THE MAGAZINE OF THE **NATIONAL AXIAL SPONDYLOARTHRITIS SOCIETY**

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9-15 September 2019

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All About NASS

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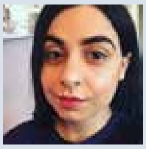

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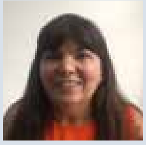

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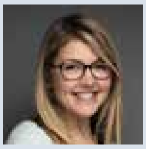

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Doing our bit for the environment

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WELCOME!

Welcome to AS News. In this magazine, some of our talented creative artists talk about the role of axial SpA (AS) in their lives. Singer and vocal coach Kelly Fraser tells us how she sometimes feels trapped in her body. Artist Andy Cutler discusses his project 'Perspective, Division and Harmony' which shows how difficult it is for people to understand what it's like to live with axial SpA (AS). Sculptor Hazel Reeves shares how axial SpA (AS) has affected her work and how she manages it.

It has been an incredible year for NASS. Our membership has grown by 10%, we have created the first ever parliamentary committee on axial SpA (AS) and, at our AGM on June 8, members present voted unanimously in favour of a change in our name and legal status.

We have always supported people with non-radiographic axial spondyloarthritis as well as ankylosing spondylitis. By moving to the umbrella term axial spondyloarthritis, which is now the preferred terminology among rheumatologists, we can encompass all of the people we support in a single term and reflect better the typical diagnosis that patients now receive in 2019.

We will still be called NASS, working to reduce the delay to diagnosis, improve the quality of NHS care, and support people to manage their condition. We will continue to raise public awareness and bring this important condition to the attention of parliamentarians, policy makers and healthcare leaders.

Our new legal status as a Charitable Incorporated Organisation will mean members have no liability for any debts should something disastrous occur.

I think 16 November 2019 is a big date in the axial SpA (AS) calendar. At our NASS Voices conference in London we will be publishing a landmark report from our All Party Parliamentary Group on the diagnosis and treatment of axial SpA (AS) in England. It will show significant shortcomings, and we will be using the report to lobby NHS organisations, policy makers and parliamentarians. We want Every Patient, Every Time to receive early diagnosis and effective care.

At the same conference, we will be announcing the successful applicants for the Aspiring to Excellence programme. We'd love you to join us in London for this important event.

I want to congratulate NASS Derby who are celebrating their 35th anniversary and to Barbara Foster who has been branch secretary for all that time. What an incredible achievement!

Thanks to all our fundraisers who are using increasingly wonderful and varied ways to raise money for NASS, like Ben Kennedy who carried a boiler up a mountain! You can read their stories in the Celebrating Success section.

You may have seen the media activity around Remember a Charity week in September, which encourages people to consider leaving a gift to charity in their Will. We are delighted that supporters have since let us know that they have included NASS in their Will. Thank you, thank you, thank you. Your generosity will allow us to carry on with the ambitious goals that we have set ourselves so that we can be there for everyone affected by axial spondyloarthritis.

Thank you for your continued membership and support of NASS. I hope you can see just how hard we are working on your behalf. And thank you to the outstanding staff and trustees of NASS whose energy, determination and focus is helping us to bring new visibility and attention to axial SpA (AS).

Best wishes

D.L

Dr Dale Webb

NEWS IN BRIEF

Members Day 2019

Thank you to everyone who was able to come along to our Members Day in Birmingham this summer.

We covered a huge range of issues from the latest updates in axial SpA (AS) from Dr Moorthy to managing pain with mindfulness. In the afternoon everyone got involved in Bhangra, Ballet and tried out the Alexander Technique.

Professor Julian Knight from Oxford the Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS) has very kindly turned his very popular talk on functional genomics into an article for the magazine (see page 10).

During our AGM the members present voted unanimously in favour of a change in our name and legal status.

On the 1 November 2019 we re-launched our charity as the National Axial Spondyloarthritis Society.

We are still NASS.

We are still supporting everyone affected by axial spondyloarthritis.

We are still working to empower people to understand and manage their axial spondyloarthritis.

We are still working with rheumatologists, physiotherapists, nurses, GPs, MPs and a whole host of others to transform the way axial spondyloarthritis is managed in the UK

Our new legal status as a Charitable Incorporated Organisation will mean that members have no liability for any debts should something disastrous occur.

Save the Date

Our next Members Day will be 20 June 2020

Goodbye and thank you to...

A number of our long serving trustees stepped down at the AGM this summer. They have all worked hard over a number of years for NASS and we are very grateful for their time and efforts.

Claire Harris

"I have been a trustee of NASS for the past 11 years, so it is definitely time to step down but I shall miss the support, the brilliant team and wonderful opportunities that being a trustee of this remarkable charity has let me have.

Just a few of my more memorable moments include: working on Back to Action, presenting at the ASIF meeting in Turkey, meeting shoppers with back pain in Reading and Bath town centres whilst standing by a giant model of a spine. Then there have been the parliamentary events and now the APPG meetings and finally many special memories associated with NASS Members Day including this year's event held in Birmingham seeing Dale resplendent in his Bhangra dance costume.

