BACKBONE

Issue #4 | Winter 2025

CONTENTS

2025 - Our new era 3

Celebrating our fundraisers & donors 4

Ailie Harrison art competition 6

SSR research project: recently funded 8

The ABCD of scoliosis: help us spread the word 10

Pixie's scoliosis journey 11
By Carla Wells (Mum)

Managing emotions with pain 13
By David Craig and Katy Gordon

My life with scoliosis 16
By Doreen Burton

Living with scoliosis and osteoporosis 19
By Sarah Leyland

Q&A with Werkha 22

Zorab Symposium 2025 25

A journey of resilience and recovery 26
By David Clay

2025 – OUR NEW ERA

BY LESLEY MCGINTY, CHIEF EXECUTIVE

Welcome to this latest edition of Backbone.

I'd like to begin with the most important message of all: THANK YOU!

To every fundraiser, to everyone who made a donation, to every community member who attended our patient events, to all those who took time out to speak at our events – both regional and at our International Philip Zorab Symposium - and to everyone who has supported our campaigns this year—we are immensely grateful. This year has definitely been our year, and none of it would have been possible without the support of our amazing community.

My thanks must also go to my fantastic staff team, who have been inspirational in their innovation and commitment to their roles. We greatly appreciate the support of the Board of Trustees, led by our Chair, Ian Nelson, who has been a superb leader. We wish him well in his "retirement" and welcome Rebecca Weil as incoming Chair. Our patrons, HRH Princess Eugenie, and our founder Stephanie Clark, continue to be a strong supportive presence in our lives.

Reflecting on the past year, we've seen so many highlights. From Step for Scoliosis and Mindful March, to Embrace Your Curve, the Snowdon Climb, and our Scoliosis Awareness Month campaign built around the ABCD of Scoliosis. Each event, each story, and each person involved has played a vital part in driving awareness, raising funds, and strengthening our shared community.

In June, world renowned experts joined us for our International Philip Zorab Symposium in London to discuss research in the field of scoliosis. There is more about the IPZS later.

Two of our most recent projects have felt particularly special. Firstly, our Back to School campaign introduced something entirely new: our very first children's book about scoliosis, Phoebe & Her Spine. Every copy sold supports the creation of resources for schools, helping us reach young people, promote early detection, and ensure scoliosis is better understood. Thank you to everyone who has purchased and shared the book so far—we hope this is only the beginning of a much bigger impact. If you haven't already, you can support this work by buying and sharing the book (available on our website)—every purchase makes a difference.

Secondly, we recently launched our scoliosis

Our amazing documentary short cast

documentary short. To those who joined us at the premiere in London, and to everyone who has since watched, shared, or offered feedback—thank you. This project was born out of a desire not only to raise vital awareness, but also to create a resource for those who are newly diagnosed. By bringing together a range of voices and experiences, we wanted to reflect the diversity of scoliosis, and to show that no two journeys are the same. Our hope is that the film becomes an enduring means of support, empathy, and understanding. We'd love for you to continue sharing the film far and wide so it can reach and support as many people as possible.

Looking ahead, our mission remains clear: to support, to inform, and to keep building a community where every person affected by scoliosis feels seen and understood as well as funding innovative research projects. Together, with your continued involvement and support, we can achieve even more.

So, as you read through this edition of Backbone, please join me in celebrating the progress our charity has made this year, and I hope you will join us in the journey that lies ahead.

Thank you, once again, for being part of our story.

CELEBRATING OUR FUNDRAISERS & DONORS

Every year we are blown away by the creativity, generosity, and determination of the SSR community — and 2025 has been no exception. From mountain climbs to quiz nights to epic physical challenges, you've all found brilliant ways to raise awareness and funds for scoliosis.

While the big events often grab the headlines, it's just as important to celebrate the quieter heroes — the individuals and families who put in time, energy, and love behind the scenes. Whether it's organising a local fundraiser, giving up birthday presents in exchange for donations, or setting up a monthly gift, these acts of kindness and commitment have an enormous impact on our work.

This year, we've seen school students, sports teams, families, and friends come together to champion our cause in ways both fun and inventive. Each effort, no matter the size, moves us closer to making life better for people with scoliosis — and every pound raised helps fund research, resources, and support for those who need it most.

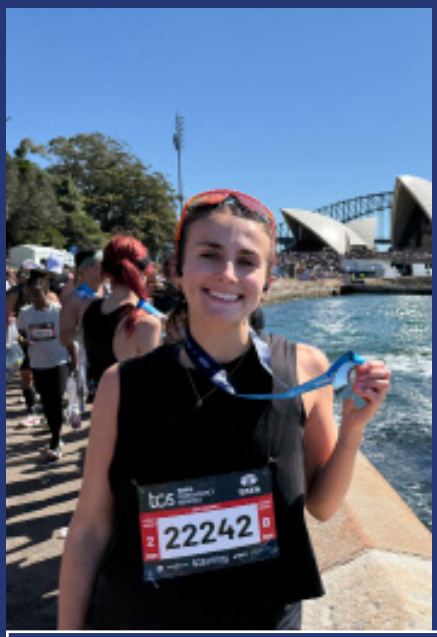
To every fundraiser and donor: thank you. Your generosity keeps SSR moving forward, and we couldn't do it without you.

Maisie Avis - 10 mile walk

Laura & Maisie - Caledonia Park 5k

Jo Rouse - Ultra Race 55km

Shona Keane - Sky Dive



Jessica Maclean
- Syndey Marathon Challenge

Alexandra Shirley
- Half Marathon

Leah Masterson - Walk, jog & swim 64 miles

Wayne Ingram
- Proceeds from Wayne's powerful book are supporting SSR

Jason Spicer - 5k a day

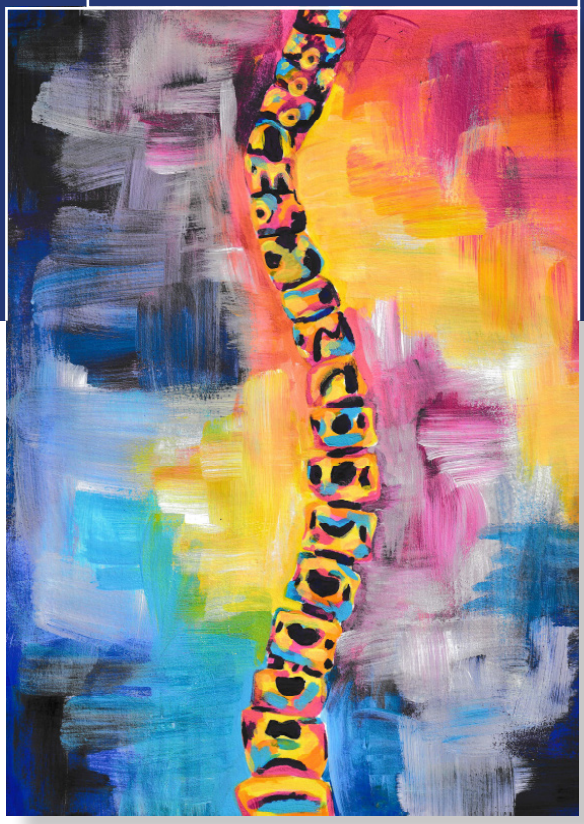
Rachel Davis - Half Marathon

AILIE HARRISON ART COMPETITION

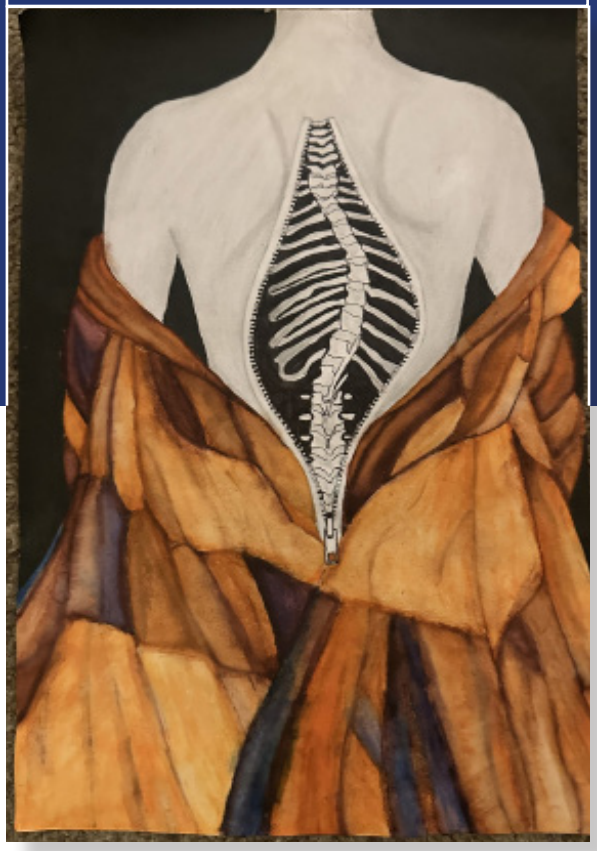
Thank you so much to everybody who submitted an entry to the Ailie Harrison Art Competition. We have had some incredibly unique, creative, and personal entries and picking a winner was extremely difficult.

Please see our 3 winners below:

1st Place - Lily Bass - Age 16.



