

BACKBONE

~ 100th issue ~



BACKBONE

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A note on the front cover

This is a special issue of *Backbone*, we have reached 100 and we wanted to commemorate this by commissioning a unique front cover. Hannah Webb is a graphic design student at Manchester School of Art who is now seven years post scoliosis surgery. She first created the Wonky Spine illustration for an exhibition at the Whitworth, Manchester called 'Take Hold' which celebrated positive body image and self-worth. The design is of Hannah's spine, pre-surgery. She said, 'at the time I didn't think it was mighty fine, but now I see things differently. I hope this will encourage others with scoliosis to feel the same.'

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Designed by: Emily Wilson

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LATEST NEWS

Farewell

It is with great sadness that we have to announce we will be saying goodbye to our National Director, Claire Curley. Claire joined SAUK in 2015 and has run SAUK alongside our sister charity the British Scoliosis Research Foundation (BSRF) for over 4 years. Claire has been an incredible asset to SAUK, we are very sorry to see her go but wish her all the best for the future.



Isobel Gray Awards

Don't forget to send us your nominations for the Isobel Gray Award and Roll of Honour! Email info@sauk.org.uk for an electronic version. The Isobel Gray Award recognises people who have made an extraordinary contribution to SAUK and the Roll of Honour those who have shown outstanding courage while undergoing treatment.

SAUK Raffle

This year's exciting prizes courtesy of William Young Charitable Trust:

- 1st prize - £750
- 2nd prize - £500
- 3rd prize - £250

The SAUK Raffle is a vital way for us to raise money to continue our services as we rely solely on donations. A huge thank you to all our donors and to everyone who has been selling our tickets over the years.

The raffle will be drawn in early December so get your tickets back to us in good time - best of luck!

500 Club

Be in with a chance of winning the jackpot. and supporting SAUK.

To buy a number and be entered into the annual cash draw costs £12 - you can increase your chances by buying as many numbers as you would like. To find out more or buy your ticket visit: www.sauk.org.uk/get-involved/500-club

Get in touch

If you have had experience with a ScolisSMART Activity Suit please get in touch, we would love to hear from you. Email communications@sauk.org.uk directly.

Marathon and 10K

The places for 2020's London Marathon and ASICS 10K in London will be announced later this month - keep an on your emails if you sent in an application. Thank you to everyone who did, we really appreciate you wanting to support SAUK.

You write

If you would like to write a letter for publication in *Backbone* please email communications@sauk.org.uk and mention You Write in the subject. Although we cannot publish all the letters we receive we would be very pleased to hear from you and will do our best to include your account.

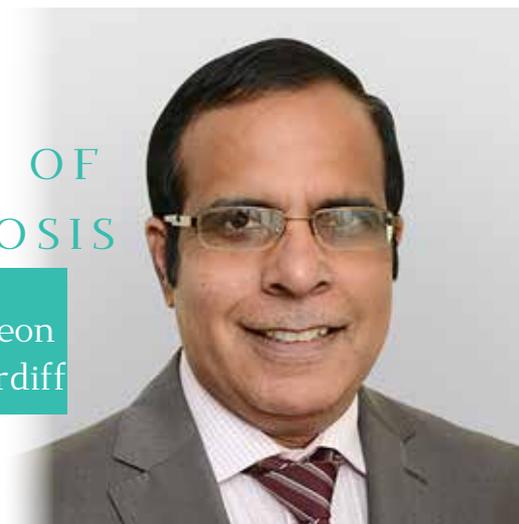
Colour Me Krazy

SAUK are delighted to announce we have been chosen as one of the charities supported by Colour Me Krazy. Colour Me Krazy is an exciting race that brings together the challenge of a 5k with a splash of colour. Race founder Matt has chosen SAUK because his mother has scoliosis and she would like to help support the next generation of people diagnosed with the condition. Please visit www.njuko.net/w/77/ for more information or to sign up!



NON-SURGICAL MANAGEMENT OF ADULT DEGENERATIVE SCOLIOSIS

Sashin Ahuja
Consultant Orthopaedic Spinal Surgeon
University Hospital Llandough, Cardiff



Management of adult degenerate scoliosis is challenging.

Almost all patients diagnosed with this type of scoliosis are usually initially treated non-operatively to help manage their symptoms.

Surgery is an option but in some patients it may not be appropriate for various reasons and some patients may select non-surgical options as their treatment of choice. Surgery in patients over 60 has a high complication rate and unless there is a clear possibility of substantial post-operative benefit it is better they be managed conservatively. Most patients would be able to self-manage their symptoms with lifestyle modification and intermittent use of medication to help the pain.

Some patients may not be able to manage their symptoms by simple measures as described above. In that case the non-surgical management would depend on the type of symptoms patients present with. The most common symptoms would be 1) back pain, 2) nerve pain or nerve related symptoms - ie, pain radiating down the legs like sciatica (pain caused by irritation or compression of the sciatic nerve) or symptoms suggestive of neurogenic claudication whereby an individual may find that they can walk for a certain distance and have to stop and sit down to help the symptoms; or

3) irregular posture. - Although scoliosis usually causes a sideways bend, patients with degenerative scoliosis may also have loss of sagittal (the anatomical plane which divides the body in half) spinal alignment because they would find that they tend to lean forwards when they stand or walk. This loss of spinal alignment can lead to muscle fatigue, which could affect the ability to walk and mobilise comfortably to carry on with the day-to-day activities and function.

Non-surgical options for management of back pain

Medication

Analgesia (pain killers) are the most common treatment option to help with pain which is usually provided by their General Practitioner. There is published evidence to support the use of analgesia to help back pain but prolonged use of analgesia should be monitored and discussed with the doctor to assess the risks.

Conservative therapies

Conservative measures - ie, physiotherapy, chiropractic treatment, osteopathy, or alternative methods which currently are gathering more support. For instance, pilates or yoga are routinely used by individuals to help with back pain. There are exercise programmes available in some places and the feedback from the individuals attending these classes is very favourable. These therapies usually help the muscles in the back so as to allow

improved control of the spine which would help with mobility and function. Various studies support muscle strengthening as a useful option to control back pain symptoms. These above options would in a way be the mainstay of treatment as they would help the condition and symptoms and help maintain function and ongoing care.

Some therapists might use other options apart from exercises to help the pain such as, TENS machines, shockwave therapy, ultrasound, accupressure, acupuncture which have mixed evidence for their effectiveness but are an option to help with the symptoms and are part of the therapist's armamentarium.

But on some occasions managing back pain is difficult despite use of the above measures and in those scenarios one of the options for management would be to consider referral for a pain management programme via the local pain clinic. The various techniques used by the pain team would usually include the appropriate use of medication to help with the pain or injections to help the symptoms. The injections that could be offered would depend on each individual's symptoms and potential pain source as per the assessment by the clinician. The options with regard to injections for back pain would include the following:

1) Facet joint injections - ie, injection of steroid into the facet joints, which are the joints of the spine that lie behind the spinal cord, and are usually done under local

anaesthetic and under X-ray guidance.

2) Facet joint denervation - if facet joint injections help symptoms for a reasonable duration then one could consider undertaking facet joint denervation or rhizolysis whereby we can ablate (ie, remove) the nerve endings supplying the facet joint. This procedure could help the pain arising from the facet joint for a long time.

The evidence for the use of facet joint injections and facet joint denervation in medical publications is variable but their use for patients with low back pain is supported by National Institute for Health & Care Excellence (NICE) as one of the options to help with symptoms.

Another option that has benefitted patients with low back pain and could be considered to alleviate symptoms is an intensive rehabilitation programme or functional restoration programme. These type of programmes usually include input from physiotherapy, pain management, and psychology. These programmes have improved low back pain symptoms. This treatment option is recommended by NICE for patients with low back pain because published evidence is fairly favourable.

Non-surgical options for management of altered posture or loss of spinal alignment

Bracing

In patients with loss of spinal alignment one could consider using mechanical measures - ie, a brace to support the spine, in addition to Conservative treatment. The various spinal braces available range from soft corset, which is essentially made of canvas type material, a soft corset supplemented with metal strips supporting the back, or a fully moulded jacket made of thermoplastic which is usually moulded to fit around the trunk.

These braces can help to support the spine and improve spinal alignment, which could potentially help mobility and function in a similar fashion to a knee brace or braces used for other joints in the body. Again the published evidence for use of bracing is varied and this method is not commonly uses in day-to-day practice, although on a

case-by-case basis a patient could be offered a brace that could be used on occasions to help with function and mobility.

Walking aids

Some individuals use walking aids that help them to be in an upright position rather than bending forwards. These aids potentially help with walking and function. They can vary from a walking stick, two sticks, crutches, or the use of other devices, such as rollator frames. Walking aids are usually very useful in managing patients with degenerative scoliosis by helping to improve their mobility and function. They also provide a sense of security and safety and help to avoid falls that could have other inadvertent consequences.

Non-surgical management of symptoms related to spinal nerve pain

Some patients with degenerative disease may have nerve-related symptoms because of a trapped nerve causing sciatica or difficulty walking any distance. Generally such patients prefer to sit after walking a specific distance, which in the medical terms is called neurogenic claudication. Surgery is usually the preferred treatment for patients with nerve related symptoms. But such surgery can be challenging, because if it is done to free the nerve - ie, spinal decompression - it may be inadequate since the surgeon may have to stabilise either a short segment of the spine or a longer segment so as to correct and realign the scoliosis. Both options have their inherent risks. But as discussed above, surgery may not be an option for everyone with nerve pain and degenerative scoliosis.

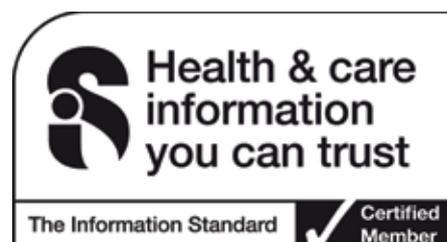
As for back pain, analgesia would be an appropriate first line non-surgical treatment. Some of the additional drugs usually prescribed by doctors are gabapentine, pregabalin, or amitriptyline to help with nerve-related symptoms.

If the pain is persistent despite medication a spinal nerve block can be tried, which is done under local anaesthetic and with X-ray guidance. Local anaesthetic steroid is injected around the specific nerve root to help and control the nerve-related symptoms. This procedure could not only

be used to control nerve pain but also to help to localise the pain source so that if required the patient could have limited surgery to decompress the nerve to help improve the symptoms.

Epidural injection is another option that is used to help with symptoms. It is usually done under local anesthetic and X-ray guidance and would either be a caudal or a lumbar injection and both go around the spinal cord rather than a specific nerve root in spinal nerve block. Caudal epidural is injected just above the level of the tail bone and the lumbar epidural is injected into the lumbar spine, which is roughly at the level of the waist line. The published evidence fairly supportive of spinal nerve blocks or epidural injection.

The management options are for the common mechanical symptoms that patients with degenerative scoliosis would present with. One may have to utilise one or several of the options to help with the symptoms. The decision about the best options to offer to help with symptoms would be based on the clinician's or therapist's assessment.



Sources are available from SAUK on request. This article is an Information Standard medical article. There is more information about the Information Standard on our website, at www.sauk.org.uk/about-us/the-information-standard.

A conversation with...

Eva BUTTERLY

Eva Butterly grew up in Rush, County Dublin, before going on to study Drama and Performance at the Conservatory of Music and Drama in Dublin city. She has worked in theatre and film/television, appearing in Pixies, The Smoker, and The Dame Who Wore Red shoes, but most notably as Margaery Tyrell Mummer in Game of Thrones. Her main passion though is exercise. Eva runs her own personal training studio in Rush where she specialises in training people with scoliosis. Eva is also the host of The Scoliosis Warrior podcast where she speaks with people on different topics surrounding the condition and is a strong advocate of body positivity and scoliosis awareness.

SAUK: Can you tell me about being diagnosed with scoliosis. What is your experience of living with it? What has helped you deal with it?

EB: When I was 12 my teacher noticed that my shoulder was slumped to one side. She informed my mam, who took me to see a chiropractor, where I was diagnosed with scoliosis. I received chiropractic treatment for 6 months, but my back got progressively worse. I was sent to see an orthopaedic surgeon, who advised me that I required immediate surgery because my curvature was so aggressive. I had two spinal fusion operations - the first to insert metal rods either side of my spine to prevent my curvature from getting worse, the second to remove the rods, because the hardware became infected. I wore a body cast for a year after that to secure my spine, and thankfully there have been no further complications since.

Growing up with scoliosis was hard, my body felt very alien to me and I had trouble finding clothes to fit. The backs of chairs in schools always caused a lot of discomfort, and I felt very different from other girls my age. I would say hands down the biggest thing that has helped manage my scoliosis has been weightlifting. Strengthening the muscles that surround my spine has helped tremendously with pain and also the overall aesthetic appearance of my back.

SAUK: You've become a role model for people with scoliosis and have been on various platforms describing how weightlifting has really helped you. Can you tell me about that about that and your personal trainer mission.

EB: I started going to the gym at 18. My brother was really passionate about weight training, and he taught me all the basic compound lifts such as deadlift, squat, and overhead shoulder press. Because of the way my body was shaped (long legs, long arms, short torso) I was well suited to lifting weights (particularly deadlifts), and I really enjoyed the feeling of strength that came with this new practice. For so many years I didn't feel in control of my body, I felt like there was an outside force governing everything I did. Through weight



Above: Eva Butterly, photo credit to Stephen Black photography
Right: Eva (left) as Margaery Tyrell Mummer. Image source: IMDb.com.



lifting, I developed a new-found confidence in myself, which was very empowering to a previously self-conscious teenage girl. So I continued to train 4-5 days a week and over the course of a few months my body started to change. I became a lot more symmetrical, and my pain pretty much disappeared.

I believe there is a misconception when you have chronic pain or scoliosis that lifting weights will further exacerbate the pain. This makes you fear exercising, which further adds to your pain - it is a vicious cycle! However, many studies show lifting weights not only relieves back pain and improves the functionality of the spine, but it also increases your bone density. Strong muscles have a much easier time holding the spine in place, and strong bones help to prevent degeneration of the spine as we get older. Another amazing side-effect of lifting weights is the mental strength developed through the practice.

So my mission is to empower people to take control of their health through resistance training. I also advocate for the importance of well-balanced nutrition and mental health. I want people to know that they don't have to be a slave to their scoliosis, and there are lots of things they can do to help themselves manage the condition.

SAUK: What message would you have for anyone who has been diagnosed with scoliosis?

EB: Go online and get yourself some support. Thankfully we are living in an age where there are so many resources available for those with scoliosis. Don't be afraid to reach out, be curious about your condition, ask questions about the best treatment options available. Scoliosis is not only physically difficult but it is also a struggle mentally, and it is easy to feel very alone on the journey. Reaching out to other people can help lessen the load.

About the BSRF



SAUK has a sister organisation, the British Scoliosis Research Foundation (BSRF). The BSRF exists to promote research into the treatment of scoliosis in the UK.

Each year the BSRF funds research into scoliosis, and it holds an international symposium every 2 years to spread knowledge gained from research.

Although treatment exists, there is currently no cure for scoliosis and in most cases the cause remains unknown. Each year, the BSRF provides funding, subject to a formal application and review process, for those doing high quality research into all aspects of scoliosis.

BSRF funded research has provided better understanding of both the causes and treatments of scoliosis, resulting in earlier intervention and better treatment for patients. Currently we are funding grants to people engaged in research into scoliosis.

