

# ALS Surgery Special

Being placed on the waiting list for surgery yourself or having a child awaiting surgery can be a very worrying time. We do know that being well prepared and hearing from others who have been through the procedure can help. With this in mind we have put together a 9 page special to provide more in-depth information about the surgery. We start with some of our members talking about their experiences of AIS surgery and sharing the advice and tips they wish that someone had given them before the operation.

## Naomi Dover

I had my surgery in 2011 at the age of 11. I now visit many others who are due to have their scoliosis surgery. Advice I often give them beforehand, which I had not been told before, is to take a moisturiser and lip balm, I found my face and particularly my lips went dry in hospital after the operation and these came in handy. Also due to being stiff the few days after, I advise people to take pyjamas which button up the front as these are easier to get on after the operation.

I also advise girls to take in dry shampoo and baby wipes to keep fresh for the first few days after the operation. You can't wash your hair or shower for a couple of days and these just meant that I felt clean when family came to visit. Also a visiting rota was useful during my time in hospital so I could plan to always have family and friends around me when possible.

My sister Lucy and I had the operation a week apart. As well as books and magazines, we also took in an iPad

and a wireless internet dongle, so that we kept busy and had access to the internet to keep in contact with friends.

I also believe that speaking to someone who has been through the operation before going through it helps a lot. We went to see a girl who had had the surgery 2 years before, which put our minds at rest. She showed a positive and confident personality, which made us realise in the long run it is worth it. It also allows those going for the operation to ask questions of people who have been through it themselves.

Lucy is now 19 and I'm 16. We are both fit and healthy and believe it's the best decision we have made.



## David Moss

Here is my experience of AIS surgery. Going into the surgery, I was extremely nervous because I didn't know what to expect. I told myself that in a few months I could look back on it and be proud of what I had done, but in reality I was going over every scenario in my head of how it could go wrong. If I knew then what I do now, I would have been much more confident about going into the operating theatre.

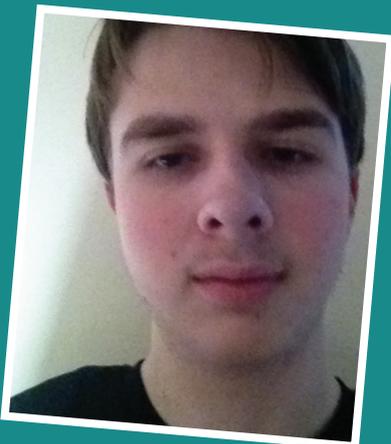
Just after the operation, I felt really sick but it was because I had just had lots of anaesthetic. I was put on a high dependency ward for a day.

The second ward was strange for me. The time seemed to slow down. I would be either talking to my family or watching videos on my phone but the days seemed like weeks.

Every day I progressed. I was having tubes taken out, eating more, and becoming more active. On the fourth day in the ward I stood up for the first time. In my opinion, that's when you really start to see the benefits of the surgery. I had grown nearly 4 inches in just over 8 hours! I dwarfed my family, who before the surgery were the same height as me. After that, I had the confidence to progress to walking, sitting for prolonged periods of time, and climbing stairs.

I had 6 weeks of recovery time after I first got home. Returning to everyday life was one of the highlights of having the surgery. Everyone was astounded at how tall I was and how well I looked.

More than 6 months on, I'm really seeing the benefits of having the surgery. There is now no difference between myself before the surgery and after the surgery, other than the fact that I am taller, fitter, and have more self-confidence.



## Lorna Dorans

My daughter Amber, 13, had spinal fusion last February to correct a double curve. Here are some hints and tips to help adolescents facing surgery:

Amber found it extremely difficult to eat due to the combination of surgery and drugs, but very light things like yogurts, custard, jelly and maize snacks such as Quavers were her favourite as they don't take a lot of effort to eat and taste yummy! Lots of fluids are also important.

Take things into hospital to help pass the time and keep your mind off the serious stuff. Items like your phone, iPod or MP3 player, and headphones are a must.

Try to remember that the surgery is worth it even though you won't feel like it at the time. Amber is now straight and pain free and very proud of her scar, and her personal motto is "bent not broken".

From a parent's point of view, it's hard to watch your child go through major

surgery but it's worth it for the end result. With love and support from family and friends they'll come through the other side much stronger. Try to stay calm and remain positive, the surgeons and after care team are wonderful.





**Harriet MacKinney**

I was diagnosed with scoliosis in the beginning of 2013. I was told I had two curves of almost 50° each. The main issue, however, was that my lower curve was also twisting. 7 months later I had half of my spine untwisted and fused. I was in hospital for 15 days in total, off school for 2 months, and wore a back brace 24/7 for 6 months.

I'm now just over 15 months post-op and have a top curve of 25° and barely a bottom curve at all! I'm back to trampolining and have recently mastered my back somersault unassisted! I am doing PE A-level and haven't let surgery get in the way!

For anyone getting ready for surgery; I'd like to let them know that although it is a really scary thing, it's manageable. You will be in pain (it would be silly to think you won't be) but the pain does not last forever. It seems like it will when you're in hospital asking for more morphine (I'm surprised they had any left after I was there!) but as soon as I got out of my back brace, I started to feel more normal.

Support from your friends and family is vital. I can never thank them enough for helping me through my surgery.

Before my surgery I wish someone had told me to plait my hair! I left it in a bun and it meant, 3 days spent brushing out the massive knot that was my hair. It was awful. I also wish someone had told me not to argue with my physiotherapist because they will just make you walk more!

