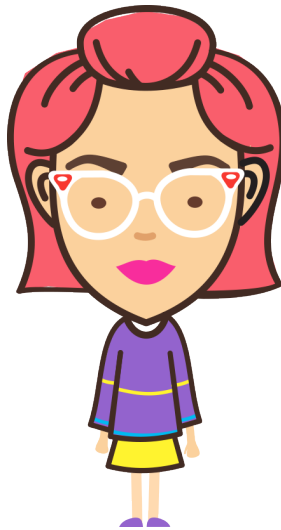


COMING INTO HOSPITAL FOR SPINAL SURGERY

Hospital Journal & Information



"Scoliosis surgery changed my life; It made me stronger and happier, pain free with a more positive body image"
- Laura



"I was so tired and emotionally drained from the whole experience which I can only describe as being on a roller coaster"
- Jane



"Following on from surgery I am able to lead a more comfortable life"
- Liam



"Remember to be kind to yourself, celebrate each small milestone and be proud of your achievements."
- SAUK (Scoliosis Association UK)

INFORMATION ABOUT THIS JOURNAL

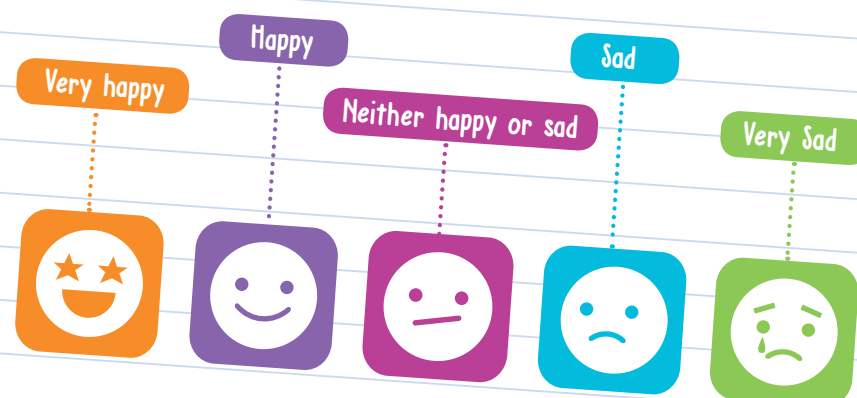
Coming into hospital to have an operation can be a little scary, especially when you don't know what is going to happen. The doctors and nurses understand that this can sometimes leave you worried or confused. This journal will help to explain what might happen while you are in hospital with tips and friendly advice from other patients, their families and The Scoliosis Association UK. In hearing the stories of other people that have been through similar experiences to yours we hope that you find this journal helpful in explaining how you might be feeling, your recovery and what happens when you get home.

There is space in this journal for you and your family to write all about your hospital stay, day by day. Making a note of the daily plan that the nurses and doctors have told you will help you to remember what is going to happen and also help you to prepare.

You will have some good days and you will have some bad days and that is completely normal. Writing down the good things that happen can make you feel happy and sometimes writing the bad things can help to make you feel a little better.



The face chart can help you to describe how you are feeling. The faces describe different feelings without having to write them in words. Try and write in your journal at the same time every day, perhaps after tea or during the evening.



MEET THE PATIENTS!

The stories contained in this booklet are from real patients and families who have kindly provided their personal experiences of scoliosis surgery.



LIAM

Liam had surgery in 2011 when he was 19 years old. Liam was born with cerebral palsy affecting his right arm and both of his legs for which he needs a wheelchair. Liam's scoliosis is caused by his cerebral palsy and is commonly known as neuromuscular scoliosis.



JANE

Jane is Aimee's mum. Aimee had surgery in October 2015 when she was 14 years old. She has adolescent idiopathic scoliosis. Aimee's curve caused her breathing problems and her operation was planned in two stages. Her story has been included because it is important for people to see that sometimes not everything goes exactly to plan. Despite this Aimee is doing well and went on to make a full recovery following her surgery.



LAURA

Laura was diagnosed with adolescent idiopathic scoliosis when she was 13 years old. In 2003, at the age of 18 she underwent surgery to correct her curve, for her the best place to operate was from her side. Since her surgery she has been volunteering for the Scoliosis Association UK and she is their Regional Representative for the Midlands, helping to support other scoliosis patients.



Other information provided in this journal is provided by the Scoliosis nurse and surgeons, physiotherapists and The Scoliosis Association UK (SAUK).

The scoliosis nurse and surgeons have provided information about what to expect each day that you are in hospital. It is important to remember that every person is different and for that reason it may take some people longer to recover than others, some people may go home sooner than others and some people may do exactly what is written in the journal on each day.

The physiotherapy department have provided information around their role and how they will help you to recover after your operation. They have worked with the scoliosis nurse to put together an exercise programme for when you get home, you don't have to do this but it may help with your recovery and help to build up your strength.

The Scoliosis Association UK – is the only national support organisation in the UK for people with scoliosis. They provide advice and support to people who are affected by scoliosis and raise awareness about the condition.

SOME OF THE PEOPLE YOU WILL MEET IN HOSPITAL

Medical team

Doctors who specialise in looking after young people will be on the ward most of the day and at night whenever they may be needed.

Nursing teams

Nurses and nursing assistants will look after yours and your family's needs throughout your hospital stay. Some of the nurses you may not remember as they will have looked after you when you were sleeping during the operation or just as you were waking up after the operation

Play specialists

Will show you around the hospital wards before your operation and chat with you before and after your operation. They provide supportive play for children and young people to help them adjust to the hospital setting.