Current research

Edge Hill University received funding to improve young people's engagement during planned spinal consultations for adolescent idiopathic scoliosis. The result was a fantastic animation called What to Expect which talks patients through the diagnosis and treatment process for scoliosis. It can be viewed on our Facebook page: www.facebook.com/BritishScoliosisResearchFoundation.

The BSRF also gave funding to the University of Bristol to look into the natural history of scoliosis from aged 13-24 using a population based approach. The Bristol study was building on the ALSPAC (a cohort study of children born in Avon between 1991 and 1992) to see if scoliosis could be identified before it fully developed and if predictions could be made about the curve progressing.

International Phillip Zorab Symposium

On the 20th and 21st June, 2019, the BSRF hosted its 16th International Phillip Zorab Symposium in Dublin, Ireland. BSRF welcomed experts in scoliosis to share and discuss their research. Highlights included talks and debates from Brian Ciruna, James Sanders, Greg Reading, Amer Samdani, and Emma Clark. The event was a huge success.

Travel Grant

The Charles Manning Award provides small grants to healthcare professionals with an interest in scoliosis, as a contribution towards travel costs incurred when visiting relevant institutions. Contributions towards the cost of attending conferences or meetings directly related to your field of expertise may be considered. To find out more visit www.bsrf.co.uk/research-grants/the-charles-manning-award



SCOLIOSIS AND BREATHING

Prof Anita Simonds
Professor of Respiratory & Sleep
Medicine, Royal Brompton &
Harefield NHS Foundation Trust



Disorders of the skeleton affecting the spine and rib cage fall broadly into the categories

of scoliosis (lateral curvature of spine), kyphosis (backwards curvature), lordosis (forward curvature), and pectus (breast bone) abnormalities. The degree of lateral curvature in scoliosis is expressed by the Cobb angle, and is calculated from a standing X-ray as shown in Figure 1. There must also be a rotatory element.

The existing classification of scoliosis is via causation: congenital (seen at birth), neuropathic (caused by neurological or neuromuscular problems such as muscular dystrophies or poliomyelitis), and syndromic (associated with other conditions, -eg, Marfan and Klippel Feil syndrome). Each has particular consequences for breathing. However, by far the most common subtype is idiopathic scoliosis (75%), and most of such curves develop in adolescence. Idiopathic means the cause is not known.

Adolescent idiopathic scoliosis (AIS) is diagnosed between the ages of 10 and 18 years. In total there is an incidence of 3% for curves between 10° and 20° and 0.3% incidence for curves greater than 30°. The female to male ratio of curves greater than 30° exceeds 10:1.

Juvenile idiopathic scoliosis occurs in children aged 4 - 10 years and accounts for 15% of scoliosis cases. It is more

likely to progress than adolescent-onset curves, and can be associated with spinal cord conditions such as syringomyelia and Arnold Chiari syndrome.

Infantile scoliosis occurs after birth but before the age of 4 years and is quite rare, with an incidence of 4% of scoliosis cases. By contrast with adolescent-onset and juvenile-onset scoliosis, it is more common in boys, and the curve is more likely to be to the left side of the chest, than right.

These early-onset curves, in particular, may also be linked with pulmonary hypoplasia (under-developed lung) and thoracic cage abnormalities, increasing the risk of long-term lung and heart complications. Congenital scoliosis often occurs as a result of failure of normal vertebral development during the fourth to sixth week of pregnancy. It is associated with congenital cardiac defects in about 10% of cases.

For scoliosis, such curves are related to underlying neurological or neuromuscular conditions such as cerebral palsy, muscular dystrophies, and spinal muscular atrophy. In contrast to idiopathic curves, these can be more rapidly progressive and may advance after maturity. Furthermore, pulmonary function will be related to chest wall restriction but additionally by underlying respiratory muscle weakness if present.

Acquired structural scoliosis may occur as a result of thoracic surgery, traumatic onset spinal cord paralysis, a tumour affecting the thoracic spine, or radiotherapy

to the spine if these conditions occur in childhood or adolescence, before spinal growth is complete.

How can scoliosis affect breathing?

The major effect of skeletal chest wall and neuromuscular disorders on pulmonary function is to cause a restriction in lung size, which is called a restrictive ventilatory defect. Any significant scoliosis or kyphosis results in a loss of height, so that arm span instead of height is required to predict normal lung volumes. In general, individuals who have a thoracic Cobb angle greater than 70° are subject to clinically significant lung size limitation. In children with early-onset scoliosis, serious

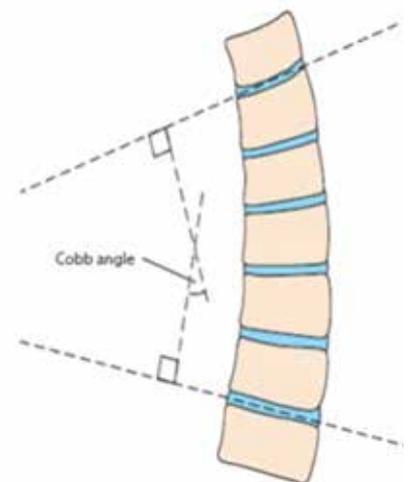


Figure 1: Spine showing measurement of Cobb angle from intersection of horizontal lines drawn at top and lower vertebrae of curvature.

ventilatory limitation is unlikely if the curve is less than 30°. Lumbar or even low thoracic curves are unlikely to impair pulmonary function because they do not restrict the lungs.

The simplest breathing tests measure the total volume of air breathed out in one second (forced expiratory volume, FEV₁) and the total volume breathed out after a maximum breath in (forced vital capacity, FVC) – see Figure 2.

While both scoliosis and kyphosis diminish lung volumes, a lateral (sideways) curvature has a more profound effect on chest wall functioning. Restriction implies that both FEV₁ and FVC are reduced in proportion, so the FEV₁/FVC ratio remains normal. This distinguishes scoliosis from conditions such as asthma and chronic obstructive pulmonary disease where FEV₁ is disproportionately reduced compared to FVC. A significant obstructive ventilatory defect is rare in adults with scoliosis and kyphosis, unless the individual has coexistent asthma, chronic obstructive pulmonary disease, or upper airway obstruction. However, in some patients with scoliosis and lordosis, bronchial torsion (twisting) or bronchial compression by adjacent vertebrae can occur. This is an important catch that measuring lung volumes can help us identify. If bronchial compression or torsion is suspected a computerised tomography (CT) scan of the chest can be done to help to confirm this.

The relationship between breathing



Figure 2: Measurement of FEV₁ and FVC using handheld spirometer

impairment and the extent of curvature is complex and cannot be predicted accurately from the Cobb angle alone. The four underlying major determinants of a reduced FVC are the number of vertebrae involved in the curve, the higher the position of the curve, the Cobb angle, and the degree of loss of normal thoracic kyphosis. In paralytic scoliosis, lung volumes are reduced not only by chest wall restriction, but also by inspiratory muscle weakness.

Gas transfer or diffusing coefficient (KCO) is a measure of the ability of the lungs to transfer oxygen into the blood stream. This tends to be raised in scoliotic patients, because extra-thoracic compression squeezes more air than blood out of the lungs, thereby decreasing accessible alveolar volume. Importantly a low KCO value is suggestive of problems such as pulmonary hypertension (high pressure) in the pulmonary circulation or intrapulmonary disease, so should be investigated further.

With respect to chest wall mechanics seems like an odd word to use when applied to breathing but is a physiological term describing how difficult it is to expand the chest and take breaths. Compliance indicates how stretchy the chest wall is, and scoliosis can make it stiffer. Chest wall compliance is an important determinant of lung volumes and the work of breathing. Individuals with a Cobb angle of less than 50° experience a minimal reduction in chest wall compliance, whereas compliance is likely to be greatly reduced if the Cobb angle is great than 100°. A direct relationship between Cobb angle and compliance is not seen in patients who have neuromuscular disorders, since respiratory muscle weakness contributes independently to chest wall stiffness. Alteration in chest wall properties cannot solely be attributed to the mechanical condition of scoliosis, as a decrease in compliance has been recorded in patients affected by chronic respiratory muscle weakness in the absence of scoliosis.

Although lung expansion is compromised by chest wall properties, primary lung pathology is unusual in adult patients who have idiopathic scoliosis. However, lung compliance is reduced because small lungs are more difficult to expand. A

simple analogy is blowing up a balloon – expanding it initially is much harder than increasing its volume once it has grown to the size of say, an orange. The lung consists of small air sacs (alveoli), and changes in pulmonary characteristics largely arise from an alteration in alveolar forces caused by chronic breathing at low lung volumes. In neuromuscular patients, collapse of some of the alveoli or larger lobes of the lung may complicate the picture as the respiratory muscles fail to expand all areas of lung. However, in early-onset scoliosis, failure of lung development (pulmonary hypoplasia) and undergrowth of the pulmonary vascular bed may occur. Diaphragm weakness and loss of lung stretchability may inhibit alveolar development in fetal and early life, causing further loss in lung volume and gas transfer ability. Recurrent pneumonia may occur in neuromuscular patients who have weakness of the swallowing muscles, or an ineffectual cough. Pulmonary scarring is also seen in patients who have old tuberculosis, and these individuals may have areas of lung damage that can lead to frequent infections (bronchiectasis). Cystic lung changes affect some individuals with neurofibromatosis or Marfan syndrome.

During sleep we rest our muscles, including most of our breathing muscles, instead relying on our diaphragm. In addition, our drive to breathe from the brain is reduced, especially during rapid eye movement (REM) sleep, resulting in more gentle breathing at night, but in people with moderate and severe scoliosis this process can be magnified (nocturnal hypoventilation).

In individuals with respiratory muscle weakness and chest wall restriction, nocturnal hypoventilation in REM sleep is seen when FVC falls below 60% predicted and tends to extend to non-REM sleep – ie, the whole night when vital capacity is less than 40%. In a study of patients with nocturnal hypoventilation as a result of mixed respiratory muscle and chest wall disorders, 70% progressed to daytime ventilatory failure within 12 months and 90% within 2 years of the first appearance of symptomatic nocturnal hypoventilation. Nocturnal hypoventilation is therefore an indication to start breathing support at night with nocturnal non-invasive ventilation.

How can you measure breathing?

Lung volumes should be measured as shown in Figure 2, or in a pulmonary function lab. Arterial blood gas measurement (O₂ and CO₂ level measured in an arterial blood sample), and assessment of respiratory muscle strength with mouth pressures are helpful, particularly in the group who has neuromuscular disease. Mouth pressures are measured by a simple inspiratory and expiratory test. Cough effectiveness can also be measured by blowing into a mouthpiece device.

A fall in FVC greater than 15% predicted on lying in the supine position (flat on your back) indicates significant diaphragm weakness. A high daytime CO₂ level is associated with an inspiratory mouth pressure less than 30% predicted. As well as inquiries about daytime breathlessness and exercise tolerance, individuals should be asked about symptoms of nocturnal hypoventilation (morning headache, poor sleep quality, frequent waking from sleep, nocturnal breathlessness), and if any are present, the individual should be referred for monitoring of respiration during sleep - a sleep study carried out by Respiratory Medicine or Sleep Hospital departments. Simple overnight measurement of oxygen level (oximetry) can be done at home with a clip on the finger or ear. More detailed tests involving assessment of carbon dioxide level and respiratory pattern can be done in hospital overnight.

Who is at risk of breathing problems?

The good news is that almost all individuals who have a thoracic spinal curvature will not develop cardiorespiratory problems as most have small curves, that are more likely to be adolescent in onset, and therefore do not require long-term respiratory follow-up.

But clearly, it is important to be able to identify the small number at risk of problems so that appropriate monitoring and timely therapeutic intervention are done. Decades ago heart and lung failure were the primary cause of death in patients with severe idiopathic thoracic scoliosis. Such an outcome is now hardly ever seen

because treatments such as non-invasive ventilation are highly effective. Factors to look at to predict those at risk are, firstly, age at onset of the scoliosis. In patients who developed cardiorespiratory problems attributable to their scoliosis, 90% had an early-onset curvature. A vital capacity of 50% predicted is an important cut-off figure, since those with a value less than 50% predicted at presentation are much more likely to develop respiratory decompensation than those who have larger lung volumes. In an historic untreated cohort with idiopathic scoliosis followed for 20 years, respiratory failure occurred in 25%, all of whom had a vital capacity less than 45% predicted and a thoracic Cobb angle greater than 110°.

What can be done to help breathing?

For people with scoliosis and breathlessness as a result of chest wall restriction the first step is to see your GP who can measure your breathing or refer you to a respiratory medicine department to be assessed in more detail.

If there is a significant restrictive ventilatory defect and breathlessness is problematic, a pulmonary rehabilitation course can be helpful. This course consists of an exercise programme tailored to personal needs, coupled with advice on breathing control and healthy living. There is good evidence that pulmonary rehabilitation, particularly the exercise component, reduces breathlessness and enables the individual to walk further. The specific programme will take into account the scoliosis, and problems with any pain or truncal (torso) asymmetry. It is crucial to continue the exercise after the course ends, otherwise the benefits are lost. Your GP or respiratory physician can refer you to a pulmonary rehabilitation course either in the community or at a local hospital. Courses usually last around 6-8 weeks, with twice weekly attendance.

If the vital capacity is less than 50% predicted and/or there are symptoms of sleep disturbance such as waking with breathlessness or morning headaches, a sleep study may be done. In those with very small lungs this may show nocturnal hypoventilation during sleep. Here the

oxygen level drops and carbon dioxide (waste gas) level rises. This can be treated with a small breathing machine at night. Usually this treatment is needed for those with muscle or syndromic conditions, or early onset scoliosis. It is most unlikely to be needed in people with adolescent onset scoliosis. Recently we have been able to help many children and young people with scoliosis and neuromuscular disorders such as Duchenne muscular dystrophy and spinal muscular atrophy. Many now grow to adulthood, which was not possible before the development of non-invasive ventilation.

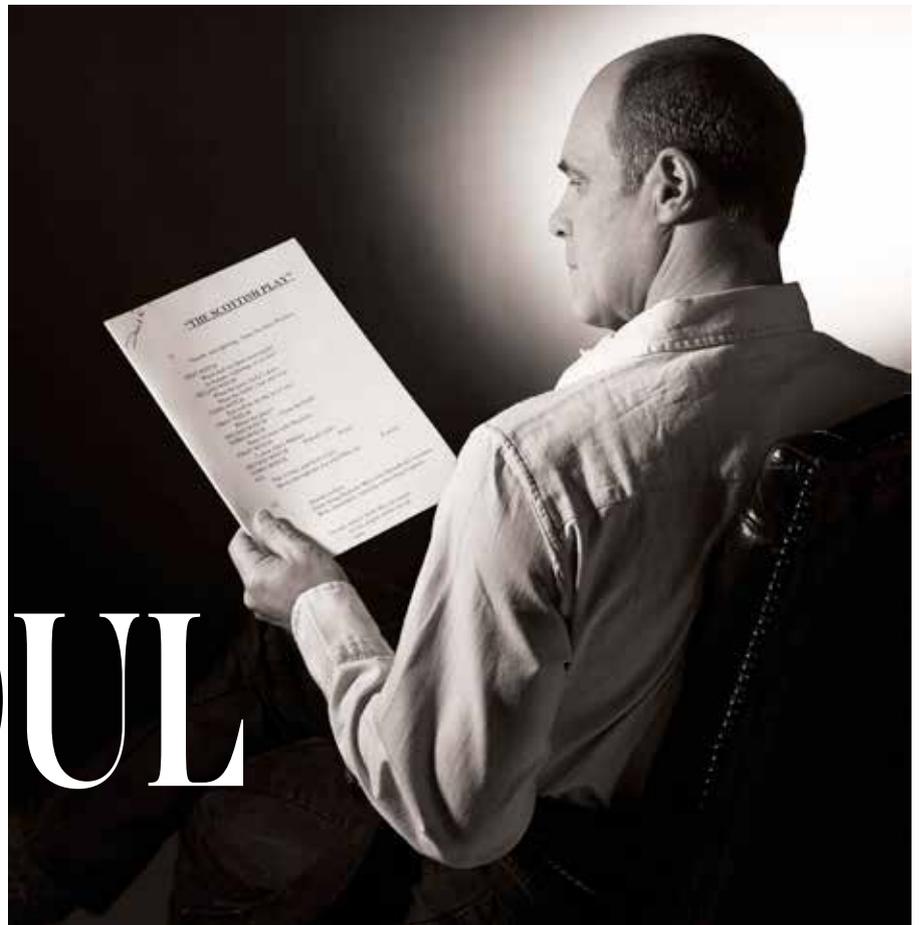
How can I keep healthy?