2nd Place - Daisy York - Age 15



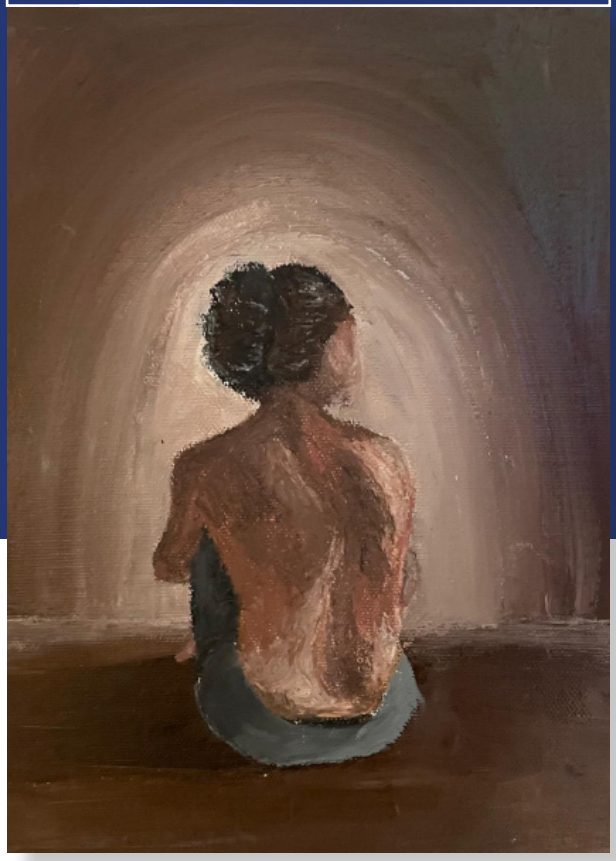
3rd Place - Samantha Bye - Age 27

And our runners up / honourable mentions:

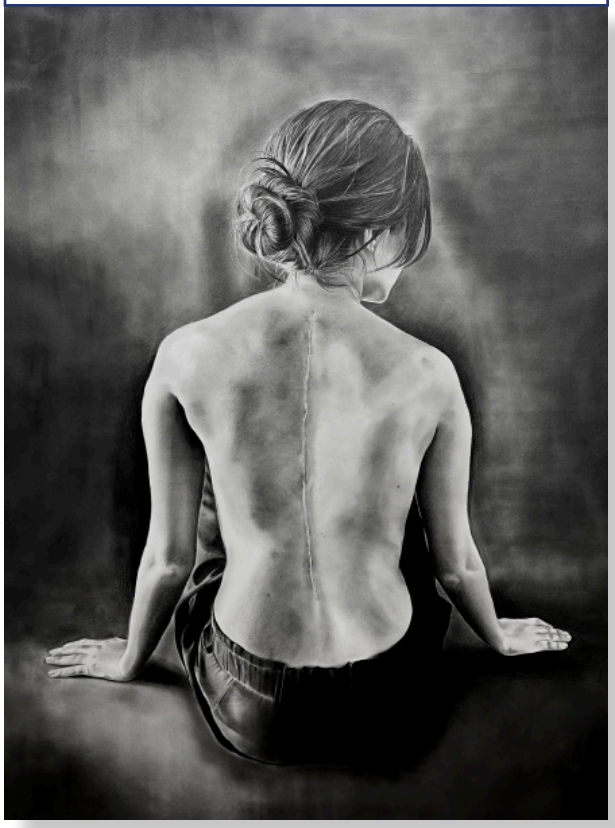
Runner Up - Georgina Rainey - Age 18

Runner Up - Megan Butcher - Age 19

Runner Up - Hannah Meyer - Age 16



Runner Up - Nandini Kotawala - Age 21



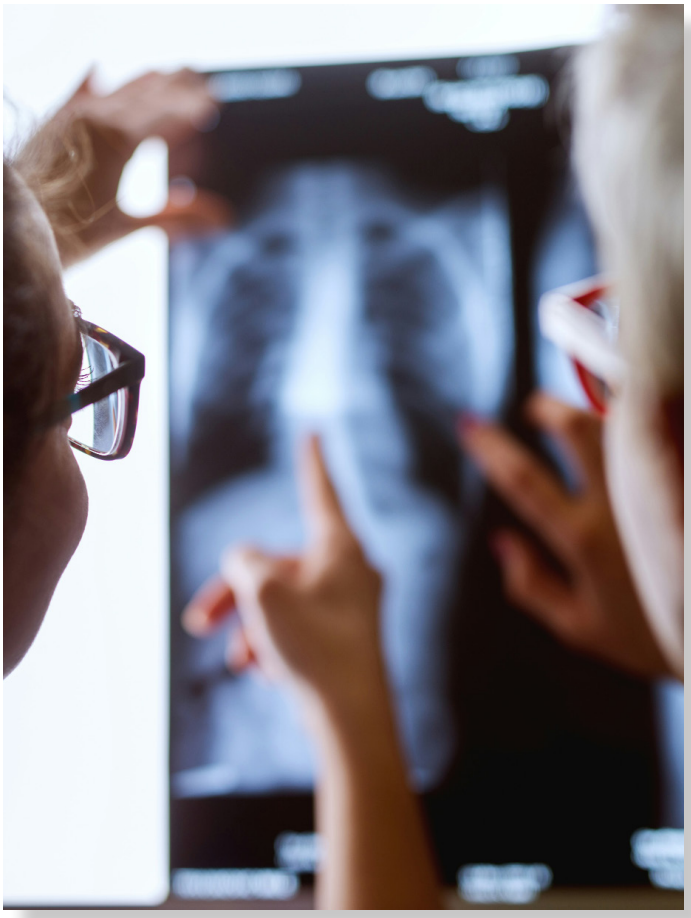
SSR RESEARCH PROJECTS

RECENTLY FUNDED

At Scoliosis Support & Research, one of our core aims is to help uncover more about scoliosis — from its causes and how normal spinal growth becomes disrupted, to the ways it can be detected and monitored, as well as the short and long term effects of the condition and its treatments.

When deciding which projects to fund, one of the main criteria we use is the Priority Setting Partnership, based on feedback from patients and supported by the James Lind Alliance. This was first published in 2018 and featured in a previous edition of *Backbone*.

Here are some of the exciting projects that SSR has recently funded, many of which are already underway or have been completed:



Scoliosis severity and its effect on walking

It is known that severe scoliosis can affect walking. This project aims to study the relationship between the severity of spinal curves and the extent of walking (also known as gait) disturbance, as well as how surgical treatment may improve or alter this problem.

In the study, patients were assessed while walking across a platform fitted with sensors to measure the size and direction of forces. SSR first approved funding for this project in 2018, but progress was delayed due to challenges with patient recruitment during the pandemic, followed by the closure of Stafford University's biomechanics department. The work has now resumed at the University of Dundee.

Art-based research on the impact of adolescent idiopathic scoliosis

This unusual but important project uses art to explore the impact of scoliosis on patients. Initially met with hesitation, the project was ultimately funded after the committee recognised its value in helping health professionals, patients, and the wider public gain new perspectives on scoliosis and its treatment options.

A grant of £38,759.73 was awarded to Birmingham University. The project has since been published in *BMJ Medical Humanities* and *The Lancet Child & Adolescent Health*, and the artwork is set to be exhibited at the IKON Gallery, Birmingham.

Thoracic vertebral shape in scoliosis

Exeter University was awarded £39,948 to develop a new way of describing how individual vertebrae become deformed within scoliosis curves. This method could help predict how scoliosis might progress, supporting decisions around surgery or bracing.

The research was awarded first prize at the 2024 British Scoliosis Society meeting, and has been submitted for publication in *Scientific Reports.*

Metal wear and failure of magnetically operated scoliosis rods

Magnetically controlled growing rods, introduced in 2009, allow surgeons to adjust spinal rods non-invasively as a child grows. However, experience has shown that the expansion mechanism often fails due to metal wear.

A grant of £14,456 was awarded to Newcastle University to measure the amount of wear debris in failed rods. This study is important to determine whether the debris could be harmful. The project has been completed, presented at an international meeting, and submitted to the *Journal of Engineering in Medicine.*

Scoliosis core outcome set

Assessment of treatment outcomes in scoliosis is complex, particularly because many young patients initially have no pain, disability, or noticeable cosmetic issues. Standardised questionnaires are widely used, but the most common one is increasingly seen as inadequate.

A grant was awarded to Queen's University, Belfast to develop a new, improved outcome set. The work has been completed and submitted to *Bone & Joint Open.*

Predicting brace treatment compliance

Braces can help avoid surgery, but wearing them is often difficult for patients. Non-compliance can mean wasted time and worsening scoliosis.

Sheffield University received funding to identify the factors influencing brace compliance, and developed a 'brace adherence prediction questionnaire.' The findings were presented at an international scoliosis meeting earlier this year.

Full-time versus night-time bracing

Also led by Sheffield University, this study is investigating whether full-time bracing (23 hours a day) is more effective than wearing a brace only at night. This project is still in progress.

Gait stability in scoliosis

Research has shown that scoliosis can disturb gait. This project, supported by a grant to University College London, investigated whether gait changes measured by specialist equipment could correlate with scoliosis severity.

The results showed a clear relationship. Whether this approach could become a simple, practical alternative to X-rays needs to be established.

Trunk shape in scoliosis

The asymmetrical appearance of the trunk is one of the most visible effects of scoliosis. New 3D imaging technology now makes it possible to capture these changes more easily and potentially track scoliosis progression without repeated X-rays.

