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WELCOME TO BACKBONE – AND WHAT'S AHEAD BY WILL THOMMES, FUNDRAISING & COMMUNICATIONS MANAGER

s we open this edition of the magazine, we want to begin with a heartfelt thank you to our community – and share a little about what's coming next.

You may already be familiar with some of the team, but for those we haven't yet had the pleasure of connecting with: I'm **Will**, and I've recently rejoined **Lesley McGinty** (Chief Executive) and **James Alculumbre** (Community Engagement Manager) as Fundraising & Communications Manager. I know many of you have already been in touch with the team, and I'm excited to be part of what's ahead.

As you're probably aware, in January 2023, Scoliosis Association UK (SAUK) and the British Scoliosis Research Foundation (BSRF) officially merged. Then in January 2024, we began a new chapter as **Scoliosis Support and Research** (SSR) – a name that reflects both areas of our mission: support and research. We're building on decades of dedication, and we can't wait to share what's coming next.

Looking ahead to Scoliosis Awareness Month

June is fast approaching, and with it comes Scoliosis Awareness Month—a time to shine a spotlight on scoliosis, celebrate our community, and drive real change. This year, we're bringing you an exciting lineup of events, campaigns, and ways to get involved.

A special event in London

We're excited to mark Scoliosis Awareness Month with a highlight event in London, celebrating our incredible community. This special event will shine a light on inspiring stories, raise awareness, and feature insightful presentations from specialists in the field. Join us as we come together to support our mission and encourage vital donations.

Introducing the ABCD of Scoliosis

Our theme for this year's campaign is the ABCD of Scoliosis, a simple yet powerful mnemonic created by health care professionals to highlight key aspects of scoliosis awareness and early detection.

The goal is to raise awareness about the importance of early detection. To support this, we're creating a concise animated video to make



Tom Marjoram speaking at our Norwich Event, 2025

the information accessible and memorable. We're excited to share these with our community and hope to have a long lasting effect and raise vital awareness.

How you can get involved

We'll be collaborating with key advocates to kick off the month, and we'd love for you to join us too! Here's how you can help:

- **Spread the word** Share our posts, videos, and campaign messages on social media.
- **Get involved** Take part in fundraising challenges like Step for Scoliosis or host your own awareness event.
- Watch out for our videos Created in collaboration with BSS, these animations will be a powerful tool in raising awareness.

This is your sneak preview of what's to come—let's make this the biggest Scoliosis Awareness Month yet! Stay tuned, get ready, and help us to have a lasting effect.

WHATEVER YOU DO, DO IT FOR US!

We've had some incredible fundraisers this year, and we're so grateful for the effort, resilience, and commitment our community continues to show year after year. It really does make such a difference. A huge shoutout to all those who ran in the 2025 London, Brighton, & Manchester marathons in April!

As of May 2025, our runners have raised an incredible **£48k** (including gift aid). We're beyond proud of every single participant who took on the challenge for SSR. Keep an eye out for photos of our amazing fundraisers in action!

There are so many ways, big and small, to support our work – from taking on a marathon, hosting a quiz night, or completing a 30-day challenge, to joining our Step for Scoliosis initiative. However you choose to get involved, every step, mile, and event helps raise vital funds and awareness. If you'd like to fundraise for SSR or have any questions, please email **fundraising@ssr.org.uk**.

Let's celebrate some of the amazing people who have raised money for SSR this year.



A HUGE THANK YOU TO EVERY DONOR

Our work wouldn't be possible without the support of every single member of our community.

- To those who have donated, whether once or regularly thank you.
- To those who've shared our message, joined an event, or offered words of encouragement thank you. To the families, friends, and individuals who support us — thank you.

You are the heart of what we do.

Because of you, we can fund vital research, offer life-changing support, and continue building a future where everyone affected by scoliosis feels seen, supported, and empowered.

We truly couldn't do it without you.



Erin Kiersey - Dance Challenge



Ann Thomas -Galaxy UK Pageant & Step For Scoliosis

Matt Bellamy - Sheffield Half Marathon



AILIE HARRISON ART COMPETITION

Thank you so much to everybody who submitted an entry to the Ailie Harrison Art Competition. We have had some incredibly unique, creative and personal entries and picking a winner was extremely difficult.

Please see our 3 winners below:





3rd Place - Norah Ballantine-Drake - Age 12



And our runners up / honourable mentions:







Runner Up - Charlotte Wigginton - Age 18

Runner Up - Helen Wilde - Age 70





PATIENT EVENTS: A look back at 2024 and what's ahead for 2025 By James Alculumbre, Community Engagement Manager

A t SSR, we understand the importance of patient events for our community. These events not only provide valuable information about scoliosis and treatment options, but also serve as a platform for individuals to connect, share experiences, and learn from experts in scoliosis. Our patient events are central to our mission of supporting and empowering those affected by scoliosis, and we are excited about the upcoming events in 2025.

Looking back: a successful 2024 patient event

In 2024, we held our patient event in Nottingham, which was a tremendous success. Hosted at the Mercure Hotel on Sunday, 6th October, from 10:00 AM to 4:30 PM, the event welcomed approximately 90 attendees. The day was filled with insightful presentations from leading experts in scoliosis.

• **Mr Shafafy**, an orthopaedic spine consultant, shared his expertise on adolescent idiopathic scoliosis and the various surgical options available.

• **Louise Neale**, a physiotherapist, offered invaluable information on bracing and physiotherapy techniques.

• **Professor Nas Quraishi**, an orthopaedic spine consultant, discussed treatments for the ageing spine, highlighting the evolving needs of older patients with scoliosis.

• **Caroline Freedman**, a personal trainer, spoke about the importance of exercise for individuals living with scoliosis, providing practical advice on how to maintain mobility and strength.

The event was not only informative, but also provided a wonderful opportunity for attendees to meet others with scoliosis, discuss their own experiences, and ask questions. It was heartwarming to see such a strong turnout from our community, and we are grateful to everyone who attended and contributed to the event's success.

Looking ahead: 2025 patient events

As we move further into 2025, we are excited to announce the continuation of our patient events across the UK. Following the success of the event in Norwich on March 22nd, we are now turning our focus to the remaining events of the year, which will take place in London, Sheffield, and Belfast. These events will allow more individuals with scoliosis to access the information and support they need.



The remaining patient events in 2025 are as follows:

- London June 29th
- Sheffield October 4th
- Belfast Date TBC

Each event will feature talks from leading orthopaedic consultants on both surgical and non-surgical treatments, as well as sessions on physiotherapy and the lived experiences of individuals with scoliosis. The topics discussed will cover all age ranges, from adolescent idiopathic scoliosis to treatments for the ageing spine. These events are a fantastic opportunity for the community to learn more about scoliosis, treatment options, and hear from those who have lived with the condition.

Our patient events are also a great way to meet others who understand the challenges of living with scoliosis. They provide a safe space for individuals to discuss matters that are important to them and share advice and support with others who are going through similar experiences.

Join us in 2025

We're looking forward to welcoming you to one of our patient events in 2025. Whether you're seeking advice, looking to connect with others in the community, or simply wanting to learn more about scoliosis and its treatments, our events are the perfect opportunity. Stay tuned for more details about each event, and we hope to see you there!