Mostly this is common sense. Importantly don't smoke, exercise regularly and keep to ideal body weight. Even putting on a little weight can make people with scoliosis breathless. Influenza vaccination is recommended in those over 65 years, or if you have an additional breathing problem such as asthma. If possible, keep an eye on your vitamin D level and take supplements if this is low. Many people are vitamin D deficient so it could be argued that all scoliosis patients should take vitamin D supplements. A bone densitometry scan is helpful in showing if individuals have osteoporosis, which can be treated with bisphosphonate tablets +/- calcium, as advised by your GP. Upper respiratory tract infections are usually viral and settle with symptomatic measures such as paracetamol and rest. If symptoms don't settle within a few days and are associated with production of green or yellow phlegm and increased breathlessness, then a check-up with your GP is advisable as an antibiotic might be required.



Sources are available from SAUK on request. This article is an Information Standard medical article. There is more information about the Information Standard on our website, at www.sauk.org.uk/about-us/the-information-standard.

DAVID RINTOUL



Photographed by Lord Patrick Lichfield for SAUK's Getting It Straight Campaign, 2002

Ailee Harrison kindly invited me to be a patron of the Scoliosis Association UK when I was playing ITV's Doctor Finlay some 25 years ago. We made four series, it was popular both here and in the USA and, personally, led to a fair amount of public recognition - people saying hello to you in shops, appearing on chat shows - that sort of thing. Unless you're very well established that side of an actor's life tends to come and go, Dame Fortune's a Fickle Jade.

A couple of years ago I was playing the Ghost and the Player King in Andrew Scott's Hamlet at the Almeida Theatre and in the West End. Andrew, of course, played Moriarty in BBC One's Sherlock and he was met with a great queue of admirers after each show after an autograph, or these days more commonly selfie, hunters all of whom he very generously obliged. I slipped out of the stage door confident that I would get home a good half hour before he did but was often met with a sub-queue of my own. The photograph that I was asked to sign bore only a passing resemblance to my everyday self - a wild-eyed lunatic in a white wig, sitting on a dangerous-

looking metal throne. The Throne. The Throne in The Game of Thrones.

It happened like this...

My agent asked me to go up for an un-named part in the series, the only description being that he should 'have authority and be stark raving mad'. I turned up to join a roomful of people who I flattered myself were much more suitable candidates than I was. I was given a short script and ranted a bit into the camera. A few days later my agent rang and said that I had got the part. 'It's just a day's filming, David! Oh. 'Just a few lines' Oh. 'But it's to play The Mad King' Who? (I hadn't seen the series).

For those of you who are in the same boat let me fill you in. Familiar from advertisements for the series is a very pretty, very blonde young woman, the heroine, Daenerys Targaryen. I'm her Dad. Another hugely well known (to the aficionados) character is Jaime Lannister, otherwise 'The King Slayer'. I am the King he slew and the slaying was very briefly re-imagined by the backward-seer Bran Stark. Got all that?

Anyway, terms were negotiated, I was whisked off to North London in an automobile of spectacular specification, fitted with a fetching white wig and given a fearsome non-disclosure agreement to sign. It was when I dropped a few indiscreet hints to my niece, a great fan of the series, and she guessed that 'You're playing Him?' that I realised the magnitude of what I'd agreed to.

I was flown out to Belfast and spent an agreeable day shouting my silly head off in the old Harland and Wolff's paint shop which is now the permanent set for the Game of Thrones' Throne Room. I called Joanna, my niece, as I was sitting on the iconic Throne. She was impressed. So that was that; a day's work.

I've just finished 7 months filming the third series of 'The Crown'. Because I've signed another fearsome non-disclosure agreement I can't tell you anything more. I can say, however, that I spend a lot of screen time with the delightful Olivia Coleman. Meanwhile, at the time of writing, I'm back on stage playing a Leningrad sewage worker.

SAUK DONATIONS

A huge thank you to all of our amazing supporters for your generous donations. We greatly appreciate all the donations we receive and you are vital in ensuring we can continue our important work, providing support and information for people with scoliosis.

Cathy Acaster, Adetomike Adeniji, Jeanette Akunebuni, Jennifer Airlie, Ami Andrews, Tita Ann, Michael Antoniou, APS Legal and Associates, Kath Arina, Alex Ascham, Fazeela Ashraf, Matthew Atkinson, Val Aviv, Frances Ayrtton, Julia Aziz, Debbie Balaam, Chris Banks, Weronika Baranowska, Sarah Barnes, Soph Baxendale, Gillian Beaton, Michelle Beesley, Sam Belk, Vron Bell, Paul Bell, Caroline Bell, Jack Bellamy, Richard Belson, Matthew Bevin, Lorna Bennett, Mary Birch, Ian Birdsey, Avril Bishop, Lorraine Black, Michelle Blackman, Sophie Bostridge, Martin Bourne, Andrea Bowers, Kate Bown, Donald Boyd, Stuart Boyes, Victoria Bragg, Claire Brennan, Laetitia Bridge, John Bridgewater, Janice Brisband, Ngaire Broadbelt, Craig Brown, Michael Brown, Dawn Bryan, Louise Buckle, Terri Buffery, Josh Bull, Helen Butcher, Marissa Cacayan, Charlie Calcutt, Christine Calladine, Debbie Calland, Mollie Campbell, Katie Campbell, Gordon Cargill, Kezia Cargill, Caitlin Cargill, Laura Carlin, Ali Chambers, Anna Chapman, Lisa Charman, Chelsie Charvill, Neil Chittick, Harry Chinn, Ellis Chiverton, Ian Churchward, Lynn Clifton, Tracey Clare, Sarah Clarke, Alan Clarke, Emma Clarke, Paul Clyde, Kim Cocks, June Cole, Sophie Cole, Anthony Colgrave, Marie Conlon, Stella Cook, Rachel Cooley, Anna Corbett, Nicky Cordiner, Nicky Cornish, Nina Corrin, Julie Costello, Joan Coughton, Jade Cotton, Andy Cotton, Ruby Courtenay-Flack, Gilly Cox, Mike Llywelyn Cox, Alex Cozens, Mackenzie Crompton, Peter Cross, Kevin Cruickshank, Thomas Cumberland, Dale Cunningham, Molly Cunningham, Daniel Currall, Lizzie Cutts, Alan Dagnall, Angela Dale, Brian Dallison, D'almeida, Georgia Danziger, Howard Davies, Paul Davies, Pam Davies, Claire Davies, Cathy Davis, Nick Day, Heidi de Schouwer, Fiona Dearden, Simon Dennis, Lisa Dennis, Cheryl Denny, Annette Dolman, Matthew Drapper, Jim Driebeek, Lorne Dryer, Janet Dufton, Nicola Dugard, Evan Dunn, John Dunnet, David Dyer, Stewart Eaton, Michelle Edser, Siacn Elisabeth, Sarah Elisabeth, James Ellis, Ellen Ellis, Joanne Ellis, Alison Ellwood, Uchechi Eluwa, Christina Evans, Harry Evans, Bethy Faber, Steve Faber, Sarah

Jane Faber, Sarah Facer, Sally Farmer, Iain Farquhar, Chloe Farquhar, Jordan Firth, Agnieszka Fisher, Alina Fisher, David Flanagan, Dave Forbes, Emma Forbes-Laird, Margaret France, Lola-Rose Freer, Clare Freer, Nick French, Jacquie Galloway, Andrew Gascoyne-Cecil, Nicole Gillen, Rosie Gilks, Gary Good, Scott Goodall, Shirley Goodgroves, Mica Gooding, Sarah Goodsell, Chris Graham, Claire Graham, Liz Graham, Margaret Grahame, Charlotte Green, Erica Greene, Emilia Greenfield, Hannah Grennall, Debbie Groom, Menald Gumallaoi, Tiggy Gurney, Tess Gurney, Michi Hacken, Angharad Haddock, Monika Hall, Carol Hambly, Alex Harding, Steve Harper, Sallyanne Harris, Harrison, Nicola Harrison, Helen Haseltine, Lindsay Hastings, Ann Healy, Dawn Heath, Alan Heeks, Charlotte Heeks, Alisha Hellard-Smith, Sharon Herron, Victoria Hiley, Elissa Hill, Rebecca Hill, Jon Holloway, Waltraud Holzer, Bernice Hopper, Angela Horler, Phil Hurley, Emily Hurley, Margaret Hurley, Frances Hutchison, Kayleigh Irvine, Liana Isadora, Marina Jakovleva, Barbara Jane, Emma Jane, Wendy Jarret, Helen Jenkin, Vicky Johns, Sarah Johnson, Flora Johnston, Stuart Johnston, Sarah Jones, Hannah Jordan, Nat Joyce, Beverley Kane, Aidan Keelaghan, Keith Keen, Jo Keenan, Lily-Beth Kelley, John Kelly, Roger Kerrison, Stanley Kiki, Jane King, Ethan King, Joanne King, Allan Kissack, Andrew Knapp, Helen Knight, Jennifer Lack, Wendy Lakin, Stefan Lander, Jennifer Langridge, Samantha Langston, Charlie Laryea, Henry Latham, Dawn Laville, Marie Le Novere, Sue Ledwidge, Andrew Lee, Henry Lee, Katy Lee, Saskia Lee, Laila Leisibach, Hannah Lerwill, Martin Liebeck, Liz Lieven, Ddiane Llocherty, Albert Lorenzo, Rebecca Loudon, Victor Lourenco, Kirsty Low, Kay Manzoor, Victoria Margeson, Steven Marshall, Karen Marshall, Elliott Marter, Jason Martin, Karen Martin, Yvonne Matthews, Patryk Matuszewski, Gerry McCann, Sarah McCann, Steven McCracken, Rebecca McComiskey, Kirsty McDonald, Medbh McGowan, Robert McIntyre, Graham McKay, Stewart McKay, Lizzy McKean, Fiona McLaughlin, Vicki McLellan, Ruth Meredith, Joyce Miller, Flora Miller, Angela Mills, Naomi Milner,

Paul Minter, Andy Minter, Cristian Mircea, Mihaela Mircea, Alyson Mitchell, Lee Moore, Jenny Morning, Calvin Morrice, Roger Morris, Jackie Moss, Darren Moss, Briony Moss, Stewart Moulton, Alison Mower, Robert Moyney, Sophie Moylan, Erica Moylan, Ian Mullin, Vicky Mullins, Clare Munden, Ellie Murphy, Nikki Murphy, MA Murphy, M Murphy, Róisín Murphy, Caroline Nicholas, Simon Niebuhr, Amy Noble, John Noble, Mariusz Nowak, Michael O'Brien, Alison O'Neil, Jess O'shea, Tina Owens, Helen Page, Lorraine Parrott, Zara Parkes, Emanuelle Paulson, Debbie-Anne Paxton, Corren Perks, Lydia Perry, Peter Phillips, Karen Pickard, Lavva Playmobilette, Aimee Poole, Derek Porter, Margaret Porter, Harley Potter, Debbie Potter, Sue Preston, Joe Puckrin, Hana Purslow, Lorna Raper, Sandra Reason, Katie Redgell, Karen Reding, Nikki Reeves, Douglas Rew, Julie Richards, J Anne Rillon, Tom Roberts, Carolyn Roberts, Allen Roebuck, Jade Rose, Kerry Rosier, Claire Rowan, Abbie RS, Sharon Sams, Tara Satyanand, Peter Saunders, Jacky Scarlett, David Scranage, Daniel Sclare, Kim Shaw, Dan Shelton, Andrea Shippey, Alison Shorten, Luke Sifleet, Tracy Simmonds, Yvonne Simmonds, Caroline Simpson, Ian Simpson, Sandy Simpson, Simmo Simpson, Rhona Sinclair, Georgina Smith, Adam Smith, Colin Smith, Mel Smith, Nikki Spence, William Stark, Julie Stead, Slade Stevens, Linda Stewart, Peter Stewart, Ian Stickland, Alex Stickland, Chrissy Stone, Katie Story, Claudia and Paul Stroomer, Tracey Summers, Martin Symons, Suzanne Symonds, Suzanne Symonds, Ella Symonds, Michel Taddei, Caitlin Tawse, Eben Taylor, Petter Thams, Eliza Thom, Sarah Thompson, Tori Thompson, Kelly Timson, Phil Timson, Paul Titman, Rick Todd, Louise Toms, Danella Tracey, Lynn Travis, Michaela Tucker, S Tumath, Joanne Tunney, Leanne Van Niekerk, Jennifer Vanstone, Nikki Von Glehn, Nigel Walker, Adi Walwyn, Richard Wand, Hellen Ward, Neil Warren, Jez Warren, Mike Warriner, Anna Waterhouse, Mr & Mrs Watson, Pam West, Kath Wharton, Lisa White, Paul White, Edwina White, Dawn Whitear, Lauren Wilkie, Helen Wilkins, Marion Willatt, Barbara Williams, Elizabeth Williams, Fiona Williams, Lisa Williams, Sam Williams, Taylor Williams, Kate Willis, Claire Wilson, Helena Wilson, Tracey Wilson, Fifi Wise, Janet Wise, Faith Withington, Charl Wllams, Natalie Wong, Alan Wright, Graeme Wright, Kathryn Wright, Lindsay Wright, Maureen Wright, Mingxi Zhang, Sophie Zinonos Bruce

SAUK - FUNDRAISERS

A huge thank you to all our amazing fundraisers for your fantastic efforts to support us. People have run, swum, cycled, walked, baked, and danced in the name of SAUK.



There have been talks, book sales, and a night at the opera. We are so grateful for all your hard work over the past few months; we really couldn't continue our work without you.