Over the past 11 years there have been three CEOs and each has brought something different to NASS and has moved the charity forward. It has been a privilege to work with them. I hope to stay in touch and contribute by continuing as a member of the NASS Medical Advisory Board."

Ruth Miller

"Reflecting back on my 9 years as NASS Trustee so much has changed! NASS has gone from strength to strength, achieving so much to improve the quality of life for people with axial SpA (AS). All this has only been possible through the hard work and dedication of the team, trustees and supporters. I shall, of course, continue to be a member and wish you all well."

Jean Morton

"Well done for all that you and the team are doing. It's been a privilege getting to know how NASS operates. I will always have a great fondness for the charity."

Peter Wheatley-Price

Andrew Keat

Dr Andrew Keat has been involved in NASS for many years and contributed so much. We were sad to see him go. Thank you to his colleagues and some of his long term patients who gathered to say goodbye and thank you.

NASS Voices
is coming to London

On Saturday 16 November NASS is running an event at the Queen Elizabeth II Conference Centre in London. It's a chance for you to...

- Meet others affected by SpA (AS).
- Learn what's new from Dr Antoni Chan, a rheumatologist with a special interest in axial SpA (AS).
- Find out more about managing your flares.
- Work with a voice coach to keep your ribs flexible.
- See if the Alexander Technique could work for you.
- Discover how to care for your feet.

Helpful, informative and interesting day

Book your place now by visiting www.bit.ly/NASSvoices or call Helen on 0203 011 5133

This event will also include the launch of our landmark report into the diagnosis and treatment of axial Spa (AS) in England.

In March our All Party Parliamentary Group on axial SpA (AS) commissioned an enquiry into the diagnosis and treatment of axial Spa (AS) in England. The enquiry has now finished and has identified significant shortcomings across the board. We will be launching the report at the event.

NASS isn't just identifying the problems in diagnosis and treatment. We're also leading the efforts to improve care with our national initiative *Aspiring to Excellence*.

Join us to celebrate the rheumatology services who have been successfully awarded a place on our *Aspiring to Excellence* programme.

Creating a lasting legacy

Mid-September saw the wonderful Len Goodman take to the media to promote Remember a Charity in your Will week. You can see him on the front cover with our trustee Gillian Eames when they met to discuss the huge difference that gifts left in Wills can make to charities.

Did you know that 40% of all of NASS's income over the last two years has come from gifts in Wills?

The incredible and generous people who have chosen to leave a legacy gift to NASS will be remembered by us for ever. Their generosity is allowing us to continue to provide our information and support services like the Helpline and updated guides. They are covering the cost of ground-breaking research, and are helping us to plan our campaigning work to ensure a better future for everyone affected by axial SpA (AS).

This year in Remember a Charity week, the key focus was on myth busting – here are a few common misconceptions about writing a Will, or leaving a gift to charity:

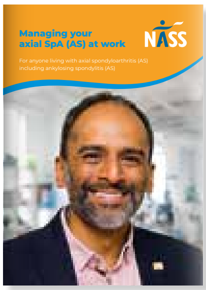
1. **"Only rich people need to make a will"**
   If you die without a will, there are certain rules which dictate how your money, property or possessions should be allocated. This may not be the way that you would have wished your money and possessions to be distributed, so everyone should make a will.
2. **"Making a will is difficult and expensive"**
   Making a will doesn't need to be complicated, and NASS works with the National Free Wills Network – giving our members and supporters the opportunity to meet a local solicitor and have a simple Will made or updated for free.
3. **"You can't take care of your family if you leave a gift to charity"**
   We would always want you to ensure that your family, friends and loved ones are taken care of in your will. Once that has been done, only then should you consider leaving a gift to NASS or any other charity.
4. **"If I left a gift to charity, it would need to be a huge amount, and I don't have that much to give"**
   A gift to charity can be any amount, creating a lasting legacy in your name. All gifts, big or small are truly appreciated. You can leave a specific amount, a percentage of your estate after all other gifts and payments have been made, or even a specific gift to a charity.

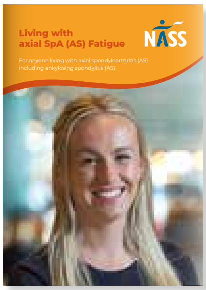
If you would like more information about leaving a gift to NASS, or would like to be referred to the National Free Wills Network, please call Katie on 020 8741 1515, email katielyall@nass.co.uk or visit www.nass.co.uk/legacy.

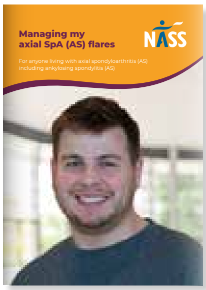
WHAT’S NEW AT NASS

Check out our new guides

We have completely updated our range of information guides. Thank you to all the health professionals involved in writing the guides especially Dr Stefan Siebert for his work on the biologics guide, Emily Clarke for her work on the flares guide and Dr Jane Martindale for completely re-writing our fatigue guide.