INTRODUCING JULIA CARLILE A journey of strength and dance

Best known for her inspiring journey on Britain's Got Talent as part of MerseyGirls, Julia Carlile has captured hearts worldwide with her resilience, passion for dance, and determination. Despite her battle with scoliosis, she has continued to break barriers, transitioning into acting and using her platform to raise awareness.

Julia's story is one of strength, determination, and hope. We're thrilled to have her on board and look forward to working together to support and inspire others facing similar challenges.

i! I'm Julia Carlile, I'm 23, and I was diagnosed with scoliosis at the age of 6. I was lucky enough to be diagnosed so young and receive treatment early. From ages 9 to 16, I wore three different back braces, which were very challenging during my teenage years. I've always had a deep love for dance, and my spine doctors always said it was great because it helped keep my spine flexible. They hoped this flexibility would allow the back braces to work and straighten the curve.

I wanted to do everything I could to avoid having spinal fusion surgery because I was aware it would stop my dancing career by taking away the flexibility in my spine completely. Unfortunately, despite all our efforts, my spine kept curving and getting worse. In the end, I booked surgery for spinal fusion. During this time, I also found myself on Britain's Got Talent, where my journey took an unexpected turn. The show ended a month before my planned surgery, but I was fortunate enough to be flown to America by Simon Cowell to undergo two VBT (Vertebral Body Tethering) operations. This procedure preserves spinal flexibility, allowing me to continue dancing.

The surgeries went great, and for the next 2 years, I was able to continue pursuing my dream of being a dancer. However, my spine was determined to curve, and I eventually developed kyphosis. Despite my best efforts, my spine continued to present challenges.

Now, I'm 2.5 years post-op from two fusion surgeries, which involved breaking the middle part of my spine before fusing it, as it had fused on its own in the kyphosis position. I now have two metal rods in my back, I've grown 5 inches, and I am absolutely thrilled with the results. While I can't dance the same way as I once did, my passion for dance remains, and it hasn't stopped me from continuing to embrace life.

I am excited to get involved with this charity and raise awareness about scoliosis. We are not alone!



ENSURING A POSITIVE EXPERIENCE DURING SCOLIOSIS SURGERY: Helpful tips for staff, families, & patients

S coliosis surgery is complex and comes with significant risks. Fortunately, expert surgical teams work diligently to minimise these risks and achieve excellent outcomes. The support teams around them play a crucial role in making the perioperative period as positive as possible for patients.

This article provides guidance for hospital staff, families, and patients to help create the best possible experience. While every patient and family are unique, these insights—drawn from experience—may be useful.

Staff

Working with young people who have scoliosis is a privilege granted to 23 Trusts across the UK. Each of these centres has a dedicated team of experienced professionals guiding patients through their surgical journey. Specialist nurses often serve as the primary point of contact for families, coordinating care and developing strong relationships within the multidisciplinary team. These nurses stay connected through email and online meetings, sharing best practices, and learning from one another's experiences.

A positive and enthusiastic team culture is essential. Attributes like innovation, optimism, and supportiveness are contagious and reflect directly on patient care. We recommend that all staff caring for young people undergoing scoliosis surgery observe a procedure at least once. Understanding the physical and psychological challenges firsthand enhances empathy and helps staff provide more informed support during recovery. While it's important to be compassionate, staff should also encourage and gently push young patients, as prolonged bed rest can hinder recovery.

Since most staff members have not personally experienced scoliosis surgery, connecting patients and families with others who have undergone similar journeys can be invaluable. Our closed Facebook group has proven to be a powerful means of peer support, allowing those with lived experience to offer guidance and seek advice.

Clear, timely communication is key. Families should always be kept informed, and staff should be



*Kadie and Alyssa met through our Facebook group, and Kadie later visited Alyssa in PCCU (paediatric critical care unit) after her operation.

approachable, open, and honest so that young people and their families feel comfortable asking questions and expressing concerns.

Preparation for surgery should include written materials or online resources to reinforce verbal advice. Given the stress and sheer volume of information involved, it's easy for families to forget details. Addressing the unknown is crucial—allowing young patients to visit the ward beforehand, see pre- and post-surgery X-rays, and view photos of healed scars can help alleviate anxiety.

Understanding individual preferences for information is also essential. Some young people want to know everything and ask numerous questions, while others prefer only the basics. Tailoring communication to each patient's needs fosters trust and reduces stress. Discharge planning should begin immediately after surgery to ensure a smooth transition home. This includes preparing discharge letters and prescriptions in advance. Post-discharge, families should have access to specialist nurses and ward staff for any concerns that arise.

Families

The period leading up to scoliosis surgery is often stressful for parents and caregivers, who worry about the risks and their child's ability to manage pain and recovery. Many try to hide their concerns, believing they are protecting their child. However, young people are highly perceptive—they often sense their parents' anxieties and, in turn, hide their own feelings to avoid causing further worry.

Open, honest communication is the best approach. Remaining positive and reassuring while acknowledging concerns helps build trust. Including siblings in discussions is also important, as they may feel left out or become anxious if information is withheld.

In the lead-up to surgery, plan quality family time—such as fun outings or a holiday—to create positive memories and provide something to look forward to. Packing for the hospital in advance can also help reduce stress. While hospitals typically provide packing lists, families have recommended additional items such as:

- Handheld fan
- Cooling spray
- Lip balm
- · Cold drinks & hydrating fruits
- Eye mask
- Earphones (wards can be noisy)
- Microfibre towel & dry shampoo
- Water bottle with a long straw
- V-shaped pillow

During the hospital stay, parents may find themselves the target of their child's frustrations this is natural. If possible, arrange for someone else to step in occasionally, allowing time for rest or a brief walk outside. Despite the challenges, many parents report that their relationship with their child strengthens through this shared experience.

Patients

Before surgery:

- Maintain a healthy diet rich in protein.
- Keep your skin as clear as possible.
- Strengthen your core through exercise.

- Ask questions—don't let uncertainties cause unnecessary worry.
- Connect with others who have undergone the surgery for firsthand insights.
- Avoid smoking or vaping, as these can negatively impact bone fusion.
- Take practical steps like trimming toenails and shaving or waxing legs before surgery, as these tasks will be difficult afterwards.
- If you have long hair, consider scalp plaits for easier maintenance in the hospital.

During Surgery & Recovery:

It's easier said than done, but try to stay as relaxed as possible. Interestingly, young people with severe learning disabilities often cope well with surgery because they don't experience anticipatory anxiety. While you may have expected to be independent, many patients find they want family or caregivers close by during their hospital stay—and that's completely okay.

Keep yourself occupied. Distraction is a great coping tool. If possible, arrange for friends to visit a few days post-surgery when you may be feeling low. A positive mindset is crucial—accept that there will be tough moments, but know that they will pass. When feeling down, try reframing your thoughts by acknowledging the struggle and following it with a "but luckily..." statement. This mindset shift can be powerful for resilience.

Example: "I'm feeling sore and tired, but luckily I'm already a day closer to recovery."

Positivity is a key factor in both short-term recovery and long-term well-being. Good luck, and remember—your experiences can help others in the future!