Surgical team

You will have met with your surgeon in clinic quite a few times before your operation. After your operation, the surgeon, his assistants or the surgical doctors will visit you on the ward every day to make sure that you are recovering well after your operation and to talk to you and your family about how your operation went.

Anaesthetic team

These doctors help you to sleep throughout your operation and make sure that you do not feel any pain during the actual operation. They also advise the staff on how to manage any pain after the operation too.

Scoliosis nurse

The Scoliosis nurse is your point of contact. You will usually meet your scoliosis nurse in clinic before your operation. She will give you her contact details and see you every day on the ward before and after your operation. When you get home the scoliosis nurse will ring you to make sure that everything is ok. If you have any problems or need any advice you can contact your nurse.

Ward assistants

These are the people who clean the ward, collect your menus and serve you food and drinks at meal times.

Pharmacist

The pharmacists on the ward check your medications and will often talk to you about any medications that you were taking before you came into hospital.

Therapy team

The physiotherapists will see you after your operation and show you different exercises do when in hospital and when you get home.

HOSPITAL CHECKLIST!



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

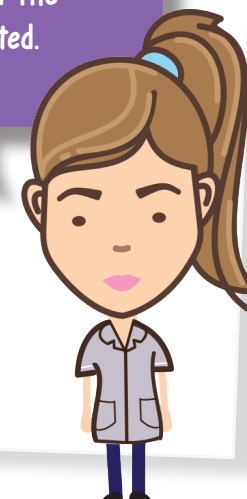
If you have a favourite teddy or toy that you usually sleep with it is a good idea to bring this with you.



Pillows

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

Although there may seem to be a lot of items to bring into hospital try and fit it into one bag as space around the bed can be limited.



Medical Team

Nursing Team

Play Specialist

Surgical Team

Anaesthetic team

Scoliosis Nurse

Ward Assistant

Pharmacist

Therapy Team

COMING INTO HOSPITAL AND GOING TO THEATRE

You will come into hospital the day before or on the morning of your operation. It is important that you have a shower on the morning of your operation as this makes sure that your skin is clean ready for the operation and it may be the last time you have one for a few days! The nurses will give you a special pink soap to wash your hair and skin with. Lots of different people will come to see you on the ward. Nurses will be around to admit you onto the ward and take your observations. The surgical team will come and see you to talk briefly about the operation although you will have done this in more detail at your clinic appointment. The anaesthetist will come and ask you questions and talk about going to sleep for the operation. When the theatre is ready for you a porter will come and collect you. You will stay on the bed and a nurse will take you and your family down to the theatre. You will see lots of nurses and doctors all wearing similar outfits and hats. Here you will be asked a few more questions before going into the anaesthetic room where you will go to sleep. Depending on your age, your size and what you would prefer, you will either go to sleep by breathing in air through a mask that makes you sleepy or through an injection into the tube in your hand. Once you are asleep you won't know what is happening around you until after your operation when you are woken up.



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JANE REMEMBERS...

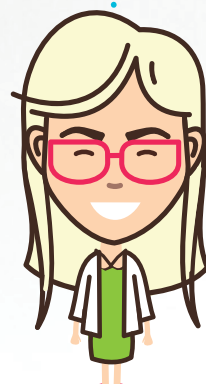
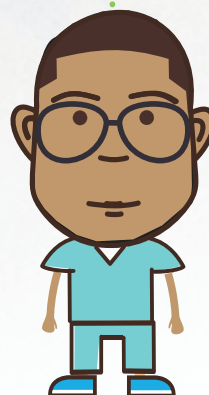
On the day before the first operation we met with the surgeon and the nurse practitioner who supported us throughout the day. The nurse practitioner explained what was going to happen during the day which made the transition a lot easier as there were lots of appointments to attend. We went home that night and came back the following morning for the operation. The anaesthetist came to see us and explained what would happen. We were asked if we had any questions, I had some written down which was a good thing to do as if I hadn't I would have asked nothing as at this point my mind was blank. I felt scared and apprehensive but tried to stay positive as I knew that Aimee was scared too. As a parent you want to be in control of what happens to your child. I was worried that Aimee would be in pain and that I wouldn't be able to do anything about it. The operation felt as though it went on forever and then we received a call from the surgeon to say that all had gone well.

For Aimee's second operation we came into hospital on the morning of her operation. We all felt a little apprehensive but it was a very quick process as Aimee was soon taken to theatre. Aimee was still in hospital when she went for her third operation. She was very quiet and we were very anxious. The operation would only take half the time that the others took and even though I knew she was in good hands I still felt sick and the day seemed so long.



Surgical Team

Anaesthetic team



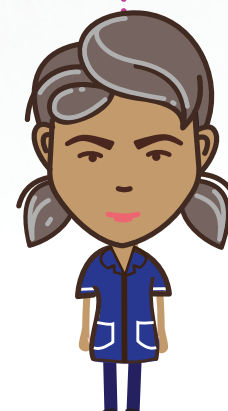
LIAM REMEMBERS...

The day had arrived!!! That was my first thought on that morning, it was the day I'd been dreading for months and I built myself up to thinking I'd know what to expect but of course nobody knows and I still remember the feeling of butterflies and how I wanted to be sick with nerves to this day. To stop the anxiety I started to think about the after effects of the surgery and how it would improve the value of my life and I managed to keep these thoughts in my head until we drove closer and into the hospital grounds. As I arrived on the ward a nurse greeted me who showed me to my side room and I said 'So this is where I will be staying in the hotel NHS', this was a comment I didn't expect to make on a day that would have a huge impact on my life but the people who know me know that I like to use humour in stressful situations. I showered in Hibiscrub to get rid of the bacteria from my body and I was still managing to have a laugh and joke with the nurses. Soon 8:30am arrived and so did the hospital porter to wheel me down to theatre, the anxiety returned as I stared up at the lights as we passed each corridor. As mum and I approached the theatre doors my tears started to fall, we were met by the theatre staff and shortly after the anaesthetist put me to sleep.