Thank you also to all those NASS members who kindly took the time to read the guides and give us your very useful comments.

Every NASS guide now features a NASS member on the front cover and a little bit of their personal story inside. Thanks to those volunteering to be the friendly face of NASS.

You can download your copy from the Resources section of the NASS website or email admin@nass.co.uk if you’d like us to post you out copies of the guides. Please include your postal address in the email.

Give our new series of stretches a try

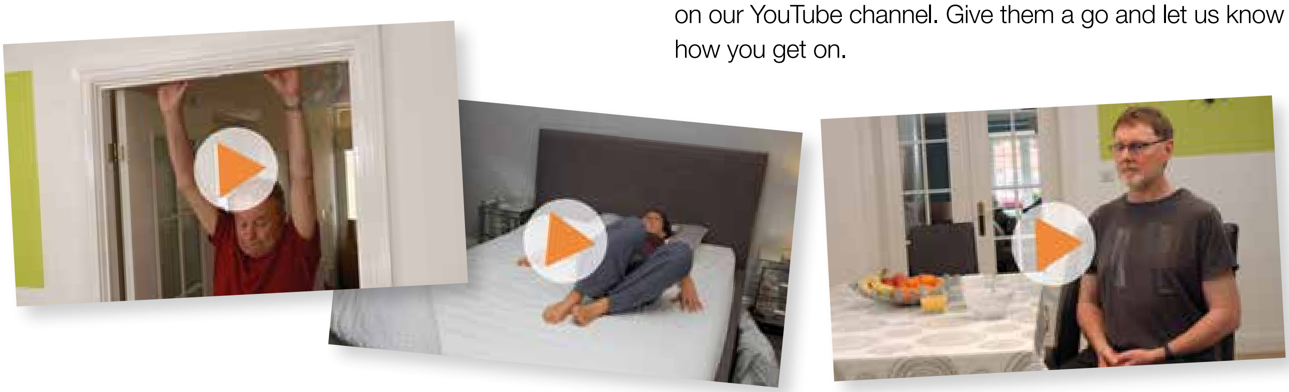
We been working with a group of physiotherapists with a real interest in axial SpA (AS) to develop a new series of videos. It’s really important to stretch when you have axial SpA (AS) but it can be hard to find time to fit stretching into your life.

Our 11 new stretch videos show you how you can fit some simple but very effective stretches into your daily life. No Lycra. No trainers. No gym.

They include stretches you can do in bed in the morning and stretches for while you wait for the kettle to boil, at the kitchen table and on the sofa.

Everyone featured in the videos has a diagnosis of axial SpA (AS). Particular thanks go to members of our NASS Southampton branch who gave up two days of their time along with NASS trustee Monika Mayhew

You’ll find them in the Exercise section of our website and on our YouTube channel. Give them a go and let us know how you get on.



Our NASS information has been commended

We were thrilled that NASS received 2 commendations at the BMA Patient Information awards

The British Medical Association (BMA) patient information awards were established in 1997 to encourage excellence in the production and dissemination of accessible, well-designed and clinically balanced patient information. The awards are highly sought after so we were delighted both of our entries were recognised.

ASone – highly commended

ASone, our portal for younger people living with axial SpA (AS) was highly commended and shortlisted for the overall award. ASone received praise from the judging panel:

If one was a patient this is what one needs. It is excellent because it is very realistic and practicable. It offers a very good range of practical sessions for helping patients cope with daily living problems linked to more theoretical discussions on progress in understanding the nature of AS and the potential role of novel medications.'

Your AS Journey – commended

Our interactive tool Your AS Journey was also commended at the awards.

When the NICE Spondyloarthritis Guideline was launched in 2017 we wanted to ensure people living with axial SpA (AS) understood what care they should expect from health professionals. We developed Your AS Journey to ensure everyone knows how they should be diagnosed and managed.

Thank you to all our ASone contributors, supporters and members of NASS, and our funding partners for helping us achieve these awards.

BMA

Patient information awards
Highly commended

Get involved

with Facebook Helpline Live

We've been trying out some Helpline sessions live on Facebook. So far we've covered biologic therapy and PIP. Let us know what topics you'd like us to cover in future sessions. Email sally@nass.co.uk

NASS HELPLINE
LIVE

The NASS Summer Raffle NEWS

Thank you to all of you who sold (and bought) tickets for our Super Summer Prize Draw.

We're delighted to announce that it raised a grand total of £5,700.

The winning tickets were drawn on Friday 6 September. Congratulations to the following:

1st Prize of £1000

Jillian O'Mahoney

2nd Prize of £250

Mary Dyke

3rd Prizes of £50

Graham Jones
Mrs M Holmes
Mr R Ford
Mr M Hepworth

We will not be running a Winter raffle this year, but do look out for more raffle tickets in the Spring edition of AS News.