A team at Teesside University received funding to compare 3D imaging with X-ray findings as curves change over time. The project is about to begin.

Intervertebral disc stiffness in scoliosis

Stiffness in spinal discs is a feature of progressive scoliosis. Earlier ultrasound-based methods of measuring stiffness were not reliable enough to predict progression, but a newly adapted technique could be more accurate.

A grant of £113,542 was awarded to the biomechanics department, now based at the University of Dundee, to explore this issue. The research could greatly improve decision-making for young patients with small spinal curves.

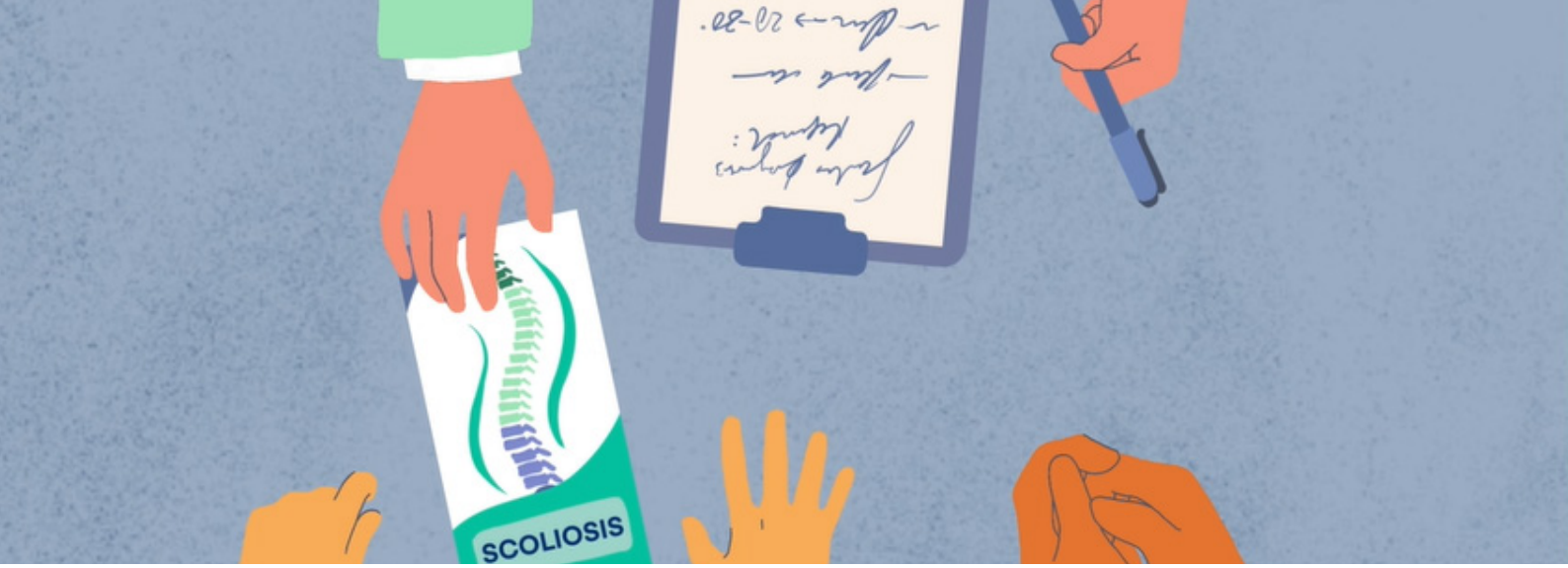
Decision-making in scoliosis surgery for adults

Scoliosis is more common in people over 60 than in young people, but outcomes of surgery in older patients are less predictable. Many surgeons avoid operating beyond a certain age, yet patients often request surgery because of severe symptoms.

This project, funded with £77,031 and led by Aston University, is studying the decision-making process in patients over age 55 across three UK scoliosis centres, with the aim of making recommendations for improved approaches.

Looking ahead

These projects highlight the breadth and depth of SSR's research funding — from biomechanics to patient experience, and from childhood to adulthood. By supporting this wide range of studies, we hope to create a future where scoliosis can be better understood, more effectively treated, and ultimately easier to live with.



THE ABCD OF SCOLIOSIS

Spreading a life-saving message

By Will Thommes, Fundraising & Communications Manager

Early detection can make all the difference for people living with scoliosis. With this in mind, we are proud to continue highlighting the ABCD of Scoliosis, a simple yet powerful way to recognise the early signs of the condition. Originally launched during Scoliosis Awareness Month, the ABCD campaign remains a central part of our ongoing work to support families, schools, and communities to spot scoliosis early.

The ABCD method is easy to remember, and easy to use:

- **A – Asymmetry**: Notice uneven shoulders, hips, or waist.
- **B – Bend Forward**: Look for rib or back bulges when bending.
- **C – Check for Curve**: Spot any abnormal spinal curvature.
- **D – Diagnosis**: Confirmed by a specialist X-ray.

Scoliosis causes an abnormal curve and twist of the spine, affecting people of all ages, but most commonly young people. By spotting it early, treatments can be less invasive, recovery can be better, and the overall quality of life can improve. According to the NHS, three to four out of every 1,000 children will require specialist care for scoliosis, making awareness and early intervention truly vital.

To bring the ABCD method to life, we created a concise animated video featuring social media influencer and scoliosis advocate, Grace Tutty. Grace, 23, from Surrey, knows scoliosis first hand. Diagnosed in Year 7 after her mother noticed a change in her posture, she underwent two major operations to correct a life-threatening spinal curve. Today, she uses her platform to support, educate, and empower others.

Grace says:
"I'm so happy to be involved in this campaign to raise awareness for early detection of scoliosis. I hope this campaign opens up conversations about scoliosis and the benefits of catching it before it progresses. So many of my followers suffer in silence with scoliosis, and the more awareness we can give the condition, the better."

We want to extend a heartfelt thank you to Grace for lending her voice and experience to this campaign. Her involvement ensures the message reaches a wide and diverse audience, helping families and communities to recognise scoliosis early.

Mr Sudarshan Munigangaiah, Consultant Orthopaedic and Spine Surgeon, adds:
"The number of children and adolescents presenting with large scoliosis curves to hospital in the UK is increasing. Our eyes don't see what our mind doesn't know. This is where the ABCD of Scoliosis comes in handy."

To support the campaign, we've also created a free ABCD of Scoliosis poster. Perfect for schools, clinics, community centres, or your home, it's a practical way to help spread this life-saving message. You can download, print, and share it widely, helping us reach as many people as possible and encourage timely detection.

Together, with your support, we can make sure early detection becomes the norm rather than the exception, giving young people the best chance for effective treatment and support.

PIXIE'S SCOLIOSIS JOURNEY

Strength, determination, and hope

At Scoliosis Support & Research we are dedicated to supporting children and families navigating scoliosis. Every journey is unique, and we are honoured to share the inspiring story of Pixie—a young girl whose resilience and determination continue to inspire those around her. Below, her mother, Carla Wells, shares their family's experience.

When Pixie was 11 years old, I noticed something unusual during a bridesmaid dress fitting—her shoulder blade was sticking out. Concerned, I took her to the doctor, only to be told that the asymmetry was probably due to her active lifestyle playing netball. Unsatisfied with this explanation, I sought a second opinion from a physiotherapist friend, who quickly identified the real cause: Pixie had scoliosis.

With a referral in hand, we returned to the doctor, and X-rays confirmed a 44-degree spinal curve. The consultant recommended a back brace, explaining that while it wouldn't straighten her spine, it could help prevent further progression. Pixie was fitted for her brace and chose a pink design—a small but meaningful choice that made the experience a little brighter. She playfully teased me about what I would have chosen—a multi-coloured leopard print!

Adjusting to the brace wasn't easy. In an effort to help, Pixie's Grandad and I went to IKEA to buy different types of pillows, hoping to find one that would provide the best comfort. At first, I had to cut up makeup pads to place in areas where the brace caused discomfort, but within weeks, Pixie adapted and was sleeping soundly without them. Wearing the brace in public was another challenge. On her first shopping trip with it, Pixie fainted due to the heat and the strain of adjusting to being in a brace. This experience led us to introduce a gradual schedule, allowing Pixie to build up to wearing it for the recommended 19 hours per day. Within 2 weeks, she had reached her goal.

3 months later, a follow-up X-ray brought incredible news—the brace had already helped correct her spine by 10 degrees. After 9 months, another out-of-brace X-ray showed further improvement, reducing the curve to 35 degrees. Seeing these results motivated Pixie to continue wearing the brace with dedication.

When Pixie reached the 1-year milestone, we celebrated her hard work with a cake that displayed the total hours she had worn her brace, along with cupcakes decorated with photos of her braces. We also surprised her with a balloon to show how proud we were. As a fun incentive, her dad and I had promised her £1 for each day she met her brace-wearing target. By the end of the year, we owed her £365—a testament to her

unwavering commitment!

Pixie has now worn her brace for over a year and remains as determined as ever. She ensures she reaches her daily hours and adjusts for special occasions by making up the time elsewhere. To help friends and family understand her journey, she created an Instagram page where she shares updates and raises awareness about scoliosis.

The local physiotherapy team has also played a crucial role in her journey, setting regular challenges to strengthen her back muscles. The kindness and support from medical professionals have made a great difference, as has connecting with another family going through a similar experience.