By Cheryl Honeyman and Katie Stanton

Paediatric Spine Specialist Nurses, South Tees Hospitals NHS Foundation Trust

ELIZABETH'S STORY A lifetime of gratitude for scoliosis surgery

Surgical treatment for scoliosis has evolved dramatically over the past 60 years. Whereas surgery was once considered radical, it has now—with the use of implanted rods and screws—become a standard procedure with far shorter recovery times. Yet even in the mid-20th century, under challenging conditions, successful outcomes were possible with timely intervention. Elizabeth van der Graaf's story is a testament to the life-changing effect of scoliosis surgery, as well as the resilience of those who undergo it.

was just 9 years old when my mother, a former radiographer at St Bartholomew's (Barts) Hospital in London, noticed an abnormal curvature in my spine during a routine tuberculosis screening X-ray. At the time, in 1959, my family was living in Angola, where my Dutch father worked for an Amsterdam-based import/export company. When the curvature worsened over the next 3 years, my mother and I took a 5-day sea voyage to Cape Town to consult an orthopaedic specialist. The recommended treatment? Twice-weekly exercises and a half-inch addition to one heel. It was a conservative approach, but it soon became clear that more intervention would be necessary.

In 1963, I started at boarding school in Cape Town. But my condition continued to progress, and my parents decided to seek medical advice in Europe. Mid-year, my mother and I travelled to Amsterdam, where we could see specialists and lodge with my family. We also travelled to Edinburgh to see Professor J I P James, one of the leading scoliosis experts of the time. Other specialists had offered alternative treatments, including one doctor who suggested I sleep in an adjustable plaster mould for 8 years, and another who believed corrective exercises alone would suffice. Meanwhile, innovative techniques in Poland involved surgically implanted springs to straighten the spine. However, Prof James advised against these methods, stating they would provide only temporary relief. Instead, he recommended spinal fusion of several thoracic vertebrae using selfgrafts from my hip bone, followed by 4 months in a plaster cast, and 8 months wearing a Milwaukee brace. Given my family history of tall stature and my delayed physical development-I had not yet started menstruating at 13-he believed that immediate surgery would be the best course of action. A Harley Street specialist confirmed his recommendation, and my father's company provided unwavering support, even arranging business travel so he could be with us at critical moments.

In October 1963, I was admitted to Edinburgh's Princess Margaret Rose Hospital for thoracic spinal fusion. Most of the other girls in the ward-whose strong Scottish accents I struggled to understandwere undergoing operations for polio-related conditions. My operation was a success, but the initial days of recovery were gruelling. I wrote in an essay for the hospital school: "I was put on a frame and stretched until I felt I would not be in one piece, but two. Then I was covered in wet, hot plaster up to my chin. A hole was cut in the plaster, and I was taken to the operating theatre. Next thing I knew, it was morning, my back hurt a bit, and I could not turn over." The first few days were difficulttwo nurses were needed to shift my plasterheavy body every 20 minutes-but by the third day, I managed to turn over on my own, a small victory that felt enormous at the time. My only real complaint was about food: I could barely open my mouth enough to eat with a teaspoon, and I could not look down to see my plate because of the cast!



Since we had no close family with whom we could lodge in Edinburgh, my mother and I left the hospital after a month, once I had mastered sitting in a wheelchair for an hour each day. Our journey to Amsterdam was a logistical challenge: I was stretchered onto a plane to London, transferred onto another flight to the Netherlands, and then carried up a steep staircase into my grandmother's flat. Over the next 2 months, I slowly regained mobility, venturing out for short drives, and even tackling the stairs. During this period, my cousin Els kept me entertained with card games,



Beatles records, and Dutch lessons.

5 months post-surgery, my mother and I returned to Edinburgh for a crucial follow-up. A hole was cut in my plaster cast for an incision to confirm that the bone grafts were taking. 10 days later, I was fitted for a Milwaukee brace—a contraption of metal uprights, leather pads, and a neck ring. Despite its cumbersome design, I was delighted with it. My mother noted in a letter home that I could now bend easily, something that had been impossible under the 35-pound weight of my plaster cast.

8 months after the surgery, I was eager to return home to Africa and resume my education. The journey back was another adventure: a drive to Brussels, flights via Lisbon to Angola, and finally, a return to school in Cape Town. Although I had missed over a year of lessons, I focused on catching up, and by November, I was finally able to remove the Milwaukee brace. Initially, I felt incredibly weak, but my strength soon returned. My teeth, displaced from months of pressure against the brace's chin rest, gradually realigned on their own.

A year post-surgery, X-rays were sent back to Edinburgh, and Prof James confirmed that my spine had stabilised and my growth was complete. My life afterwards was active and fulfilling. I enjoyed skiing, waterskiing, tennis, swimming, hiking, and camping. I pursued university degrees in Cape Town and Paris, moved to Canada, married, and built a successful career as a conference interpreter, initially in Ottawa and later for the European Union in Brussels. I also became a mother and, eventually, a grandmother.

Now in my 70s, I have experienced some agerelated spinal changes, including secondary curvature and lumbar degeneration due to the stress on my unfused lower vertebrae. While I have had to adjust my activities—no more gardening, for instance—I remain active with aquafit classes and long walks, and have been able to continue pursuing a 20-year passion for pottery. Further treatment may be necessary if severe pain or neurological symptoms arise, but for now, I am grateful for the life I've been able to live.

Before my operation, the orthopaedic specialist in Cape Town wrote to my parents: "Elizabeth will thank you for the rest of her life for what will now be done to her." He was right. I will forever be grateful to my parents for the difficult decisions they made on my behalf, and to Prof James for giving me the chance to live a full and active life.



UNDERSTANDING THE SCOLIOSIS CARE PATHWAY

Child and adolescent pathway

GP diagnosis

Often, the first healthcare professional you will see will be your GP - general practitioner (or another member of the practice). Some people who have contact with other healthcare teams may see a specialist physiotherapist or another member of the healthcare team.

The person you initially see will usually listen to any concerns you have about your (or your child's) back and ask you some initial questions, perhaps including when you first noticed the issue and how it affects you.

You should be prepared for an examination of your back, as well as your tummy, arms, and legs. Doctors will often take note of any differences in the shape of the body on one side compared with the other or a difference in the height of the shoulders.

The most common examination test involves simply asking you to bend forwards, allowing the healthcare team to get a line of sight down the spine, which highlights any rotation of the spine. The rotation causes one side of the spine to move forwards and the other to move back, making one side appear more prominent when looking down the spine in the bent-forward position. This is often called the Adams' forward bend test (after the person who first described it).

If the person assessing you suspects you may have scoliosis, you will most likely be referred to someone more specialised in the assessment and management of scoliosis.

Small spinal curves

May be referred for physiotherapy

Physiotherapy can be key to the management of scoliosis. The spine receives much of its support from the muscles that surround it. Having strong,

well-conditioned muscles can really help you. In many cases, the discomfort felt by patients is caused by the uneven pull on the ligaments and the uneven work of the muscles that control and support the back.

It is also important to consider that the muscles of the arms and legs can become tight as your bones grow. The muscles can often take a little time to catch up with this growth. In the meantime, they can become tight and restrict normal movement, which can put more strain on the spine. Some simple stretches performed regularly can help improve this tightness faster, allowing the body to move more freely.

