

...SCOLIOSIS...

A pre and post
Surgery
Guide

From the patient's perspective!

FOREWORD

Scoliosis surgery involves a large and complex operation with the potential for serious complication. I therefore feel it is essential for all patients to be as well informed as possible before agreeing to such surgery. Whilst we seem to be getting much better at providing information about the surgery, logistics and potential complications, the experience of our patients is often overlooked. I am therefore very grateful to Gill and Abbi for putting this booklet together, which gives valuable insight from a patient perspective about scoliosis and scoliosis surgery.

Mr A A Cole BmedSci DM FRCS (Orth)
Consultant Orthopaedic Spinal Surgeon
Sheffield Children's Hospital / Northern General Hospital

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I am delighted to introduce this surgery guide written by Gill and Abbi. Undergoing scoliosis surgery is a daunting undertaking for patients. This booklet provides very valuable information for patients contemplating surgery. Modern techniques can make a significant difference to a patient's back, but this booklet provides a great overview of what they can expect. We are indebted to Gill and Abbi for putting this together. It is a big decision for patients to go ahead with this surgery, and this booklet should prove very helpful.

Mr N W A Eames MBChD MD FRCS (Orth)
Consultant Orthopaedic Spinal Surgeon
Musgrave Park Hospital, Belfast

INTRODUCTION

This booklet is mainly aimed at young people and adults who are facing corrective surgery for scoliosis - often having 'slipped through the net' as children. It aims to provide accurate and up-to-date information which is often difficult to find. Also, many internet sites use horror stories of failed surgeries to promote their own expensive alternative treatments and therapies.

Included are small sections on the types of scoliosis, spinal fusion instrumentation, anatomy of the spine, pre-op tests, post-op tips, home recovery and physiotherapy.

We do not attempt to address all the obviously complex causes or individual clinical management of the condition, as that is the role of the medical team.

However, where we feel this booklet is different is that we hope to provide reassurance by sharing our own experiences, including photographs of our pre and post-surgery X-rays and curve measurements.

Hopefully, this should help alleviate some of the fears surrounding the surgery. It also provides an insight into the different recovery times experienced, which depends on many factors including age, the length of the fusion and whether there are any additional complications.

Our main reason for producing this booklet stems from our own frustration in trying to find relevant information prior to surgery, and support during the early post-operative period. We also provide the reader with links to other useful information resources, including the website where further stories of post-op recovery can be found.

WHAT IS SCOLIOSIS?

Scoliosis is defined as an abnormal lateral (sideways) curvature of the spine. It also involves rotation of the vertebrae, causing a characteristic 'rib hump' and protruding shoulder blade or hip, depending on the location of the curve. It falls broadly into two main categories:

IDIOPATHIC SCOLIOSIS - meaning "no known cause". This is the most common form and is sub-classified into infantile, juvenile, or adolescent, depending on the age of onset. Scoliosis in adults can either be a progression of untreated adolescent scoliosis, or be caused by degenerative changes in the spine due to advancing age.

CONGENITAL SCOLIOSIS - caused by vertebral anomalies present at birth. Scoliosis can also develop as a secondary symptom of another condition, such as Cerebral Palsy, Spina Bifida or Marfan's Syndrome.

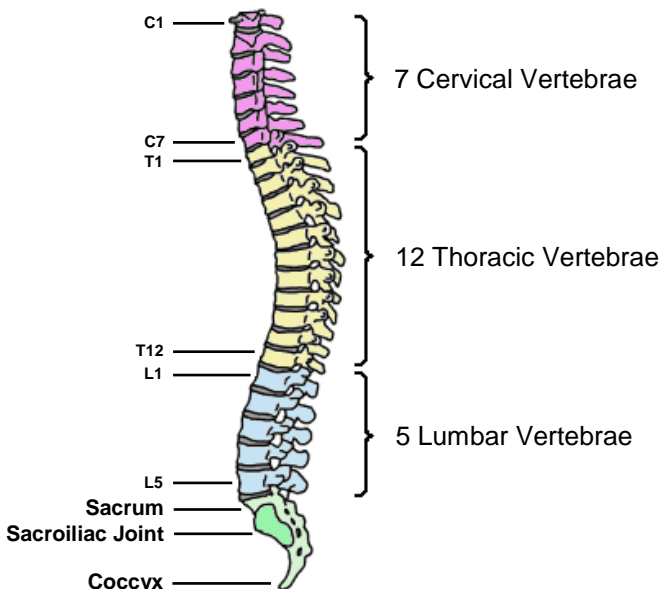
SPINAL FUSION INSTRUMENTATION

Modern surgical techniques involve attaching titanium rods to the vertebrae using a combination of screws and hooks. The spine can then be de-rotated and the curvature significantly reduced. Fragments of bone, taken either from the pelvis or ribcage, are then placed along the length of the instrumented spine and this results in the vertebrae fusing together into one long bone, thereby stopping further progression of the curve. Although the rods are used as a temporary "scaffold" to hold the spine in place while this fusion occurs (typically within 6-12 months), they are usually left in place afterwards to avoid further surgery to remove them.

