGE)

Surgery on the spine can result in injury to the nerves or the spinal cord – these send and receive messages from your brain to the rest of your body. At its worst this could leave you permanently paralysed and so in a wheelchair. This could mean that you would not be able to move or feel your legs and may not be able to control how you wee and poo. The risk of this is less than 1%. This means that 99% of the time this risk won't happen.

Sometimes the injury may not be as severe, but could still cause some weakness and numbness that needs you to depend on walking sticks or splints. The risk of this is also less than 1%.

More often a small patch of numbness without weakness could happen. This is more common (around 2%) and usually does not cause any problems to function and everyday life.

Modern surgery techniques and equipment allow us to monitor your spinal cord and keep the risks so low that over 95% of people that undergo this surgery have none of these nerve issues, including the minor ones.

INFECTION PROBLEMS WITH THE WOUND HEALING

Risks of infection vary widely between people and the type of surgery you are having. Your surgeon will give you an estimate, but it is between 2-5%. The risk of infection is higher with a bigger operation, if you are older and if you are in a wheelchair. We protect you from infection by operating carefully and by giving you antibiotics for the surgery. The operating theatres we use are also specialised to reduce infection and a lot of the preparation for your surgery is to reduce this risk.

Mild infections at the top of the wound are usually dealt with by dressings and tablet antibiotics, these are the most common. Deeper infections can become more troublesome and need repeat operations to sort them out. Sometimes the only way to get rid of an infection is by taking out your metal implants. This may cause some of your scoliosis to return.

EYE DAMAGE

Most scoliosis operations are done with you lying on your tummy with your eyes closed and your face protected. Despite all the care we take, there is a small chance of scratching the eye accidentally during the operation. This will feel like you have something in your eye and will need ointment to protect the eye from infection. This usually settles without problems.

Very rarely the eye or eyes may have too much pressure on them during the operation. This can damage them and affect the eyesight and even cause blindness.

This is very rare (less than 0.1%) and more than 99% of people that have the operation will not have any eye issues at all.

SKIN DAMAGE

Most scoliosis operations are done with you lying on your tummy with your eyes closed and your face and all skin areas protected. As these operations can take a few hours, there is a small chance of skin damage caused by pressure. This usually settles without problems, but may need dressings and treatment. This is uncommon.

BLEEDING

Any operation carries a risk of bleeding more than we expect, this can be for all sorts of reasons. The theatre team are prepared for this and we will use lots of methods to keep the amount of bleeding low (the way we operate, drugs, anaesthetic methods). If there is a lot of bleeding, we may have to give you some blood (blood transfusion). To help prevent the need for a blood transfusion we are able to give you your own blood back through a machine called a cell saver. We will also give you iron tablets before your operation. You must let your surgeon know if you are not willing to have a blood transfusion for any reason.

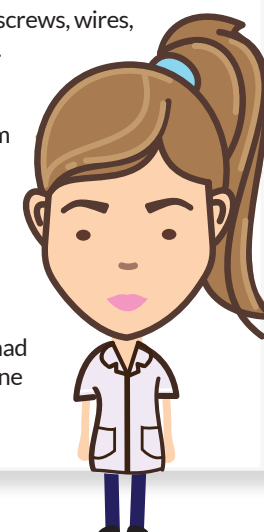
COMPLICATION TO OTHER AREAS

During any surgery, unexpected things can happen that we may need to treat in addition to your main problem. Examples include chest infections, kidneys not working properly after an operation and thrombosis (blood clots) in the veins in your leg. In young people and children the risk of thrombosis is rare, but we will try and prevent this by using special stockings and pumps on your legs after the operation. All the preparation and care we take for your operation will reduce these risks but if they happen we will treat them. Very, very, rarely complications can happen that are life threatening. The chances of this are very low, but bigger operations, blood loss and other diseases can affect this risk.

IMPLANT (METALWORK) PROBLEMS

Scoliosis surgery is carried out by using screws, wires, hooks and rods to straighten your spine. Sometimes these can loosen, move or even break. This probably happens less than 2% of the time. If the metal problem causes pain or other problems, further surgery will be advised. These problems can happen sometime after surgery – even years after.