The physiotherapist will assess you and your back to identify any tight muscles and any weak muscles. Some people may be given specific exercises to target certain muscle groups. You will also receive advice about general back care and the importance of doing some form of exercise/ activity that you enjoy on a regular basis. It is noteworthy that physiotherapy and exercises cannot 'correct' structural curves, but in very minor curves, they may be able to slow or limit progression.

May have an X-ray or MRI

An X-ray is taken while you are standing so that we can appreciate the shape of the spine when you are in an upright position. It will be explained to you how to stand exactly (and there can be some slight variation in this), but the image below gives an idea.

When having an X-ray (if you are female), you should be prepared to answer a question about pregnancy – this is not a judgment but an important safety question.

An MRI

An MRI is a magnetic scanner that gives the team a 3D image of the spine and its nerves. This is not essential for providing you with a diagnosis, but it can sometimes offer the team some really useful information to plan your care. Because it uses a large magnet, there are several safety questions you should expect to be asked – this is entirely normal. If you have any piercings, you'll need to remove them to have an MRI. The MRI scanner itself can be noisy, and often you'll be given headphones to help with this.

You'll be closely monitored during the scan, and there is always a mechanism (often a button to press) if you feel as though you cannot carry on.

You may be referred to the scoliosis team and have ongoing monitoring

Some healthcare teams can make a decision without the involvement of the spine surgery team for smaller curves. This might involve regular assessment to check that the curve does not progress or get larger.

Often, once a diagnosis of scoliosis is suspected, you'll be referred to the scoliosis clinic. This usually consists of several people, including a spine surgeon, specialist physiotherapists, and specialist nurses (clinics can vary).

If the curve is small, the initial decision may be to simply keep a watch on the curve. You'll usually be seen again at an appropriate time interval to see how the curve changes over time.

You may be seen by an orthotist for a brace and monitored (this includes what a brace is, how it is worn, the reason for wearing a brace, etc)

An orthotist is a specialist who can measure and create equipment to support the body – this can include a brace for scoliosis.

What is a brace? – A brace is a tight-fitting, hard plastic jacket (with padding) that aims to slow the progression of a scoliosis curve by applying pressure to the body that will affect the spine. You should not expect a brace to improve the shape of your scoliosis – only to slow its progression.

Different braces are advised to be worn for varying numbers of hours throughout the day. Your team will explain this fully to you. Often, the recommendation will be to wear the brace both day and night to get the maximum effect.

It should, however, be taken off for exercise, and the brace should not stop you from moving and being active. Having well functioning muscles is important for scoliosis.

What to do if there is rapid progression of spine curvature?

If you feel as though your curvature is getting worse, you should communicate this to the team looking after you. It does not always mean that urgent intervention is required, and you should continue to be active. How quickly a curve progresses can vary from one person to the next, and sometimes people notice that their curve is worsening during periods of rapid growth, usually during adolescence.

Large spinal curves

You may still be referred to a physiotherapist for assessment

This is just as important as with small curves. Keeping the muscles around the spine (the core) strong and keeping the surrounding muscles (particularly the hamstrings) flexible can have a very positive effect on your symptoms. It can also help with any recovery if you have a procedure.

You will probably be referred to the scoliosis team

Once a diagnosis of scoliosis is suspected, you'll usually be referred to the scoliosis clinic. consists of a variety of people, including a spine surgeon, specialist physiotherapists, and specialist nurses (each clinic can be different).

They will arrange for you to have appropriate imaging (X-ray +/- MRI – see above), and based on the results, they will advise you on their opinion about the best management. This may involve advice to monitor the spine and review you after an appropriate timeframe with further X-rays to see how the curve is changing over time. It may also be to refer you to the orthotics team for a brace.

You may be recommended surgery

Surgery for scoliosis can sometimes be recommended. An operation will always be a joint decision, with the patient and family being involved in the final decision. The scoliosis team will explain why they feel an operation would be beneficial and will discuss what the surgery involves. Not everyone likes to hear the details around this, but it is important that the risks are explained to you to help you to weigh up whether the procedure is the right decision for you.

There is no 'rule' about who should and should not have surgery, and it is a very individual decision, taking lots of different things into account. What is right for one person may not be for the next. This is also the case when a surgeon decides what exactly to do to control the scoliosis. Some operations may involve fusing the spine so that it cannot progress further, while some aim to control the spine while still allowing it to grow (sometimes with a plan to fuse it when growth is minimal). Your scoliosis team will be able to explain their decision to you, so please do ask any questions you might have.

After surgery

The journey after surgery can vary depending on the type of operation that you have. The scoliosis team will be able to explain the details of any pathway to you, which may vary. Please use the below explanations as broad information only – any advice from your treating team overrides anything in this document, and if you are in doubt, please do ask your treating team.

In general, you should expect to have a review of the surgical wound at around 14 days after operation. This review will mean removal of any dressings and inspection of the wound for good healing, and to ensure there are no issues. If everything is going well, then you will likely be allowed to get the wound wet shortly after this appointment (usually not soaking in the bath, however).

It will take a while for you to get used to the new body shape, and it will be normal to feel tired and have some pain (painkillers can help with this). People often find that regular movement helps to make the pain feel better (it also has some other benefits).

Initially, you'll probably be given some breathing exercises to make sure the lungs get air all the way to the bottom. It's also important to keep everything moving – often you'll be advised to do some simple exercises with the shoulders and hands, as well as the knees, feet, and ankles, to keep the joints from getting stiff.

If you can, walking should be gradually built up over the first 6 weeks, doing just that little bit more every day. By 3 months, you should be able to manage some longer walks, perhaps with some hills. By 6-12 months, we would expect you to be at a level normal for you.

Swimming can be really helpful for recovery but should be approached with some caution – obviously, you shouldn't get into a pool until the wound is fully healed. Initially, it might mean starting with walking in the water for that little extra resistance. You should be careful around the potentially slippery pool edges. Your scoliosis team will guide you through this.

Cycling on a static bike can usually be introduced gradually from about 6 weeks, slowly building up to short outdoor rides on flat ground by 3-6 months. Running should not be undertaken in the first 3 months because the repetitive jolting might be harmful (and most people would find this difficult to tolerate anyway). When it is introduced, it should be very gradual and built slowly.

Other sports should usually be avoided initially and then very gradually introduced – concentrating

initially on control and gentle, limited movements and slowly building up. Contact elements in sports and those which involve impact/risk should generally be avoided for at least a year to allow any fusion to become fully stable.

Adult pathway

Diagnosis

Diagnosing adult-onset scoliosis can be difficult. Most people will initially present to their GP or to a community MSK (musculoskeletal) service. After listening to your concerns, the healthcare professional will usually want to examine you. This examination will include an inspection of the back and possibly also a wider examination of the arms and legs. This broader examination aims to look for potentially linked conditions and to assess for any nerve issues related to the problem.

Depending on the regional pathway of the area where you live, the GP might be able to access some further imaging. In some regions, these are limited to specialists to help minimise the need for potentially unnecessary repeated investigations.

X-ray

A common starting investigation is a standing X-ray of the spine, usually taken with the elbows bent and touching your shoulders. The X-ray should be taken without any support for the body (if possible) to ensure they are as true a representation as possible. In adult scoliosis, X-rays taken from the side are particularly important since it is the imbalance in this direction (tilting too far forwards or backwards) that can have the biggest effect on you. Sometimes, the X-ray will need to include the

legs to explore the methods you may use (maybe unconsciously) to compensate for your scoliosis.