Nursing Team

Medical Team



If you are going to have an operation it may feel scary to you, but try not to worry. The teams in the hospital are there to look after you. About 8 hours before your operation you will be asked not to eat or drink anything, you may feel hungry or thirsty but it is important the surgeons can carry out the surgery on an empty stomach. When it is time to go to theatre, you will be brought down to a room and given medicine by the anaesthetist, which will make you go to sleep. The anaesthetist will make sure you don't feel any pain during the operation. Going to sleep for an operation is just like going to sleep at night time, you will feel sleepy really quickly and fall into a deep sleep. The next thing you know it will all be over and done with and you can begin your recovery.

LAURA REMEMBERS...

My scoliosis surgery was the first operation I had ever had, so I felt scared not knowing what to expect and I was worried what it would feel like, but it wasn't scary at all. I tried to get a good night's sleep the night before my operation, even though I felt very nervous! When I woke up the nurses were so kind and helped me to prepare for what was about to happen.

When I was taken to theatre, my Mum and Dad came with me, hugged me and told me they loved me and would see me later, and I felt very lucky that they were there. I also took my Winnie the Pooh teddy bear with me. The nurse held my hand when they put the medicine in my arm, at first I felt very sleepy, it didn't hurt, then I closed my eyes and the next thing I knew I was waking up again, about 10 hours later!



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MY HOSPITAL JOURNAL

Today the day is...

How I'm feeling today



Not so good things that have happened today

Good things that have happened today

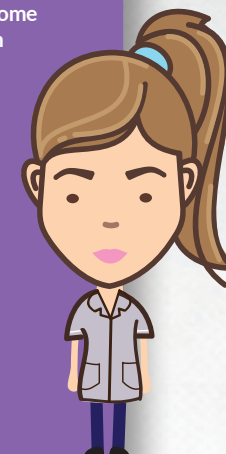
Today's plan for my recovery

WAKING UP IN RECOVERY

After your operation you will wake up in recovery. There will be a small tube in your hand that connects to long flexible tubes called drips. Medications and fluids will be given to you through these tubes. You may have one or two tubes, called drains, that come out of your skin by the operation site, these help to drain any extra fluid that your body makes from around the operation site and usually stay in for a day or two. There will be a catheter that goes into your bladder to drain your wee, this is so that the nurses and doctors can monitor your kidneys and also help you to rest after the operation. You are allowed to have sips of water as your mouth may feel a little dry.

Sometimes the anaesthetic can make you sick. If this happens the recovery nurse will give you some medication to help. You may not have lots of pain as strong pain relief is given to you during the operation which will stay in your body for a while and help to keep the pain under control. There will be an oxygen mask over your nose and mouth to help with your breathing.

You will feel very sleepy and this is normal after an anaesthetic. The doctors will wake you up a few times to ask you to wiggle your toes. It is important that you show them that you can do this, even if it is a little annoying! Once the doctors and nurses are happy that you are recovering well from the anaesthetic and operation you will move to the high dependency ward for monitoring.



LIAM REMEMBERS...

I went straight to the recovery ward from theatre where I spent the night. I kept asking for a Mars bar but I was still very groggy feeling the effects of the aesthetic which made me sick. I had a very disturbed night waking up, being sick, asking what the time was and dosing off again, this happened to be every 10 minutes in what felt like an eternity. The following morning I ate a dry piece of toast, which seemed to go down very nice but when I got back on to the ward I saw the piece of toast reappear. I then spent much of my first day sleeping.



LAURA REMEMBERS...

I remember very little from waking up after my surgery, it felt a bit like when your alarm goes off for school and you are so sleepy you don't want to get up! I remember the doctors and nurses saying my name and asking me to wiggle my toes, which I did! I was warm and I was comfortable without any pain, I remember a lot of machines around me but it wasn't scary at all.

I kept going back to sleep and dreaming. My Winnie the Pooh bear was tucked in bed next to me and the nurses had put a little hospital bracelet on him saying that he was also poorly. It helped me smile!



JANE REMEMBERS...

When Aimee woke up from her first operation she was very upset, the anaesthetist explained that this was a side effect of the anaesthetic

After Aimee's second operation we knew we needed to be in recovery when she woke up. This time she was much better, there were no tears and she seemed a lot calmer than her first operation. During the second operation there were some changes on the spinal cord monitoring when Aimee's spine was moved. The surgeon put temporary rods in to Aimee's spine and planned to take her back to theatre a week later to straighten the spine once we knew that no damage was caused to the spinal cord. We thought this to be a reasonable plan as all we wanted as parents was for Aimee to breathe better which would improve her quality of life.

During the third operation I was so anxious, we left the hospital but had to come back soon after as I couldn't stand the waiting. I spoke to the nurse practitioner and she contacted the anaesthetist who told her that Aimee was still in theatre but that it was going well. As soon as the operation was over i went in to recovery. I was told that everything had gone to plan, the spinal cord monitoring was normal and in fact the operation was more successful than originally thought. Aimee would have better lung capacity and therefore we had achieved our goal. We all felt so relieved!





You won't remember much about recovery but if somebody from your family is with you they may want to tell you what recovery was like.