Metalwork can set off metal detectors in airports. Your surgeon may be able to give you a letter to show that you have had surgery requiring metalwork in your spine



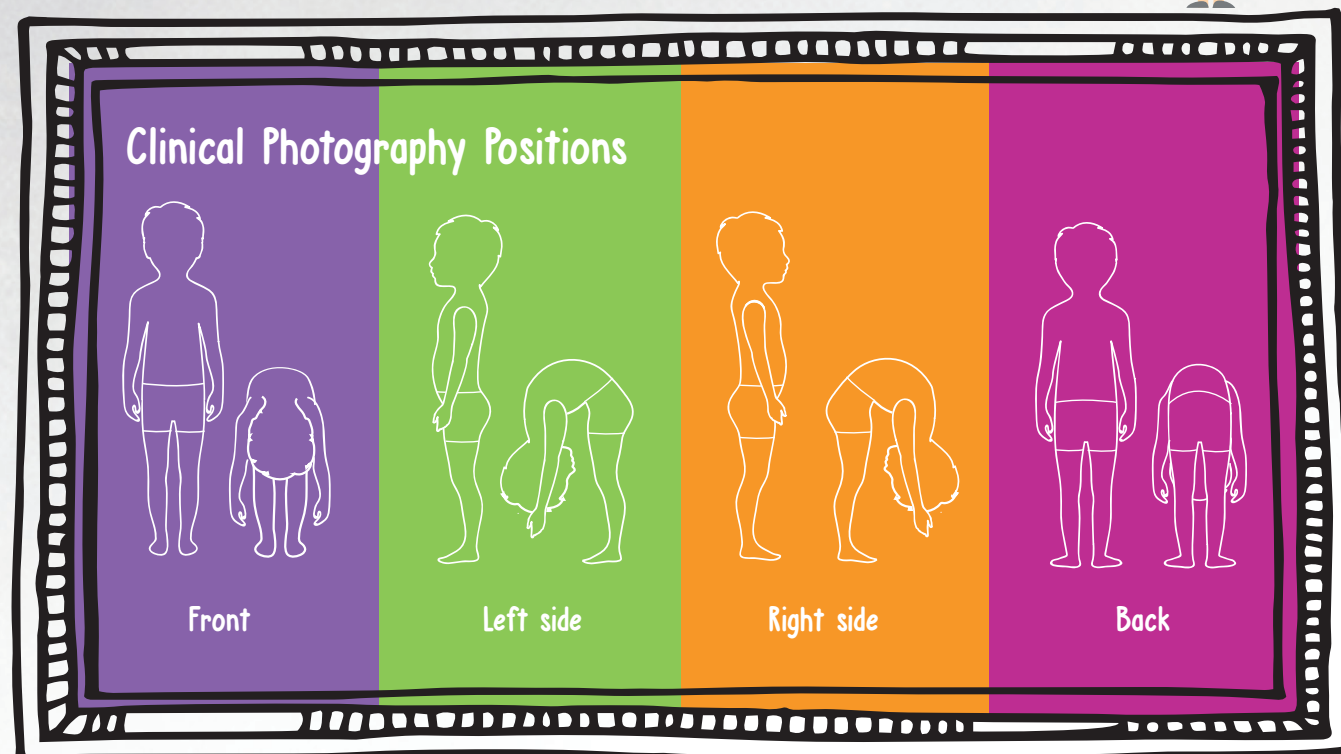
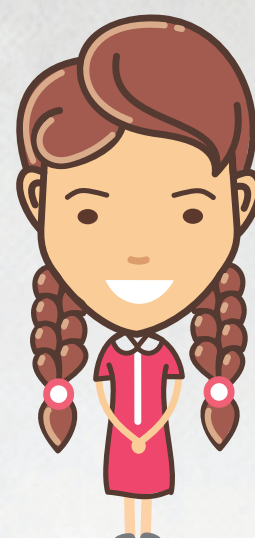


If you have decided to go ahead for surgery, your surgeon will have put you on a waiting list. There is usually a wait before your operation and the amount of time can vary. You should have the contact details of the Scoliosis Nurse Specialist; if you have questions.

Your case will be discussed by the team looking after you and preparations for surgery will be made. Some tests will be organised while you are waiting.



Clinical Photography Studio



OK...SO WHAT HAPPENS NEXT?

TESTS YOU NEED BEFORE YOUR OPERATION...

All of these tests are done before your operation, usually on the same day as your pre-operative clinic appointment. Although we do try and arrange for all of these tests to be done on the same day there are occasions that this may not be possible.

X-RAYS

By now you will be used to having X-rays at your clinic appointments. At some point before your surgery, you will have X-rays again. This time you will be asked to bend from side to side and also to have your spine stretched over a hard cushion whilst X-rays are taken. These help us decide where we need to put the screws and rods in your spine.