MRI

An MRI uses a powerful magnet to produce 3D images of the spine. It provides detailed images of the nerves, discs, and other structures. Having the pictures taken while lying down also allows the surgeon to assess how your spine changes when no weight is placed on it.

To have an MRI, you will be asked a series of screening questions for safety, which is normal and essential to ensure the safe planning and performance of the scan. As for small curves, you will be asked to remove any metal objects, such as piercings, and you may be asked to change into a hospital gown.

For the scan you lie on a flat surface that moves in and out of the doughnut-shaped scanner. The scanner can be noisy, but headphones are usually provided to help minimise the noise. Throughout the scan, the radiographers will be monitoring you and will communicate with you. If you have any issues, you will be given a button to press to pause/ stop or to request assistance.

CT scan

A CT scan is similar to an MRI in that you will be asked to lie on a flat surface that moves in and out of the scanner. However, it does not rely on magnets, so the safety questions will differ. A CT scan is excellent for examining the structure of the bones themselves (rather than the bones, discs, and other tissues seen in an MRI). It also produces high-quality 3D images that allow the team to have a comprehensive understanding of the anatomy of your spine to plan management.

Bone Density Scanning

Bone density scanning, commonly referred to as a DEXA scan, is one method used to assess bone density. Emerging methods are also being explored for this purpose. The scan involves taking specialized X-rays of different bones, usually the spine and hip, to measure their density. This measurement is then compared to known average values to determine whether your bones are of appropriate density. The reason for measuring bone density is to evaluate the quality of your bones, because bone quality can affect the strength of fixation points, such as screws used in surgery.

Physiotherapy

At any point in your pathway, you may be referred for physiotherapy. Seeing a specialist physiotherapist offers many benefits. Regular movement and weight-bearing exercises positively affect bone quality and density. Having strong core muscles and flexible joints (especially in the hips) can help your body compensate for scoliosis and support the spine. With persistence, some people notice significant improvements in both pain and function as their muscles become better conditioned.

The exact physiotherapy approach will vary from person to person, depending on your abilities and pain levels. It usually focuses on increasing mobility and conditioning the core muscles (back and abdomen) to support the spine while staying active. Physiotherapy may sometimes include hydrotherapy (swimming pool exercises), but this will be explained to you by your therapist.

It is important to understand that physiotherapy is something you actively do, not something done to you. The aim of the therapist is to guide and teach you through recommended stretches and exercises, but they cannot do them for you. Keep in mind that it takes time for physiotherapy to show positive results, and if you stop doing the exercises, the benefits will diminish.

The surgical team

An appointment with a spine surgeon may not always be necessary. However, if you do meet with the surgical team, it will be to discuss your symptoms and the effect they have on your daily life. If additional imaging is required, the surgical team will arrange these tests to help guide their decision-making.

Decisions about surgery can be complex, depending on the severity of your condition and the results of any investigations. There may be several treatment options, ranging from simpler interventions such as injections to more major operations. However, surgery is not always the best option, and sometimes other treatments, such as physiotherapy, may be more appropriate. The team will carefully consider both the risks (which can be significant) and the benefits (which are not always clear and never guaranteed) in their management decisions. If surgery is not recommended, it does not mean the healthcare system has given up on you. In fact, ruling out surgery can sometimes open up other treatment options!

Pain management

Many adults with scoliosis will eventually work with the pain management team at some point during their journey.

The role of the pain management team is to manage the pain you are experiencing. Although they may provide interventions to reduce pain, they also focus on teaching coping strategies to minimise the effect of pain on your daily life. Their approach differs from that of the surgical team, which focuses more on the physical aspects of your condition. The pain management team often uses a broader strategy, incorporating various modalities, including psychological aspects of pain and, in some cases, group sessions.

It's important to approach pain management with an open mind to fully engage with the service and get the most benefit. Pain management often works well alongside physiotherapy, helping to manage pain while improving function.

By Tom Marjoram and the spinal team Norfolk & Norwich University Hospitals



INTRODUCING NATALIE GOOD

Natalie Good has been making waves in the music industry since she first stepped onto the live circuit at just 13 years old. A self-taught pianist and singer-songwriter, her talent and determination have earned her recognition on some of the biggest stages. Many first saw her in 2020 when she auditioned for ITV's The Voice UK.

Since then, she has collaborated with well-known artists, with her latest release, Loving You Ain't Easy, remixed by MOBO Award-winning DJ and producer Sunship. Her music has been featured on BBC Introducing and played on major platforms, while her interviews on Vibe Radio 107.6 and London Live TV continue to amplify her story. Beyond music, Natalie's resilience in overcoming challenges including scoliosis—has made her an inspiration to many.

We sat down with Natalie for an in-depth conversation about her journey, struggles, and triumphs in the music industry and beyond.

Can you tell us a bit about yourself and what first inspired you to pursue music? Has scoliosis influenced your music or the messages in your songs?

I started writing songs and learning to play the piano by ear when I first began wearing a brace, since this was my only option for a creative outlet. I had to quit my other extracurricular activities, which were all physically demanding on the body, such as dancing, jiu-jitsu, and swimming. It has certainly influenced my journey to becoming a musician and songwriter.

It started out as a form of self-help. I began performing on a live music circuit called Success Express, singing and showcasing my original material at live events, which led me to pursue music as a career.

I am an established international multi-genre artist, performing globally as a professional solo act, in eight-piece show bands, acoustic duos, and DJ live bands. Most recently, I have performed at Vivz World Fashion Week runway at London Fashion Week 2024, the UK Glamour Awards, and premium Mayfair and Soho hotels, as well as private members' clubs, nightclubs, rooftop bars, and restaurants. I have also performed at luxury celebrity and high-profile figure weddings, corporate events, religious ceremonies, and private parties.

I have performed all over the world for highprofile brands, names, and venues, ranging from Samsung in Morocco to Wembley Stadium, where I sang in the England football players' lounge. I have performed in a 1950s female trio for the Soap & Glory Christmas UK roadshow tour, played private events at Windsor Castle while accompanying myself on the piano, and sung for oil corporations on private yachts in Monaco. I have also supported well-known artists such as Rick Astley, Alexandra Burke, and The Script at The Dorchester (Mayfair Noah's Ark Ball); Sister Sledge with her band at The Ned; and Russell Watson at the Wildlife Festival. Additionally, I have performed for the President of Kazakhstan at the United Nations show, singing in an established three-part pop girl band.

I write, record, and produce my own music, releasing it independently. My original music has been featured on ITV's Love Island All Stars, Netflix series The Ultimatum: Marry or Move On and Teen Mom: The Next Chapter, and BBC Introducing, as well as being played on air and leading to an interview with Vibe Radio 107.6 and London Live TV. This exposure gave me the platform to start performing my music at festivals across the UK, including The EARTH Festival, as a semi-finalist in the 2024 Coffee Music Project songwriting competition.

I have also been interviewed on TalkTV UK Live, taking part in a discussion with Conservative MP Caroline Nokes and TV hosts Kevin O'Sullivan and Alex Phillips, addressing the topic of misogyny that women experience within the music industry.