Despite her diagnosis, Pixie continues to thrive in netball. On Scoliosis Awareness Day, her teammates showed their support by wearing green wristbands and ribbons during a tournament—where they finished in second place! Recently, Pixie even trialled for her county netball training squad and was selected.

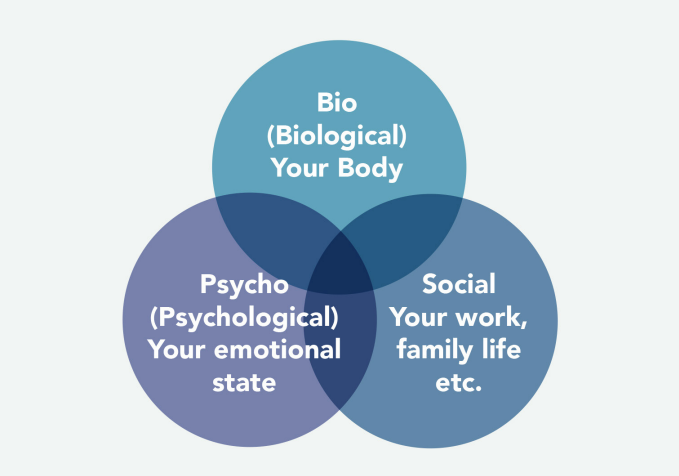
In addition to netball, Pixie remains active and recently completed her first 5K park run. Her resilience and determination shine through in everything she does. I gifted her a sign that reads, "Tell me that I can't, and I will show you that I can." It perfectly encapsulates Pixie's spirit.

While the future remains uncertain, and surgery may be a possibility, Pixie is giving this journey her all. No matter what happens, she will always know that she did her absolute best—and that is more than enough.

By Carla Wells (Pixie's Mum)

MANAGING EMOTIONS WITH PAIN

A special contribution from **Pain Concern**, offering guidance and support for managing emotions alongside pain



Here we help you think about how chronic pain can give rise to difficult feelings and thoughts. We'll look at how this can affect your life and how to address these emotional effects of pain.

Chronic pain can greatly affect day-to-day life – relationships, daily activities, sleep, employment, and all aspects of general health. These changes cause emotional strain on top of the pain. Many people experience a 'vicious cycle' that can make pain harder to deal with.

To think about how pain gets mixed up with emotions and the other things going on in our lives, healthcare professionals use what's called a 'bio-psycho-social' model, as shown above.

The bio-psycho-social model recognises that all three areas interact in our overall experience of pain.

Here we'll focus on the emotional part of the pain experience. Without always having a clear picture of the cause of the pain or a recognisable diagnosis it can be difficult to consider the emotional side of pain without thinking 'so is it all in my mind?'

'They said it was "all in my head"'

Commonly, people with pain feel they have been told that pain is imagined, psychological, or all in their head. This in itself can be very upsetting. We asked a GP why people might leave the consultation room feeling this way:

One GP said "GPs ask patients about how they're feeling or how life is because we recognise pain can be affected by these factors, not that they're the main cause. The skill we have to develop is reassuring them that we're looking at all the factors behind their pain, and it's not that we think they're mad."

You might leave your consultation wondering:

- Why do they want to talk about how I am feeling?
- Why are they asking me about my life?
- Why won't they focus on my pain?

Thinking about the bio-psycho-social model of pain helps to explain this – healthcare professionals ask these questions to get as full a picture as possible.

Another GP said: "Knowing where they are in life, what their family situation is, other things that are going on in the family, what they might be worried about, how they feel they have to limit themselves or push themselves - you need to have that discussion with them."

It does not mean the GP is not interested in the

physical aspects of your condition. Looking at the full picture of your pain and how it affects you (including your emotional wellbeing) could mean that they are better able to help you manage the whole experience, putting together the different parts of the jigsaw.

How might chronic pain make me feel?

There is no 'one-size-fits-all' answer. Emotions and thoughts differ from one person to the next and over time. What we do know is that the emotional effect can be long lasting and overwhelming, partly because of changes to the brain caused by chronic pain. We spoke to a wide range of people with pain about some of the negative feelings and thoughts that they have experienced:

So I get the idea pain can affect my mood – so what?

People in pain often talk about 'carrying on regardless' or 'pushing through' and may feel that ignoring difficult emotions is the best approach. However, recognising some of the negative feelings and thoughts you may experience can be helpful in managing your pain in the long term, as well as reducing some of the suffering it can cause.

Managing your emotions

The close links between the centres of pain and emotion in the brain make it almost impossible to have pain without having negative emotions as well. Recognising the emotional impact of chronic pain can be a first step towards being able to manage both pain and emotions better and might include becoming more aware of how you are feeling in the first instance. Becoming gradually more active, eating well, developing some better sleep routine strategies, and planning for flare-ups can all help manage the emotional side of the pain.

People have found the following messages helpful in managing their emotions.

1. DON'T STOP DOING THINGS. ACTIVITY CAN PROVIDE PLEASURE AND A SENSE OF ACHIEVEMENT, EVEN WITH PAIN

When you are feeling low you might not feel motivated to do the things that you usually enjoy, like spending time with family and friends and other social activities. However, avoiding enjoyable things can further entrench negative feelings. Try to keep doing the things you enjoy and spending time with the people you care about, however discouraged you feel.

2. TAKE A STEP BACK

When we feel low, we can often get caught up in believing a range of very negative aspects of our situation, the future, or ourselves. Taking a step back to observe what you're feeling and what you're saying to yourself can often be helpful. We can see things more clearly from a distance sometimes.

3. GIVE YOURSELF CREDIT FOR WHAT YOU HAVE DONE

Day-to-day activities and responsibilities become hard to fulfil when living with pain. It's important to recognise what you ARE doing. No one can do everything every day.

Acknowledge whatever you've managed to achieve despite the pain. On your worst days try to find even very small things in the day that will give you a little bit of pleasure, or give you a small sense of achievement.

Instead of keeping a pain diary, what about making time each day to write in a journal for 'My Achievements'. Make sure you give yourself the credit you deserve.

4. IDENTIFY TRIGGERS AND LEARN TO MANAGE THEM

Very often the same patterns make us come unstuck. Look at what led up to the way you are feeling. Is there something (not necessarily the pain itself) that always triggers stress, upset, etc.?

How you react to situations and what you say to yourself can trigger upset in the same way as the pain can. Is there a way to become more aware of the triggers so you can make a choice about how to respond?

5. WATCH OUT FOR HOW THOUGHTS AFFECT YOUR STATE OF MIND. BE KIND TO YOURSELF!

Be aware of any tendency to judge yourself or your situation, or to assume that the outcome will be for the worse or that others think badly of you. When in pain you may have a tendency to criticise yourself.

Simply becoming more aware of what you are saying to yourself can be helpful. It allows you to step back and see thoughts for what they are – just thoughts.

Could you learn to give yourself the support you would give to a close friend? Recognise and celebrate even small successes, gently encouraging yourself when the going gets tough.

6. IT'S OK TO ASK FOR HELP AND ACCEPT IT WHEN IT'S OFFERED

To manage the intensity of pain we need a team of people around us who we can call on for support – family, friends, colleagues, or neighbours. Who could you turn to on a really bad day?

If your mood is very low or you feel very anxious or frustrated, don't expect to manage all that and your pain by yourself. Speak to your GP or try a support group for people in pain in your local area.

Improving your mood is not a cure for chronic pain. Managing thoughts and feelings can be difficult and you may have to work on it for a while before you see any benefits. However, eventually, feeling more positive may reduce the pain and the amount of suffering associated with it.

'Barriers to Self-Management of Chronic Pain in Primary Care' (British Journal of General Practice, 2017) and contributed to 'Communication and Relationship Building with People in Pain' (Core Standards for Pain Management Services, 2021).

David Craig
Dr Craig is a Consultant Psychologist at NHS Greater Glasgow and Clyde. He has over 20 years' experience working in chronic pain services and leads NHS Greater Glasgow and Clyde's community Pain Education Sessions.

Katy Gordon
During her time as Pain Concern's research officer, Dr Gordon developed the award-winning Self-Management Navigator Tool. She is author of 'Barriers to Self-Management of Chronic Pain in Primary Care' (British Journal of General Practice, 2017) and contributed to 'Communication and Relationship Building with People in Pain' (Core Standards for Pain Management Services, 2021).

These articles are reprinted with kind permission of Pain Concern.

These articles were first published by Pain Concern in Pain Matters magazine.

Pain Matters is guest-edited by experts from around the UK and features articles from healthcare professionals and people living with pain. Subscribe here (https://pocketmags.com/pain-matters-magazine) for guidance on techniques for self-management and updates on the latest pain research.

DOREEN'S STORY

My life with scoliosis

At the heart of every individual's journey is a story of resilience, determination, and hope. In this piece, we share Doreen Burton's inspiring story, a woman who has faced the challenges of scoliosis with grace, optimism, and an unwavering commitment to living life to the fullest. Through her experience, Doreen offers a powerful reminder of how maintaining a positive outlook, embracing alternative therapies, and focusing on staying active can help overcome even the most difficult obstacles.

I was born in Reading, Berkshire, in October, 1948, and diagnosed with scoliosis at the age of 14, when I noticed my skirt hanging incorrectly because my hips did not align. My mother took me to the doctor, and I was given hospital appointments twice weekly to do various exercises. This inconvenienced me somewhat, as I had to leave school early, cycle, and walk 25 minutes home before catching a 15-minute bus ride to the hospital.