Understanding the functional genomics of AS

Ongoing research in the Knight group at the Wellcome Centre Human Genetics, Nuffield Department of Medicine, Oxford University

Giuseppe Scozzafava and Professor Julian Knight

NASS members attending Members Day this year may remember that Professor Julian Knight gave a presentation about the functional genomics of immunity, with particular focus on ankylosing spondylitis, which is one of our main research projects.

The Knight Group

The Knight group is a team of about 20 biologists, clinicians, and bio-informaticians studying the immune system through the lens of medical genomics. We look at diseases where there is a disrupted immune response: in some cases too little (such as in rare primary immunodeficiency disorders), sometimes too much (sepsis, ankylosing spondylitis). All the diseases are linked by having a strong genetic component.

It has been long known that genetic variation of one gene in particular, HLA-B27, is associated with ankylosing spondylitis and yet this gene only accounts for a minority of the heritability of this disease. Clearly other factors are at play such as other genes and environmental factors.

Several genome-wide association studies (GWAS) have been carried out over the years focusing on different diseases. Some of these studies compared the DNA of thousands of AS patients with that of thousands of control samples and found many places of differences in the sequence between patients and controls, some within new genes, but many in non-coding parts of the genome.

One of the main findings of the Knight group has been that these non-coding variants are major drivers of diversity in the immune response and play a role in regulating the amount of transcription of the gene they control. In other words, they tell the cell how much of a chemical cell messenger to make.

If too much is produced an exaggerated immune response is mounted. If the amount is in any way inappropriate, the immune response can become dysregulated.

These non-coding variants can provide insights into potential new therapies by developing molecules that could modulate the immune response back to normal levels.

Current GWAS studies have identified at least 48 locations in the genome associated with AS involving over 113 sequence variants. These associated variants are mostly non-coding and little is known about how they functionally act.

The fundamental questions we are trying to answer are: what do these genes do, how do they interact with each other, which are the cellular metabolic pathways influenced by these genes and how can this provide new ways to understand the disease and treat patients.

One approach is to look at the same type of immune cell populations (monocytes, T cells) and perform different tests to gain information from different angles about gene regulation and do these tests in samples obtained from both AS patient and healthy volunteers. By comparing the results we should be able to make connections and get a clearer picture of the function of different genes.

DNA is the repository of all information necessary to make, duplicate and maintain our cells. It is a dynamic molecule and, at different times, it is read by molecular machinery to transcribe, copy or repair it.

Human DNA is a very long molecule but is never seen as a linear molecule inside the nucleus of cells simply because it would not fit – it is over 3 billion letters of code (bases) that would stretch out to about 3 meters in length. Therefore, it has to be packaged, tightly wrapped around proteins called nucleosomes and then sets of nucleosomes get further packaged to form the chromosomes that are visible under the microscope.

When tightly condensed the DNA is referred to as closed chromatin and the DNA is not accessible to other molecules. For the DNA to be available to other molecular machines the DNA needs to be in open chromatin conformation. If we were able to look at the open chromatin at a genome wide level, we would have a snapshot of what's happening.

Luckily a new technique called Assay for Transposase-Accessible Chromatin using sequencing (ATAC-seq) allows us to do just that! We have applied to our AS patient samples and compared it to control individuals.

Another technique we use is Chromatin Immuno Precipitation Sequencing (ChIP-Seq). This identifies which proteins interact with DNA and how they may control gene regulation. This allows us to produce a map of where critical regulatory events are happening in the genome and how this might be affected by disease-associated genetic variants.

Many of these sequence variants are non-coding and have an effect on the regulation of gene activity. Wouldn't it be great if we could modify with ease and precision these variants and then observe the effect on the cell function? A new technique allows us to do precisely that: it is called "clustered regularly interspaced short palindromic repeat", CRISPR for short and commonly described as "gene editing". We have used this technique to selectively remove particular sequences and found that the associated gene regulatory control region (promoter) showed altered chromatin state, which resulted in the down-regulation of the gene.

By combining these different techniques to study the variable DNA in axial SpA (AS) patients we are putting together a detailed map of the functional genomic landscape of the disease and how genetic variants act. Armed with this information we hope we can find a disease-specific signature, which, in turn, would inform the selection of new therapeutic targets. None of this research would be possible without the involvement of axial SpA (AS) patients in our research for which we are hugely grateful.

CAMPAIGNING

**EVERY PATIENT
EVERY TIME**

APPG gets underway

We reported in the Spring edition that the first meeting of the All-Party Parliamentary Group for Axial Spondyloarthritis was due to take place on 19 March. Since then we have had two meetings. The first focussed on the impact of living with axial SpA (AS). The second meeting looked at the provisional results of the Freedom of Information request and best practice in implementing the NICE Guideline.

Special thanks go to our speakers at the meetings: NASS members Hannah Scott and Max Poplawski, Dr Andrew Keat, Dr Jon Packham and Dr Antoni Chan, as well as Nicola Greenway and Sharada Chunduri Shoesmith from the National Institute for Health and Care Excellence. Thanks also go to Derek Thomas MP and Labour Life Peer Lord Dale Campbell-Savours for chairing the group and their continued support.

Our third meeting will be held in January 2020 and will focus on the delay to diagnosis.