This year, my original music will be featured in a British independent film, in which I also have a small acting role as a nightclub singer. Filming is set to begin in March, and I'm excited to bring both my music and performance to Amazon prime movies and Netflix!

Can you share the moment you were first diagnosed with scoliosis and how it felt as a young girl?

This is always the hardest part to talk about because even now, revisiting that memory brings me to tears.

I was trying on a dress for my sister's Bat Mitzvah when I noticed my shoulder blade sticking out in the shape of a pyramid. Horrified, I ran to my mother, crying. With her medical background as a trained nurse, she quickly composed herself and booked me for an emergency appointment with a spine specialist at Bushey Bupa Hospital.

That day changed our lives forever. I was diagnosed with scoliosis. The specialist explained that I had both lumbar and thoracic scoliosis, meaning my spine formed an 'S' shape, which was causing my rib cage and shoulder blade to be out of alignment with my body.

The surgeon gave me two options: undergo major, irreversible spinal surgery to insert two titanium rods, or try to prevent progression by wearing a plastic back brace for 22 hours a day until my bones finished developing. My parents chose the brace, hoping to avoid surgery.

The process of being cast for the brace was incredibly difficult. Every 6 months, I was taken to Stanmore Orthopaedic Hospital, where male technicians applied wet plaster of Paris to my torso to create a mould. As a growing teenager, standing in my underwear, feeling exposed, was humiliating. The brace itself was uncomfortable, hot, and restrictive. It affected my confidence, my mobility, and my mental health.

What misconceptions do people have about scoliosis that you wish they understood?

Because I work hard to present myself well on stage and on camera, people often don't realise that I have scoliosis. I constantly adjust my posture to make my shoulders look even, and I avoid wearing backless outfits because I don't always like how my back looks on camera.

One of the biggest misconceptions is that scoliosis is just a minor inconvenience. In reality, it affects every aspect of my daily life. I am often confronted on public transport for not offering my seat to priority passengers, and I have had to show strangers my spinal X-rays just to justify why I physically cannot stand for long periods. The pain is real, but because it's invisible, people don't always believe it.

Crowded spaces also pose a challenge. I have to be mindful of being bumped or shoved, as even small bumps can trigger intense pain. Standing for concerts is unbearable unless I'm able to dance movement helps relieve some of the discomfort.

How does scoliosis affect you as a performer, especially when you're on stage?

Performing is physically demanding. Between carrying equipment, dancing in heels, and travelling with heavy suitcases, my body is constantly under pressure. To make things easier, I drive myself to most of my shows now—public transport with luggage is unbearable—but even driving aggravates my scoliosis, forcing my longer leg into further misalignment.

To manage the pain, I stretch constantly and often have to click my neck and back to relieve tension. The people who I work with are used to it by now, but I try not to talk about it too much—I never want anyone to assume I'm unfit for work. The truth is, pursuing a career in music while managing scoliosis, spondylitis, and ADHD requires incredible resilience.

I performed at the UK Glamour Awards, where I was asked what glamour meant to me. Without hesitation, I answered: 'Escapism.'

That moment was profound. I realised that music, performance, fashion, and even glamour have all been ways for me to mask pain and transform struggle into something beautiful. Growing up, my reality was hospital visits, spinal specialists,



four white walls, the smell of medical equipment, the sound of scanning machines—all of it. In that moment, I understood the depth of my own words: 'Every glamorous person is running from something ugly within.'

That night, I felt more connected to my audience than ever. How I hold people's hands, how we share that moment together. We were all there, running from something, yet healing together through joy and music. That's why I love what I do.

How has your scoliosis changed or evolved as you've become older?

Over the years, my scoliosis has progressed a lot. Between the ages of 13 and 29, my spinal curves worsened by 10 degrees. An X-ray 2 years ago revealed that I was just 5 degrees away from the threshold for urgent surgery. After consulting with specialists, I've been advised to avoid surgical intervention for as long as possible and focus on alternative methods of pain management.

To improve my quality of life, I am working toward relocating to a warmer climate. Heat helps to relax my muscles and alleviates much of the chronic pain caused by scoliosis and spondylosis (arthritis of the spine). My goal is to create an environment where I can manage my condition in the most natural and effective way possible.

One of my most effective forms of pain management is somatic breathwork. I highly recommend the somatic breathwork classes for both pain relief and nervous system regulation. The techniques have been incredibly helpful in managing the physical and emotional aspects of scoliosis.

What message would you give to people newly diagnosed with scoliosis?

Scoliosis can be your poison, your power, or your purpose—it's up to you to decide.

I know how overwhelming it feels at first. I was diagnosed at 13, and overnight my life changed. I suddenly had to wear a rigid plastic back brace for 22 hours a day, for 3 years. There was no time to process it; I was thrown into a reality where grief hit me all at once. I felt robbed of my teenage years the freedom to wear whatever I wanted, to blend in at parties, to move without restriction. I remember sitting on the sidelines in PE, watching the other kids run, thinking, 'Why me? Why couldn't it be someone else? Why do I have to struggle? Why can't I just be normal?'

The truth is, you will never be 'normal.' And that's not a bad thing. You were chosen for something greater. You have the power to turn this struggle into your strength, to lead with authenticity. It's up to you whether scoliosis becomes your secret weapon or your weakness.

I always knew I wanted to build a platform through music and use it to uplift others in the scoliosis community. Every time I put on that back brace something that made me feel so self-conscious—I would tell myself, 'One day, I'll create a fashion line for back brace wearers that makes us feel empowered instead of restricted.' That mindset shift is everything. You have to start believing that this is happening for you, not to you.

It's easy to feel defeated physically, mentally, and emotionally by scoliosis. But winners push through. They prioritise physical therapy, fitness, stretching, and mindfulness—even when it's tough. They work with what they have and find ways to improve their quality of life, even if it takes ten times the effort. If you allow the condition to consume you, it can lead you down a dark path. The choice to stay strong, flexible, and resilient is yours.

Invest in your well-being—whether that's physiotherapy, chiropractic care, massages, or movement that eases your pain. You may be a little bent, but you are far from broken. You have every right to stand tall—authentic, courageous,



unashamed, lionhearted, and limitless.

What are some of your goals for the future, both musically and personally?

Musically, my dream is to tour the world, performing in stadiums, major festivals, arenas, and renowned venues. I envision my original music being played across radio stations, television, advertisements, and retail spaces—reaching audiences everywhere. I also aspire to appear on popular TV shows, further sharing my artistry with the world. The possibilities are endless, and I'm excited for the journey ahead.

My ultimate life goal is to use my platform to validate and empower anyone facing an invisible battle, not just those with scoliosis. Growing up, I didn't have any idols who resonated with me as a young aspiring artist struggling with scoliosis. If I can be that person for someone else, I feel that I've fulfilled one of my life's purposes: to heal and make a difference in the world.

In my successful years, I've promised myself that I would raise awareness for scoliosis, not only to fund research for a non-surgical and permanent cure but also to empower those who suffer in silence, especially young, newly diagnosed teens. One of my dreams is to create a fashion line designed to make back braces more glamorous, so those who wear them can feel confident, rather than self-conscious.

