A young person’s guide to

Scoliosis
What is scoliosis?

A normal spine curves slightly in and out between your neck and lower back when looked at from the side but looks straight from the back.

People with scoliosis have a spine that curves in an "S" or "C" when looked at from the back. This sometimes causes one shoulder to be higher than the other or the hips look tilted and the body leans to one side. The spine may also rotate or twist slightly causing the ribs to stick out on one side.

A slight curve of the spine is a common condition, and for 90% of children this will correct itself in time. However some children will need treatment such as a brace and/or physiotherapy. Some will need an operation to straighten the spine.

We have no way of preventing scoliosis from happening. In most cases the cause of scoliosis is unknown and this is called idiopathic scoliosis. This type of scoliosis can start in early childhood, but more commonly develops during teenage years when there is a growth spurt.
What does the surgery involve?

There are two approaches to scoliosis surgery:

- an anterior fusion, where the surgical cut is made at the side of your chest
- a posterior fusion, where the surgical cut is made on your back

One or both of these approaches may be needed. Your surgeon will discuss this with you and your family. If you have two stages, you may be on bed rest for approximately one week between the stages.

After an anterior release or fusion, a tube is inserted into your chest temporarily. This is to drain excess fluid and is called a chest drain.

You may need to wear a brace or corset after your surgery.

If you have one operation (single-stage), you are likely to stay in the hospital for 5 days.

If you have two operations (two-stage), you are likely to stay in the hospital for 14 days.
Preparation before your admission

Nutrition
Good nutrition before the surgery will help you to recover and heal well after the operation.

Make sure that you eat well during the weeks building up to the operation, especially if you are below the ideal weight for your height. Eating three meals a day and two or three nourishing snacks in between can help this.

Avoid periods of not eating, strict weight reduction and fasting in the weeks and days before the surgery. This will affect your body’s stores of nutrients, making the operation less safe and may prevent it from taking place.

Occupational Therapy
You will receive a questionnaire from the occupational therapy department before your surgery. It is really important to complete this questionnaire and return back to us. The information you provide will help your occupational therapist support you in safely returning home.

Depending on how far down your back your surgery goes, you may need to be careful when sitting on low furniture, such as your toilet, bed and chair. Your occupational therapist will advise you about this.
What to bring with you

• Wash items like shower gel and shampoo
• Toothbrush and toothpaste
• Loose fitting pyjamas with loose T Shirts
• Your own clothes, including close fitting vest tops to wear under your brace
• Well fitting slippers (preferably no flip flops)
• Normal footwear/shoes
• Any regular medication you take
• Books or other entertainment, although we do have a good selection of activities on the ward and each bed space has a television
• Small amounts of any snacks and drinks that may help tempt your appetite after surgery. For food safety reasons choose long life and individually wrapped items
• Mobile phone charger
What happens when you are admitted to the ward?

When you arrive on the ward, you will be shown to your bed space and introduced to the nurse looking after you for that day.

Your nurse will weigh you and do your ‘observations’ (blood pressure, heart rate, oxygen levels, temperature etc).

They will ask you some questions about your health. If there are any questions you don’t want to answer in front of your family, you can talk to your nurse in private.

The nurse will then show you and your family around the ward so you all know where everything is.

There will be more than one nurse looking after you throughout your stay. We try and have the same nurses looking after you as much as possible.

For girls it is important that they are not pregnant when they come into hospital for their operation. It is also important to let the nurse know if you are taking the contraceptive pill. This is because there are risks in having surgery if you have taken the pill 6 weeks before your surgery date.

The nurse also needs to know if you smoke, as this may make you more at risk of serious chest infection after surgery. There is support available for this during your stay in hospital.
Who else will you see during your stay?

Surgeon
You will be seen by your surgeon or one of his/her team. They will talk to you and your family about the operation and will ask your parent/guardian to sign a consent form to allow the operation to happen. You can sign the form as well.