Freedom of Information request

In May we sent out a freedom of information request to all Clinical Commissioning Groups and NHS Trusts in England. We asked them to answer ten questions about the services that they offer for people with axial SpA (AS) and then collated the results to have a better picture on how things are looking around England on a national level.

Some of the most striking results were:

- Just 21% of CCGs have an inflammatory back pain pathway in place
- Very few commissioners have local arrangements to raise awareness of axial SpA (AS) in primary care
- One fifth of services do not offer specialist physiotherapy
- Only 43% of Trusts have a dedicated axial SpA (AS) clinic
- Only one quarter of rheumatology services offer access to psychological services

The final report will be published on 16 November at the NASS Voices conference in London.

Not only England

NASS members in other parts of the UK don't worry, we haven't forgotten about you. We sent out the same questions to Health Boards in Wales, NHS Trusts in Scotland and Local Commissioning Groups and Health and Social Care Boards in Northern Ireland in August. These results are currently being analysed and the results in Scotland will be presented to the Cross-Party Group for Arthritis and Musculoskeletal Conditions in November. We are also looking at the best mechanisms for sharing the results in Wales and Northern Ireland.

Update on hydrotherapy pools

We have been working to save two hydrotherapy pools in Bedford and Hammersmith.

Jill and Dale met with Imperial NHS Trust, who cover Charing Cross Hospital in Hammersmith. The initial discussion saw the Trust seemingly unconcerned with the issues that we raised around alternative arrangements, which included using a swimming pool for exercising in water. However, they have since contacted us to say that they are looking for funding to refurbish the pool.

The fight with Bedford Hospital has been more tricky. NASS started a petition resulting in a public consultation. Jill appeared on Three Counties Radio with NASS member Peter Kellythorn to discuss the issue. Both also attended the Bedford Council Health Overview and Scrutiny Committee along with the Chartered Society for Physiotherapy (CSP) where the council noted that the petition had brought this issue to their attention. Without NASS the pool would have been shut immediately with no alternative arrangements in place for hydrotherapy. NASS and the CSP have been working together behind the scenes to exert as much pressure as possible on Bedford Hospital NHS Trust. At the time of going to press we are awaiting a decision.

What next?

We know that NASS alone cannot stop the closure of hydrotherapy pools. We are now looking to lead a coalition consisting of a range of people living with different conditions, patient groups, professional bodies and commissioners to discuss how best to promote hydrotherapy. We already have many organisations on board including the National Rheumatoid Arthritis Society, Parkinson's UK and Shine Charity for Spina Bifida. We are hoping to hold a meeting late autumn to discuss how we can get hydrotherapy recognised as a vital treatment for a variety of people.

Call to Action

We are asking NASS members to get in touch with their local Healthwatch and Clinical Commissioning Group (CCG), sharing the local results their area to help keep up our FOI results in their area where services are not up to scratch. If you would like to get involved email jill@nass.co.uk.

NASS Allies develop GP referral template

NASS has developed a new referral template with the Royal College of Chiropractors and Institute of Osteopathy. It has been endorsed by the Royal College of GPs and the Chartered Society for Physiotherapy.

The template was developed following a survey of osteopaths and chiropractors found that GPs often did not take their recommendations for referral to rheumatology on board. We hope that it will help to reduce the delay to diagnosis.

'Elephant in the Room' at Scottish Parliament

Dale joined the Cross Party Group for Musculoskeletal Conditions and Arthritis at their reception in the Scottish Parliament on 15 May. Dale was also joined by representatives from our branches around Scotland for the event, Elephant in the Room. The event was a drop in for MSPs, and aimed to raise awareness of arthritis.

Dale will be presenting to the group in November, talking about the Every Patient Every Time campaign in Scotland and delivering the national Freedom of Information request results as we have done for England at the APPG in Westminster. Many thanks to those who regularly attend meetings on behalf of NASS - Iain MacDonald, Eddie McGill and Murray Brown

Aspiring to Excellence

At our House of Commons event in December 2018 we announced a new programme called Aspiring to Excellence.

Its aim is to create improvement in the diagnosis and treatment of axial SpA (AS) by providing expert support to participating rheumatology departments and by creating a national learning network to share experiences and results. Services will also be reviewing ways to improve patient experience overall.

NASS has worked hard to secure the financial support of funders so that we have the resources to bring this ambitious and important programme to life.

We opened applications for the first round of participants on 1 May at the British Society of Rheumatology conference, with a very successful launch event. We were delighted to receive 11 applications. We will be announcing the sucessful applicants on 16 November at our NASS Voices event.

Cannabis-based medicinal products

A survey conducted by NASS in November 2018, in response to the announcement that guidance was being developed by NICE, shows that 52% of people have used cannabis-based products for pain relief, often in conjunction with other medications, particularly non-steroidal anti-inflammatory drugs, simple pain killers and biologic drugs. Of these:

- 4% had used nabilone or dronabinole (as covered in the draft guidance)
- 52% had used cannabis oil (available in health shops, no prescription needed)
- 55% had used herbal cannabis (street version, illegal currently in the UK)

Anecdotal evidence currently exists that many patients find cannabis-based products can provide pain relief; there is however a lack of clinical studies. The NICE Guidance does not recommend use of nabilone or dronabinole for use in chronic pain due to cost.