Scoliosis is a highly isolating condition; we don't get "disabled badges," but we experience real challenges that can make everyday activities excruciating. Waiting in long lines, standing for long periods, or enduring cold weather can trigger agonising pain, leaving us struggling to walk the next day, which has a domino effect on our work and personal lives.

I want to give voice to this misunderstood and unseen community. I am committed to doing everything I can to raise awareness and bring positive change.

INTRAOPERATIVE NEUROMONITORING IN SCOLIOSIS

Who are we?

We work in the Spinal Cord Electrophysiology Group to deliver intraoperative neuromonitoring (IONM) during surgery for spinal conditions. The team in Sheffield has been providing and developing the IONM service for over 35 years. Adam started working in IONM 7 years ago, coming from a background of studying and training in neurosciences and audiology, whereas Chloe started working in IONM a few months ago.

Chloe was diagnosed with adolescent idiopathic scoliosis (AIS) at 17 years old and went through the entire spinal fusion process fairly quickly—which was actually done by the spinal team here at Sheffield Teaching Hospitals! The surgery was in 2018, and she joined the team at the end of 2024.

Why is intraoperative neuromonitoring important?

Undergoing spinal surgery can be daunting. Your consultant will discuss some of the potential risks, one of which may be paralysis. The operation involves inserting screws into the bones of the spine and manipulating its position to make it straighter, which can be risky.

IONM helps to reduce the risk of paralysis by warning the surgeon of potential damage to the spinal cord, which, for many patients—including myself back in 2018—is one of the most frightening conversations during pre-op appointments. Having a uniquely qualified team dedicated to preventing that major fear provided immense reassurance, and it is one of the reasons I am so passionate about the topic and about communicating that reassurance to other patients.

How does it work?

Your nervous system consists of your brain, spinal cord, and the nerves in the rest of your body. These nerves send sensory signals, such as heat and touch, up the spinal cord to the brain. Motor signals are triggered in a part of your brain called the motor cortex, and these signals travel down the spinal cord and along the nerves to the muscles in your body to enable movement.

We can generate motor and sensory signals by

using small, safe amounts of electricity to stimulate your nerves and brain. We then record the response at the other end. If it is a sensory signal, we stimulate your nerve and record from the brain or spinal cord. If it is a motor signal, we stimulate the motor cortex in your brain and record from your muscles.

We compare the signals recorded at the start of the operation with those recorded later in the procedure, informing the surgeon if we detect any important changes.

Does IONM make the operation safer?

Yes. Using IONM absolutely makes your operation safer. This is because if neurological deficits are detected, they can usually be reversed if action is taken within 20 minutes. A 2020 study in Edinburgh (Tsirikos et al.) in adolescent idiopathic scoliosis (AIS) patients found that while changes in responses were rare (0.84% of cases), 83% of the changes were reversible once detected. Thus, without an IONM team, these changes may not have been identified until after surgery, increasing the risk of paralysis. Having an IONM team also gives your surgeon greater confidence in the safety of your spinal cord.

IONM itself has been used for many years and is very low risk. We work closely with the anaesthetic and surgical teams to make it as safe as possible. In some cases, we may use only sensory or motor monitoring—for example, if a pre-existing neurological condition means we cannot obtain useful responses. In these circumstances, we will still do as much as possible to provide IONM that enhances the safety of the operation.

The one patient who had IONM changes that did not reverse regained movement and sensation to pre-operation levels within 3 months of the procedure.

Who does intraoperative neuromonitoring?

Most IONM for spinal surgery in the UK is carried out by healthcare scientists. There are many different specialisms within healthcare science. The main groups involved in IONM are:

• **Neurophysiologists**, who do various diagnostic tests to investigate the function of the nervous

system.

 Medical physicists, who bring expertise in recording electrical signals from the human body.

IONM teams may work within the NHS or for a private company. They are highly trained to monitor these signals and to collaborate closely with anaesthetists and surgeons, ensuring they are alerted to any important changes.

IONM is also used to improve the safety and efficacy of neurosurgical procedures.

What should you expect from your IONM team on the day?

You probably won't even notice we've been there since our whole job is done while you are asleep during surgery. From my own experience, I remember a few sticky marks on my legs from the stickers we use to hold the electrodes in place. We place multiple electrodes across various parts of your body to cover several different muscles. For scoliosis operations, we position electrodes on the legs, feet, and hands, as well as on the scalp and back of the neck. This allows us to monitor the entire spinal cord and different levels of nerves throughout the spine.

The small electrodes on your body are attached to our system, enabling us to observe all the motor and sensory responses from the stimulations on our computer screen. Some of these signals are extremely small (as little as a millionth of a volt), so a crucial part of our equipment is the amplifier. This device enhances the signal and removes as much noise contamination as possible, ensuring that the recorded signal is clear and of high quality for the session.

We communicate regularly with the surgeon so that we can check your responses at all the key stages of the surgery, such as when each screw is placed. Because the nervous system can sometimes take up to 20 minutes to show signs of a potential IONM issue, we continue monitoring even after the surgeon has finished correcting the scoliosis. The most important thing to remember is that we are there to make you safer as a patient and to reduce the risk of paralysis—a concern that many of us probably heard about during one of our pre-operative appointments.

Why do you choose to work in IONM?

Adam: I find the scientific aspects of IONM fascinating. A great deal of effort goes into ensuring we obtain high-quality, reliable signals, and there is something incredibly satisfying about recording such small electrical responses from the body to understand what is happening inside it. We also have a fantastic team here in Sheffield, and the process of working together to achieve the best outcome for the patient is extremely rewarding.

Chloe: I love being able to apply my scientific skills in an environment where I have been on both sides. Combining my education with my personal experience of scoliosis and surgery means I am always thinking of ways to improve things, and I'm incredibly fortunate to work with such a great team who really support and value that unique perspective in our development. The biggest piece of advice I would give is to ask questions. If you have any questions about IONM, your surgeon will be well informed to answer them, or they may go to your local IONM team for further guidance.

References

Tsirikos, A. I., Duckworth, A. D., Henderson, L. E., & Michaelson, C. (2020). Multimodal Intraoperative Spinal Cord Monitoring during Spinal Deformity Surgery: Efficacy, Diagnostic Characteristics, and Algorithm Development. Medical principles and practice : international journal of the Kuwait University, Health Science Centre, 29(1), 6–17. https://doi.org/10.1159/000501256



Figure 3. Adam and Chloe in surgical theatres.

ZOE'S STORY How Pilates changed my life with scoliosis

Zoe shares her inspiring journey of overcoming scoliosis challenges through Pilates and how it led to a new career helping others.

When I was 12 in 2013, my mum was adjusting one of my dresses when she noticed something unusual—although she pinned the dress in a straight line, it appeared wonky when I wore it. Confused, she took a closer look at my back and realised my spine wasn't straight; it was curved. Neither of us had heard of scoliosis before, and we had no idea that a curved spine was even possible.

After consulting our GP and having an X-ray, I was diagnosed with adolescent idiopathic scoliosis (AIS). My spine had an S-curve: a right thoracic curve measuring 30 degrees, and a smaller left lumbar curve. The consultant reassured us that my growth plates were nearly fused, meaning the curve wouldn't progress further. He said I wouldn't need surgery or monitoring, so we believed him and moved on. For 7 years, I didn't have another X-ray.