Here is a space for your family to write about what happened when you were waking up from your operation



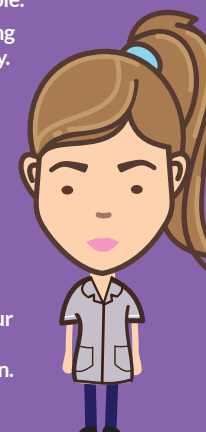
HIGH DEPENDENCY CARE

There are lots of things going on around you in the high dependency ward. It can be a little noisy with different alarms and sounds; this is normal and shouldn't stop you from being able to rest. Here you will be kept comfortable on your bed and encouraged to move a little so that your skin doesn't get sore. If you find it hard to move on your own the nurses will give you some help.

As the anaesthetic and pain killers are wearing off you will probably start to feel some discomfort and pain. This is normal and the nurses will give you pain relief to help to ease it. You may also be able to give yourself pain relief by pressing a hand held button that is attached to the pump at the side of your bed. You will hear the nurses and doctors call this a PCA and that is short for patient controlled analgesia. Sometimes the pain relief can make you sick; this is normal and doesn't happen to everybody. If it happens to you, medication can be given to help ease the sickness. The drips that give you medication will still be attached to your hand or neck. These can sometimes get in the way when you are moving around the bed but the nurse will help to position them to make you more comfortable.

The nurses and doctors will look at the dressing over your wound regularly throughout the day. If the dressing becomes a little wet then the nurse will add some pads over the dressing to help keep it dry. You may still have the oxygen mask on or it may be a nasal cannula that sits around your ears and just inside your nostrils to give you oxygen and help you to breathe. You will be offered something to eat and drink providing that you are not too sick.

You may stay in here for a day or two after your surgery and that all depends how well you are recovering from the anaesthetic and operation.



PHYSIOTHERAPIST...

We will come and see you to listen to your chest, teach you some breathing exercises and how to move in the bed. This will help with your recovery and help you to feel more comfortable.

LAURA REMEMBERS...

After a night's sleep, I started to feel a bit more 'with it'. I was in a little bit of pain but I had a PCA which I could press when I started to feel too sore. Remember to press this when you can, it will help.

I felt a bit sick, but I was given some medicine and it went away. I remember feeling taller and longer, like I was stretched out. My body felt very different, but I quickly got used to it. I had a lot of tubes in me and there were a lot of machines around me, beeping. I even watched a bit of TV. I had small sips of water but I couldn't eat much at first and I was taught breathing exercises by the physiotherapist.

My Mum and Dad sat with me by the bed. They said I was talking a lot and not making any sense, which they found funny! I mostly slept.



JANE REMEMBERS...

Aimee went to paediatric intensive care (PICU) after her first operation. Her care was outstanding, she was closely monitored and the environment was very relaxed. She stayed there overnight and was able to move around on the bed extremely well. The pain relief made her really sick which meant that she had no appetite.

After Aimee's second operation she spent two days on PICU. The nurses and doctors made sure that her spinal cord wasn't injured by checking her reactions and that her legs and arms were working properly. Aimee had Ketamine for pain relief and although she wasn't sick straight away she did have some sickness. The surgeon explained to Aimee what had happened and this made her mood really low as she thought that this was going to be the last operation. I tried to be positive as I knew how disappointed she was.

In her third and final stay in PICU the care was outstanding once again. The sickness was back but regular medication helped to take some of the sickness away.



MY HOSPITAL JOURNAL

Today the day is...



How I'm feeling today



Not so good things that have happened today

Good things that have happened today

Today's plan for my recovery

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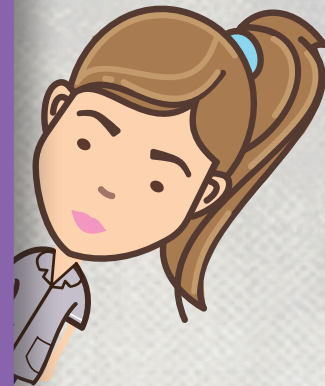
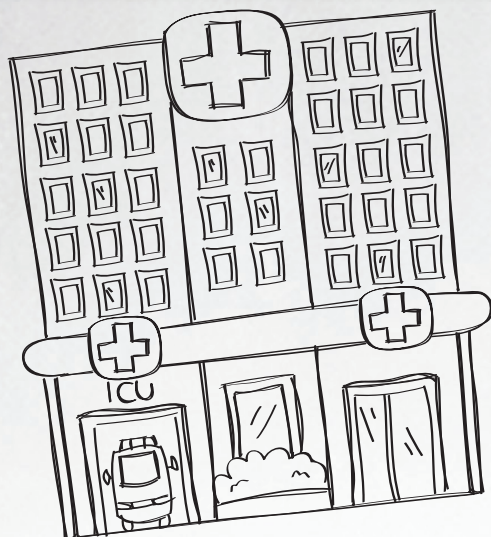
Today's plan for my recovery

ON THE WARD DAYS 1,2 AND 3

When you move from the high dependency ward you may be in a side room or you may be in a bay with other young people and their families. At first you will be kept comfortable on your bed and encouraged to move so that your skin doesn't get sore. The physiotherapist will see you every day and encourage you to do a little more each time they see you. If you find it hard to move on your own the staff and your family can help. You will probably feel some discomfort and pain, this is normal and the nurses will give you pain relief to help to ease it.

If you have a PCA you can use this to give yourself pain relief. It is a good idea to press the button before you see the physiotherapist or get out of bed. For as long as you are on the PCA there's a chance that it may make you sick; if it happens to you medication can be given to help ease the sickness. Some of the tubes and drips that give you medication may still be attached to your hand. By day three on the ward you should expect that they will be removed unless you still need medication into the tubes. The catheter may still be in your bladder, this usually comes out when the pain relief medication that goes into the tube in your hand is stopped. The drains in your skin will be taken out when your body stops making the extra fluid; this usually happens a day or two after your operation. You may still have the oxygen mask or nasal cannula to give you oxygen and help you to breathe.