As there is a lack of research into these drugs, and as so few NASS members have used those covered in the guidance, NASS does not feel that it can appeal the recommendations by NICE. We do recognise the benefits that many get from using cannabis based products though and so support the call for more research to be done.

Identifying and sucessfully treating fractures in Axial Spondyloarthritis

Patients with advanced axial spondyloarthritis (axial SpA) are three times more likely to sustain a spinal fracture than a member of the general population. These fractures can often be missed by X-rays, and often need surgical treatment.

Authors:

Mr Alexander Durst
Specialist Registrar in Trauma and Orthopaedic Surgery Norfolk and Norwich University Hospital

Mr Nick Steele
Consultant Spinal Surgeon Norfolk and Norwich University Hospital

Professor Karl Gaffney
Consultant Rheumatologist Norfolk and Norwich University Hospital Medical Faculty, University of East Anglia

CT Scanner

Risk of spinal fractures

When axial SpA (AS) progresses, the ligaments and discs in the spine can become stiffer and fuse. These are the areas that should provide spinal mobility and flexibility.

In some cases, the spine can lose its normal shape and can develop a forward curve which is known as kyphosis. As the kyphosis progresses, the back can develop a "?" shape. This can make it difficult to look straight ahead, as your head starts pointing downwards and it makes a fall more likely.

Along with this, you can develop osteoporosis and the combination of a weaker and yet more rigid spine increases the risk of spinal fractures.

Normally spinal fractures only occur with bigger accidents, like falling from a height. With axial SpA (AS) doctors need a higher index of suspicion that much simpler 'low energy' injuries can result in a spinal fracture.

Diagnosing spinal fractures

Doctors also need to be aware that these fractures can be particularly difficult to identify on plain spinal x-rays. As spinal surgeons, we recommend that any axial SpA (AS) patient with a suspected fracture, should also have a CT scan. A CT scan is a more complex type of X-Ray where a 360 degree image of your bone is created by compiling hundreds of X-Rays pictures together using a computer. This gives a clearer picture of the spinal bones resulting in an increased likelihood of identifying a fracture.

In rare cases where a CT scan does not identify a fracture, we may also get an MRI. An MRI scan takes slightly longer than a CT and unlike a CT also looks at the soft tissues surrounding the bones including the spinal cord, nerves and ligaments. Spinal surgeons will also get an MRI scan if they are concerned a fracture may have resulted in spinal cord or spinal nerve injury.

It can be difficult for some axial SpA (AS) patients to fit into the narrow tube for an MRI scanner. Some people can also find this very claustrophobic, although this can be successfully managed with oral sedatives.

A very serious spinal cord or spinal nerve injury can result in weakness and /or a loss of feeling in limbs, or even paralysis with a loss of normal bladder and bowel function. Any unusual change to bladder and bowel function associated with new back or neck pain needs to be urgently investigated.

Managing spinal fractures

Fractures need to be immobilised to be able to allow them to heal in the correct alignment. There are many different ways to immobilise spinal fractures. For the neck, a collar can be used and for the chest and lower back, braces are available.

The problem with this approach in more advanced axial SpA (AS) is that braces may not fit well or comfortably due to kyphosis. There is also an increased risk of further injury and falls due to the pre-existing mobility problems. Furthermore, osteoporotic axial SpA (AS) spinal bones are less likely to heal and usually take much longer to unite.

This is why spinal surgeons often recommend surgery to help stabilise the fracture and allow the spine to heal without the need to wear a brace. Stabilising the spine and using titanium metal alloy rods and screws can also significantly help treat the pain, reducing analgesic requirements and improving post-operative mobility and independence.


MRI Scanner

Axial SpA (AS) spinal surgery fracture fixation requires a very experienced spinal anaesthetist and spinal surgical nursing teams due to the unique surgical challenges presented by the spinal alignment. With an experienced team in a specialist spinal surgery unit, and with safe and careful planning these challenges can be overcome.