Fast forward to 2020. The pandemic forced me to complete my first year of university online. During this time, I started experiencing major discomfort in my neck. Every evening, it would feel extremely tight and painful. I began seeing an osteopath regularly, which helped a lot, but they suggested I get another X-ray.

By the end of 2020, I had another X-ray and a virtual consultation with a different specialist. To my shock, my scoliosis had worsened—my thoracic curve had increased to 40 degrees, and my lumbar curve had reached 30 degrees. I was now on the threshold for major spinal fusion surgery. The consultant didn't seem to understand why I was so upset, but mentally, I knew I couldn't go through with surgery. After making this clear, he finally mentioned another option—scoliosis-specific physiotherapy. Why he didn't start with this, I'll never know!

Since scoliosis-specific physiotherapy wasn't available on the NHS, I had to pay privately for treatment. In the summer of 2021, I completed an intensive physiotherapy course that changed my life. My physiotherapist helped me understand scoliosis, how it affected my muscles, and gave me the means to exercise safely and confidently. Before this, I had lived a sedentary lifestyle, unsure of what movements were safe for me. By the end



of the course, I had even grown a centimetre taller! My physiotherapist explained that reducing spinal curvature could lengthen the spine, making this increase possible. Although I was told I needed to do 30 minutes of physio every day for the rest of my life, I was relieved—anything was better than surgery.

A year later, I had another scan, and the results were incredible—my scoliosis had stabilised! There was no further progression, and my consultant officially discharged me. However, as university life became busier, I struggled with motivation and didn't keep up with my physiotherapy as consistently as I should have.

By July 2023, I had graduated and started working full-time at a charity. My job required commuting to London twice a week and sitting at a computer for long hours. Within months, my back pain returned with a vengeance. By October, I was in so much pain that I had to take 2 weeks off work. My entire back had seized up, from my neck down to my pelvis, and I experienced nerve pain in my ribs that sometimes left me unable to move my right arm. It was terrifying. Even though my scoliosis had stabilised, I was still on the threshold for surgery. I attempted to restart my physiotherapy routine, but my back was so tight that it felt counterproductive. Desperate for relief, I booked an appointment with an osteopath.

This osteopath was incredible. While the first few sessions were painful due to my extreme muscle tightness, she managed to greatly improve my back. She recommended I try Pilates, specifically a class designed for scoliosis. After some research, I found Curva Spine (formerly Build & Breathe Scoliosis) and attended my first class in October, 2023. Even after just 45 minutes, I felt a remarkable difference—my back felt looser, and I was more mobile.

At the same time, I realised my current job wasn't sustainable. I needed a career that wouldn't exacerbate my back issues. But what kind of job didn't involve hours of sitting at a desk? Then it hit me—what if I became a Pilates instructor? Not only would it benefit my own back, but I could also help others facing similar struggles. Within 3 months, I completed my Pilates instructor training and launched my own business.

My goal is to create accessible Pilates classes that cater to everyone, regardless of their experience or health conditions. I want people to prioritise their health and well-being, feeling empowered and strong in both mind and body. I've been teaching for nearly a year now and absolutely love it! I offer in-person and online classes, and I recently launched an online membership. Watching the my Pilates community grow has been so rewarding. A full-circle moment for me was joining the Curva Spine team, where I now teach a scoliosis-specific class once a week.

Pilates has transformed my life. My back pain has decreased greatly, and my scoliosis hardly affects me anymore. If I skip classes for a week, I quickly feel the difference. Because of Pilates, I can do things I love again, like travelling to see friends and attending concerts (I even made it to The Eras Tour last year!). I finally feel free to live my life without pain.

I want to help as many people as possible fall in love with movement and understand what works for their bodies. Scoliosis can make you feel restricted and uncertain about exercise, but you're not alone. You are stronger than you think, and you deserve to take care of yourself. Movement is for everyone—you just have to find what works for you!



Details of Zoe's classes can be provided by SSR on request.

LEAVING A GIFT IN YOUR WILL

Scoliosis Support and Research (SSR) is dedicated to promoting and funding highquality research into scoliosis and other spinal conditions, while also providing vital support and information to those affected. By leaving a gift in your Will, you can help us continue this important work for future generations.

Why make a will? A will ensures that your wishes are carried out after you die, helping to look after the people and causes that matter most to you. Without a Will, your estate will be distributed according to intestacy laws, which may not align with your intentions. Gifts to charities like SSR are exempt from Inheritance Tax and may reduce the overall tax burden on your estate. We strongly recommend consulting a solicitor to ensure your Will is legally sound.

What your gift will do - Leaving a legacy to SSR helps us to:

- Fund innovative research to improve scoliosis diagnosis and treatment.
- Provide trusted support and information to individuals and families.
- Raise awareness to ensure earlier diagnosis and better outcomes.

Ways to leave a legacy - You can leave a gift to SSR in one of the following ways:

- A share of your estate (residuary legacy): A percentage of your remaining estate after other gifts and expenses.
- A specific sum (pecuniary legacy): A fixed amount of money.
- A specific item: Such as property, shares, or valuables.

Suggested Wording for a share of your estate: I give [fraction/percentage] of the residue of my estate to Scoliosis Support and Research, Registered Charity No. 1181463, to be used for its general charitable purposes.

For a fixed sum: I give the sum of £[amount] to Scoliosis Support and Research, Registered Charity No. 1181463, for its general charitable purposes.

For a specific item: I give [description of item] to Scoliosis Support and Research, Registered Charity No. 1181463, for its general charitable purposes.



For more information, please contact us at:

info@ssr.org.uk

Your legacy can make a lasting difference for people affected by scoliosis. Thank you for your support.

CALL FOR **RESEARCH APPLICATIONS** Help us go 'BACK to Basics'

A t SSR, we are committed to funding innovative research into all aspects of scoliosis. Our mission is simple: to go BACK to Basics and identify a cause. We invite appropriately qualified professionals to apply for funding and contribute to this vital area of research.

Who can apply?

Applications are open to scientists, clinicians, and allied health professionals, including nurses, psychologists, and physiotherapists. International applicants are welcome, provided they collaborate with a UK-based centre.

Applications undergo an initial assessment by our Grants Committee before peer review. The final decision is approved by our Trustees. Decisions are typically reached within 3-4 months.

Before applying, we strongly encourage you to read the **SSR grant conditions** on our website. We also offer travel grants to support early career researchers in presenting their work at conferences.

Our funding programme includes three categories of research grants:

Small exploratory grant

- Aimed at new investigators developing preliminary research concepts.
- Maximum award: £15,000.
- Duration: Up to 1 year.
- No pilot data required, but the research should generate data to support future grant applications.

New investigation grant

- Targeted at new investigators initiating more substantial research.
- Maximum award: **£40,000**.
- Duration: Up to 2 years.
- Preliminary data is desirable but not essential.

Major research grant

- For experienced researchers undertaking significant spinal deformity research.
- Maximum award: £100,000 per year.
- Duration: **Up to 2 years**.

• Requires evidence of prior research experience, necessary resources, and preliminary data.

These grants aim to support outstanding and effective research that advances our understanding of scoliosis and spinal conditions.

For further details or to discuss your application, please contact us at **020 8964 1166** or **info@ssr. org.uk**.

Together, we can make a difference in the lives of those affected by scoliosis.





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