Anaesthetist
An anaesthetic doctor will come to see you and discuss the options of going to sleep with you. You can either have some medicine through a small drip, called a cannula, which is normally put in the back of your hand. A numbing cream called EMLA can be used before the drip is put in. The other option is to breathe the anaesthetic gas through a clear mask that goes over your mouth and nose for two to three minutes. The gas smells a bit like felt tip pens.

Occupational Therapist
The occupational therapist will see you to go through the information you have provided about your home environment and about returning to daily activities at home, school and leisure activities.

Physiotherapist
The physiotherapy team will see you the day after your surgery and help you to start to get out of bed.
**Therapy Technician**
The therapy technician will work alongside the occupational therapists and physiotherapists during your stay.

**Dietitian**
Good nutrition before and following surgery has been shown to reduce complications, improve wound healing, and maintain muscle strength. Helping your recovery and rehabilitation will reduce the amount of time needed to stay in hospital. The dietitian can offer advice, suggest dietary adaptations and treatment to help you meet your requirements.

**Play Specialist**
The Play Team on Coxen ADU work Monday to Friday and their job is to help you prepare for your surgeries and procedures. They also help to reduce any fears and anxieties you may have about being in hospital or your operations. They have a wide range of art and craft and DVD’s/Games to help keep you distracted.

**Clinical Psychologist**
The psychology team can help you and your family cope with the stress of hospitalisation, medical treatments and feelings you might experience like fear, anxiety, anger or sadness. We also teach strategies for managing pain or swallowing tablets. Our service is available before, during and after admission.
The day of the operation

On the day of your operation you must not eat or drink, this is called "fasting", for a short time before your operation (6 hours for food and 2 hours for water). If you suffer from constipation make sure that you open your bowels before the surgery. This is important and may delay your recovery.

When you are asleep the anaesthetist will put in the drips that you will need to safely have your operation. As you will not be able to get out of bed to get to the toilet immediately after your surgery you will need to have a urinary catheter. This is a small tube that goes into your bladder and drains your urine into a bag. This will also be put in whilst you are asleep.

After your surgery you will go to the Children’s High Dependency Unit or CHDU. You can ask your nurse if you or your family would like to see the CHDU before surgery. There is a folding bed so that one of your family can stay with you overnight.

Your drips and urinary catheter will be there when you wake up, but they will be removed as soon as possible after your operation. You will also have lots of tubes and wires attached to you. These are for monitoring you, giving you oxygen and pain relief.

You will stay on CHDU for at least one night because you have had a big operation and need close monitoring. When the doctors are happy, you will return to your ward.
Medication

You will have a pump above your bed with a syringe that contains strong pain relief. This is called patient controlled analgesia or PCA. The PCA has a button attached to it that you can press. Only you should push the button, not your parents/family, especially while you are asleep. The pump will give some pain relief through a tube in your hand. You cannot give yourself too much medication as the machine is programmed to give you a controlled amount. While you are on your PCA, your nurse will have to do your observations every two hours. This will mean they will wake you up during the night. This is important as the strong painkillers in your PCA can slow down your breathing and make you feel very drowsy.

You may have an epidural which is a pain killer that goes into your spine through a small tube in your back. A special machine will give you a set amount every hour.

We will also give you regular pain killers such as paracetamol as a tablet or a liquid.

You will have a bag of fluid hung up above your head and a pump will give you a set amount every hour through a tube in your hand. This is to make sure you do not become dehydrated. Once you start drinking, this can be removed.

You might need antibiotics to help prevent or to treat any infection. If you feel sick after your surgery or experience any itchiness, the nurses can give you medicines to help this.
Pain is normal after surgery and every effort will be made to manage your pain but you may not be completely pain free for the first few weeks. You will only be discharged from hospital once your pain is under control.

You will be able to discuss with your nurse which way you prefer to take medication i.e. tablet or liquid.