I grew 8 inches in height from age 11 to 15, and my mother was convinced that carrying a very heavy satchel on my right hip was the root cause of my curved spine. I saw an osteopath in my teens, who recommended I sit on half a cushion (to balance my hips), which I did for a while.

I grew eight inches in height from age 11 to 15, and my mother was convinced that carrying a very heavy satchel on my right hip was the root cause of my curved spine. I saw an osteopath in my teens, who recommended I sit on half a cushion (to balance my hips), which I did for a while.

Shortly after my 15th birthday, my mother slipped a disc in her neck and was in a plaster cast, then a collar. She went on holiday to Cliftonville and was recommended a local osteopath who, after her first visit, told her to throw away the collar. She literally skipped down the road and didn't look back. As a result, my mother decided to take me to the same osteopath, whom I visited on a number of occasions. He had previously been a doctor but chose not to pursue Western medicine and instead opted for alternative therapies. He also lectured in London and America. On one occasion, I attended one of his lectures, where he mentioned me and the "half cushion," which he firmly dismissed. Lo and behold, the osteopath who had originally recommended this form of treatment was actually in the audience! Rather embarrassing.

I began work at 16 in the Accounts Department for British Telecom, where, after just one week, I met my future husband, and we married 4 years later. Between the ages of 25 and 27, I had two miscarriages and, as a result, reduced my hours at work. By the age of 29, I had two lovely daughters and had no problems during both pregnancies, but subsequently my ribcage on the left-hand side began to protrude, possibly caused by the muscles weakening during the pregnancies.

At 30, I was offered an operation to correct my spine, which entailed lying on my back for 2 weeks, having my skull drilled into to attach traction equipment, followed by an operation down my back to insert rods, plus opening my front for further work. After this, I would have to endure a plaster cast for 6 months and a brace for 4 months. My two daughters were 6 months and 3 years old, and my husband worked full-time, so this was completely out of the question. My osteopath told me that my internal organs would need to

resettle and adjust, and if the knife slipped, I would be paralysed for life. His ethos was always, "The power that makes the body, heals the body."

I was fortunate enough to stay at home and look after my daughters. When my youngest was 7, I was invited to work at the children's primary school as a welfare officer, looking after a child with special needs. I still keep in touch with this child, who is now married with two children. I then helped more children, some of whom were completely illiterate, and taught them how to read.

Around the age of 40, I was watching a television programme in which a lady with crippling arthritis and very limited ability was being shown how to use a mini trampette. She began by holding onto a chair and was only able to move very slightly, but after continued use, her mobility dramatically improved. I immediately thought, "I'm getting one of those!" I have used it religiously for 10 minutes every morning for nearly 40 years (unbelievably, the original trampette!). I also used to hang from a support bar every day to try and help straighten my spine, and I was given traction equipment to use at home. My back would always ache if I was on my feet for too long, so I would do my best to take short rests whenever possible.

Sadly, I lost my father to lung cancer in 1987, and my mother subsequently passed away a few years later from melanoma. The following year, we moved to Devon. Unfortunately, there were no jobs available in any of the local schools, and I loved working with children, but I was lucky enough to secure a part-time job with a local insurance agent, where I stayed for 20 years.

In 1993, at age 44, my eldest daughter persuaded me to join the local tennis club. I was extremely reluctant at first, having not played for 25 years, but I was accepted as a member and went on to be treasurer for many years, chairperson for 7 years, and am currently president. I was also a league team captain for a few years and played regularly about 4 times a week.

Around 2012, my husband was diagnosed with Parkinson's, and he developed dementia 6 years later, and became incontinent. We eventually had carers twice a day. This was the one and only time my back became a physical problem and caused me undue distress because I was unable to meet my husband's night-time needs and care.

If I have to get up in the night, I often find mobility difficult, especially if I have been lying on my back. I am always very optimistic, laid-back, and positive, but as my husband deteriorated, my daughters sensed I was becoming less patient and more stressed and gave me their full support when I made the worst decision of my life—to move my

beloved into a local care home. I visited him every day without fail and sadly lost him at Christmas 2017. We were together for 53 years and married for 49 (sadly, just missing our golden wedding anniversary). After his passing, it was a case of sink or swim. I opted to swim, and although it hasn't always been plain sailing, around my 70th birthday (2018), I was diagnosed with breast cancer and underwent two operations and twelve sessions of radiotherapy. Also, a very close widowed friend was diagnosed with Alzheimer's, and as a result, I have dedicated a lot of time to helping her and providing ongoing support.

I retired at 61, joined the local University of the Third Age (U3A), and started learning bridge. I also undertook 10 years of voluntary work for Citizens Advice. This was an advisory position that involved face-to-face meetings, which I thoroughly enjoyed. Unfortunately, Covid resulted in many system changes that meant all client interaction was moved online/phone calls, and because of this practice, I made the decision not to return.

I am now 76, take no painkillers, and exercise for around 40 minutes every morning before breakfast, which involves bouncing on my

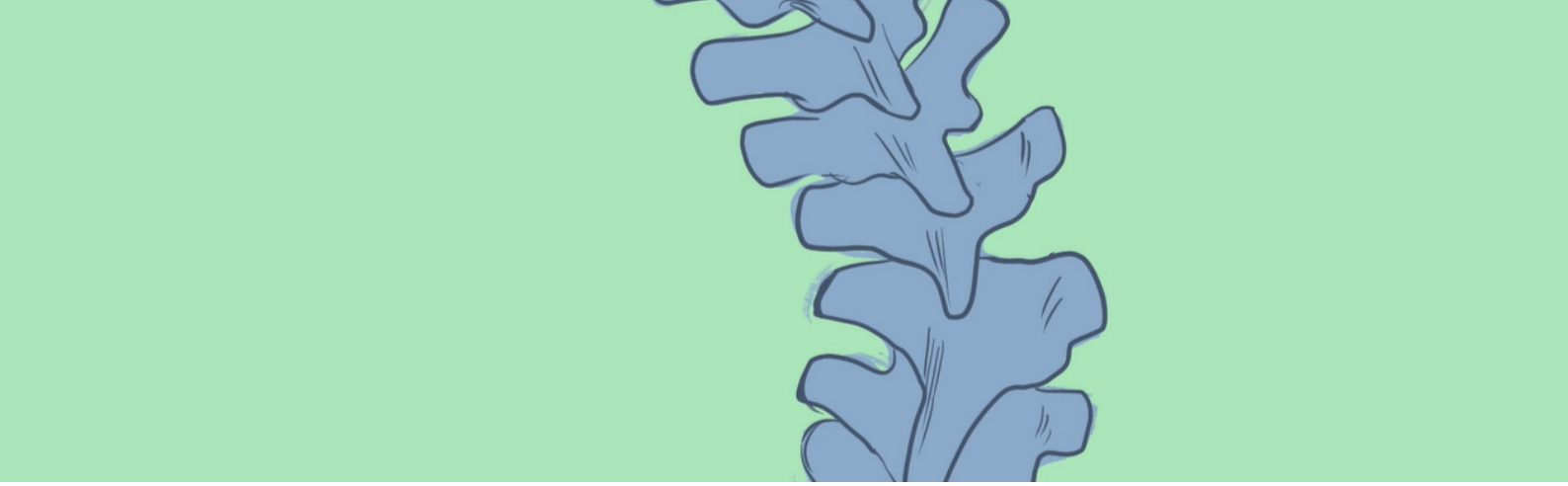
trampette, yoga, and 10 minutes on the exercise bike. I still play tennis a few times a month, walk my Springer Spaniel every day for about an hour, play bridge a few times a week, skittles once a week, and socialise regularly with family and friends. I also attend a weekly seated-yoga class with a very knowledgeable and highly skilled instructor, who has given us all a real insight into how our bodies function. I feel this will be especially useful when I can no longer do my usual floor exercises and require a chair instead.

I love and maintain my home and garden and still manage to work around 45 minutes before needing a rest. I see an osteopath every 3 months and have recently started reflexology. Since my teens, my height has reduced by around 4 inches. The only downside of my scoliosis (apart from having to rest regularly) is selecting suitable clothing to disguise my protrusion, and I now carry a small inflatable cushion for when I sit because I have a small bone protruding in my back. Fortunately, I am a capable seamstress (I made my own wedding dress) and can, therefore, alter many of my clothes.

My immune system seems very strong, and I rarely get ill and have never had flu. I sleep around 7 hours every night and maintain a healthy, balanced diet. I also take a variety of vitamins every day, including Chondroitin, MSM (methylsulphonylmethane), turmeric, omega 3, etc. I love life and live it to the fullest with a very positive outlook.

I assumed by now I would be on painkillers and possibly need the use of a wheelchair, but I strongly believe exercise, alternative therapies, and a positive outlook have prevented that, and thankfully I'm still able to look forward to the future.

Finally, my daughter, who I've been dictating this to, would just like to add that, apparently, I never complain, and every morning when she calls me about 8am, she asks me how I am, and I always reply with the same answer, 'I'm fine.'



Living with scoliosis and osteoporosis: FAQs answered

At Scoliosis Support & Research, more and more we hear from our community about people living with both scoliosis and osteoporosis. These two conditions often overlap, particularly later in life, yet the links between them can feel confusing. We wanted to provide a clear and reliable outline of what osteoporosis is, how it connects to scoliosis, and what it means for bone and spinal health.