It is important that you eat and drink as this helps your body to heal and give you the energy to recover. It is normal to not have much of an appetite so having small meals and snacks may help. Drinking water will help to keep your kidneys working well. You should try and do as much for yourself as possible but don't push yourself too much. You will get tired very quickly and need to rest.

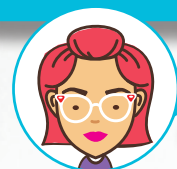


JANE REMEMBERS...

After her first operation Aimee had patient controlled analgesia (PCA). This made her sick and she had some pain which meant she could not think straight. The Physios came to see her and she managed to stand up with some support. She was told that she was doing well but she found it quite difficult and became a little grumpy.

Three days after the operation which was a Friday is when Aimee found it the most difficult. She had some pain but wasn't telling the nurses, we were both very tired and emotional. The thought of another operation was not very appealing! I spoke to the nurse practitioner and found her support invaluable, life on the outside does not stop as well as it being very difficult in hospital too, I felt alone and isolated. After operation number two it took a little while for the pain to be under control.

I made sure that Aimee pressed the call button to tell the nurses when she needed pain relief and this seemed to work well. After a couple of days the drains and catheter were removed and Aimee made good progress with the physios. Aimee was low in mood so to cheer her up we brought the dog to the hospital entrance where she was able to give him a cuddle, this helped! Third time round Aimee's nurses worked really well as a team and managed to keep her pain at bay. The care she received was outstanding.



LIAM REMEMBERS...

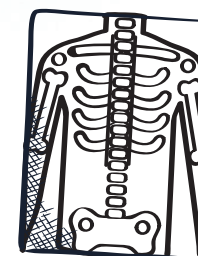
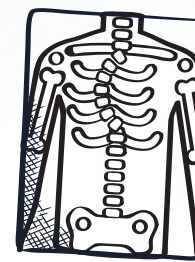
Day 2 on the ward came around quickly and I remember the physiotherapists coming to see me, they wanted to get me out of bed and standing up! I told them to go away and come back when I was more comfortable, less groggy and didn't have any drains or machines hooked up to me. I still didn't feel up to eating much and was still drifting off to sleep at any given chance.



LAURA REMEMBERS...

I spent two days on HDU. I had to have an x-ray taken before I went to the ward and I had to have the chest tubes, catheter and drains taken out. This hurt a bit, but I was given pain relief and it was over very quickly then I was free of the tubes! I had a lot of dressings on me and I still felt very tired. I was very nervous about the physio visiting me on the ward and I was worried about moving my 'new' spine, but the metal work is strong and you won't hurt yourself or damage it in anyway, just be gentle. It feels strange when you first start to move around after scoliosis surgery, but I went very slowly and only went as far as I could manage.

At first I sat on the edge of the bed, which made me a bit dizzy and was painful but then I tried really hard and stood up for the first time. I was so happy to stand up, I felt taller. My new back held me up just fine and although I was a bit unsteady and unsure at first, the nurses and physios helped me to take my first small steps!



About 48-72 hours after the operation the drips may be removed. You may still have your catheter in at this point or you may need to use a bed pan. Don't worry, lots of patients use bed pans and the nurses are very used to helping with this! As you start to move more you will be able to get to the toilet yourself, if the toilet is in your room you could probably walk to the toilet but if it is on the ward you will be helped with a wheelchair at first.

PHYSIOTHERAPIST...

It is important that you start to get moving after your surgery. We will teach you how to roll from side to side on the bed and sit up on the edge of the bed. You will need help to do this at first, you might feel dizzy and sore but this will get easier. Once you can sit up we will help you to stand and take your first steps. By day 3 you should be sitting in a chair for short periods to eat your meals and start walking to the bathroom with some help.



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PHYSIOTHERAPIST...

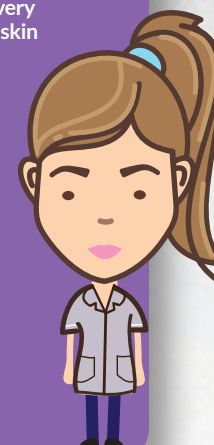
We will encourage you to do short walks around the ward several times a day to build up your strength, reduce discomfort in your back and improve your balance. If you have stairs at home we will practice how to go up and down on the hospital stairs before you go home. If you need to wear a brace or plaster jacket after your surgery we will ask you to practice standing for longer periods so you will be ready for your fitting.



DAY 4 ONWARDS

You will probably feel some discomfort and pain, but this should get a little easier every day and is normal. The nurses will give you pain relief to help to ease it. The tubes and lines that give you medication are usually removed by now. If you still need medication that goes into the tubes they will stay in for as long as you need this medication. Sometimes you may need to have a new tube put in and this will be done by a nurse or doctor on the ward. The catheter will be removed by now which means that you will use the toilet to have a wee. Sometimes it can take a while to have a poo after your operation, if this happens medication can be given to help. The nurses and doctors will want to look at your dressing every day that you are in hospital and check that your skin isn't getting sore.

You can eat and drink as normal. It is a good idea to have 5 or 6 small meals throughout the day to help give you energy and remember to drink plenty of water or diluted juice. You should try and do as much for yourself as possible but don't push yourself too much. You will still get tired very quickly and need to rest. Depending on the type of surgery that you had your surgeon may want you to wear a brace or jacket for 6 to 12 weeks after your surgery. This is usually fitted after you've been on the ward for a few days but for some people it may be sooner. You will need to stand for between 20 and 40 minutes while this is fitted.