Recovery from surgery

It is very important that you don’t stay in the same position for too long following your surgery as you will become stiff and may get sores on your skin if you have pressure on the same parts of your body for too long. Your nurse will help you change your position at least every four hours by rolling you either onto your back or side with your shoulders and hips moving at the same time. This is called log rolling and helps prevent twisting your back in bed.

Helping your body to recover

It can be difficult to eat and drink well after your surgery. Eating and drinking well after the operation will help you feel better and recover more quickly. Good nutrition after surgery has been shown to reduce complications, improve wound healing, maintain muscle strength and reduce the amount of time you need to stay in hospital.

If you are struggling with eating, the nurses can offer you a Build Up milkshake as a supplement while your appetite is poor. You may be referred to the dietitian for more help.
Constipation is a common problem after surgery and this can reduce your appetite. You will need to take the laxative and anti-sickness medications prescribed for you. The following tips can also help:

- Drink well throughout the day (6-8 glasses of fluid)
- Have a hot drink before breakfast; this can be helpful and soothing
- Prune juice helps; try mixing with apple juice for a sweeter drink if you prefer
- Chewing sugar free gum for at least 30 minutes three times a day is helpful
- Eat as much as you can at breakfast, lunch and supper times

If you are only able to eat small amounts, have a nourishing snack in between your meals mid-morning, mid-afternoon and at bed time to help improve your intake. Ask the ward hostess about what is available and for help with the menu if you need it.

If you feel sick, not eating can make this worse. The doctor will be able to prescribe some medication to help you feel better and to be able to eat again. Ginger in ginger biscuits and flat ginger ale, peppermint and flat coke can be helpful.

You will be given a wash in your bed each day and your sheets changed. You can do as much of your wash as you feel comfortable doing, your mum or dad can help the nurse if you like. Around your urinary catheter site will need a very good wash daily to prevent infection. Once you are able to get out of bed and move around, your catheter will be removed and a nurse will help you have a shower.
The recommended precautions following surgery are:

Upper back surgery

- Avoid twisting
- Avoid lying on your stomach
- Avoid lifting heavy objects (not more than 2lb (1kg) in each hand)
- Avoid being pulled up under your armpits or legs
- Avoid jarring your spine
- Reduce risk of falling by removing hazards from environment.
- Avoid PE and swimming as instructed
- Wear Brace as instructed

Lower back surgery

- Avoid twisting or bending your back
- Avoid bending your hips more than 90 degrees (like the corner of a square) whether lying, sitting or standing
- Avoid lying on your stomach
- Avoid lifting heavy objects (not more than 2lb (1kg) in each hand)
- Avoid being pulled up under your armpits or legs
- Avoid jarring your spine
- Reduce risk of falling by removing hazards from environment.
- Avoid PE and swimming as instructed
- Wear Brace as instructed
Getting moving afterwards

The type of operation you have will affect how quickly you can start moving.

Single-stage (one operation)
If you have a single-stage fusion you should be able to start moving the day after your operation. You may have a chest drain inserted if you have an anterior release.

The physiotherapy team will come to see you the day after your surgery. Here is a guide on what to expect:

Day 1
- Initial assessment
- Introduction to bed exercises; which you should continue independently
- To sit on the edge of bed
- To stand and begin to take steps

Day 2 - 3
- Continue bed exercises
- Progress walking
- Begin sitting in a chair; aim to sit for 15-45 minutes

Day 4 - 5
- Walking independently
- Aiming to sit in a chair for a minimum of 45-60 minutes.
Two-stage (two operations)

Depending on your surgeon you may be required to stay on bed rest in between your operations.

You may have a chest drain and will need to do breathing exercises which will be given to you on the day after your first operation. You will also be given bed exercises to complete independently.

If you are on bed rest, you will be allowed to start moving after your second operation. You will then follow the day-to-day guide as per single-stage fusion.

If you are allowed to start moving after your first stage we will guide you through the process.