We are grateful to the Royal Osteoporosis Society for contributing this expert piece, which we hope will help raise awareness and support our community in understanding both conditions more fully.

What is osteoporosis?

Osteoporosis is a condition where your bones become weaker and break more (fracture) easily, sometimes after a minor bump or fall – or even as the result of a cough, sneeze or hug if your bones are very weak.

These types of breaks caused by osteoporosis are referred to as 'fragility fractures'.

Who is affected by osteoporosis?

While typically associated with post-menopausal women, osteoporosis also affects men and younger people too. It's estimated that over 3.5 million people in the UK are currently living with the condition, with one in two women and one in five men over the age of 50 are expected to break a bone as a result.

What causes osteoporosis?

After reaching the age of 30, your bone density starts to decrease very gradually. This becomes more important for women who have gone through the menopause, as levels of oestrogen, the female sex hormone that helps keep bones strong, decrease.

There are risk factors that both men and women should consider, including having a family history of osteoporosis, or a linked health condition such as coeliac disease or rheumatoid arthritis. Smoking and not eating a healthy balanced diet can also increase your osteoporosis risk, while medications such as corticosteroids and some breast cancer or prostate cancer treatments can affect bone density too. It's important to speak to your doctor before making any changes to your medication.

What are the symptoms?

Osteoporosis is known as the 'silent condition' as it doesn't have any symptoms - it's the broken bones as a result of osteoporosis that cause pain, rather than the condition itself. Spinal fractures can also lead to height loss and a hunched spine, which can be a sign that someone has osteoporosis.

How is it diagnosed?

As a first step, you can complete the Great British Bone Check from the Royal Osteoporosis Society to find out if you may be at risk of osteoporosis. If your doctor thinks you might have the condition, they can refer you for a range of scans and tests, to help them find out if your bones have lost strength. There's no simple way to look inside your bones, but a combination of different tests can be used to build up a picture of your bone health, and your risk of breaking a bone. The most commonly used test is a DXA scan, which uses very low dose X-rays to measure the density of your bones.

What are the medicines used for osteoporosis?

You may be offered an osteoporosis medicine to help strengthen your bones if your risk of breaking a bone is increased.

Osteoporosis medicines can work by slowing down

cells that break down bone (osteoclasts) – known as 'antiresorptive' drugs, or by stimulating the cells that build new bone (osteoblasts) – known as 'anabolic' drugs. Some medicines work in both these ways.

What are the dangers of osteoporosis?

Osteoporosis as a condition is vastly under-diagnosed and therefore many people with an increased risk of breaking bones miss out on the medicines that can strengthen their bones. Spinal fractures are a common sign of the condition, and while sometimes people aren't even aware that they've suffered a spinal fracture, for others they cause debilitating back pain and height loss, making daily tasks once taken for granted suddenly impossible.

Another potential end result of osteoporosis can be a devastating hip fracture, which can completely shatter someone's life, sometimes causing loss of independent living and permanent disability. Sadly, it can sometimes result in people dying earlier because they never recover properly.

What lifestyle and diet measures should people introduce to prevent osteoporosis?

Lifestyle plays an important role in maintaining good bone health, and having a low body weight, smoking, and drinking too much alcohol are all risk factors that you can change.

Weight-bearing impact exercises (such as walking, jogging or racket sports) and muscle-strengthening exercises (such as lifting weights or using resistance bands) are a great way of keeping your bones strong too.

Eating a balanced diet with a wide variety of foods from each food group will usually ensure that you have all the nutrients needed to build and maintain healthy bones.

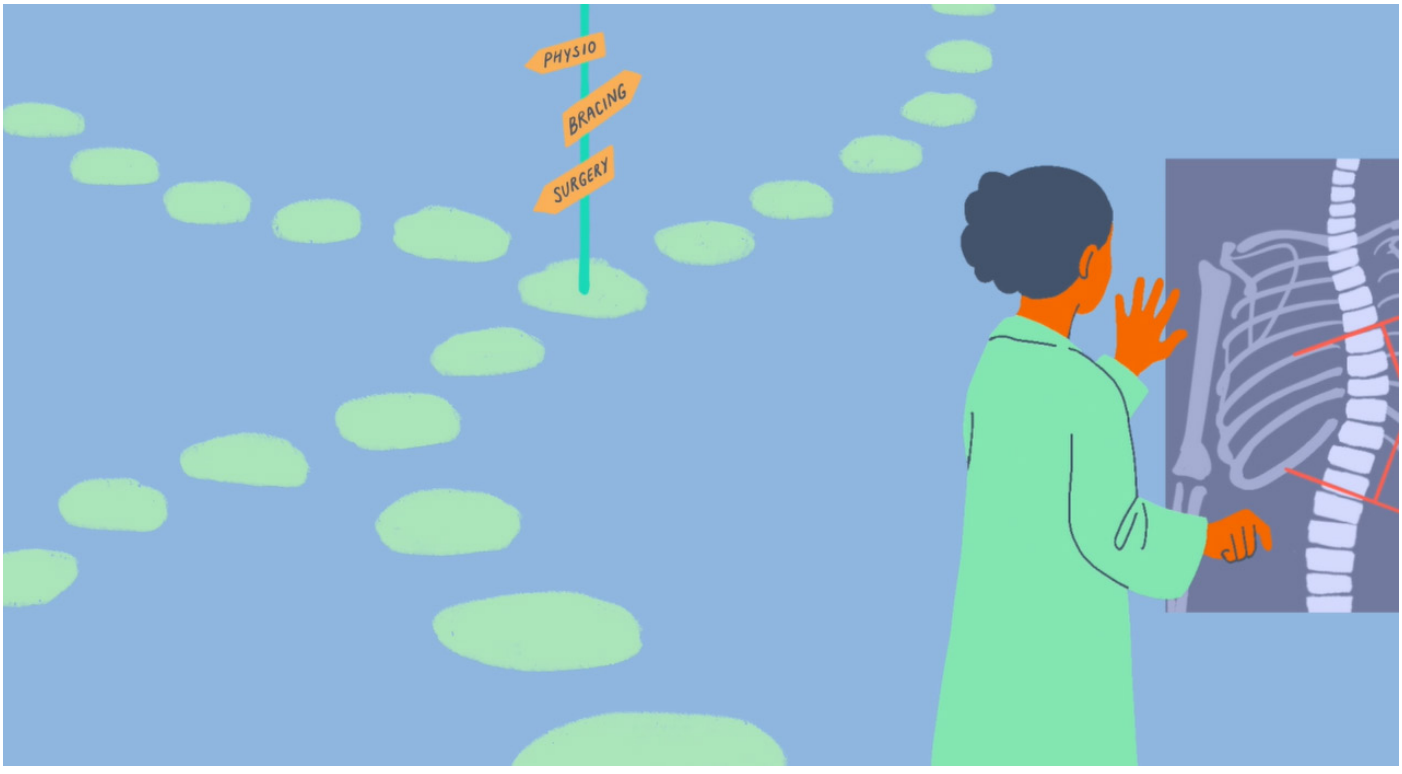
Vitamin D is important, since it helps your body to absorb calcium, which gives bones their strength. You can get vitamin D from safe sunlight exposure, although you should consider taking a daily supplement of 10mg (400 units) of vitamin D from the end of September to the beginning of April. Most adults need 700mg of calcium a day, although those at risk of osteoporosis may be advised by their doctor to increase their intake.

How can you help to manage the pain from broken bones?

If you've broken bones, you may be able to manage the pain with pain-relieving medications, depending on the severity of your pain and what's causing it. If you're experiencing persistent pain, talk to your healthcare team for advice and support.

There are also some practical steps you can take:

- Understand your pain and what triggers it
- Pace yourself by planning and prioritising your daily tasks
- Learn relaxation techniques
- Find something to distract you from the pain
- Some muscle-strengthing exercises can help with pain
- Together with your healthcare team, make a 'flare up plan', to help you cope through an



episode of pain
• Know who is there for you, if you need help – the Royal Osteoporosis Society has a network of support groups and an online community forum
• Be aware of how your mood can affect your pain levels

Other ways to help relieve pain, such as complementary therapies, hydrotherapy, or using a TENS machine, may also help.

Scoliosis-specific FAQ

What are the differences between the two conditions?

While scoliosis is either a condition you are born with or that develops during life, osteoporosis usually develops as a result of another condition or medication, or as part of the ageing process. It's a weakening of the bones, making them more likely to break. This can result in broken bones, especially of the wrist, hip, and spine.

Scoliosis means a sideways curve and twisting in the spine. In osteoporosis, the spinal fractures heal but the bones stay in a flattened or wedge shape, often causing an excessive outward curve in the spine (kyphosis). Though the fracture pain resolves, surrounding structures – muscles, ligaments, and nerves – are often affected by the changed spinal shape, resulting in long-term pain.

Where are the similarities between the two?

Osteoporosis and the type of scoliosis that develops during later life are what, in medical terms, are called 'degenerative skeletal' conditions. This means the normal processes in the body get out of balance, often as part of old age. This leads, for both scoliosis and osteoporosis, to changes in the shape and workings of the skeleton.

Both conditions affect the spine. Scoliosis, and spinal fractures with osteoporosis, can cause long-term pain as well as issues with body image, such as a loss of self-esteem because of postural changes.