I made a YouTube video about my journey if you'd like to watch - My Scoliosis Story

**Olivia Wilkes**

I'm now just over 15 months post-op and have a top curve of 14 years old, my curve when first measured was 67° and by the time of the surgery it was around 80- 85° (2 months after my first X-ray). Before I was diagnosed I had never heard of scoliosis and was not aware of how many people it actually affects.

Before my operation I knew what I was having done and why, which is very important. However, I didn't look online at images of what an X-ray would look like after the spinal fusion. This helped massively, because if I had, I would have been extremely nervous and wouldn't have wanted to go ahead with the surgery. I had no choice about the operation because my curve was

increasing day by day.

My operation was on a Monday and took 7 hours. I left the hospital on the following Saturday. My personal top tip is to bring a memory foam pillow (not too firm) to rest your back on during the way home as the roads can be bumpy.

After 2 months I was back at school part time, which was a huge achievement. A week after that I asked if I could be back full time- and I never thought I'd say that!

I recently went back to the hospital for another check-up and received the best news I could ever imagine... 3 months after the surgery the X-ray showed my spine was nearly fully fused! The consultants said they have never seen such a quick recovery! They asked me about my diet, which includes a lot of fish, fruit, vegetables, and green tea.

I have done my research into green tea and people say it has many great benefits, but it never said anything about helping spines to fuse!

I do a lot of dancing and have been dancing my whole life. My next appointment is in March, and if recovery has continued at the same rate, I may be able to start dancing again... 6 months after my operation!



**Margaret Sarfas**

In 1993 my son was operated on at 13 years old. He had an 88° curve so most of his spine is fused together. The surgeon did tell him that things might change a bit in his life but my son has such a positive attitude. He teaches Arboriculture at a college, which involves: tree climbing and cutting down huge trees using chainsaws. He also climbs Snowdon when he gets the time! I am a proud mum so I thought I would share his story.



**Rebekah Cooling**

My name is Rebekah. I'm 18 years old and underwent surgery almost 2 years ago. I wanted to share my advice with you because I know how scary it is and how isolating and upsetting the run-up to surgery can be - not only with the existing

pain but also with the worries about the operation. I also know how helpful it is to have someone to talk to who's been in the same position as you. So, here are some things I'd like you to know...

If you're having surgery, it's ok to be afraid. Just know that you're not alone and you can always contact me if you would like someone to talk to (email below). Gentle exercise such as yoga or Pilates can help with back pain. Just don't overdo it! Back massages also help!

Finally, even if your confidence and self-esteem are dwindling, please try to focus on what you're going to look like after the surgery. You'll be straight again and are likely to be taller- I grew 2.5 inches! Remember that to deal with this condition and to go ahead with surgery shows courage and determination despite fear. You are so brave.

If you want to reach me, you can contact me by email: [bexcooling@hotmail.co.uk](mailto:bexcooling@hotmail.co.uk)

**Gill Botazzi**

As mum of a fused adolescent, we had a very positive experience. The surgeon was great; he had a good bedside manner and put our minds at rest. My son, who is 15, is keen that this response is all positive and said he would do it again if he had to. We were lucky enough to have had private treatment, I don't know how it differs!

I felt that I wasn't informed enough before surgery, about the recovery and what to expect; did I need to buy anything? Was he going to be able to put his shoes and socks on himself? Would he be able to go back to school on the bus? Would he be able to go up and down stairs?

I didn't feel confident I could care for him properly once we got home. How would we manage pain? Would I need to take time off work? How long would I need? I arranged a month off work, another mother who was there at the same time as us had booked two weeks. I didn't need a month as it turned out but it was nice to have some extra



time for myself.

Now it's all over and it was fine, I feel I worried unnecessarily. I had visions of a much slower recovery so maybe some idea of time frame would be better. Recovery went very smoothly and the care was great.

**Elizabeth Carr**

I remember reading an article pre-surgery in Backbone about what to take to hospital and one of the things was tops with large necks. What it should have recommended was tops that are large in general, because anything tight will be uncomfortable on the dressing as well as hard to remove. A surprisingly useful thing we took to hospital was a headphone splitter so that my mum, dad and I could watch TV together (the volume was turned off at 7 so you could only use headphones). I took a DVD player but didn't really use it. I would definitely recommend taking photos into hospital, even just a few, as they made me much happier.

Elizabeth writes a blog about her experiences at <http://afterscoliosis.wordpress.com>



**Charleigh Ridgely**

I'm now about 8 weeks post-op and recovery is going amazingly well. I started my dancing again, about 6 weeks after the operation. The surgery went well, but I had a few complications; they had to wake me up during my operation as my spine wasn't happy. I also lost a lot of blood and was in intensive care. I didn't realise at the time how poorly I was. I'm now anaemic but getting a lot of support from my dance school, family, friends, and the doctors.

To all the people who are still suffering with scoliosis- stay strong because you're not alone! Also don't be scared to show off your scar because that's what makes us scoliosis survivors.



**Izzy Anstee**

I had spinal fusion surgery in January 2014 so have just passed the first anniversary of my operation! My tips and hints for others would be:

- Watch out for anaemia after surgery (I lost a lot of blood and it hindered my recovery)
- As much as you will hate it, sitting up more and more will improve your comfort in the long run
- Always take a pillow in the car for long journeys
- Walking a little bit everyday will work wonders

Hope this helps!