MRI SCAN

An MRI scan is a specialised test to help us look at your spinal cord and other structures in your spine. This is to make sure that there are no other issues we need to be thinking about before your scoliosis operation. The MRI scan can take some time to do – you may be in the scanner for 45 minutes to an hour. You will be given separate information about MRI scans.

LUNG TESTS

Lung tests are done to check if your lungs are working well enough for your operation. You will have an appointment to attend the lung clinic where you will be asked to blow into a machine that will take measurements of how well your lungs work. Sometimes you will be asked to have a sleep study. This is an overnight stay at the hospital where your oxygen, carbon dioxide levels and breathing patterns are monitored whilst you sleep. Not everyone needs to do this test.

BLOOD TESTS

Blood tests are required to make sure that your body is in its best possible condition for the operation. Our nurse specialist and anaesthetic team will talk to you about how these will happen. We can use cream to numb your skin if you prefer.

SKIN SWABS

Swabs (like cotton buds rubbing the skin) are taken from 2 or 3 sites on your body to check if there are certain bugs there that we may have to get rid of before the operation.

NERVE TESTS

Sometimes you will have to see the neurophysiology team before the operation. These are the people that help keep an eye on the spinal cord to make sure it stays well during your operation. They may want to do some tests on your nerves beforehand to see what they are like. Electrodes (sticky pads) are placed on your skin to pass small electric currents that may make your muscles jump a little as they are testing your nerves.

CLINICAL PHOTOGRAPHY

These are photos taken of you before your operation so we can compare them to how things look after the operation. They are done with you in your underwear so wear boxer or gym shorts and a sports bra or crop top for girls. You will be photographed from the back, front, side and bent forwards.

Only professionally qualified medical photographers will take your photographs, NO other person will be allowed to take these photographs. They will be kept on a private database as part of your medical notes and treated with strict confidentiality; they will NOT be used for public display. Occasionally photographs are used for teaching or research purposes, but consent to use your photographs would always be obtained from you or your legal guardian beforehand.

CLINIC APPOINTMENTS

As well as the tests above, there will be some clinic appointments. Some of the tests will be during these appointments. You will have a preoperative assessment appointment with the Nurse Specialist. They will make sure you have understood everything and often do the blood tests, swabs and organise X-rays. They will also make sure you have iron syrup or tablets before your operation and you will also be given a special soap to use before your operation. The Nurse Specialist will arrange for you to have a tour of the hospital, including the ward and the intensive care unit. This will help you familiarise yourself with the hospital for when you come in.

You may meet one of the anaesthetists in a clinic. They will help you to go to sleep for your operation and ensure you don't feel any pain during the actual surgery. They will talk to you about the operation and check that you are ready and fit for it. They will let the surgeon know if they feel you need more tests before your surgery.

You will also have a clinic appointment with your surgeon, who will go over everything about the surgery and answer any questions. The surgeon will review the benefits and the down sides of an operation. If you are under 16 you and your parents will be asked to sign a consent form with the surgeon that shows that you all agree and understand what has been discussed and you feel you have been fully informed.

WHAT WILL I NEED TO BRING INTO HOSPITAL?

☐ Nightwear, dressing gown, slippers

Nighties and pyjamas that fasten at the front will be easier to take on and off, make sure that your slippers have a good grip and backs on them so that you don't slip over.

☐ Loose fitting clothing to go home in

Loose clothing is easier to get on and off and won't rub on your skin. Remember to bring a warm outfit to go home in.

☐ Underwear

Comfortable underpants and girls may find crop tops more comfortable than bras as the straps may rub the wound.

☐ Toiletries

Miniature bottle of shower gel and shampoo will be enough and will take up less room in your bag.

☐ Lip balm

Your lips will get dry and cracked after your operation. Try to avoid Vaseline or anything that contains petroleum jelly.

☐ Moisturiser

Your skin can get very dry.

☐ Wet wipes

These are handy for when you want to freshen your face and hands, especially in the first couple of days when you won't be walking around much.

☐ Medication

It is important that you bring into hospital any medication that you usually take.

☐ Hair brush or comb

Your hair can become tangled easily with lying in one position. If you have long hair it's usually best to tie it up in a bun or a plait.

☐ Snacks and drinks

Try to avoid fizzy pop as this can make your tummy feel bloated.

☐ Music/books/pens/tablet

Days can be long when you are in hospital so it's always useful to bring in items that can help pass the time and keep you entertained.