Grev Kartz completed the Birmingham Velo 100 mile bike ride and raised £901.25

Nicola Carlin-Lander ran the Derby Half Marathan and raised £371.25

Lauren Murphy completed the Great North Run and raised £412.50

Jill Tindale completed a sponsored walk raising £1565

Monica & Lucy Duffy completed the Kilt Walk and raised £1100

Liz Graham tackled the Peak District Challenge and raised £538.75

Gemma Porter completed the Run Disneyland Paris 2019 and raised £836.25

Kimberley & Nigel Scarle organised a go-karting day and raised £800

Lee Henry ran the Bath Marathon and raised £316.25

Martin Symonds completed his Coast to Coast 10th Anniversary Ride 2019 and raised £484.58

Abbie Hill raised £205 with her fundraising activities

Gemma Beer hosted an ISAD cake sale and raised £50

Carol & Kim Gordon walked from London to Brighton and raised £505

Waitrose and Partners Westfield organised a collection and raised £400

Ann Liebeck completed the ASICS 10K and raised £53.25

Janice Olsen hosted an ISAD cake sale and raised £303

Foys Solicitors and Toni Cheetham raised £500

Diana Scott organised a Fundraising Raffle & Art Exhibition that raised £262

Marie Steel raised £316.25

Joe Ward completed the 2018 Prudential Ride, London-Surrey and raised £43.75

Alison Barnes raised £125

Mike Warriner ran the London Marathon and raised £942

Gaby Welch completed the 2018 Simply Health Great South Run and raised £790

Fillongley Young Farms Club raised £150 with a fundraising event

Mrs Schofield held a fundraising collection at her yoga class raising

£200

Mr & Mrs Dunsheath raised £770 by requesting donations in lieu of gifts at their recent wedding

Nottingham University Academy of Science & Technology 6th Formers raised £95.30 with a fundraising event

Mrs Northedge raised £140 by selling her crocheted butterfly keyrings

Stephanie Stanley sent £40 from the annual Brighstone Christmas Tree Festival in aid of SAUK

Doreen Lindgaard donated her £30 fee for a talk she have about her late brother Colin Pillinger (Beagle 2 Mission 2 Mars) as well as a further £100 for a talk at Rotary Club, Bristol

Alex Marchant sent SAUK £150, from Amazon royalties pertaining to Grant Me the Carving Of My Name, an anthology of Ricardian short fiction.

SAUK received £19 from the christening collection of **Darcy Grace Borkett**

Blagdon Estate held a coffee morning and raised £80 for SAUK

In memory of..

Our thoughts are with those who have lost loved ones and we are so grateful they chose to donate to SAUK in their memory.

£232.72 was received in memory of **Stephen Albert Allen**

£212.75 was received in memory of **Peter Francis Roberts**

£152 was received in memory of **Pauline Mary Fielden**

£225.80 was received in memory of **Leo Burke**

£231 was received in memory of **Claire Hodgkinson**

£680 was received in memory of SAUK member **Christine McCoy**

£300 was received in memory of **Betty Barr**

£105 was received in memory of **Joan Beechey**

Further cheques were received in memory of **Joan Paine**, bringing the total to £215

Facebook birthday fundraisers

Georgia Alison, Clare Johanna Ansell, Liam Aston, Lily Bermingham, Ava-Maria Birch, Eleanor Bloomfield, Lucy Burton, Donna Campbell, Olivia Cargill, Stephanie Clark, Hannah Clements, Shannon Cordiner, Lee-Gemma Crockford, Neil Dallison, Paula Desseaux, Rawden Enever, Megan Fisher, Nikita Gilkes, Natalie Good, Alicia Hamilton, Frances Head, Julie Hughes, Nina Marie Ibbotson, Austin Ikponmwosa, Kaiya Kaltio, Madeleine Kerrison, Soninha Lourenco, Monica Lumsden, Samara Mezher, Denise Minter, Elle Morgan, Aaron Moss, Samantha Owers, Mared Emlyn Parry, Angela Rillon, Cathy Robinson, Bethany Smith, Emma Somerville, Lauren Taylor-Carbis, Sarah Louise Todd, Caroline Toms, Shui Tse, Olivia Tunn, Emily Warrener, Richard Williams, Lauren Wright

Legacies

Patricia Hill left SAUK a very generous legacy earlier in the year and we've received a further legacy of £14,768.06 bringing the total to £63,747.65. We are incredibly grateful for being remembered by Patricia.



Diana Scott's SAUK fundraising raffle and art exhibition



Jill Tindale sponsored walk event



Kimberley & Nigel Scarle organised a go-karting day



Martin Symonds during his Coast to Coast Challenge



Monica & Lucy Duffy completing the Kilt Walk



Nicola Carlin-Lander after completing the Derby Half Marathan





International Scoliosis Awareness Day



Christine Jaureguiberry - Yoga Challenge

Christine Jaureguiberry organised two Instagram challenges:

#scolimotions with @yogaberry.scoliosis @backupyogi @korsinina @scoliyogagirl

This was a 7-day challenge focusing on the emotional effect that scoliosis has. We talked about our diagnoses, fears, effects on relationships, and our self-image.

#WeYogaForScoliosis with @yogaberry.scoliosis @backupyogi @marypowellyoga @scoliyogagirl @raunchyyogi

This was a 10 day yoga challenge where we had a different yoga pose every day. To enter people posted their version on the pose on Instagram and we did a prize draw at the end to win some places on Yoga for Scoliosis courses and memberships.



Natasha Sutton - Zumba Challenge

Natasha organised a Zumbathon at her local gym in Telford. This was 2 hours of uninterrupted dancing like a loony in a gym with other amazing people - raising a fantastic £163 for Scoliosis Campaign Fund (SCF).



SAUK Photoshoot and lunch

To celebrate ISAD SAUK hosted a photoshoot and lunch in Finsbury, North London. The day was a scorcher, 33°!

A huge thank you to all our amazing volunteers for coming and modelling for us, we really appreciated you making the trip to London on a very hot day. Thank you to Patricia and Beatrice for producing the wonderful photos.



Liz Graham - Peak District Challenge

Liz completed the Peak District Challenge to celebrate ISAD and raised an amazing £538.78 for SAUK. This was an ultra event, covering 100 km of beautiful Peak District countryside over the 2 days. Liz has scoliosis, which is why she wanted to raise money for the charity. Having tried the distance before and not completing because of back pain, she was really pleased to finish this time! Physiotherapy exercises to increase core and glute strength have been really helpful in supporting her to complete this event.



Libby Warren - School cake sale

Libby organised a cake sale at her school for ISAD. She helped make all the cakes herself with help from mummy and nanny, and was extremely excited to sell them to her friends. Libby raised a wonderful £55 for SAUK.

Rachel Simpson - Cotswold Way 100km Ultra Challenge

Rachel walked 100km over 2 days in order to raise money for SCF.



Shona Keane - ISAD Fun Day

Shona organised a Fun Day and raised an incredible £ 629.68 for SCF.

ISAD weekend also happened to fall on the 20th anniversary of losing her mum to pancreatic cancer. She wanted to do something special to mark the occasion. She also did it to show support for her daughter Issy who was diagnosed with scoliosis last year. Rachel raised an amazing £780 for SCF.

SCF - THANK YOU

We are grateful to all our amazing fundraisers for all your hard work over the past few months organising various events and raising an incredible amount of money for SCF. We really couldn't continue to do what we do without you, so a massive thank you!



London Marathon

We were absolutely blown away by our London Marathon team this year. A huge thank you to our fantastic team who collectively raised an incredible £15,900.06!

- Josh Angus raised £3925.26
- Mark Fosker raised £ 2789
- Leon Jones raised £1559
- Helen Maitland-Evans raised £ 3566.25
- Lisa Riding raised £ 3921.18
- Adam Smith raised £ 139.37



Left: Helen Maitland-Evans. Right: Rachel Murdock. Centre: Lisa Riding and family. Bottom: Mark Fosker and family

Donations

A huge thank you to our generous donors:

- Michael Robinson
- Maria Senner
- David Smith
- James Greenway
- Nicki Icke

In memory of...

- Clive Newton donated £292.20 in memory of his wife Sally.
- Victoria Feaver donated £62.62 in memory of her mother Mrs Susan Pridmore.

We would like to thank you both for your generous donations, we are incredibly grateful. Our thoughts are with you and your loved ones during this time.

ASICS London 10K

We had another excellent group of people running for SCF in the ASICS 10K who raised an amazing £2798.25. Thank you so much for your support.

- Sophie Moore raised £897.50
- Rachel Murdock raised £ 333.75
- Luke Herbert raised £1063.75
- Ann Liebek raised £56.25
- Simi Bali raised £ 447



Fundraising

- Carl Basker completed the National Three Peaks Challenge and raised £716.75
- Jess Bishop participated in a sponsored silence and raised £288.75
- Lynette Linkson completed the Jurassic Coast Challenge and raised £1048.75
- Paige Newman ran a 5K raising £325
- Ellie Newton and her son Alfie took part in the Wirral Coastal Walk raising £456.25
- Coedi Preston completed the Yorkshire Three Peaks Challenge and raised £285
- Chantelle Thompson ran the Bristol 10K raising £476.25
- Robert Watson completed the Hackney Half Marathon, raising £1285
- Amy Wilson ran the Sheffield Half Marathon, raising £355
- Rachel Simpson completed the 28Cotswold Way 100km Ultra Challenge and raised £780
- Jo Woods completed the Cotswold Way

- Challenge and raised £488
- Sue & Jude Widdicombe's cycle challenge raised £623.25
- Rachel Lafferty completed a 5K North Coast Beach Run raising £47.50
- Laura Sherlock ran the UK Fast 10k at the Etihad Stadium raising £596.25
- Natasha Sutton organised a zumbathon raising £163
- Neil Grosse completed Race to the King (back to back marathons) raising £745
- Rebecca Chaffe organised a cake sale and raised £364.76
- Anotonio Phillips abseiled down the Spinnaker Tower and raised £330.51
- Harry Loftis swam the Serpentine raising £487
- John Gallagher completed the Manchester Marathon and raised £552.93
- Anthony Liot completed Mountain Mayhem and raised £1323.75
- Shona Keane's ISAD day raised £629.68



Carl Basker



Rob Watson and friends



Neil Grosse and Mike



Chantelle Thompson

SAUK

yesterday and today



Ailie Harrison, Co-founder of SAUK



**Stephanie Clark, Co-founder of SAUK
with Isobel Gray**



Dr Phillip Zorab, Scoliosis Specialist

Stephanie Clark, Co-founder and Chair of the Trustees

One day about 38 years ago Ailie Harrison said to me that one of Dr Phillip Zorab's patients, Isobel Gray, had said to her, 'You know, what we need is a self-help group for people with scoliosis'. That sowed a seed that grew into what SAUK is today. Ailie asked me to join her and we approached Phillip Zorab for help. He wrote to 500 of his patients and about 200 replied and formed the first members of what was then known as the Scoliosis Self-Help Group (SSHG).

Ailie and I, together with Stuart Spencer, now one of SAUK's Trustees, all worked with Phillip Zorab at the Cardiothoracic Institute at the Brompton Hospital in London – hence our interest in scoliosis. I started my time there working with Dr Yves Cotrel at L'Institut Calot in Berck Plage, France. There were about 400 children with scoliosis receiving treatment at that institution and they had a hard regimen to follow of months of intensive physiotherapy and treatment with plaster casts or traction. Once they were fairly straight they would have spinal fusion with Harrington rods. The results were amazing, but the patients were in hospital for at least 10 months and saw their families only at weekends. It was tough for them. Phillip Zorab used to check the lung function of patients before they were operated on by Mr Charles Manning at the Royal National Hospital in Stanmore. Many of our

older members will recognise these names!

Ailie set up the SSHG, registered it as a charity, and ran it from her dining room for several years before moving to an office in the Disabled Living Foundation, London. The organisation grew quickly and before we knew it we had about 3000 members from all over the UK and Eire. At that time scoliosis clinics were few and did not offer the kind of support we were able to give. Our early Trustees were Ailie, myself, Isobel Gray, Andrew Minns, and Miss Min Mehta, FRCS, who used to treat babies at RNOH Stanmore. Pauline Grey and Brenda Sullivan joined us to help Ailie as the organisation got very busy, and it was a great little team. We used to hold regional meetings, much as we do today, and our newsletter appeared four times a year and was written by Ailie. As we expanded our remit and activities we decided to change the name to Scoliosis Association (UK). We also moved to Iwebury Court. There Denise Aulsbury joined us and is still with us today. She and her husband Mick have helped us out on many occasions completely voluntarily.

SAUK could not have done as much to help people with scoliosis, their families, and their friends without the help of our many volunteers. Quite early on we recruited members from around the UK who were based



in the NHS areas at the time. People who wanted to be put in touch with others with similar experiences were, and still are, referred to their local representative who helps them by matching their needs with those of others. Originally called Regional Secretaries, our Regional Representatives as they are now known also do a lot of fundraising for us and hold meetings for their area. Many areas have more than one representative and now we hold training days for them every two years.

Our Trustees play a vital part in our activities. Anita Simonds is one of Dr Zorab's successors at the Brompton Hospital. She has written our booklet on pregnancy and scoliosis and is a world renowned practitioner and researcher. Thanos Tsirikos is a scoliosis surgeon in Edinburgh, which at present is the only centre in Scotland that treats scoliosis patients surgically. Carol Richards is the mother of a daughter with scoliosis and a long time Trustee. She designed and entered a scoliosis garden to the Chelsea Flower Show some years ago to raise awareness of the disorder. Linford Christie, who was an active Olympian runner at that time, opened the garden for us, which was a great success. Susannah Kraft has scoliosis and a family history of the disorder. She is marvellous at helping out with financial matters and much needed. Stuart Spencer and myself did research into scoliosis,

as I mentioned before, and our latest recruit Nicolas Jones is one of Ailie's grandsons and a doctor of medicine.

One of SAUK's main aims from the beginning has been to raise awareness of scoliosis and one of Ailie's many projects was to do just that. About 20 years ago Ailie applied on behalf of SAUK for a lottery grant and was successful. This allowed us to have three parts to the project. The first was a schools teaching pack, which was part of the biology syllabus and taught pupils about scoliosis. It was so successful that many schools asked for further packs the following year. The second part was a wonderful exhibition of photographs taken by Patrick, Lord Lichfield, of people with scoliosis, celebrities, and a scoliosis surgeon. The exhibition had a marvellous launch in London, which was attended by many of the celebrities and Lord Lichfield. It then travelled to Salford, Edinburgh, Belfast, and Cardiff. <https://www.sauk.org.uk/about-us/our-history> The third part was a letter to over 30 000 GPs telling them about SAUK's work and urging them to refer patients to scoliosis centres for assessment and treatment. This all took place in 2001-02. We were very fortunate to have Lord Lichfield as Patron at that time, until his death. He had his studios near SAUK's office and Ailie walked in one day and asked him to be a Patron. His reply was 'what would I have to do?', implying he

Linford Christie, Ailie Harrison, Min Mehta, Carol & Hannah Richards, and Laura Blows

was very busy, to which Ailie replied 'nothing at all!' However, he did come up trumps for us in our awareness campaign.

Our latest project on raising awareness is a collaboration with the Royal College of General Practitioners, conceived and organised by Nick Jones to incorporate a module about scoliosis in the GP training programme. SAUK has been very fortunate to receive some large legacies lately and we have been able to fund this venture from those. We have also set up a fund from the legacies to help people with travel expenses, which can be very high, and purchasing of items such as equipment, known as the Hill, Pedder, Minns fund. Our present National Director, Claire Curley has been instrumental in getting these projects off the ground.

SAUK has grown and expanded its activities tremendously and I have been able to touch on only a few here. None of it could have been achieved without the fantastic support of our members and some generous organisations. SAUK will, I hope continue to serve its community to the best of its ability for many years to come. One big thank you from us all to you all for your wonderful efforts and strength in coping with scoliosis.