ANATOMY OF THE SPINE

The mobile part of the spine is divided into three regions, known as Cervical (C), Thoracic (T) and Lumbar (L). Each region has a distinct number of vertebrae, numbered from C1 to C7, T1 to T12 and L1 to L5 respectively. In scoliosis, the curve is named after the specific region of the spine in which it is found, with curves in the thoracic area being the most common. Sometimes scoliosis involves more than one area, an example of this being thoracolumbar scoliosis, where the curvature spans both the thoracic and lumbar regions of the spine.

LATERAL (SIDE) VIEW OF THE SPINE



When the consultant surgeon examines your X-rays, he will decide which vertebrae will be included in the fusion. For example, a fusion from T5 to L5 would involve fusing all the way from the fifth thoracic vertebrae to the very bottom of the lumbar spine, 13 vertebrae in total.

PRE-OP TESTS

Pre-op testing tends to vary from hospital to hospital, but there are certain ones which will apply to everyone.

MRI SCAN - Most patients awaiting scoliosis surgery will require one of these at some point since it allows the surgeon to check for abnormalities of the spinal cord and identify any neurological anomalies which could cause complications during the surgery. Don't worry, you won't feel anything, but they are *very* noisy!

LUNG FUNCTION TEST - This assesses the volume of air your lungs can hold. This may be reduced due to the curvature of your spine. It involves blowing into a cardboard tube - which is attached to monitoring equipment - for as long as you possibly can. Easy-peasy!

BLOOD TESTS - Just a little prick, honest! These tests are essential to check for such things as anaemia and electrolyte balance, to ensure you are healthy enough to undergo the operation. Adults will also have a blood pressure check and possibly an ECG to monitor the heart.

X-RAYS - Most patients will have up-to-date X-rays taken before surgery, including ones taken while bending from side to side. From these images the surgeon can determine which part of your curve is structural and whether there are any compensatory curves. They also allow the general flexibility of your spine to be assessed. The X-rays will be referred to throughout the operation to get the best result possible.

Patients will also be weighed and measured - you may find the surgery adds several centimetres to your height!

POST-OP TIPS!

If you are in pain, say so...don't wait until it gets too bad.

Don't try to be too independent - use your call button, the nurses are there to help you and won't mind at all.

Ensure anyone who touches you washes their hands first. This is very important to avoid cross-infection between patients, family and friends.

Always use the 'log roll' method when getting in and out of bed to avoid twisting the spine. The hospital nurses or physiotherapists will show you how to do this.

Try to stay out of bed for a slightly longer period each day to develop your pain tolerance, but don't overdo it! You may feel very dizzy the first time you try to stand up but don't worry, this will pass in a day or two.

Drink plenty of fluids (yoghurt drinks are especially good) but don't worry if you don't feel very hungry at first, your bowels will be sluggish due to the anaesthetic.

Once your hunger returns, try to eat small amounts as often as possible. You may have lost a lot of blood, so make sure you eat iron rich foods...lots of greens!

Coughing and sneezing will be very sore immediately after surgery. You could try to reduce the impact of this on your spine by wrapping your arms around your chest first in a 'hug'!

If you feel up to it, get someone to grab a wheelchair and take you on a little tour of the hospital.

COMMON POST-OP CONCERNS

NAUSEA / SICKNESS - Some people may feel nauseous (or even actually be sick) after a general anaesthetic but this should soon wear off. However, you will usually be receiving morphine via a PCA machine for a few days after surgery and this can also cause dizziness and nausea. If this persists after the morphine has been withdrawn, it is worth checking if you are sensitive to one of the other pain medications you are taking.

NUMBNESS AND PAINS - Don't worry, this is completely normal as many of the nerves will have been damaged during surgery. Some numbness can persist for months afterwards, but most should gradually resolve as the nerves recover. However, this recovery can cause quite sharp pains at times, so it is something to be aware of.

LOOKING WORSE! - Occasionally, shortly after surgery, you may feel you actually appear worse than before! This can happen for a number of reasons. It may be that you are 'guarding' against the pain and 'holding' yourself unnaturally at first, making your shoulders appear more uneven. Also, when the spine has been curved for a number of years and is suddenly much straighter, it takes a while for some of the back muscles - which have not been used much before - to gain the necessary strength to help support it. Again, this will improve over time. It is also normal for some slight re-emergence of the rib hump as your spine 'settles' into its' new position. This should slow down once the spine begins to fuse.

FRUSTRATION - Having to rely so much on others can be extremely frustrating and it's quite natural to feel moody and irritable at times like this. It may help to remind yourself that you are still recovering from major surgery!