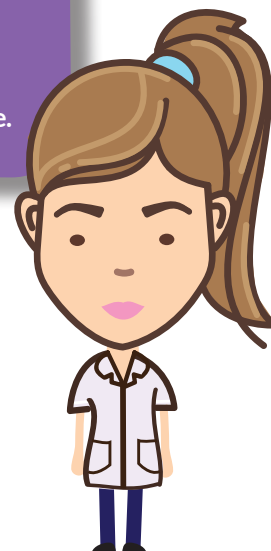
☐ Toys

If you have a favourite teddy or toy that you usually sleep with it is a good idea to bring this with you.

☐ Pillows

When you leave hospital, having pillows in the car will help to keep you comfortable for the journey.

When you come into hospital try to keep your personal belongings to a minimum, as space is extremely limited. Necessary items for both patients and family members are listed above.



DAY OF THE OPERATION...

You will have to shower the night before and the morning of your operation with special soap. You will be asked to come to the hospital on the day of the operation or the day before.

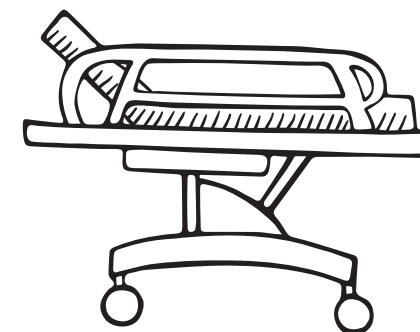
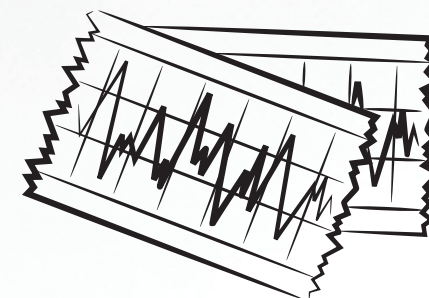
You will not be able to eat for 4-6 hours before the operation, but you can usually drink a little water or diluted juice for up to 2 hours before the operation.

The ward nurses will meet up with you and make sure you are ready for your operation by asking you questions, weighing you, taking your blood pressure and some other tests.

The Nurse Specialist, anaesthetist and the surgeons will meet you again to answer any questions.

When it is time for your operation, you will be taken to the theatre by the porters. If you wish your mother or father will be able to go with you, they will have to walk but you will be pushed in your bed!

The anaesthetist will help you go to sleep in the theatres and then you will have your operation.



AFTER THE OPERATION...

When you wake up, you will have a lot of tubes and drips to keep you well and help your pain. You will have a catheter – a small tube that drains away your wee, so you don't have to worry about getting up to go to the toilet.

You will usually wake up in the recovery ward just outside of theatre. Your parents can be there very soon after you wake up.

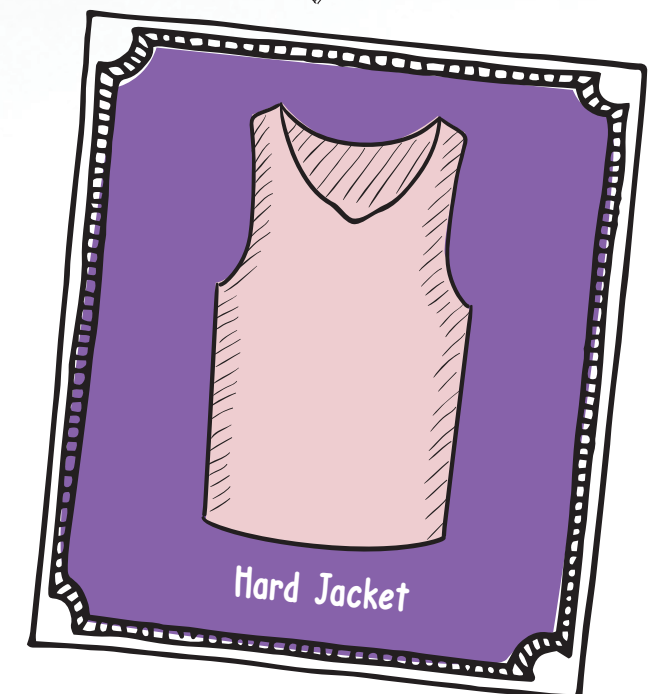
You may have a night or two on a high dependency or intensive care ward before you go back to the ward.

You will have lots of painkillers to help calm down the pain. You will probably be quite sore for the first 2-3 days and then pain gets easier.

In that time all of the nurses and doctors will be looking after you. The physiotherapist will see you to start some exercises and help you sit, stand and walk.