LIAM REMEMBERS...

Day 4 came and it was one of the better days as I knew that by the end of it I would be hooked up to less machines and some of my drains would be removed. Later in the afternoon I was visited by the physiotherapists again but as I was slowly starting to feel better and I also knew that if I wanted to get closer to going home I had to stand up and use what little strength I had to strengthen my legs and sit in my wheelchair again. It was the first time in ages that I could remember where I stood up straight and even managed 30 minutes in my chair. I was extremely proud of myself and felt like it was going to be worth all this pain if it meant I could lead a better life, by bedtime I was in a lot of pain with my back and needed the nurse every 30 minutes because I needed to move, the feeling of euphoria from earlier had disappeared and then I realised I had a long road to recovery ahead.



LAURA REMEMBERS...

After a couple of days I no longer needed the PCA, instead the nurses came round and gave me pills to swallow to help my pain. I didn't have much of an appetite. By this point other family members and friends were allowed to visit me and it was a big help to have them with me. They bought presents and kept me distracted. I had a lot of glue in my hair from the spinal cord monitoring and we used nail polish remover to get rid of it, but it took a while! Before I could go home the physios needed to see that I could do the stairs and they gave me advice on how much to move when I got home – it's important to follow their advice.

It was difficult having my brace fitted as it is hard to stand up after the operation for so long but the orthetist, nurses and my Mum were with me and everyone helped me to feel better. The brace is made of plastic which they put in a hot bath to make it warm and flexible, then they wrap it around you and as it cools it hardens into the shape of your body. Wearing a brace after surgery can be uncomfortable and hot. I wore seam free vest tops underneath my brace and used talcum powder, which helped. Make sure you stock up on these before surgery.



JANE REMEMBERS...

The first time round Aimees condition vastly improved on day 4 which was a Saturday. She managed to walk around and started to eat more although she still felt a little sick. She had a great nursing assistant who lifted Aimees mood and helped to give her a shower.

After the second operation Aimee knew there would be a third and there were a lot of ups and downs. Aimee would have left hospital at that point but I just reassured her that she would benefit from it in the end. Having the nurse practitioner gave us continuity and enabled us to ask questions, this was a very new experience to us all and was scary! Aimees surgeon was so pleased with her progress that she was able to leave hospital 3 days after her third operation.



MY HOSPITAL JOURNAL

Today the day is...



How I'm feeling today



Not so good things that have happened today

Good things that have happened today

Today's plan for my recovery

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GETTING READY TO LEAVE HOSPITAL

You are usually ready to go home from hospital between 5 and 7 days after your operation. Some people go home before this time and some people go home after, it all depends on how well you feel after your operation.

Before you go home an x-ray will be taken of your spine. This lets the doctors look at the position of the screws and rods in your bones. Like the x-rays before the operation, you will need to be able to sit or stand upright for these.

- ☐ Your pain is managed with tablet or medicine pain relief.
- ☐ You are eating and drinking with no problems.
- ☐ You are able to have a wee with no problems.
- ☐ Your wound and dressings are dry.
- ☐ You feel well with no fever, sickness or other concerns.
- ☐ You are able to walk on your own if this is how you moved around before you came into hospital.
- ☐ You are able to walk up the stairs if you have stairs to walk up at home.

Your dressing will be removed 10 days after your operation. This will either be done in the hospital, by nurses who will come to your home or at your GP surgery. If you have a non-removable cast on the dressing will be removed when you come back to see the doctor in clinic.



SCOLIOSIS ASSOCIATION (UK)

It is best to travel home by car with the seat reclined and it is a good idea to have a pillow to help cushion your back when you go over bumps. Ask the driver to go slowly and carefully.

A follow-up appointment will be arranged for about 6-8 weeks after the operation. Wear comfortable, warm, loose clothing, which is easier to get on and off, especially if you have a brace. Supportive footwear is a good idea. When putting trousers, socks and shoes on, it is easier to do it lying down rather than standing. Try to get dressed every day rather than staying in your sleepwear. It is best to sit on a firm chair or sofa and sleep in a firm bed. The physiotherapists will show you how to sit comfortably before you leave the hospital.

LIAM REMEMBERS...

Three more days had flown by and by this time I had been on the ward and in hotel NHS for a week. I was still feeling in pain but I had managed to increase the length of time I spent in my chair each day and I was up to 1 and half hours sitting pain free by the time I was set to be released from hospital and I felt ready to go home. The next day I came home, very tired, sore and in pain so I got straight into bed. It felt good to be home and in my own surroundings ready to begin my ongoing recovery and have my mum help me to eat my dads homemade curry.



JANE REMEMBERS...

Aimee was able to return home after she had walked up and down the stairs with the physios.

Sickness was an issue which meant that she didn't eat very much, we had medication to help the sickness and slowly her appetite came back.

We went home a week after the first operation. Following the second operation Aimee had to stay in hospital for her third operation a week later. Following this she was able to go home after three days.



PHYSIOTHERAPIST... BEFORE YOU GO HOME WE WILL...

- Show you the best way to sit to keep comfortable and help your posture.
- Show you how to get in and out of bed.
- Show you what exercises to do when you get home.