COMING HOME

It is a good idea to bring in some loose-fitting clothing for your journey home. Nothing tight around the waist as your wound will be tender, or hard to get over the head as it will be difficult to raise your arms. Try to avoid socks as they are very tricky to put on when you can't bend!

Bring several pillows for the car journey - you'll need them! Mastering the art of getting into a car without twisting your body can be very difficult at first. Try sitting on a plastic carrier bag, raising your knees and then swivelling your legs slowly round into the seat well. Also, every little jolt will hurt at first, so ask the driver to go slowly and try to avoid going over speed bumps.

Tiredness is normal, you will probably sleep quite a lot during the day at first. This is partly due to the pain medication but also is your body's way of recovering.

Try to sit up as much as possible during the day, but make sure the chair is not too low or soft. Propping up with pillows in a fairly firm chair is better than sinking into a squishy one! Also, get up at regular intervals for a little walk around so you don't become too stiff.

Hot water bottles - or wheat bags that you warm up in the microwave - are excellent for pain relief. Just be careful not to get them too hot, remember you may still be numb in some areas and unable to feel the full heat!

Be sure to have help getting in and out of the shower for the first few weeks. Use this time to have someone check your wound for signs of infection. If in any doubt at all, have it checked by your surgeon, (or a member of his medical team), before being prescribed any antibiotics.

SOME POSSIBLE TIMESCALES

As a general rule, the younger you are when you have surgery, the quicker you will recover. The body has amazing powers of healing - especially when you are young - plus the spine is often more flexible, making the surgery itself easier on both you and your surgeon!

Your consultant will give you specific instructions as to when it is safe for you to resume various activities. Short walks outside are usually encouraged as soon as possible after you get home. Very gentle activity in the swimming pool may be the next thing you're allowed to do, followed by a gradual re-introduction of other activities such as sports and dancing. Older patients will often require physiotherapy to help them recover function whereas younger patients rarely need this. In fact, many children are actually back at school within 4 - 6 weeks!

The following are therefore only a very rough guide based on our own personal experiences:

2 - 3 WEEKS: Started taking short walks outside.
Took first trip in the car to visit friends.

4 - 5 WEEKS: First trip out to lunch. (Abbi)
Attended a school awards event. (Gill)

6 - 8 WEEKS: Trip to cinema - still rather uncomfortable.
Ventured into town. (A bit daunting!)

9 - 12 WEEKS: Went to a wedding reception. (Gill)
Very gentle activity in the swimming pool.

4 - 6 MONTHS: Feeling much more comfortable. Most restrictions are lifted by about 6 months.

PHYSIOTHERAPY

Physiotherapy has three main roles in the support of the medical management of scoliosis:

1. Conservative treatment and management pre-op.
2. Post operative rehabilitation in those who need it.
3. Advice and information on long-term self care and symptom interpretation.

In order of importance, Physiotherapy has 4 key goals of treatment:

1. Recovery of function (what you can do), this may be despite some pain.
2. Help you be clear on any do's and don'ts with regard to your scoliosis.
3. To provide long-term exercises to maintain the muscle strength and support around the spine, particularly at mobile spinal segments either side of any fused levels.
4. Help with pain relief if possible.

The role of exercise in the treatment and management of scoliosis is still evolving. However, at this time you should be clear that exercises do not prevent the development of scoliosis nor do they halt the progression of the curve. They may make you stronger and fitter so that you are capable of doing more with the problem you have. This applies both before and after surgery. In some cases, exercises may help reduce your pain.

This section on Physiotherapy was kindly provided by:

Mr Peter Barrass MSc MCSP SRP
(Spinal Extended Scope Physiotherapy Practitioner)

GILL'S STORY

I was diagnosed with idiopathic (thoracolumbar) scoliosis at 14 years old but I was told the curve wouldn't get any worse. Unfortunately, this wasn't the case and by the time I was in my late 20's I was in quite a lot of pain. I had further X-rays taken which showed a marked progression of my scoliosis. However, I was told that it was too late to do anything about it and that was the end of that, or so I believed...

Fast-forward 20 years and several niggling health problems later, my GP began to suspect that they could be due, in part at least, to my twisted posture. I was referred to Mr Cole who stunned me into silence (not easy!) by saying he would be happy to perform the surgery to stabilise my spine. I wasn't promised any great cosmetic results due to my age.

I underwent the surgery in August 2006 aged 49 and the procedure was a complete success. I had an instrumented scoliosis correction from T5 to L5. My 80° pre-op curve was reduced to 47°, which is really quite amazing when you consider that my spine was very stiff and had self-fused at the apex of the curve. My surgery lasted around 8 hours and went without complication, although I did lose quite a lot of blood and needed a 2 unit blood transfusion the day after surgery.