COPING WITH PAIN

Masood Shafaty
Consultant Spinal Surgeon
Nottingham University Hospitals



Adult degenerative scoliosis is a common condition,

thought to affect about one in 3 adults. In most people the condition affects all three planes, ie, sideways (scoliosis), front to back (kyphosis) and cross-section (rotational). Occasionally in some degenerative conditions, one vertebra slips forward or sideways from the one below.

How does degenerative scoliosis arise?

In most cases, degenerative scoliosis happens out of the blue with no pre-existing spinal conditions, in which case it is called de-novo scoliosis. In other circumstances, degeneration (wear and tear) occurs in someone who is known to have had childhood scoliosis. Conditions can also develop after previous spinal surgery either at the site of that surgery or above or below it. Whatever the form, the underlying cause is malalignment of the spine.

Why does it develop and what is degeneration?

The process of degeneration is a fact of life. Just the same way that skin becomes wrinkled, hairs become grey, other tissues of the body including spine will undergo degeneration. The speed, pattern, and extent of degeneration varies according to each individual and is determined by the interplay of the genetic make-up and environmental factors. Some 90-

year old spine may not show any sign of degeneration whilst the spine of a 40-year-old may be degenerate from top to bottom. Some environmental factors such as heavy physical jobs and smoking have shown some association with this, disorder but we do not have all the answers.

Does spinal degeneration always cause degenerative disease and if not, why?

The pattern of degeneration in the spine is not always symmetrical, similar to the way shoes wear out. It is not completely understood why but, in some individuals, discs are worn out before other small joints of the back (facets) and sometimes the discs are worn out more on one side than the other. This pattern may be influenced by the way that we are programmed to walk, carry things, or do tasks. Whatever the reason if several discs of the spine are worn out on one side more than the other side it is natural for the whole spine to lean to one side. This is an extremely simplistic way to look at spinal conditions because other factors such as protective muscular spasms or leaning forward or sideways to relieve nerve compression may make the spine look curved.

Is degenerative disease a dangerous condition and is it likely to progress?

Generally, it is neither dangerous nor sinister unless associated with other conditions or if there is serious compression

of nerves or spinal cord, which is not very common. That said, the risks depend on the size and type of the curve. The curve in degenerative conditions is often stable and progresses very slowly, if at all.

Is degenerative disease in adults always painful?

Degenerative disease could exist for many years without the patient knowing about it and is discovered when the patient is investigated for other reasons and the curvature of the spine is picked up. It is, therefore, reasonable to assume that scoliosis may remain without any symptoms for many years. What triggers the symptoms is not entirely clear.

What do symptomatic patients with degenerative disease present with?

The most common complaint is pain which in terms of severity could range from minor discomfort to severely disabling and in terms of character could take the form of a minor annoying dull ache, to sharp stabbing, to burning. Location of the pain could be around the area of maximum curvature or in areas or joints where compensation is taking place to balance the body upright. It could also present as sciatica type pain (pain caused by irritation or compression of the sciatic nerve) in the distribution of a nerve or nerves which, as a result of the combination of wear and tear and curvature, have been pinched. Other complaints may include numbness or

weakness in the distribution of the pinched nerves, loss of height as the discs lose their height and the curve folds on itself, or simply appearance of the curve itself becomes unacceptable.

What could be the cause of pain in this type of scoliosis? And is pain a sign of continuing damage leading to my back crumbling?

As I mentioned above, degenerative scoliosis is not always painful but when pain is present – like all pains – it is perceived as a sign of damage. However, the pain associated with degenerative scoliosis, in the absence of other conditions, is mostly not a sign of continuous damage nor an indication that the spine is crumbling. This pain can be attributed to various causes directly or indirectly related to the condition and depending on the cause, pain can present with different characteristics, patterns, severity, and location. They include but not limited to the following circumstances:

1. Pain of muscular origin can take the form of muscular fatigue, exhaustion, overwork, or protective spasm. When

severe curves. Under these circumstances, efficient line of gravity falls either in front of the body called sagittal imbalance, or side of the body called coronal imbalance or combined called global imbalance. Under these circumstances, the muscles have to work much harder to maintain an upright posture and therefore express the unhappiness of their overwork by pain and spasm. This pain that a lot of people find difficult to describe can be sharp, stabbing, catching, or continuous pressure like someone digging a blunt object in that area.

Initially and if adjacent parts of the spine or nearby other joints such as hips and knees still are supple and have flexibility, the patient compensates, and this is called compensated imbalance. For example, if the line of gravity falls in front of the body, in order to maintain a forward line of vision, the patient may have to extend their necks and hips which in turn leads to pain in the back of their neck and at the front of their hips. When the limit of this mechanism is reached then the patient has to bend their knees, which leads to pain felt in their thighs and at the front of their knees. In rare circumstances, the whole compensatory mechanism fails - known

stenosis (the literal meaning of stenosis is the abnormal narrowing of a passage in the body). Spinal stenosis can cause nerve pain described above as well as a different type of pain called spinal claudication. This is an unpleasant cramping pressure felt in the lower back, buttocks, the back of the thighs and calves when standing and walking and relieved by rest and sitting. Although the symptoms are often symmetrical (felt on both sides equally) the pattern and severity vary in different people. The pain due to pinching of the nerves sometimes can be associated with tingling and pins and needles, sometimes numbness and much less commonly, weakness. Although any of the above can occur in the absence of scoliosis, degenerative scoliosis is commonly associated with them. Pinching and irritation of the nerves can also happen due to the condition alone. When the spine is bent sideways, the nerve holes on the side where the spine is bending (concavity of the curve), naturally get narrower which, if severe could pinch the nerve. Conversely, nerves on the side where the curve is bending away from (convexity of the curve) can be stretched leading to similar symptoms without any physical pinching.

3. Pain due to actual degeneration of the spine in the area of the curve. Although the process of wear and tear is slow and often not painful, occasionally this process, for some individuals, becomes irritated and inflamed and therefore painful. The spine or vertebral column is formed by joining of individual bones called vertebrae. The adjacent vertebrae are joined by discs in the middle of the front of the spine and two small joints on either side of the back of the spine called facets. The pain can come from the inflamed discs, facets, or both. This pain is likely to be a continuous ache or even pain with stiffness which presents at both rest and movement. There may be some night discomfort and turning in bed can also cause pain. There may also be an associated protective muscle spasm.

4. Mechanical and instability pain. Occasionally when scoliosis is severe and the trunk gets shorter as a result of wear and tear, the patient tilts on one side. Consequently, the lower ribs on the concavity of the curve knock on the top of the pelvis and this causes a mechanical pain. This pain is called costo-pelvic impingement. In such cases, there

“Generally, adult degenerative scoliosis is neither dangerous nor sinister”

the spine is straight, the line of gravity passes through the energy-efficient line for muscles to maintain the posture in different activities. However, when there is a spinal condition even when mild and there is no significant disturbance in the line of gravity, muscles on either side of the spine have to work differentially to maintain the upright posture, which leads to exhaustion and overwork of a group of muscles. This in turn presents like a dull ache with a bit of burring or hot feeling or even numbness or odd sensation in that group of muscles. This feeling is typically not felt when lying down or resting, or early in the morning, and is felt mostly at the end of the day when standing on your feet for a length of time. Carrying shopping, rucksacks and other weights often make it worse. Muscle overwork and pain becomes worse with more

as a decompensated imbalance in which a person cannot maintain an upright balance even with help.

2. Pain due to pressure on a nerve is called neuropathic pain. The process of wear and tear can sometimes narrow the routes taken by individual nerves travelling from the spine to supply different parts of the limbs. As a result, these nerves can be pinched. The pain as a result of this is a sharp, annoying, and unpleasant and sometimes makes people nauseous. The pain is typically continuous but is worse at rest which is why people with this pain stand and walk around to relieve it. It can also cause sleep disturbance. It may cause protective muscle spasm in the back. Degeneration can also cause narrowing of the whole of the spinal canal leading to a condition called spinal

will be no space between the pelvis and the ribs. As explained earlier, occasionally one vertebra may start to slip either forward or sideways called anterolisthesis and lateral listhesis respectively. When the slippage is excessive, sudden movement in line with the direction of slippage causes a sharp pain followed by longlasting muscle spasm and a dull ache.

5. The types of pain described above need to be distinguished from those due to more serious underlying problems, which when present require more urgent attention. These types are:

If the pain is unrelenting and continuous, day and night with sometimes history of loss of appetite and weight loss or if there is a history of previous treatment for a tumour or cancer;

If the pain is associated with fever, and night sweats;

If the pain is associated with a recent history of fall or accident after which the pain has become worse;

If the pain is associated with significant numbness and weakness in one or both limbs, particularly if there is a history of disturbance in bladder and bowel control.

Thus, adults with degenerative scoliosis may have one or a combination of different types of pains. The problem remains how the problem can be explained to the professionals and how professionals can work out what type of pain is being described and try to relate that with the patient's history, examination, and investigation. This remains the most challenging part of trying to help a patient with degenerative scoliosis. Pain is entirely subjective and for that reason people cannot often fully describe the physical, emotional and psychological burden that their pain has put upon them. More frustratingly for them is when their treating

professionals show signs that either they do not understand their description of pain or worse they do not believe them. More recently in some pain clinics, there has been a move towards the use of images to help patients describe their pain.

What is the best treatment for degenerative scoliosis?

In the management of such disease, one size does not fit all and the best treatment for each patient is the one that is individually tailored for that patient having taken into account the symptoms, condition, fitness, and patient's choice.

“I have tried physiotherapy and did not work. How could you correct my curve with that?”

Physiotherapy as part of a comprehensive physical therapy programme remains the initial and mainstay of treatment for degenerative scoliosis in adults

As mentioned above some symptoms in this condition relate to muscular overactivity and spasm as a result of imbalanced posture. Although physiotherapy will not be able to correct the curve, it will improve the tone and strengthen the muscles to cope with the condition better. Physical therapy, however, needs to be supervised at least initially so that it takes into account characteristics of that individual so that if the patient cannot cope with one set of exercises a different regimen is tried. Furthermore, sufficient time needs to be allowed for improvement to be perceived. It will also need to be of multimodality including massage and local treatment. Along this line, yoga, pilates, swimming and overall remaining active have shown to help. Along with physiotherapy, sometimes

psychotherapy including cognitive behavioural therapy is helpful.

“Are you saying I am imagining all of this?”

There is no doubt that degenerative scoliosis in some cases can cause disabling pain but why some people cope with this pain better than others may at least in part have an explanation in the patient's psychological well-being and coping mechanisms.

Continuous pain combined with a fear of the unknown together with a sense of getting old and hence a failing body is known to lead to psychological maladjustment and even clinical anxiety and depression. That is why combining physical and psychological therapy is effective in treating chronic pain. Some people can simply cope with the pain and some people find it difficult for the reasons above. It doesn't mean you're mad but it is how the mind works. Everybody is different.

“By taking pain killers, am I going to mask the pain so that



“Pain is entirely subjective and for that reason often people cannot fully describe... [the] burden that their pain has put upon them”



“Big surgery for ADS is not the inevitable end... there are many other ways that patients’ symptoms can be helped and controlled”

be avoided if there is a history of severe asthma, blood pressure, or gastric ulcer. Your GP is the best person to be consulted in this respect..

radiofrequency treatment of facets can give some longer-lasting pain relief which can be repeated in the future.

“Can bracing help? Can it correct the curve?”

!Is big operation the only way out or I can be helped with a smaller surgery?”

Overall bracing has not proved as effective in adults as when it is used for scoliosis in children. In severe rigid forms of scoliosis, its usefulness is very much in doubt since it can cause pressure problems and sores and sometimes respiratory compromise in at-risk individuals. In some milder and slightly supple cases, it can help with pain and spasm of muscles; however, long-term use of a brace can make the muscles weaker and hence be counterproductive with physical therapy, which is trying to build and improve the muscle condition. Bracing is also reported by some patients to control some of the sharp pains experienced when there is lateral or anterior slippage associated with their condition. Bracing, however, is not effective in the presence of spinal stenosis and can make the symptoms worse because brace takes away the protective and relieving mechanism of leaning forward.

There are occasions such as those described above, in which the most troublesome symptoms can be tied to a localised problem. Injection therapy sometimes can help to determine that.

I can damage my back further without realising? Do the painkillers have side-effects?”

Sensible and safe use of painkillers is beneficial and effective in controlling pain in this group of patients. No evidence to date has shown that the use of painkillers will mask the pain, nor has it shown that it will lead to more structural damage. In fact, to be able to comply with the physical therapy programme, it is often recommended that the patient should go on a short course of pain killers during the initial period. Overall input from a multidisciplinary team is helpful. The type and duration of painkillers depend on the type of pain, as well as the patient’s medical history and previous use of pain killers.

A general rule of thumb is to keep it simple, regular, and short course. Strong drugs such as opiates (morphine family) should be avoided, particularly over a long period.

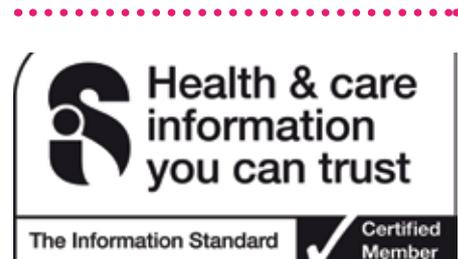
All painkillers have side-effects and certain cautions need to be exercised to reduce this risk. For example, non-steroidal anti-inflammatory drugs (NSAIDs) should

“Can I be helped in any other way?”

With degenerative disease, sometimes a specific type of pain related to a specific area predominates and if it was not for that, the rest of symptoms arising from the condition itself can be coped with. For example, a nerve being pinched in one area or a few facets in the concavity of the curve being overloaded and particularly inflamed and irritated. Under these circumstances, a targeted nerve root block or a diagnostic facet medial branch injection can help. If the medial branch block is positive in getting rid of pain, then a procedure called

Under these circumstances, a localised decompression (taking the pressure off the nerve or nerve) plus or minus a localised limited fusion surgery can be extremely effective in getting rid of or limiting most of the symptoms.

In summary, big surgery for degenerative scoliosis in adults is not the inevitable end. Although corrective surgery can be effective and successful, it is associated with a high level of serious complications, which is not acceptable to some if not most patients. There are many other ways with lower risks that patients’ symptoms can be helped and controlled with allowing the patients to have a reasonable quality of life before resorting to corrective surgery.



Sources are available from SAUK on request. This article is an Information Standard medical article. There is more information about the Information Standard on our website, at www.sauk.org.uk/about-us/the-information-standard.

REGIONAL REPRESENTATIVE UPDATES

Lynda Williams, South Wales Representative

SWS Cymru volunteers outside Welsh Government



Saturday 29th June saw a group of volunteers from SWS Cymru head off to Cardiff Bay armed with lots of goodies. We spoke to over 500 members of the public and we were amazed by the very positive response we had!

We had a group photo with friends who are affected by scoliosis on the steps of the Senedd - Welsh Assembly Building. We publicised our aim to encourage the Welsh Government to take onboard our suggestion to email a simple booklet into schools and ask them to send the booklet to parents of children in years 6, 7, 8 and 9. The

Information booklet explains what scoliosis is and how easy it is to detect, using the Touch Your Toes To Diagnose Test and explains that if they think there is a problem to go to their GP.

This we hope will empower parents who often ask 'Why didn't I find it earlier?' It will also allow the child to have a choice of treatment. We know that if a child chooses to wear a brace, they can often stop the curve progressing and in some cases children have an improvement in their curve. Even if the brace is not successful it helps to make surgery less complex.