Scoliosis and spinal fractures with osteoporosis vary enormously in the level of pain or other symptoms, both physical and emotional, they may cause. For some people there are minor changes that may even go unnoticed. For others, there are very serious pain and symptom problems that can affect quality of life.

Does osteoporosis cause scoliosis?

Not generally. In osteoporosis, weak bones can lead to spinal fractures, but it's the forward curve of the spine that becomes exaggerated – it isn't usual for the spine to become twisted or curve sideways, although it can happen if your spine is badly damaged by multiple fractures. People with an existing mild scoliosis may find it increases due to the changes caused by spinal fractures.

Does scoliosis cause osteoporosis?

No. Osteoporosis is an underlying weakening of bones. But it's possible that if bones are very weak because of osteoporosis and there's already a marked scoliosis, the uneven pressure on bones in the spine may increase the risk of them becoming more flattened or squashed down (spinal fractures).

How do I know if scoliosis or osteoporotic fractures are causing my back pain or other symptoms?

Your doctor or other healthcare professional will examine you and discuss your symptoms and medical history to diagnose what conditions you may have. An X-ray may be needed to find out what has happened to your spine, and you will be referred to a specialist for further advice or treatment if necessary.

Scoliosis and osteoporosis fractures in the spine can occur together. Further discussion and explanation after any investigations will help you to understand your own situation.

Knowing you have either scoliosis or spinal fractures can be helpful so you can understand and get any help or treatment you may need. Even if spinal fractures aren't causing troublesome symptoms, they can be an important sign that you have osteoporosis and may benefit from a medicine to strengthen your bones.

By Sarah Leyland (Osteoporosis Specialist Nurse Clinical Adviser, Royal Osteoporosis Society)

INTRODUCING WERKHA

Tom Leah, better known as Werkha, is a Manchester-based multi-instrumentalist, DJ, and producer whose work blends electronica, jazz, breaks, and acoustic textures. His latest album, Unsung Irregular—released on First Word Records—turns his personal experience with scoliosis into a deeply moving and sonically rich exploration of hidden conditions.

More than a reflection on chronic pain, the project celebrates movement, resilience, and the transformative power of music to turn discomfort into rhythm. With collaborations from Daudi Matsiko and Ríoghnach Connolly, the album captures both the intimate details of lived experience and the universal beauty of overcoming challenges.

We sat down with Werkha to discuss his journey with scoliosis, the creative process behind Unsung Irregular, and the ways music, movement, and nature continue to shape his life and artistry.

Can you share a bit about your journey with scoliosis and how it has shaped both your life and your identity as an artist?

My scoliosis was discovered after getting a strange football injury checked out and they realised I had a curved spine. After discussing my options, I declined corrective surgery – I think really because I was afraid of losing my mobility, something that is central to my lifestyle. Scoliosis has taught me a great deal about confronting physical conditions and not brushing them under the carpet, something I've definitely been guilty of in the past. This record is me doing exactly that – acknowledging scoliosis, putting the condition in front of me in a very public way, and ultimately changing the way I'm perceived.

Your album Unsung Irregular celebrates hidden conditions. What made you want to channel your scoliosis experience into music rather than speak about it more directly?

I think music is still a veiled way of presenting my experiences, so I still don't really have to speak about it directly. Everyone deals with the condition in their own way, the album is grounded in my own experiences, but it's open to interpretation – that's the advantage of not directly pinpointing or defining the message, it allows others to relate to the music in their own way. It's the beauty of interpreting a picture painted with sound.

You've spoken about disguising your own screams in the track S-Bend to represent pain. Was it difficult to bring something so personal and raw into your music?

I don't think so, it felt like it fitted the song and in turn, made it feel like the right thing to do. There's a lot of very personal meaning woven into the music, but I've always felt that if the sound complements the intention behind a song, then it brings a sense of 'completeness' to the process.

What do you think are the biggest misconceptions people have about hidden conditions like scoliosis?

I guess that we have an answer to the condition. It often feels like it's a question of form over feeling – that people see the physical effects but don't understand the pain and hidden impact that we deal with. The physical imbalance, constantly battling the feeling of being lopsided. I never realised how little scoliosis is talked about, yet how common it is – since working on this record and talking about it, it's changed the behaviour of people around me, they might ask me how I am or offer me a chair or the bed, when perhaps before I might have had the sofa. Little things, but impactful.

How do you manage the physical demands of performing live while navigating scoliosis?

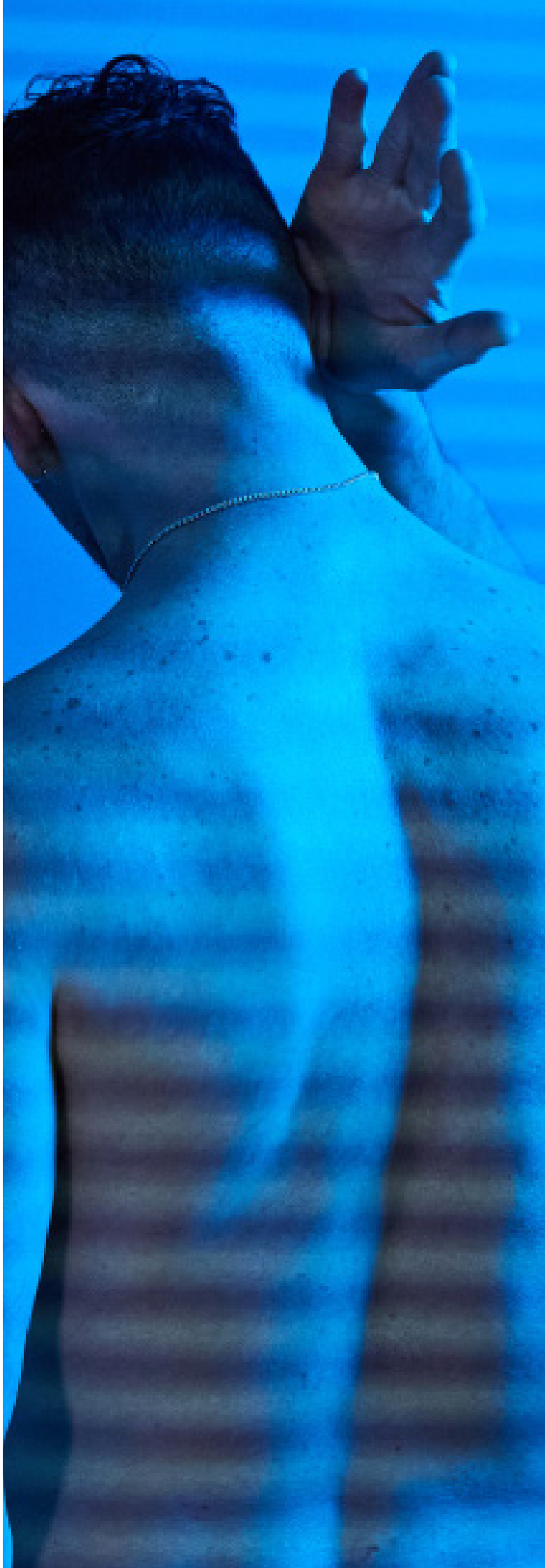
I love performing live – the adrenaline rush overcomes everything: tiredness, pain, aching. Music really is an escape, for both me and the audience. For the 45 minutes on stage, I'm pain-free, my body isn't even considering pain; that role of movement is central to both the album project and my life. When I don't move, that's when I feel a negative impact.

Unsung Irregular feels both deeply personal and universally resonant. What was the starting point for the album—did the theme or the sound come first?

I guess they're intertwined – Sastrugi was the first song I wrote for the album and the starting point for the broader theme. It was my first serious walk after a period of immobility; it was bitterly cold with snow blowing in the wind. It was difficult, but ultimately good to move. I tried to write some music that captured that feeling of timelessness, the word 'sastrugi' describes the shapes in the snow that the wind makes. The track was so important conceptually for the rest of the record, it came from a deliberately deep place, and wasn't really my normal style of music. There's a sense of bittersweet uncertainty in the song, knowing the joy of movement but not being sure if you're capable of it.

You've used geographical and natural references—like the Helm Wind in By Helm. Why was it important for you to weave the natural world into this project?

Being outside in nature has always been important to me; I'm a firm believer in the service that the natural world can give us in health. Being outside means we're moving – if we're moving, it's a positive effect, physically, culturally, and socially. When you're out walking with people you're not on



your phones, you're talking – seeking those green spaces for respite and recovery.

What role does movement and rhythm play in your healing process, both physically and creatively?

I guess rhythm represents and instructs the physicality of dancing or playing music – just feeling a beat makes you move. Rhythm plays a huge role in healing – it brings people together, to move and to socialise. I find a real comfort in that. Even recently, I've been on crutches so can't dance, but being at a party around a dancefloor was a recovery of sorts – feeding off other people's joy in movement. I get the same thing when performing – when you see people dancing, it's good for the mind and body.

Unsung Irregular gives a voice to those "fighting quiet battles." What effect do you hope this album has on listeners with their own hidden conditions?

I hope it inspires people to celebrate their own 'unsung irregularities'; I know these experiences aren't always happy, and it's important to acknowledge nuance and the dynamics of lived experiences, but there's something bold and beautiful in highlighting these 3D experiences. We have to make the best of what we've got, so I hope the record inspires people to confront themselves in their own way, and be comfortable enough to share that with others – something I wish I'd done sooner.