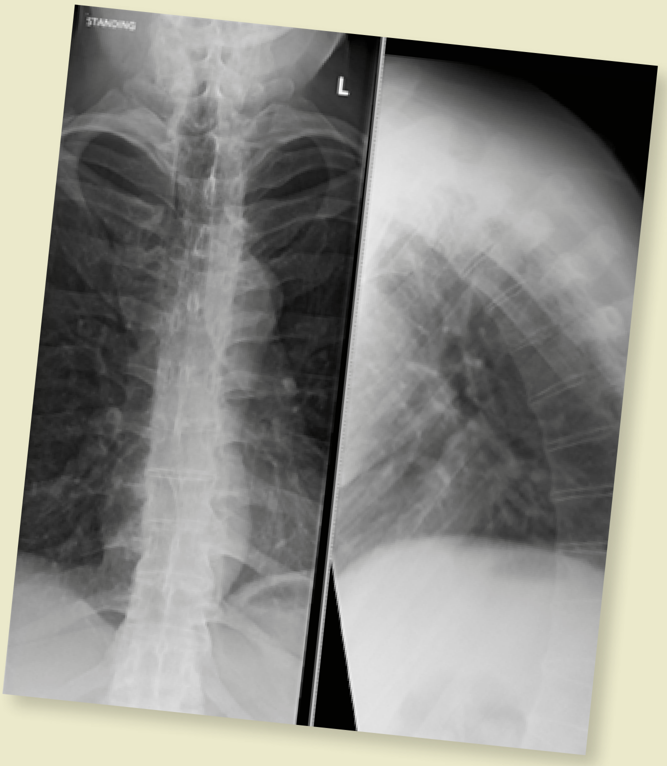
As with all surgery, there are potential risks linked with the operation, including injury to the spinal cord or spinal nerves, which in a worst-case scenario can also cause paralysis. Fortunately, these complications are extremely rare. In addition to surgeons and anaesthetists, spinal teams also work with neurophysiology technicians who monitor how the spinal cord and nerves work during the surgery. This helps reduce the risk of spinal cord and nerve injury.

The decision to offer surgery to an axial SpA (AS) patient with a spinal fracture has to be very carefully considered and discussed with the patient and their families as part of the shared decision making processes.

David's Surgery

David had quite advanced axial SpA (AS) and had seen spinal surgeons in the past to consider corrective surgery for his progressive spinal deformity. After careful consideration, he declined surgery at that time, as he felt he was coping. He was working full-time and was an enthusiastic Norwich City football fan.

One evening David was returning home by train when he was physically attacked by two youths who mocked his kyphosis. They pushed him over, which caused immediate extreme pain in the middle of his back.



David's Spine X-Rays

He went to the Emergency Department of his local hospital and had X-Rays of his spine, but a fracture was not identified and he was discharged home. Despite this, he continued to have pain in his back and although he was able to walk, work and support his local football team he found it difficult to lie down at night and couldn't sleep because of pain.

David called his rheumatologist who advised a CT scan but he couldn't lie comfortably so an MRI scan was carried out and a fracture was immediately identified. David was referred to our spinal clinic. As the pain was still intense and significantly interfering with his quality of life, it was decided to perform surgery to fix his fracture and stabilise his spine. A month after surgery his pain had gone and he was walking around quite comfortably.

David's additional spinal imaging (LEFT) CT Scan; (RIGHT) MRI Scan

David's story

I was on the train in a carriage on my own coming back from football after England beat Panama in the World Cup and two youths were taking the mickey out of my changed posture due to my AS. They attacked me as I was getting off the train and I fell, half on the train and half on the ground. They left me in a right mess.

The train staff were superb. I couldn't have asked for more from Anglian Rail.

I knew I was in a lot of pain and, though I wasn't sure, in my mind, knowing my body like I do, I knew something serious had happened.

I went straight to A&E in the Norfolk and Norwich Hospital. They x-rayed me but I was so badly bruised they couldn't see what was going on.