MY HOSPITAL JOURNAL

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AT HOME

Although it is nice to be in your own home and your own comfortable bed it is also a little scary after you've been in hospital. It is normal to feel anxious and uncertain about what you can and can't do. Here are some tips that might help to make it a little easier:

Take your pain relief regularly for at least a couple of weeks, even if you feel that you don't need them! It is normal to have some aches and pains after your operation as your bones and muscles adjust to your new posture and spine. These should get easier as the weeks pass. If you have any new or sudden pains give your nurse a call for some advice.

Eat small meals regularly to give you energy and help your wound to heal. Try to eat a well-balanced diet and remember to drink plenty of water or diluted juice.

You will get very tired very quickly and the more that you do for yourself the more tired you will become. It does get easier usually between 4 and 6 weeks after your operation. Aim to sit for 15-20 minutes at a time, rest when your body tells you to and take naps in the day if you need.

Try and do as much as you can for yourself, it is normal that you may need some help for the first few weeks. As each day goes by you will be able to do more for yourself and gradually you will get to a point where you won't need any help at all. It can be frustrating but try and be patient as recovery and healing takes time!

You will know when you are ready to go back to school, college or to work. At first it is a good idea to spend short amounts of time there, perhaps the morning or afternoon and slowly build up to spending a whole day. Most people get back to school at 4 weeks (but for half days to start with and no physical activities). Getting back to work depends on what you do and how far you have to travel, your surgeon will discuss this with you – but in general it is 6 to 8 weeks after your operation.

If you have any questions or worries don't be afraid to contact the nurse or your surgeon's secretary. It is better that you call with a small worry than to wait for it to become a big worry

After you have been at home for a week your nurse will give you a call to see how things are going. Don't wait for this call if you feel you need to speak to somebody sooner!



SCOLIOSIS ASSOCIATION (UK)

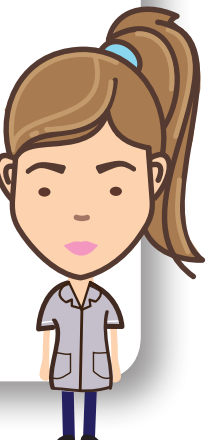
Avoid baths and shower only with a non-slip mat. You will need someone to help you for the first few days, especially if you do not have a walk-in shower. Always sit down to dry your feet by pulling them up onto your lap, or dry them with a towel on the floor; do not bend over.

Try to carry out the exercises set by the physiotherapist teams, they will help you to recover and move around more easily. It is best to sit on a firm chair or sofa and sleep in a firm bed if possible.

You will need a firm and comfortable bed, chair, or sofa. You should walk around 4 or 5 times a day for only 5 to 10 minutes, as comfortable, including visit to the toilet, etc. People vary in their ability to sit. Your back will tell you whether sitting is good or bad. You may use the stairs as necessary, but preferably only twice a day. You may sleep in any position that is comfortable and does not stress your back. Avoid lifting and twisting

Do not lift anything heavier than a kettle of water. Get up late, go to bed early, try to relax, and avoid stressing your back during the first 8 weeks. A long shoe horn and pick-up sticks are helpful. Boots and Wilkinson, and similar shops sell these items.

Going back to school or college varies from person to person.



PHYSIOTHERAPIST ADVICE

Things to avoid

- * **Heavy lifting, pushing or pulling**
Lifting your drink is fine, use two hands to carry your plates and always push heavy doors with both hands to avoid twisting.
- * **Bending over**
If you need to pick something up from the floor, bend at your knees. Put your pants, socks and trousers on from a sitting position



Good Posture

- * **Sit tall when you are eating**
- * **Try not to slouch**
A rolled up towel or small cushion behind your lower back might help
- * **Try and keep your head over your shoulders**

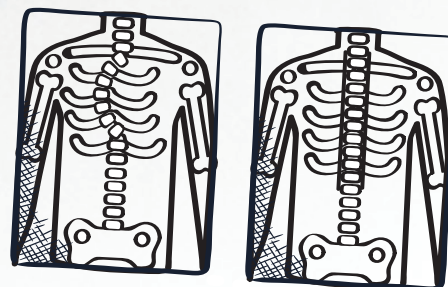
Seated Posture

Keep your head over your shoulders when seated- don't slump! A towel roll behind your lower back helps achieve this.



Keep Moving

- * **You will get sore if you sit for too long**
- * **During the day try to get up and move about at least every hour to stop you from getting stiff**
- * **When you are sitting down try moving your ankles backwards and forwards to help pump the blood around your legs**
- * **Gradually increase the amount of exercise that you do each day.**



EXERCISES



Walking

It is important to walk regularly and you will start to do this in hospital. Walking helps to pump the blood around your body and can help to make you feel better. Every day try and walk a little further.



Marching

Standing by a wall (to help keep your balance) march on the spot slowly keeping your back up tall. This works the muscles in your legs and back and also pumps the blood around your body.



Squats

Holding onto a sturdy object like the back of an armchair with your feet under your hips and facing forwards, slowly bend your knees keeping your feet flat on the floor and your back up tall then slowly straighten them up again. This will get the muscles in your thighs and buttocks working.



Calf raises

Holding onto a sturdy object like the back of an armchair slowly with your feet under your hips push up on your toes while keeping your back straight and a steady balance then slowly lower your heels to the ground. This helps to build up the strength in your calves and back.



Step ups

Using the step at the bottom of your stairs step up with one leg then the other. Step back one at a time while keeping your back up tall. Each time alternate the leg that you lead with.



Arm stretches

While standing, slowly lift your arm from your side to above your head, leading with your thumb and keeping your arm straight. Aim to reach your ear with your arm. Lift and lower one arm at a time and this will help to keep the joints in your shoulders loose.



Sit on a stool and practices good posture.