The physiotherapist will help you with your walking and exercises whilst you are on the ward. However it is also important that you take responsibility with your recovery in terms of moving around both on the ward and at home.
**Brace**

You may need to wear a brace after your surgery which is decided by your surgeon. If so, then a corset will be given for you to wear until your brace arrives. You will be advised on when to wear your brace and for how long.

Your nurse will arrange for you to be cast for a brace. You will be taken to plaster theatre by the porters. The cast can be done when you are standing up or lying down. Your surgeon will let you know what they would prefer and why.

The orthotist will fit your brace for you.
Daily activities

Following your operation, it is important for you to resume your normal daily activities as soon as possible while remembering to protect your back. There are some precautions you need to be aware of to reduce the strain on your back, thus allowing the bones in your spine to heal. Bone healing can take approximately three to twelve months to complete, but it may take longer.

Washing
Depending on how far down your back your surgery goes, you may not be able to sit to the bottom of the bath. If you have a shower over your bath you could use a bath board. The occupational therapist will advise and assess you for this.

If you are required to wear a brace, this should be removed once you are sitting on the bath board and then replaced before you get out of the bath. Your occupational therapist will show you how to transfer in and out of the bath.

If you have a separate shower, you may be allowed to stand or sit on a shower chair. Your occupational therapist will advise you about this.

Dressing
It is best to wear loose fitting clothing and front opening garments if possible. Try and sit to dress and undress as this provides more stability. Lower body dressing such as underwear, trousers, socks and shoes might be more difficult as you may not be allowed to bend down. You can get assistance from a
family member and/or your occupational therapist who will show you some techniques which may include using a “helping hand” device. Shoes should be comfortable and have low heels. Slip on shoes are easier to manage than laces.

If you are required to wear a brace, you will need to wear a close fitting seamless T shirt underneath the brace. Never wear your brace directly onto your skin.

**Before you go home**

Before you go home, make sure you are comfortable in your brace or plaster jacket. Inspect your skin regularly. If the brace is rubbing or digging, please let a member of staff know who will contact the Orthotics department. If you have a problem with your brace once you are home, please contact the Orthotics team via the main switchboard on the number at the end of this booklet.

You will have an X-ray before you go home.

There will be dressings on your wounds that the nurses will need to change. Once your wounds begin to heal, the dressings can be removed. This could be before you go home.

You should be able to get in and out of bed by yourself, sit, walk, get on and off the toilet, in and out of a bath or shower, and go up and down stairs.
Once you are home

Walking
It is important that you continue to progress with your walking. You should aim to start indoors and progress to outdoor walking within the first weeks of being at home. There are no specific exercises however we recommend getting back to a normal routine keeping in mind your precautions. Remember moving is just as important as resting!

Getting in/out of a car
You should use a car with reclining seats. Have someone recline the front passenger seat for you.

Stand with your back to the car, sit down on the edge of the seat supporting yourself with your hands on the doorframe or dashboard. Move your bottom back, then lean back against the seat (mind your head) and swing your legs in.

Get yourself into a comfortable position. You may adjust the seat back to a more upright position. Do recline it again before getting out.

Be careful not to twist your back when putting your seatbelt on.
Keeping your brace clean
Wipe the inside and outside with a damp cloth – DO NOT use hot water. DO NOT use a hairdryer or radiator to dry the brace. Canvas fronts may be hand washed and towel dried only.

Sleeping
Your mattress should be firm and should be as high as your kneecap when standing next to it.

Sitting
Sit upright and straight with both feet flat on the floor. Ideally choose a chair that has a firm seat and a supportive backrest. The seat should be as high as your kneecap when standing next to it. Avoid sitting on low, soft armchairs or sofas, on the floor or on beanbags as this causes you to bend your hips and strain your spine. Aim to gradually increase the time you spend sitting and standing each day.

School
Arrange a visit to your school/college before you return to lessons. Make sure your teachers know and understand what surgery you have had and the precautions you are following.