As you feel better, you will walk more and more, the drips and tubes will be taken away and the dressing on your wound will be checked regularly.

When you are ready, you will have an X-ray standing up or sitting upright to check everything looks ok. You may have a hard jacket to protect your back; this usually has zips on it so it can be removed. You will be asked to wear this for 6 to 8 weeks. Not everybody will have a hard jacket.



GOING HOME

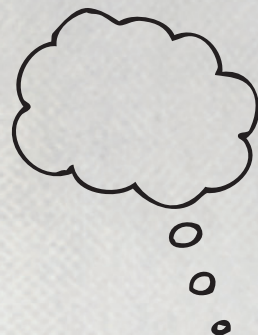
WHEN WILL I BE ABLE TO GO HOME?

When we feel you are ready, you can go home. You will have painkillers to go home with - use them to stop yourself getting into pain. Make sure you follow the instructions given to you by your doctors.

Look after the dressing on your back - if it comes off ring the Nurse Specialist or ward for advice. In terms of what you can do, your body will guide you mostly. When you are sore take things easy, as you feel better you can increase what you do. You can go up and down stairs, walk around the house and outside and sit on any chair or sofa. Early on all of this will be uncomfortable and you may have to limit how much you do.

Feeling tired is also normal for the first 2 to 4 weeks - sleep if you feel you need to, even in the middle of the day. You will be given advice by the doctors and nurses for when you go home, make sure you follow the instructions given to you.

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WASHING AND DRESSING

- Shower as soon as you feel safe to stand ensuring that the wound is covered in a waterproof dressing. Avoid having a bath until the wound is healed unless you are able to keep it completely dry.
- Loose clothing is more comfortable. Sit down to put on trousers, pants and socks as this is less strain on the back.
- Acetone based nail polish remover will get rid of any remaining glue left in your hair from the spinal cord monitoring.

SLEEPING

- Use pillows to support your back if needed. You can sleep in any position that is comfortable.
- Take the pain relieving medication that you were sent home with to keep you comfortable.

SPORTS AND EXERCISE

- Slowly build up your level of exercise according to the advice from the physiotherapists and your doctors. You will be given some exercises to do when you get home
- Walking is good and can be done at a slow pace as soon as you feel ready. Swimming is ok as soon as the wound has no scabs on it. Gentle running can start at 6 weeks or so. You should avoid PE at school for 6 to 8 weeks.
- Don't ride a bike until you are seen in clinic. You can't do any impact activities or contact sports until you are seen in clinic. You usually can't do contact sports (including skiing or competitive horse riding) for 6 to 12 months after surgery.
- Your surgeon will recommend what exercise you should and shouldn't be doing when you come to clinic for your follow up appointment after your operation.

SCHOOL AND WORK

- Return when you feel ready, normally after 4 weeks, unless your work is particularly strenuous or involves lifting. You may need to go in for part of the day only to begin with.
- Physical education will need to be avoided for the first 6 to 8 weeks.

DIET

- Eat a well-balanced diet. Do not follow a low fat or low calorie diet, as this will not provide enough nutrients for the healing process to take place.

TRAVELLING

- You can sit as a passenger in a car straight away; you may need pillows to keep you comfortable to start with. You may need to stick to short distances at the beginning.
- You can usually drive after 6-8 weeks. The rule is that you should be comfortable, able to concentrate on the road and perform an emergency stop if needed before you start driving.
- You should not fly for 3 months if you can avoid it.
- When you do fly, your metalwork will not usually set off the security alarms but can do sometimes.

LOOKING AFTER YOUR WOUND

- Leave the dressing alone for the time that the hospital has told you. The hospital will arrange for the dressing to be changed by a nurse coming to your home or you going to your GP. If the wound gets red, angry or painful call the Nurse Specialist or the ward for advice.
- If you have a waterproof dressing (ask before you leave the ward) you can have a short shower. If not then you will have to sponge bath until the wound has healed more (2 to 4 weeks). Once the dressing is off (2 to 4 weeks) do not pick at any scabs. Let the scabs come away naturally. Once scabs are off and the wound is dry you can start to go for baths and also swimming if you want. You can use bio-oils around this time too if you wish.
- You are advised to protect your scar with high protection sun factor if you go sunbathing.

WANT TO KNOW MORE?
Try the following websites:

[www.britscoliosissoc.org.uk/
patient-information/common-conditions](http://www.britscoliosissoc.org.uk/patient-information/common-conditions)
www.sauk.org.uk/
www.srs.org/patients-and-families