Gemma Beer, South Wales Representative



To celebrate International Scoliosis Awareness Day, Gemma organised a cake sale at her work, JCP Solicitors - Cardiff office.

Her efforts raised a fantastic £50 for SAUK. Everyone at JCP Solicitors enjoyed eating cake (every day for a week) and raising money for a fantastic cause at the same time.

Janice Ohlson, North East England Representative

Janice organised a coffee morning which she hosted in her garden. It went really well, and the sun shone! It was so lovely to see everyone chatting together, sharing their scoliosis stories and experiences, and supporting each other through their very varied scoliosis journeys. We had lots of cakes, bags of ISAD sweeties, and a raffle, and we raised £303 for SAUK. It is so lovely to see the friendships growing in our group with each event we host, and to see young and old joining together to support each other.

Guests at Janice's coffee morning



EXERCISES FOR ADULT DEGENERATIVE SCOLIOSIS

Francesca Howes
Extended Scope Physiotherapist in
Spinal Surgery
The Royal London Hospital, and Practice
Manager of Forest Hill Physiotherapy



Adult degenerative scoliosis (ADS) is a condition in which the spine develops an increased lateral (side-ways) curve secondary to degenerative changes within the spine.

It can arise through progression of an already existing scoliosis from adolescence that was not severe enough to warrant treatment at that time, or through the degenerative processes in a spine that was originally straight. As the joints degenerate they cause a malalignment in the back, resulting in a bend or curvature.

This malalignment can cause back and/or leg pain because of muscle fatigue (when muscles get weak, painful, and tired), and nerve impingement and may lead to a condition known as lumbar stenosis (a narrowing of the spinal canal causing compression on the nerves in the lower back). Stenosis can lead to sciatica (leg pain) and a feeling of tiredness in the legs.

Degenerative scoliosis is most common in the lower back and most frequently occurs in people over 65. It can be treated conservatively through the use of medications, injections, physiotherapy and exercise, or with surgery. Surgery is usually the last option if the scoliosis is severe, conservative treatment has failed, and quality of life is poor.

What is the role of exercise?

Exercise is important in non-operative management as well as in post-surgical recovery. It helps maintain or improve activity levels and manage symptoms better. It aims to

strengthen the muscles around the spine and take some of the pressure off painful areas to potentially achieve some pain relief. It can also help maximize mobility and strengthen the areas surrounding the lower spine, such as the neck, shoulders, pelvis, and hips. This is particularly important in those undergoing surgery, which often involves fusing some of the vertebrae (spinal bones) together with metalwork to prevent further progression of the curve, at the expense of mobility in the spine.

What exercises should I do?

Regardless of whether conservative or surgical treatment is taken there are five general exercise principles everyone should follow.

1. Remember the three S's: Strength, stamina, and suppleness.

Strength training develops the strength and size of muscles. In degenerative scoliosis it helps prevent fatigue and wasting of the spinal muscles that maintain good posture and should be included as part of all exercise regimens.

Stamina, or endurance exercise helps improve your cardiovascular fitness. Performing it regularly increases the efficiency of the heart, promotes better mental health, and increases life expectancy. In scoliosis, more severe curves can affect the ability of the lungs to expand and make you feel out of breath when exercising. Many people will therefore avoid it, which can have the detrimental effect of weight gain, lethargy (tiredness), and secondary health problems such as

high cholesterol. It is important to do cardiovascular exercise, regardless of your level of activity - for example, by doing aerobic exercise such as using a stationary bicycle or stair climbing or activities like swimming and brisk walking.

Suppleness, or flexibility, refers to the range of movement of joints. Because of the lateral curve, people with degenerative scoliosis often end up with some muscles becoming shortened (tight) and others lengthened. Exercises to develop suppleness include gentle stretches for the tight muscles and working joints through their range of motion.

2. Stick to low impact exercise

As a general rule, putting excess pressure on your spine is best avoided. Consider replacing heavy weightlifting and high-impact sports and exercise for low-impact exercise such as, swimming, gentle yoga and/or bicycle rides.

3. Pacing

Learning to pace activities is an important part of treatment, since most people tend to do either too much or too little for too long. Changing habits is hard but important in improving activity levels.

4. Aim for exercising two to three times a week

General exercise guidelines recommend that adults of all ages should undertake moderate aerobic activity for 150 minutes a week and strength exercises twice a week.

5. Make it enjoyable

Exercise should be a lifestyle habit and maintaining this long-term is far easier if you enjoy it. Don't try swimming if you don't like getting wet and can't swim, and don't spend lots of money on a bike if the idea of cycling in the colder months fills you with dread. Think about your interests and lifestyle and pick exercises that fit around them. For example if you're an early riser, plan exercise in the morning. If you prefer social activities, look into group classes in your area. Consider researching your local leisure centre or look on the AgeUK website, which have lots of programmes for the over 60s.

What exercises can you do after scoliosis surgery?

After surgery, it is often necessary to make some lifestyle changes to minimise your recovery time. For instance, bending, heavy lifting and twisting should all be avoided in the weeks immediately following a spinal fusion procedure, because your spine and incision will need time to heal.

Later in the recovery process, you can start to consider your regular exercise routine, which should be under the guidance of your surgeon, who will be able to tell you when you are sufficiently healed, alongside a physiotherapist who can guide you back to more physically demanding exercises and activities.

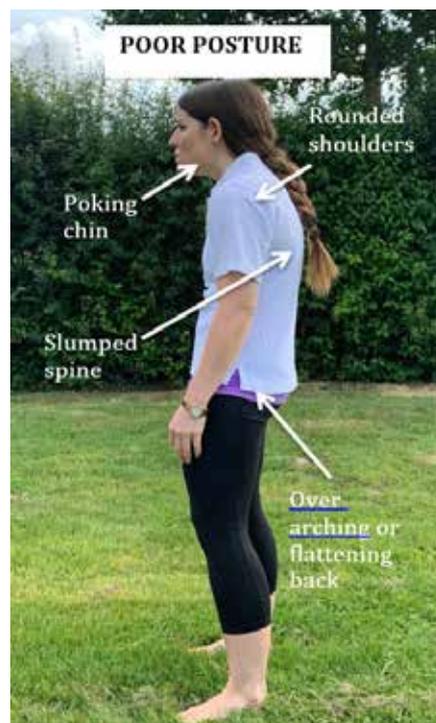
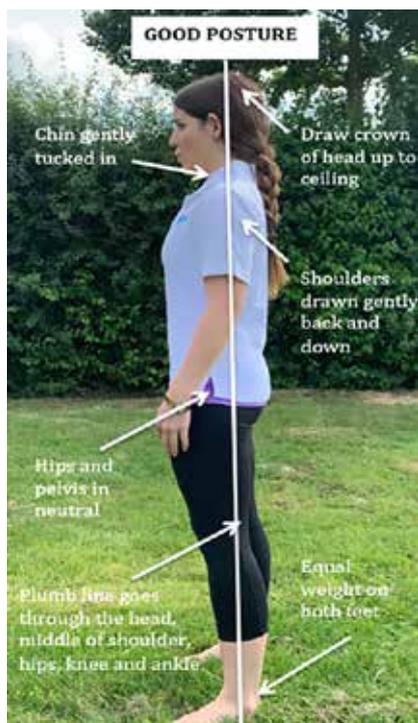
Several exercises for degenerative scoliosis are available

Posture practice

Poor posture uses lots of energy, meaning our bodies need longer for rest to recover. Good posture in degenerative disease might be difficult. Often people will lean forwards and sideways and to avoid doing this they might bend their knees and tilt the pelvis backwards.

Ideal standing posture involves having weight evenly spread between both feet. That way each joint is loaded equally. The neck should be straight, the hips level, and the pelvis in neutral rather than tilting forward or backwards. The knees should be straight or if there is a leg length difference, then one knee straight, the other slightly bent. Check your posture regularly in the mirror, or get others to check it for you. Think about drawing your diaphragm up into your rib cage to

maintain an upright position, without straining through your neck or low back. With scoliosis it may be difficult to meet the ideal posture but it is advisable to get as close to it as possible and practice regularly throughout the day.



Pelvic tilts

The pelvis is at the bottom of the spine, where the legs are attached. Keeping the pelvis neutral means it is not tilting forward or backwards. Imagine the pelvis is a bucket of water. If the pelvis tilts forward the water would spill out of the front of the bucket and if the pelvis tilts backwards water would spill out of the back. Only when the pelvis is neutral will the bucket be level and no water spill out. Aim to practice this exercise regularly throughout the day. For those who have had a spinal fusion, please check with your surgeon that you are ok to do this exercise.



Supermans

It is common to have weak core muscles with degenerative disease. Core muscles include the deep stomach and back muscles as well as gluteal (group of muscles which make up the buttocks) muscles and this exercise targets some of these.

How to do it: position yourself on your hands and knees on a stable surface. Keep the spine in a neutral position without over arching or bending your spine. Draw one arm forwards keeping the neck straight with the eyes focused between the hands. At the same time slide the opposite leg back along the floor and if you can, lift it up to hover off the floor. Hold for 3 seconds, slowly lower and continue on the opposite arm and leg. Perform 10 times and consider up to 3 sets in one sitting.



Sit to stand

Sit to stand is another exercise for strengthening your gluteal and leg muscles. It is a functional exercise we do often throughout the day but also an easy one to do whilst watching TV or reading the newspaper.

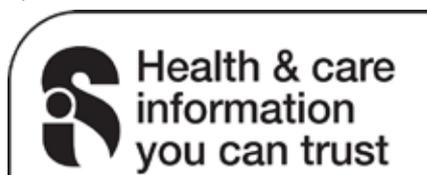
How to do it: sit forwards in a chair with your feet shoulder width apart and flat on the floor. Hold your arms across the chest to avoid using them. As you breathe OUT, bring the chest slightly forwards over your knees, push the feet down into the floor, squeeze your bottom and stand up. Slowly return back to sitting, focusing on a controlled landing. Repeat 10 times and consider doing three sets of the exercise. To make it easier or harder alter the height of the sitting surface for instance by using pillows.



Scapular squeezes

Because of changed posture caused by scoliosis the neck tends to poke forwards causing tight muscles on top of the shoulders, and around the back of the neck, leaving the deep muscles at the front of the neck and the middle of the shoulder blades lengthened and weak. This exercise aims to strengthen these muscles.

How to do it: stand in front of a mirror with your elbows bent, palms facing up. As you breathe out, rotate your hands out to the side and gently squeeze your shoulder blades back and down towards your opposite back pocket and draw your chin inwards as if creating a double chin, lengthening the neck and drawing the crown of the head up to the ceiling. Hold this position for 5 seconds, relax and repeat 10 times.



Tandem walking

Balance naturally declines with age and people with scoliosis often have poor balance caused by altered posture, which can make daily tasks difficult. Tandem walking is a dynamic balance exercise, meaning it works balance on the move, rather than just holding one static position.

How to do it: try to walk in a straight line on the floor, placing one foot in front of the other, heel to toe or just in a straight line. Do it next to a wall for support if you generally struggle with balance. Practice for a few minutes a day. As it gets easier try it whilst turning the head from side to side to further challenge your balance.



Sciatic nerve glider

Some people with degenerative scoliosis have leg pain caused by compression on the nerves exiting the spine. If this is the case, nerve-gliding exercises can help lubricate the nerve and improve its mobility, particularly after being decompressed by surgery.

How to do it: while sitting hold onto one of your legs. Flex the head forwards and flex the toes of the supported leg up to the ceiling. Then slowly extend the head gently up, straighten your knee and point your toes on that same side. Repeat the action and flow in and

out of the two positions continuously for up to 45 seconds. Focus on the symptomatic side where you get leg pain, which for some people might be both legs. If any tingling or numbness in the legs occurs, stop the exercise.



Side bending

Side bending is only for those who have not had surgery and works to strengthen the spinal muscles needed to maintain good posture.

How to do it: Position yourself lying on your side with knees bent and weight on your forearm, directly under your shoulder, hand facing forwards. Lift through your shoulder girdle and then lift through your waist to hover the bottom just off the floor if you can. If you can't fully lift it just try to activate the same muscles. Hold this position for 5 seconds, relax and try repeating up to 10 times. As it gets easier consider holding the position for longer. Do it on both sides.



It is normal to get some mild discomfort when practicing new exercises but if any of these exacerbate your pain levels for longer than 24 hours please discontinue. Finally, if you have degenerative scoliosis it is worthwhile being reviewed by a Physiotherapist who can assess your posture and physique and prescribe exercises tailored to you according to your activity levels, pain levels, and lifestyle.

MEMBERS' STORIES

Living with scoliosis as an adult

In response to the feedback we have received we made this issue of Backbone an adult-focused issue, so we asked members to share their experiences of living with scoliosis as an adult. We wanted to gather a wide variety of stories and portray honest accounts of people's experience. We are so grateful to everyone who sent us their story. Unfortunately we haven't been able to include all of them in this issue, but we will hopefully be able to use them in future issues of *Backbone*. Some of the accounts have also been edited slightly because of space restrictions, and names of specialists and companies have been removed.

This year I reach the age of 72, 58 years from when I was diagnosed with Scheuermann's disease, a developmental disorder of the spine resulting in upper back kyphosis.

I was referred to an orthopaedic consultant aged 14, when my mother noticed I was slouching and after undergoing examination and X-rays was prescribed physiotherapy. An operation was not an option in those days.

Physiotherapy took place weekly, beginning for some reason with placing my feet in warm wax baths, which was quite pleasant and apparently helped with my flat feet. I also had to walk up and down whilst the physio observed and corrected my posture, and I was given a series of exercises to help correct the curve in my back.

By chance, at the age of 17, I discovered osteopathy. An elderly man was practising osteopathy in the same building where I had a temporary job. This treatment had a noticeable effect on my posture and the curve of my spine, and when I had my next X-ray I remember the consultant singing the praises of how physiotherapy could have a strong effect on scoliosis. I did not have the courage to tell him I had been seeing an osteopath since at that time it was not an accepted practice in the medical field.

Around that time, I had been accepted for nurse training and had to undergo a medical by my GP who was reluctant

to give me a clean bill of health, but I persuaded him I would not have any time off due to illness with back problems, if he passed me fit for training. A promise I kept throughout my nursing career with the help of osteopathy.

Fast forward to the age of 62 and after several major surgeries, one involving removal of several ribs, my scoliosis deteriorated, badly resulting in a Cobb angle of 65°. I had problems with ordinary activities, such as household chores/ walking distances/ gardening, DIY, and was taking painkillers on a regular basis. This despite turning to my tried and tested osteopathy

I decided that I would attend a Schroth Clinic in London for an intensive physiotherapy course of treatment. They have developed a unique programme using the Schroth method and it is a central part of their treatment. They also use other well-established therapeutic techniques such as, Pilates amongst other things. By this time, I was a far from fit 68 year old, exercising alongside youngsters who were 15-20. I must confess I found the 4 week course onerous, exercising 5 hours per day, 5 days per week. Consequently, by the end of week 3 I became ill and had to give up. But my scoliosis had improved, the pain reduced, and I had an improved quality of life returning to some normal activities.