What excites you most about the next stage of your career as a musician, producer, and performer?

The versatility of who I work with and the ability to use different art forms and collaborations is really exciting to me. This project is about lifting the veil a bit, it's a deliberate record that pivots the conversation from movement to environment – something that really excites me. Those parallels between recovery of the self, of environment, and of culture – and how music feeds into all those. Tracks like Narrow In with Daudi Matsiko and Sastrugi are incredibly intentional – I'm aligning my unaligned body with some core beliefs that will feed into my next projects.

Finally, what message would you share with young people newly diagnosed with scoliosis, especially those with creative dreams?

Scoliosis hasn't stopped me. I understand it's the root of a lot of frustration, self-consciousness, self-loathing, and pain – that even sitting on a chair is irritating when both sides of your back don't touch it. But there's something beautiful in the physical form of a curved spine, it's interesting to look at and there's a creative pull from that which I try to apply in different ways. Physically, I'd encourage positive movements, even little ones, regularly. Address strength and mobility, don't ignore it – getting into a routine of stretching before football helped me balance the physical impacts of exercise, understanding that it would benefit me tomorrow.

ZORAB SYMPOSIUM 2025
A celebration of research and innovation

Every 2 to 3 years, Scoliosis Support and Research proudly hosts the internationally renowned Phillip Zorab Symposium, bringing together leading clinicians, researchers, and scientists to explore the latest developments in scoliosis. This June, our 18th symposium offered another inspiring opportunity to share knowledge, spark collaboration, and celebrate advancements in scoliosis care. The event continues the legacy of Dr Phillip Zorab, who dedicated his career to managing respiratory issues in severe scoliosis at the Royal Brompton Hospital and promoting research into the aetiology of idiopathic scoliosis.

Held at One Great George Street, Westminster, the 2-day event combined keynote lectures, paper sessions, debates, and opportunities to engage with cutting-edge research. Key presentations included insights into how human growth influences scoliosis behaviour, translating genetic discoveries into clinical practice, and the long-term consequences of missed or untreated scoliosis in adulthood. Emerging technologies were also showcased, from magnetically controlled growing rods to AI-supported treatment planning, highlighting the exciting innovations shaping the field.

Paper sessions explored topics ranging from brace effectiveness and adherence, to mechanical performance of spinal implants, and female-specific genetic factors for adolescent idiopathic scoliosis. Debates on scoliosis screening and the effectiveness of bracing encouraged lively discussion, ensuring that the latest evidence is critically examined and shared with the wider scoliosis community.

Importantly, the symposium also highlighted the patient perspective. Presentations from physiotherapists and our own SSR team illustrated the value of combining clinical research with lived experience, demonstrating how early intervention, holistic care, and community support can improve outcomes for people with scoliosis.

We would like to extend a heartfelt thank you to all our speakers, presenters, moderators, and delegates. Your expertise, dedication, and engagement ensure that the Zorab Symposium remains at the forefront of scoliosis research and clinical innovation.

DAVID'S STORY

A journey of resilience and recovery

At Scoliosis Support & Research, we are privileged to share the stories of people in our community who have lived through the challenges of scoliosis. Each story reflects not only the physical realities of the condition, but also the courage, determination, and resilience of those who face it. David Clay's journey began as a teenager in the 1970s and has taken him through surgery, recovery, and a career that has come full circle in the most remarkable way.

I am 63 years old, and I have lived with scoliosis since my teenage years. This is the story of how scoliosis shaped my life.

At 16, a deformity of my spine was noticed, although I was not aware of it. At that time (the mid-1970s) not many people had heard of scoliosis, and there followed many visits to GPs who suggested various exercises to attempt to straighten my spine. After several years, my spine rapidly degenerated, and I was finally referred to Harlow Wood Orthopaedic Hospital in North Nottinghamshire. This referral came through the determination of my parents alone, who had to endure the pain of seeing my condition worsen, only to be continually told the best thing to do was exercise.

Attempting pitch and putt in full plaster cast - 1980

I was fortunate with my consultant because he wasted no time in diagnosing severe scoliosis and confirming that I required surgery. This was late 1978, and there followed a wait for surgery, during which time I carried on pretty much as normal with my school life. I had two curves in my spine of 84 and 74 degrees respectively, and I was fitted with a Milwaukee brace, which I had to wear all day, but found too uncomfortable to wear at night.

I was given further exercises to do while I waited for an appointment. Then, on 5th April, 1979, I received a telegram at school asking me to attend hospital straight away as a slot had become available. I remember the day very well: it was cold and foggy, and I had to rush home from school, collect my things, and be driven to hospital by my dad. I was welcomed to Ward 3 at Harlow Wood Orthopaedic Hospital, the children's ward. At 17, I was the oldest patient there. It was a very welcoming place, and I was to spend the next few weeks lying in bed in traction to stretch my spine. Obviously, this was very boring for a teenager!

On a bright and sunny day in May, I was wheeled into theatre for my operation, which lasted for about 12 hours. I distinctly remember being woken up during the operation and asked to wriggle my toes. Apparently, this was to ensure there was no nerve damage, and I wriggled as hard as I could. I had a very large spinal fusion operation for the time, with Harrington rods inserted that went from my lower back all the way to my neck. Bone was shaved from my hips and used to fill in where the discs between my spinal segments had been. The only subsequent movement I would have would be in my neck.

The next thing I remember was waking up several days later in intensive care, surrounded by tubes and monitors. I remember a raging thirst and being told not to drink anything, but to suck on ice cubes. I was completely immobile, lying on my back.

After several days, I was transferred back to Ward 3 and heard the sounds of children playing around me. Unfortunately, I was not well because I had

developed an infection at the site of the rods. I went on to spend a further 3 months in an isolation room within the ward. I was constantly in pain and had to take an endless round of painkillers, including morphine, as well as intravenous antibiotics. The nursing staff were fantastic, and I grew to know each of them very well. By now it was high summer, and on sunny days the staff would push my bed outside into the shade of an awning, where I would lie without much awareness of where I was.

After many weeks, I started to feel better and was taken in my bed to a gymnasium, where I was taught to stand. This was a major triumph and one I will never forget. I was placed on a special bed that gradually tilted vertically. When it was fully upright the straps were released, and I stood — and was immediately sick! Over the next few days, this was repeated to get me used to standing again. I had gained two inches in height as a result of the surgery, but, at first, I struggled with my vision. Eventually, my focus returned, and I could see clearly once more.

The next hurdle was walking unaided. Supported by staff either side of me, I took very short steps. It was truly like learning to walk all over again. Soon after, I was fitted with a plaster jacket, which for me was the most painful part of the entire experience. I had become hypersensitive to anything near my spine, and even a few inches of proximity made me react violently. The removal of my stitches — one long stitch from the top of my spine to the base — was equally brutal. One nurse fainted during the process. Despite this ordeal, the staff were always caring, and I pulled through.

After some days of adapting to the plaster jacket and attempting short walks, I was finally allowed home. I spent many weeks throughout the remainder of 1979 in bed, gradually building my strength with walks.

In November 1979, X-rays showed my top curve had reduced from 84 to 64 degrees, and my bottom curve from 74 to 60.

Back at school, I had missed so much that I chose to restart a year below in sixth form. This gave me time to recover before attempting my A-levels. Shortly before sitting them, I fell ill again and was readmitted to hospital with an acute spinal infection. I had to undergo further surgery to have the rods removed, as they were largely redundant by then. Bone had grown sufficiently around my spine to support me.

Several years later, I experienced post-traumatic stress disorder. I suffered from vivid nightmares, exhaustion, and difficulty functioning. At the time,

45 years later (pitch and putt abilities not improved!)

PTSD was not widely recognised, but over time I found ways to cope. I refused to be defined by illness, and instead threw myself into study and work.

I went on to study electrical and electronic engineering at Trent Polytechnic, Nottingham. As part of my course, I worked for the Medical Physics Department at the Queen's Medical Centre. 40 years later, I still work there and now manage the Medical Engineering and Instrumentation Unit. I have overseen the design and manufacture of countless medical devices, including a Halo Gravity Traction wheelchair for scoliosis patients. The irony is not lost on me that my career has been spent helping others in the very area that once helped me.

I have been married for 35 years and have two daughters, both of whom went to university. We are now proud grandparents to twin girls in Australia. I am fitter now than ever, thanks to my wife's love of walking and cycling, which we do regularly. I also keep active with DIY projects.

Looking back, I would not change a thing. My scoliosis journey has been long, difficult, and at times traumatic, but it has given me perspective and gratitude. Every morning I wake up grateful for life — thanks to the dedication of the staff at Harlow Wood Orthopaedic Hospital, and the unwavering support of my parents.

I look forward to many more years ahead.

Scoliosis Support & Research

W: www.ssr.org.uk
E: info@ssr.org.uk
T: 020 8964 1166

Editors: Will Thommes & Stephanie Clark

All images are royalty free stock images, or author's own.
Printed in Great Britain by The Lavenham Press on Pure White Silk, a silk coated, high quality paper made from 100% recycled fibre and fully FSC certified. Produced using 100% recycled waste at a mill that has been awarded the ISO14001 certificate for environmental management. The pulp is bleached with a totally chlorine free (TCF) process. The Lavenham Press holds the FSC Chain of Custody certificate. Registered Charity No: 1181463. Please contact us if you require Backbone in a different format. T: 02089645343