I was discharged from hospital after 8 days and returned to work at 4 months. However, recovery is taking a little longer due to my age and I'm still not able to work my full hours yet. I do still have some pain which is mainly muscular and is being helped enormously by physiotherapy. I am confident that I will continue to improve as my core muscle strength improves.

As I write this I am 10½ months post-op and feeling great! Apart from some residual pain, my previous health problems have either lessened or completely resolved. I can wear nice T-shirts again instead of sacks which has given me a real confidence boost! I feel extremely lucky and I am very grateful to Mr Cole and his team for giving me this new lease of life.

ABBI'S STORY

My scoliosis presented itself when I was 17 (a little later than most) and I was officially diagnosed with idiopathic scoliosis in 2004. Throughout my youth my family and I noticed some irregularities with my body, such as having one shoulder higher than the other, and an uneven waist, but we never realised the significance of it until I started to experience back pain. After a visit to my GP, we realised how serious it was.

I was referred to Mr Hamilton, a consultant spinal surgeon, at the scoliosis clinic in Musgrave Park Hospital, Belfast. At my initial appointment I was told that I had quite a marked scoliosis - both my curves measured 80° - and that surgery to correct my scoliosis would be beneficial. Still a little shocked with what I was seeing and hearing, I knew that I needed to make the decision to go ahead with the surgery.

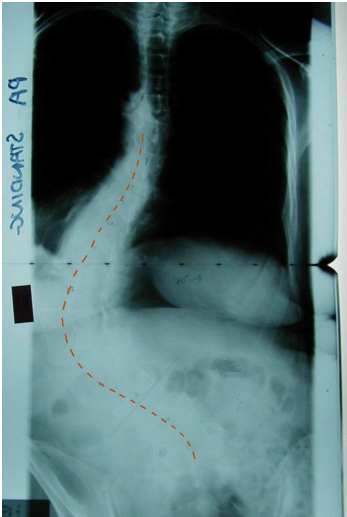
My surgery was performed by Mr Eames in August 2005 and involved a two stage approach, which included an anterior release of my thoracic spine and correction and fusion with instrumentation from T1-L4. My surgery lasted in total 9-10 hours, and there were no complications. I spent 8 days in hospital and was discharged with painkillers and a list of post-op instructions. My recovery was, at times, slow and painful, but I got there. I returned to a part time job after 5 months.

Although the surgery was a rather daunting experience, the results were amazing! My once 80° double curve was reduced to approximately 35°. I was amazed at the change that the surgeons had achieved for me, and after 10 months I was restriction free and able to get back to normality.

At the time of writing this I am almost two years post-op. I do still feel stiff at times and get occasional pain. However, overall I feel very lucky to have been blessed with two amazing consultant surgeons. The surgery has given me a whole new outlook on life, and has made me a lot stronger as a person, as well as given me an extra 2" in height!

PRE AND POST SURGERY X-RAYS

GILL



Pre-op curve $\approx 80^\circ$



Post-op curve $\approx 47^\circ$

ABBI



Pre-op, 2 curves of $\approx 80^\circ$



Post-op curves $\approx 35^\circ$

SUPPORT AND RESOURCES

Hopefully this booklet has gone some way to addressing many of the questions you may have regarding the pre and post surgery period. However, there is only so much we could include without it becoming too unwieldy.

Further stories of member's experiences of surgery and recovery can be found at: www.scoliosis-support.org

This site contains a wealth of information and experience and is mainly UK based, although we do have members from all over the World. It is possible to browse many of the forum topics as a guest. Then, should you wish to ask any questions of your own, becoming a member is a quick and simple process, and of course it's free!

OTHER USEFUL WEBSITES

Scoliosis Association (UK): www.sauk.org.uk

Information on Research: www.bsrf.co.uk

Spinekids website: www.spinekids.com
(Provides info and support targeted specifically at kids)

Useful information can also be found on the following websites, although - being US based - not all of it is relevant to UK patients.

www.srs.org

www.spine-health.com

www.iscoliosis.com

www.orthospine.com

www.scoliosis.org

www.espine.com

Booklet produced by:

Gillian Goodrich MIBMS

Specialist Biomedical Scientist (Haematology and Blood Transfusion)

&

Abigail Morrison

Second Year Occupational Therapy Student at the University of Cumbria

With special thanks to:

Mr A A Cole BmedSci DM FRCS (Orth)

Consultant Orthopaedic Spinal Surgeon

&

Mr N W A Eames MBCh MD FRCS (Orth)

Consultant Orthopaedic Spinal Surgeon

For kindly providing our 'Foreword'

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Mr Peter Barrass MSc MCSP SRP

Spinal Extended Scope Physiotherapy Practitioner

For his invaluable insight into the role of Physiotherapy

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www.scoliosis-support.org

For all the information, advice and support we've received on the site and without whom we would never have met to produce this booklet!

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