Scoliosis has not until recently interfered with anything I wanted to do at work or socially, although I have always been conscious that my back is not straight, and I have been careful with my choice of clothes. Apart from osteopathy and at times acupuncture, exercise has been part of life for me including walking, gardening, yoga, Pilates, dancing (when I was younger!). When I retired I found visiting the gym an enjoyable experience, with a programme tailored to strengthening my back and I also joined a Pilate's class which improved my muscle strength and flexibility. My recent discovery is the Alexander Technique which has helped to improve my ageing posture and recreated an awareness of how I walk, sit, and undertake other activities. I have no

doubt that I will continue to explore any technique that will keep me active as I advance further into old age.

Sue Olver

My parents married in 1938 and waited till almost the end of the war, 1943, before having me. I have been very lucky and had a very happy and fulfilled life gaining a degree in fine art which has led me to a teaching career that goes on today.

My degenerative scoliosis was almost found by accident in 2015. I was having severe pain in my lower back and it extended down my right leg. It seemed no one could find the answer to the case. It was only when I was referred to the urology department, with a possible diagnosis of kidney stones, that an X-ray showed degenerative changes in the lumbar spine. Although a small kidney stone was also diagnosed it was not thought to be the cause of the pain and I was further referred to the spinal unit at the Nuffield Hospital, Oxford. There I was given a series of appointments with the physiotherapy department to help me cope with the pain. At this time I was also prescribed diclofenac to be taken as a suppository to ease the pain in my lower back and down my leg. I hated taking painkillers but found I could not really get a good night's sleep without it. Throughout this time, I continued to lead a very active life and indulge my great passion for gardening. I could not do long sessions and sometimes I overdid it and paid the price with much pain. A Pilates class was recommended for me but I found that it gave me more pain. I think this was because I was not thoroughly examined before the class to find out what exercises would be particularly good for me. In the end I paid privately for a highly recommended physiotherapist in Henley. The physiotherapist threw me a lifeline. Her straight talking frank approach was wonderful. After an examination she gave me a set of exercises that particularly suited me.

By 2017 the pain was getting worse and I took myself off to the GP. She kindly referred me to the Nuffield Hospital

and after waiting nearly 6 months for an appointment I was seen in October 2017. After an initial X-ray the specialist confirmed degenerative scoliosis with apex L3/L4 and a Cobb angle of 48°. This had clearly got worse since the X-ray of 2015 had shown a Cobb angle of 22°. The consultant recommended a nerve blocker for the pain down the right leg. This was done at the hospital and eased the pain in the leg tremendously.

As the curve in my spine became more pronounced I revisited the doctor to ask for some new insoles to be made for my shoes. Initially I was referred to the local podiatry clinic. They gave me some off the shelf insoles which made the pain in my back worse. I pushed for some custom made insoles and these new insoles really helped my walking. It was around this time that I told myself I must find out more about the condition of degenerative scoliosis. I had never heard of this before, thank goodness for the Internet. There was so much about this illness and all the treatments that were possible, but more importantly I found SAUK. One phone call with, a lovely lady on the end of the SAUK phone and I was joined up and had access to comforting information from others who had scoliosis. Their magazines have provided further details of the condition. The list of others in the same position as myself, with contact details has been particularly good.

At the first appointment the surgeon fully explained all the options open to me with this condition, but at that point in 2017 I felt I could go on managing without surgical intervention. Throughout this time I had pain but adopted a positive outlook thinking that I could be much worse. I continued the exercises almost every day.

All my working life I have been an art teacher retiring from school teaching in 1995 and doing bits of adult teaching locally, writing a book on drawing, and painting on the iPad in 2015, and teaching art on cruise ships. I always did my exercises in the gym in the mornings!

The hospital was great and called me back every 6 months, and I had another nerve block which helped so much with the pain down the leg in 2018. I continued much as before but felt that that the shift of my body to the left was worsening so when I went for my 6 monthly appointment to the hospital I felt I needed to discuss surgery. The surgeon explained most clearly the surgery involved if they were to correct the curvature of the spine using rods. I very much valued his frank approach,

and that this showed most clearly the seriousness of the operation. My reasons for thinking about surgery were to remain active for the latter part of my life and have the operation while I was fit and well.

The consultant ordered a CT scan to look at bone density to see if an operation would be possible. Many thoughts about the operation went through my head. I absolutely love my gardening and think it is a very important part of my life and spiritual well-being. The 6 month recovery time is also quite daunting, normally very active and busy I am not sure if I could cope with this period of enforced rest. All has to be weighed up carefully in the light of long term fitness after an operation.

Visiting the hospital again for the results of the CT scan confirmed that the bone density was fine to do the operation. However the consultant thought that at this moment I was sufficiently fit and well with good mobility to delay the operation. He inferred that age was not the important factor but fitness.

At present I will continue with the exercises, and try to walk more. I will continue to visit the physio regularly to check I am doing the exercises correctly and if necessary change them. Presently I feel I am doing all I can to help myself. However, to some extent we are all powerless against nature and in the future I may need to succumb to surgery to make everyday life bearable.

Diana Seidl

Now 54 years old, I was born with a huge cavernous benign tumour of blood and lymph vessels with pockets of blood. It extends from my right thigh into my trunk, up to the diaphragm, engulfing my right kidney, and round to my right lower back. This lesion is unfortunately extending very slowly into the paraspinal muscles and also into the spinal canal.

I underwent several operations as an infant and young child mainly to remove cysts and to take biopsies. For some reason my right leg was a little longer than my left, possibly because of the increased blood supply. I was under the care of two consultants at the Manchester Children's hospital, one a general surgeon and the other an orthopaedic surgeon. I wore a small shoe raise on my left shoe.

The General surgeon, who I remember being a very nice man referred me to the Christie Hospital because he thought that my condition may benefit from



Diana Seidl painting

radiotherapy. It was 1977, and I was 11 years old. Radiotherapy was quite a new treatment back then and not as well understood and as precise as modern times. The treatment did improve the skin surface of the tumour and temporarily shrank it a little.

Over the next few years I continued to have check-ups. The tumour itself remained fairly static but I remember having a lot of back pain. The orthopaedic surgeon was sadly very arrogant and would not listen to me or my mum. I remember Mum once kicking the wall outside with frustration because he wouldn't do anything.

Eventually my GP sent me to another surgeon for a second opinion, I was 16 years old. This consultant sent me for an X-ray which showed quite a severe scoliosis. He arranged for me to have a Milwaukee brace fitted. This wasn't straight forward because of the tumour on my right thigh catching on the brace. I continued with my left foot shoe raise. I used to walk to school but was getting so much hip pain that it became impossible and my father started dropping me in the mornings and teachers would bring me home.

The orthopaedic consultant responded to this hip pain by changing me from the Milwaukee brace to a full body plaster cast! This made no difference to the pain, in fact it made it worse because I couldn't remove it to release the pressure on my hip. In desperation my GP referred me to see yet another orthopaedic surgeon in Edinburgh. This new consultant was very nice and he said from my X-ray he thought I'd finished growing and therefore I didn't need the cast anymore, I was ecstatic! He listened carefully to what my problems were and then did a very simple test. I stood with bare feet and he placed a block of wood under my left foot and asked me how it felt. I said it felt worse, so he put it under my right foot and asked again. This time it felt better!

It seems that the radiotherapy, which



John with his wife, Susan

dosed only half my spine resulted in my scoliosis and changes to skin and other connective tissue causing a flexion issue of my right hip which had also tilted badly. My bottom rib on the right side now rubs against the iliac crest of the hip bone. With all these orthopaedic changes it actually meant my right leg was functionally the short leg and therefore I'd been having the wrong shoe raised!

I continued to see the consultant every year for many years but an operation was out of the question because the tumour was too close to my spine cord. I now no longer attend clinics because there is nothing that can be done. I do still attend the Christie so that they can monitor the tumour which is still slowly extending and prone to swelling/bleeds which adds to my pain. My right kidney doesn't function properly because it's affected by the tumour. I have had kidney stones because of this and they caused the tumour to bleed through the kidney. I also have progressive iliopsoas spasm which is quite disabling at times.

All the problems I had growing up, had a huge effect on my self-confidence and body image and it took me a long time to get to grips with this. Thankfully I am much better nowadays although I'm still affected to some degree.

Despite all these problems I was a very determined person and have tried to live as full a life as possible. I played football, squash, badminton, swam, and in particular I cycled a lot! It was very difficult because I struggled to walk any distance and standing has always been difficult too, so cycling was easier for me. I cycled and camped all over the country and did numerous charity rides including John O'Groats to Lands' End and from Manchester to Lourdes. I've always enjoyed concerts, cinema, and the theatre. I worked for 26 years as a specialist podiatrist within a hospital

setting until I had to retire early because of pain and lack of flexibility. I loved my job, it was very rewarding and I miss the patients and my colleagues.

Since I've gotten older my orthopaedic problems have worsened. I don't have good flexibility and struggle to get comfortable in virtually any circumstance - ie, standing, walking, sitting, or even sleeping. I of course get a lot of pain which is to be expected all things considered, however, I still try to do as much as I can to enjoy life. Pain killers help but I also have regular massages which have considerable benefits. If I found I could no longer do something, I found something else instead! I can't walk or stand well, so now I have a mobility scooter. I can't play squash, badminton, or cycle anymore ,but I do swim and play table tennis, which helps me to retain some small amount of flexibility and fitness. I also still enjoy concerts, meals, etc. I usually find that as one door shuts another one opens. I'm not bitter and don't feel sorry for myself, I just make the best of what I've got!

Last and by no means least I have a wonderful supportive and understanding wife, Susan!

John Critchley

I am now 63 years of age and live with severe degenerative thoracolumbar kyphoscoliosis. I still manage to work a part-time position as a Ward Clerk in a hospital, and look after three grandchildren. Due to the severity of my spine now, I cannot have any further surgery, because I have been given survival odds of only 20%, and they couldn't guarantee I would be free of the pain.

I contacted SAUK and became a member because I was desperate for help. They put me in touch with other members, and gave the names of my local consultants.

In 2004, I underwent a spinal fusion with titanium rods covering L4, L5 and S1, as it was private at that time, I couldn't afford to go any higher. Whilst initially benefiting from the experience, over the time my scoliosis has worsened. I asked for referrals to specialist spinal units who dealt with specific degenerative conditions and was saddened to be informed that my curvature was so extensive that surgery was not really an option now. I agreed to try the CT S1 joint guided injections into the areas but sadly the relief only lasted 48 hours. At my recent appointment they sent me

to see a pain specialist to try and work a safe dosage of medication to control the pain.

Because of other health issues, I sleep in a chair, so the only relief I get is in the form of a hot water bottle, which does help until I move. I am determined not to let this condition control my later life, although it took some courage to write to you. Since I work, drive, and look after the grandchildren I cannot take a lot of medication. I was advised to use a walker, so I use my grandchild's buggy which enables me to do a little bit of shopping, but take that away and I can hardly stand in queues, let alone walk through a shopping centre. I have learnt to do the family shop by using loads of bags and not overfilling them. I hate the shape of my back as my spine protrudes out a lot now, and I often shut it in doors if I turn too suddenly. My clothes hang at strange angles, but still I keep going. It would be so easy to give up now and yes, some days I do feel the pain is unbearable, but somewhere I find the strength to live another day.

Gill Milstead

I was diagnosed with scoliosis in 2003, when I was 64 years old. Before then, I had had no inkling that anything was amiss. With hindsight, I realise that I did have certain minor difficulties with posture, but since I was generally very fit, I regarded that as something I needed to work on. I had ridden horses regularly for about 30 years and did all my own yard work and was in good health. The postural difficulties showed up when riding, as I was told I tended to collapse in the middle! That was probably the first sign and I was in my 40s by then. As a child, I had no problems at all, and nothing was found on any medical checks. I was always very active.

I went to see the GP because I felt I had a slight limp. I had a fall on the yard onto concrete, causing a bruise and hip pain, and although this healed, I thought it might be connected. I was puzzled, because my legs were definitely of the same length, so I thought it might be a hip problem.

The GP took about 10 minutes to come to his conclusion that I had scoliosis. My spine showed a noticeable curve when I touched my toes, and I could stretch further down my side on one side than the other. We discussed possible treatments, and decided that at my age I did not want to have an operation to correct the curve because it might cause more pain and I had none. I attended the local surgery for a physiotherapy

session, which I felt was of no significant value.

I was then referred to a consultant who X-rayed my spine, and declared that it was a curve of moderate severity, and ordered some physiotherapy for me. At the hospital, I was put into a stretching device, attached to the head and foot of a hospital bed. I was then given the device and told to use it at home for about 15 minutes at a time. Unfortunately, at home we had no bed-heads/footboards which were suitable for attachment. I attempted to attach it to the rails on the landing, but they were at too steep an angle. This caused discomfort, and so I eventually gave up and returned the device. I decided to rely on continual corrections of my posture and maintaining my fitness.

I did return to the hospital for 2 or 3 years for further X-rays and discussion of my symptoms, but after a new consultant replaced the first, he said that because I had no significant pain, I did not need to come back unless things changed. Therefore, I have not been checked by anyone for many years. I do feel that perhaps I should have been recalled every 5 years, just to make sure that I had no other problems arising from the scoliosis. I just seem to have dropped from the NHS radar as far as the scoliosis is concerned.

I stopped riding after a while because of my un-level hips. I found I was constantly slipping to one side in the saddle, and this was not good for me, or the horse, and it felt insecure. The horse was getting on in years, so I decided to retire her, but kept her until she died 4 years ago and continued to do all the yard work every day until then.

As time has passed, I have noticed that the limp has become more pronounced, and to prevent back ache, I use a wedge cushion when sitting on hard chairs, to balance my hips. I am sure that my spine is sticking out more on the right side at the back than it used to, because sitting in a dining chair can be painful if I lean back. I cannot stand or walk for long without needing rest. I manage well enough. I have learnt to adapt my life to remain largely pain free. A good, firm mattress has also proved very effective. I think that my abdomen is squashed because of the curve, and I do suffer from indigestion as a result. Again, I have adapted my diet and eat smaller meals, which helps.

Now that I am 80, I still do all my own housework, except for vacuum cleaning, which does give pain, so I have a cleaner for that. I also care for my husband, who has cancer.

Clothing is a minor problem, as anyone with scoliosis will know. Some styles simply do not work with the curve, and it is a case of finding those that do. Tight-fitting waists are a no no for me now. Trousers are a boon, and any dress without a seam at the waist, because my upper body is now much shorter than it was! I have lost about 2" in height as a result of both ageing and my curvature.

I think that there is definitely an inherited predisposition to my scoliosis, because I remember that my maternal grandmother had a pronounced hump on her right shoulder and stood with her stomach slightly forward, which I notice in myself. She never complained and lived until she was 90. My own mother never had any sign of it, just wear and tear spinal pain and later some cervical trapping for which she had an operation when in her 70s. Her operation was an emergency, because the trapping caused severe general paralysis which could have proved fatal. She lived to be 86, although was never free from pain thereafter.

I have warned my children to be aware and to check their own children for any early signs of spinal problems.

Mrs Valerie Hughes

My husband noticed that my posture was forward leaning in 2006, which prompted me to have some physiotherapy which I found unhelpful. Then some lower back ache developed a few years before a right knee replacement in 2009. After the knee operation the pain became worse and I wrongly suspected that my right leg was shorter than the left one. I had some more physiotherapy and this time the physiotherapist examined my back. I was told that I had a small curve which wouldn't get worse and was fitted with a small pad in my right shoe. This made walking easier.

Back pain again became a problem in 2011 and I was taking Ibuprofen when I consulted a pain management specialist who gave me radiofrequency denervation, which was of no help. It was after this treatment that I received a copy of the letter sent to my GP in which the specialist mentioned that I had scoliosis.