Make sure there are suitable chairs for you to sit at school. Chairs should be of a good height and have back support.
A gradual return to school is recommended so that you build up your sitting tolerance. You may find a full day at school/college too tiring initially. Most students return to school/college between 4 - 6 weeks after surgery. This does vary from person to person and could depend on your travelling arrangements to and from school.

Make sure your teacher knows you cannot do P.E. until the precautionary period has finished.

Keep your bags to a minimum weight. Use two small bags, one in each hand or a small lightweight rucksack with a total weight of 2kg. The rucksack should have 2 wide shoulder straps and be adjusted and worn closely fitting to the body. Have a locker at school to avoid carrying heavy books to and from school or have a second set of books at home. Ask the school or a friend for help if you get into difficulties.

Try to avoid the main rush when walking from one classroom to the next. Try and walk with a friend if possible.

If you are about to sit a public examination, please consult your Head Teacher as it may be possible to make special arrangements for you. The Hospital School Teacher can discuss this with you.
Hobbies and sport
Avoid any strenuous exercise, especially if pulling or pushing is involved. Contact or high impact sports i.e. rugby, football, netball, hockey, horse riding, skiing should not be attempted until about one year after your operation, and then only when given permission by your Consultant.

Non contact sports, including swimming and cycling, may be started earlier, however ask your consultant first. Every sport should be resumed gradually.

Public transport
Travel sitting down on buses, tubes, trains etc. if possible. Always wear a seat belt when available.
Looking after your scar

After scoliosis surgery you will have a scar at the site of surgery, usually in the middle of your back or on your side or sometimes both. The length of the scar will vary from person to person depending on the extent of the surgery.

To begin with your scar will be red and may be swollen, but should settle down with time. To reduce stress on the scar whilst it is healing, avoid reaching too far forward or high above your head with your arms for up to 3 months.

Everyone’s skin is different and most people do not have any problems with their scars, however, we recommend the following massage technique as it can help to soften the scar tissue and make it flatter, paler, cooler and smoother.

Massage can be commenced once all stitches are removed and the wound is fully healed. This will be from 6 weeks onwards. **Do not massage the scar before 6 weeks post-surgery.**

Use an unperfumed moisturising cream or lotion (e.g. E45, Nivea, Vaseline Intensive Care or Bio-Oil). Massage the scar and any tight/hard areas lying close to the scar for 5-10 minutes. For optimal results you should complete this 2 or 3 times per day. It may take several months to achieve a flat and moveable scar. A scar can take up to 18 months to mature fully. Protect
the scar from direct sunlight for the first 12 months after surgery. If you are planning to expose the scar to sunlight then wear a high factor sun block.

Massage Technique (someone else will have to help you)
The person completing the massage technique can use both hands working in opposite directions.

1. Sit comfortably in a chair or lie on your side. **Do not lie on your stomach and maintain your precautions as instructed.**
2. Using both hands, start with small circles along the length of the scar either with your thumbs or first two fingers. Make sure you are working in opposite directions and use a firm even pressure.
3. Next, work horizontally across the scar- to and fro in small movements.
4. Then, work vertically along the length of the scar.
If you have any concerns about the appearance of your scar you should contact your GP in the first instance.

If you have any further questions about the massage technique, you can contact your Occupational Therapist.

**Remember!**

Remember you have had major surgery to your back. You should expect to feel tired initially and it is better to rest frequently and avoid getting over tired. About six weeks after surgery you should have a follow up clinic appointment with your surgeon. Most people will be back to their normal activity levels, excluding those activities you have been advised to avoid during the first few months of your recovery.

If you discover any particular issues that are not covered by this booklet, please do contact us.

**Children’s Therapies Team**  
Tel: **020 8909 5821**
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Some surgeons discourage participation in these activities for longer periods. Please discuss with your consultant.

Approximate times you will be able to participate in these activities.
If you would like this leaflet translated into another language/large print, please contact the Quality Team on 020 8909 5439.

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