1- First tilt your pelvis backwards to round your lower back. Then use your back muscles to straighten your back and arch it. Hold approx. 1-2 mins.

2- Keeping a straight back lean forwards slowly from your hips 20 degrees and then return to a neutral position. Repeat leaning backwards 20 degrees.

Exercise Plan

First 2 weeks at home

Try and do up to 10 of each exercise 3 times a day. You could do these an hour after your medications at breakfast, lunch and teatime.

From week 2 to week 4 at home

Try and do up to 15 of each exercise 3 times a day. Increase the distance that you are walking and try to increase your speed a little. It is ok to go outside for walks on flat ground but always make sure that somebody is with you.

From week 4 to week 6 at home

Increase the distance that you are walking again, try walking up a hill but nothing too steep and certainly no mountains! It is still important that somebody is with you. Continue with your exercises however you can reduce these to once a day but try and do 2 sets of each exercise.

If you usually like to do sports and activities it is important that you wait until after your 6 week follow up appointment, here your surgeon will tell you what you should and shouldn't do. Eventually you will be able to do every activity that you want to but it is important to let your bones and body heal completely first.

FINAL THOUGHTS...

FINAL THOUGHTS FROM JANE...



On returning home Aimees recovery improved daily. She had good days and she had bad days and her emotions were up and down. At first she was unable to do things alone but after about three weeks she was able to get in and out of bed alone, take a shower alone as well as getting up and down off the toilet. She struggled to get up and down the stairs without any help but slowly that did improve.

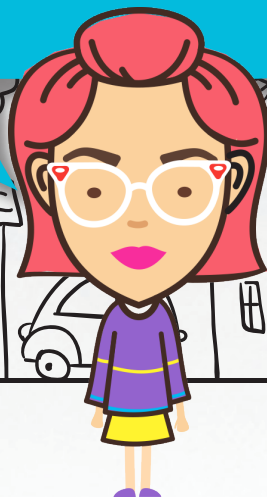
Aimee went to see her GP after about 4 weeks as she was still getting some discomfort and pain at times. Her GP prescribed her some medication and this helped.

She started back to school after about 5 weeks, just an hour a day to start off with and then we gradually built this up until she returned to her normal school hours.

I was so tired and emotionally drained from the whole experience which I can only describe as being on a rollercoaster. I found it difficult not being able to take Aimees pain away and sometimes the fact that she didn't communicate her feelings and concerns well made it even harder.

Her appetite took a while to return but I just emphasised the fact that she needed to eat to help her body to heal and give her energy. It took time but slowly she started to eat better.

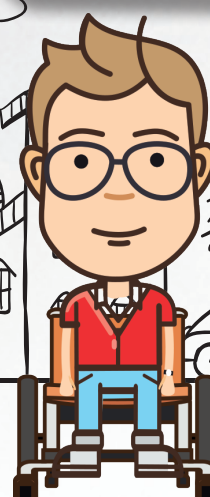
I took time off work to look after Aimee, I understand that not everybody is able to do this but I felt that she needed my support, that being said I was ready to return to a bit of normality once Aimee had recovered.



FINAL THOUGHTS FROM LIAM ...



It is now 5 years on since the surgery and I have no regrets about having it done as my quality of life has improved. I have been able to complete a university degree in a subject I love and go on to achieve a dream job at the BBC. I live a more comfortable life and for this I thank my surgeon and the nursing staff at the Royal Stoke hospital.



FINAL THOUGHTS FROM LAURA...



Going home was a difficult transition period because in hospital there is a lot of help and care but remember that there is always help on the other end of the phone. If you are worried about anything you should always get in touch with your doctors and nurses.

Recovering from scoliosis surgery is no easy task and I would advise you to take things slowly but find the right balance between resting and movement. I spent the early days feeling exhausted but I listened to advice from the hospital and walked little and often and did my exercises. It was certainly painful at the beginning although the pain was well controlled with painkillers. When you get home things will feel very different. I found it so strange that all the sinks and cupboards in my house were suddenly a lot lower - it was because I grew two inches!

I sat on a chair in the shower at first and my Mum helped me to wash my hair as it was difficult getting my arms above my head. Adapting to having a straight, fused spine is easier than you might think, your body will adjust and you will forget what it was like before the operation. If you are worried about your scar, don't be. Eventually it will fade and you'll barely see it. Once the wound is completely healed you can use bio oil or other moisturisers to help it fade.

Recovering is a long process and it can feel lonely, especially when your friends are off doing lots of exciting things and you are stuck at home. Before your operation make sure you have plenty of books to read, films to watch, music to listen to etc, so you will have lots to do at home to pass the time. If you feel up to it, a few weeks after surgery you will be able to go out for short periods of time, for example sitting in a cafe with your friends for lunch or perhaps going round to their house for a change of scenery! Be prepared that this will make you feel very tired at first, but it's all about taking it slowly and gradually doing more and more. SAUK and Back2Back can help - you can chat to other people who are going through the same thing as you and it will make you feel less on your own.

Although I lost a bit of strength and had a few numb patches, they improved with time and I recovered well from the surgery and I now have an impressive 14 inch scar that I am proud of - scoliosis surgery changed my life and made me stronger and happier, pain free and with a more positive body image.

If you would like to speak to me or be put in contact with other people with scoliosis you can contact me on my email: lauracampbell21@hotmail.com



FINAL THOUGHTS FROM THE SCOLIOSIS NURSE

Once you have been discharged I will ring you at home to make sure that everything is going well with your recovery. You can contact me to let me know about your progress, ask any questions in relation to your surgery and recovery or to discuss any worries or concerns that you may have.

Hospital switchboard
01782 715444

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