I knew nothing of scoliosis and a Google search did nothing but shock and alarm me. It was a great blessing to find out about SAUK who were holding an upcoming patient meeting. It was at the meeting that I learned that my curvature



Valerie Hughes

would get worse and that I needed to see a scoliosis specialist.

Following this I had two private consultations because I wanted to get as much information on my condition as quickly as possible. I learnt that I have left-sided lumbar scoliosis with truncal shift to the right with kyphosis. My pain score did not warrant an operation. It was at one of these consultations that I was relieved to be told both of my legs were the same length. I had begun to use a stick by this time. During time and for the next few years, I was able to have pain relief by resting.

In 2013, I was seen by a consultant and had some very helpful exercises for building my core strength, which I still do.

In 2016, I suddenly had no feeling in my right leg which was very unnerving. Feeling came and went and I remember how difficult it was, and how panicked I felt when this happened on a zebra crossing! I learnt that the nerve impairment was due to nerve root impingement but because this is a problem of numbness rather than pain there is not much to be done about it.

In another appointment in 2016 it was noted that my ribs were now resting on my pelvis and thus it seemed that my curve of 48° would not grow. I was advised that a fusion operation would be suitable due to my age, then 76 years. Since I was able to walk, albeit with difficulty, a large three stage operation would put my independence and quality of life at risk.

My most recent appointment was in December 2016 by which time I was using two sticks as balance was becoming a problem. This time I asked about having an operation to correct the trapped nerve at L5 but this not advised due to my overriding condition. Preventing falls is the priority; however I have fallen, and need help to get up.

I am now 79 years of age living in a ground floor maisonette with my lovely husband who provides most of the meals as I find the kitchen very difficult. I also have osteoarthritis and a painful shoulder. Scoliosis pain located in my right buttock is mostly felt after getting up in the morning so I take pain killers. I wash and dress myself and manage the laundry. I do most of my shopping online. I am unable to write well due to osteoarthritis and am very thankful for e-mails. Walking is now very slow and difficult.

Recently, I purchased a tricycle and have found a new sense of independence and freedom. When I'm riding it I am not aware of any of my conditions and feel like Cinderella at the ball. I go out with my husband in the car and have just qualified for a Blue Badge because of my poor balance and falls. I am very thankful to have a wonderful family, some good friends, and a lovely church. I enjoy life and try to be as independent as possible.

Mrs Dawn Devaney

My mother was a single parent to both my brother and I. Scoliosis was never noticed. I was married in 1965 and had our son in 1966 and our daughter the year later. Having a spine that was not straight never entered my mind. I never suffered from back pain and my husband and I both carried out manual restoration work ourselves on our homes and it never was highlighted then.

When I was around 45 years of age, I decided to try Tai Chi and I noticed on one particular movement a clonk sound in my back. I worked in an office and found that I was suffering from back pain, my skirt seemed to be up one side more than the other, and when I wore trousers, one leg looked shorter than the other.

I went to the doctor about my back pain and was sent for physiotherapy. The physiotherapist said that an X-ray showed my curvature. She carried out the technique to stretch my back with weights. She also said I was surprisingly supple with my scoliosis. That statement stuck in my head and I thought, how have I managed to have two children with this condition?

Back pain gradually became more of an issue with my office work and my GP sent me to a rheumatologist. He did some tests and thought that a heel raise to balance the difference in height could help. Later it was recommended

I take up Pilates to strengthen my back muscles. It was pointed out I was too old for an operation.

It was 2007 when I started Pilates and had only been a few times when I noticed an unusual small lump in my breast, that I thought it was a muscle. It turned out to be the aggressive form of breast cancer. My treatments took 2 years but I am so grateful for all the care I had from the NHS and the staff to enable me to still be in remission.

I made sure I went to a Pilate's instructor that knew their profession, she was a physiotherapist also.

About 8 years ago I asked for a one-off appointment with a scoliosis specialist and had to push a little. I wanted to know what to expect and was it best to always use a back pack so as to evenly distribute the weight on my shoulders. He told me both my legs were even! So my crookedness had evened itself up! He also told me that to carry my bag on my head if I wanted to and to do what I wanted as it was good for the soul! Hence, I have continued on my merry way ever since but cursing my back in-between times.

Increasingly, and I guess with age and degeneration, I do suffer a lot from back pain. If I stand for too long my back will really sting and in fact sometimes the pain hurts enough that I have to sit down. I now have a protruding area on my back that is obviously because the curvature has progressed over the years. I cannot ride on a bus without the pain in my back coming quite quickly into the journey, I guess because of the seating. I have now been able to go back to Tai Chi again and I have just taken up Nordic walking. The physiotherapist has given me exercises, I went to GP a few months ago because of the pain and I am trying my best to do these. Unfortunately, when you have a good day you tend to leave off the exercises, well I do. Most mornings now even with a good supportive mattress I wake up with back pain that eases off once I walk around. I also sleep with a little pillow in between my legs to take, the weight off my spine. I am not really over-weight, but maybe a few pounds off could help. I do not know if this pain will increase the older I become. Having said all that, I am alive to appreciate the beautiful countryside where we live.

Gilly Oliver

I was diagnosed with scoliosis when I was 13, my mum noticed I was looking a bit wonky. I had a Milwaukee brace for a year, then a Boston brace until I was

18, and was discharged with an angle between 30° and 40°. I was offered an operation for cosmetic reasons but chose not to have it. When I was in my 40s I felt that the curve had worsened and I was referred to a consultant at my local hospital. I have been monitored annually since then. At 51 years of age, the angle is 80-85°, and seems to have stabilised. If the angle has not increased at my next monitoring I will be discharged.

I have some back pain, if I sit, stand, or walk for too long. I work for my local council and am office based which suits me and my back. I swim a lot, and do Pilates type exercises, and believe these help keep my spine as flexible as possible.

I have enjoyed hill walking and cycling since I was little and have just returned from a cycle touring holiday in Scotland. I have found a bike I can ride, and a rucksack I can wear, which do not make my backache. For the past 15 years I have volunteered with Exmoor Search and Rescue Team, one of the 50 mountain rescue teams in the country. There are things I can't do, such as helping to lift a stretcher with a casualty on, but my team mates are very understanding and there are plenty of other roles to do.

I have quite a prominent rib hump on my back but no one seems to notice except me!

I have been lucky and have been able to manage to keep any back pain to a minimum.

Julia Balmford

I am a French woman of 68 years and was diagnosed with idiopathic scoliosis at 14 years. It was a small double curve and I was given intensive specialised exercises until my 20s. I feel scoliosis was not taken so seriously then, and I didn't have any follow-up. The exercises seemed sufficient to stop the curve progressing and I was told that the curve would stabilise when I stopped growing. That seemed to be the case until my mid-30s when the curve grew, resulting in hip rotation, loss of height, and the curve then becoming noticeable. By then I had moved to England. The surgeon I saw advised against an operation, because at my age he could not correct the curve properly, and I was fit and active and dealing with it ok.

The curve has continued to deteriorate with age and is now very advanced although I'm lucky in that my body is quite well balanced and any lateral displacement is not immediately

obvious. A few years ago I had to have an operation on my lower back to put rods and screws on L4 and L5 due to pressure on the spine and increasing pain. It was successful and reduced the pain.

Generally I have managed well with the condition and despite occasional back pain still lead a very active life, cycling and walking without too much discomfort. I have also been doing regular studio Pilates for the past 15 years which I have found very helpful to improve posture and reduce pain.

Michelle Pacteau

I am 41 and was officially diagnosed with scoliosis a few years ago. If I did have it when I was in my teens and 20s then it wasn't noticeable at all. It was only really noticed when I had my first child and I personally think the hormones related to pregnancy and giving birth created my scoliosis. It got worse with my second pregnancy. My curve is 80° so is quite severe. I am on the waiting list to have an operation but I'm still not sure if this is the best thing for me to do.

I am not really in pain, and it does not affect my life on a day to day basis. I get pain if I stand for too long. When standing up straight my curve isn't very obvious, but when I bend down my rib hump becomes obvious.

I have lost over 2 inches in height since my diagnosis which I'm not happy about. I wonder should I have an operation to improve my back and potentially stop it progressing at the cost of everything that comes with an operation

Katie Allen

I am 72 years old and developed scoliosis in my late 50s. I have had four operations, including an unsuccessful operation and one of three planned to undo the problems created by the first two. I was scheduled to have two further operations but we are holding off for the time being.

I am a great believer in Pilates and go to a class at least twice a week, have a monthly massage, and walk, using a stick, as much as possible. I really think this keeps me going. I don't want to give in to my curvature. I now have an annual review at the hospital but can see them if before this if necessary.

Jackie Evans

I am female, was born in the US in 1949 and am 70 years of age. I still work in an administration job at the local hospice for 15 hours per week, and the

physiotherapists think I'm doing really well with my scoliosis.

I was diagnosed with AIS in 1961 when I was 12 in the USA. I have an S curve with a prominent right shoulder blade but my hips are fairly level. I'm not sure if I was ever told what the degree of curvature was/is and probably wasn't consulted about what my treatment would be.

I imagined an operation in the 60s was a scary, experimental option and perhaps only reserved for more severe cases. I do remember a brace being mentioned, but that never happened. I did have was a set of exercises that I did fairly conscientiously for a few years and I probably went back for regular checks and X-rays. I don't remember much except that being a physiotherapist was a career option I considered, so my experience with them must have been positive!

My scoliosis didn't bother me much. I was always aware of it, but mostly because of how my clothes stuck out at the back over my shoulder blade. If I was tired, or had spent a long time typing, my shoulder ached, but doing my exercises helped to ease that.

I came to live in England in 1970, got married and had a child. The pregnancy was ok and not affected by my scoliosis. In my late 20s I started going to weekly yoga classes and I think they helped to keep me mobile. In my early 40s I was diagnosed with breast cancer, which was successfully treated with an operation and radiotherapy. Since then, I have wondered if it was anything to do with the X-rays for the scoliosis that I had.

In the late 1990s I started doing Pilates and have done that fairly consistently once or twice a week. From about the age of 65, I've noticed a significant loss of height, about 3 1/2 inches, and have gone from 5'8" to under 5'5". I have also been diagnosed with osteoporosis. Because I was very concerned about the fairly rapid height loss and the osteoporosis, I consulted an orthopaedic surgeon. I took some old X-rays and he saw those before he saw me. He was surprised that I was as straight and upright as I am, and said he was expecting someone more bent and wizened!

He assured me that I didn't need an operation or any dramatic intervention, but encouraged me to keep doing what I was doing.

I do get more backache now, particularly in the area between my waist and hips where I've lost most height. There are lots of clothes I can't wear anymore

because my body shape has changed, but I feel quite lucky, really, that my pain isn't too bad and I'm still able to move fairly easily. I know I should do more exercise, possibly more walking or swimming as well as the Pilates. I'm just not very good at finding the time. It will be something to do when I retire!

Christine Mills

My name is Samantha Golden and I have lived with scoliosis for nearly 35 years (since I was 12). I had the Boston Brace for two and half years to stop my curves increasing but it made my back muscles very weak. My consultant wanted to operate but it was horrendous in those days, cutting you from the front to the back. I had little pain back then so decided not to have spine fusion and live with my curves. It was most noticeable when I wore skirts. I continued to do ballet until I was 16 which helped my core.

My mum paid for a private physiotherapist, not offered to us on NHS, to strengthen my back muscles. I used to clean his practice for a discount in the end! Olivier was really lovely and he gave me hope. I went on to have three daughters. During pregnancy I had to rest my back but managed to have a 9lb baby then carried identical twins!

Sadly both my twins have scoliosis, I had no idea it was hereditary. They are now 17. One daughter has had spine fusion at Great Ormond Street Hospital because she was rapidly developing a scoliosis and the it was too late for bracing. She is amazing, patient, strong willed - you forget she's had anything done, she was back to Sport soon after, Netball and diving in the pool which is great to see. She now plays drums in her band.

The other twin was borderline for an operation which is always a harder decision. She has not had the operation and manages her back pain well. She plays guitar in a band.

Both twins and I suffer with back pain after standing for long periods or long walks but we don't let it stop us doing anything. I did a skydive recently and last year we all did gorge walking.

Having gone through my own journey I was able to support my twins. My mum also went through the trauma for me. She tried to stay positive and hide it but used to suffer the stress before every hospital appointment. You do need someone to talk to that understands we are happy to talk to anyone about our experiences.



You Write

I was diagnosed with scoliosis at the age of 21 after attending the GP to discuss shoulder strain. I am now 31 so have coped with the condition for 10 years.

Under my consultant in Birmingham, I have had numerous conversations about whether surgery was the correct route for me because I was diagnosed a little later than most people. I decided that as I am quite active and go to the gym five times a week, the spinal fusion would reduce my activity and I decided I would only be having the surgery for cosmetic reasons. I hate that my hips are different heights, but I declined an operation.

I currently live in Leicester and have come to terms with my condition, there are odd days where I feel a bit insecure but I remember that everyone with the condition, fused or not, are displaying an enormous amount of strength physically and mentally and that is something to celebrate, which led to me running Strut for Scoliosis in July, 2017. This was a fashion show which featured volunteer scoliosis and non-scoliosis models and raised awareness and funds to SAUK. It was a proud and wonderful experience. For this event I also had my body painted by local artist Emma Fay, and myself and 3 others had our spines painted for Christmas!

The scoliosis community I have found since being diagnosed has increased significantly through social media and people being open and honest with their difficulties and triumphs. This also found me connecting with scoliosis warrior and actor Eva Butterly and featuring on her podcast <https://www.instagram.com/evabutterly>.

Although there are blips, I have never been more proud to be an advocate of scoliosis.



Images by Phil J Vernon Photography

Hi. I'm Paula, aged 61 from Warrington. I have a scoliosis Cobb angle of 42°. I have lost 1.5" in height.

I saw a scoliosis specialist for the first time this summer and was told that it is progressive and degenerative and could not be helped by physiotherapy. I am fairly active, I walk, hike, and have done Pilates for the past 10 years. Surgery is an enormous step at 61 but even worse if I leave it until I am 70 or 80!

The first I heard about my scoliosis was when I fell off a horse, aged 30 and had a chest X-ray. It was then I noticed my left ribcage protruding at the front. Always been told my scoliosis was fixed and wouldn't cause me any problems so I never thought anymore about it. Aged 40 I developed neck problems, prolapsed discs etc, and arm pain. I saw a chiropractor and after a year it settled down. It was then I discovered I had one leg shorter than the other. Has this caused my scoliosis I wonder? I had lower back issues 10 years ago and now have no disc space in my lower vertebrae. The past 2 years I have been in considerable pain. I noticed what I thought was a large protrusion of tight muscle on one side of my back only to be later informed this was my spine! I was shocked, to say the least. I have considerable pain hoovering, gardening, cooking, changing, etc. So I did some research on the net and came across Scoliosis SOS in London.

Does anyone have first hand experience of their 4 week intensive physiotherapy course? It's very expensive. I have recently had a consultation with them and 2 hours of physio on a 1-1. I have come away with a lot of exercises but unsure whether to commit or not. I am looking for a Pilates and/or Yoga class specifically for scoliosis if anyone knows of one in my area? I am religiously doing stretches and spine mobility exercises every day in hope. I would love to go back to my specialist with a reduced Cobb angle! Would like to hear from anyone who has had surgery in later life and what their outcome was. How long can I put it off?

Thanks in advance

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