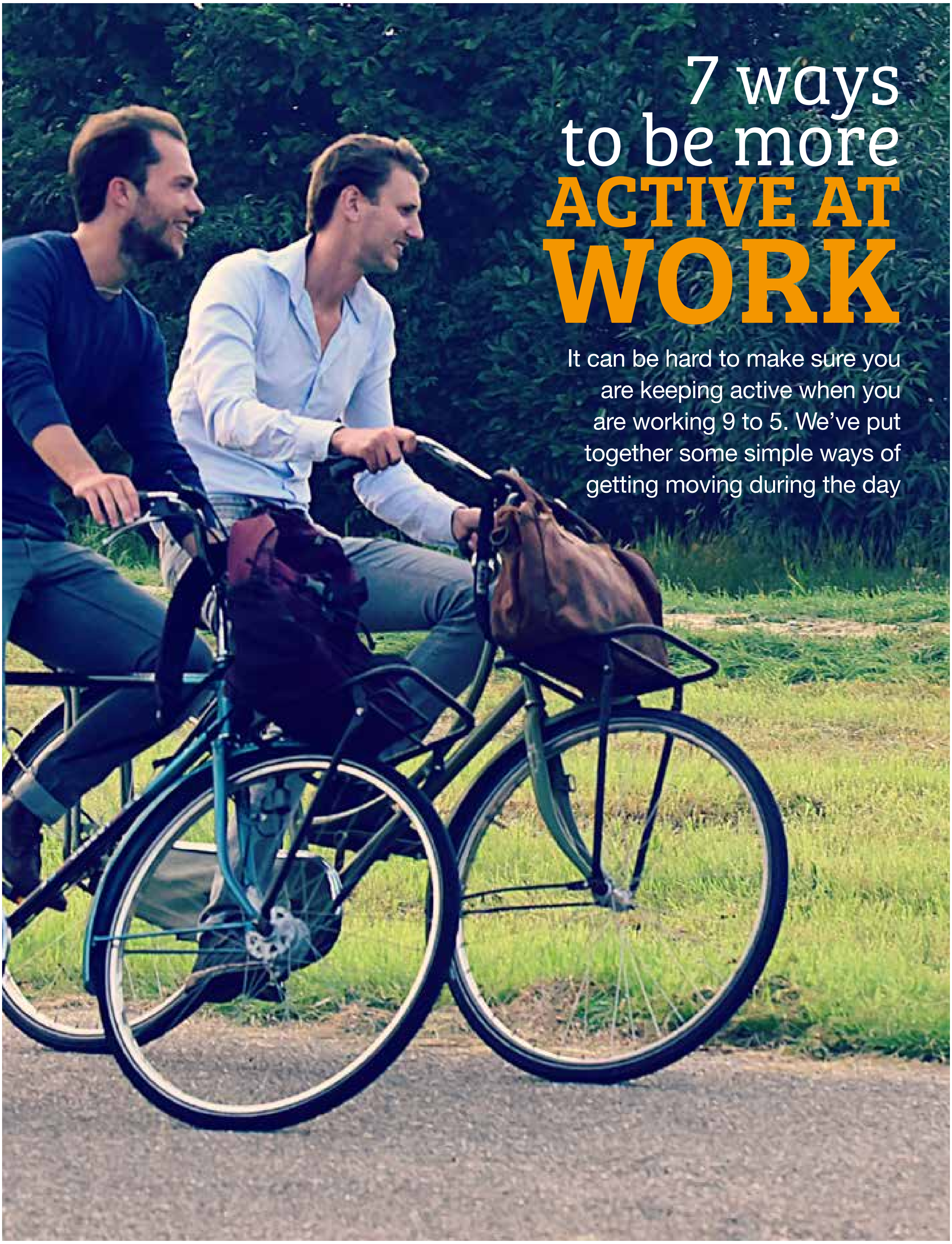
So I went home and the first week I was recuperating and getting a little better and I decided to go back to work. I went to Germany on a pre-season football tour and did everything I'd normally do but I was in a lot of pain. Come September I'd had enough and went to see my rheumatologist, Dr Gaffney which is when I had the MRI and the fracture was found.

Dr Gaffney referred me to the Spinal Surgery team and I had my surgery on 4 October.

It went really well. It's just unbelievable really, my posture is a lot better. The guys straightened me out. They have been amazing, changed my life completely. So even though those youths were absolute idiots, they actually improved my life in the end.

I was only in hospital for six days after the surgery, unbelievable turnaround. I was recovered from the surgery by mid-December but, because it was so near Christmas, I didn't go back to work until the New Year. A new start.

We were very sad to hear that David died in a car crash in August 2019. Our heartfelt condolences go out to his family. Thank you for allowing us to share David's story.



7 ways to be more ACTIVE AT WORK

It can be hard to make sure you are keeping active when you are working 9 to 5. We've put together some simple ways of getting moving during the day

One

Walk or ride at least part of the way to work

If you can cycle or walk (or even run) to work, this can be an excellent way to fit more activity into your day – and you'll arrive feeling fresh and energised, with a clear mind.

Not everyone lives close enough for this to be a realistic option, but you can still find ways to make at least part of your trip more active. If you use public transport get off a stop or two early and walk the rest of the way or if you drive see if you could park a bit further away. If it's a big car park try parking at the far side.

Experiment and try a few different things to see what works for you.

Two

Take the stairs whenever you can

Take the stairs rather than using the lift.

If it's too much for you then think about taking the stairs part of the way and walking just one or two floors.

If you struggle to walk up the stairs then how about taking the lift a floor or two higher and then walking down the stairs?

Three

Use every opportunity to get up from your desk

Pretend it's the '80s – instead of emailing your colleague walk across to their desk and have a chat with them face to face.

Encourage people to have standing or walking meetings rather than sitting around a table. Research shows standing meetings can also be a good way to increase efficiency, making sure things don't drag on unnecessarily.

For smaller groups or one-on-ones, a walking meeting can be a great way to get things done while fitting in a little physical activity. Walking meetings can also help reduce tensions and encourage more creativity and free-flowing conversation.

Four

Try a standing desk

If it's possible in your office, standing up to work can be a great choice. It needs to be easily adjustable so you can alternate between sitting and standing throughout the day.

Five

Turn waiting time into moving time

Waiting for the printer, or the kettle to boil? Take the opportunity to do some stretching exercises. Check out the NASS Back to Action exercise programme for some suggestions. Alternatively, ask your physiotherapist to show you some suitable exercises.

Six

Set a reminder to move

It's easy to get engrossed in your work and forget to move until you realise you are feeling stiff and in pain. Some wearable health devices will vibrate when you haven't moved for a while or you can set reminders to remind you to take a break. Then you could get up and go for a short walk around the building or up and down the stairs. You don't have to go for long. Not only will it get you moving, it will help clear your head, so you go back to work feeling a bit more refreshed.

Seven

Get moving at lunch time

Do take a lunchbreak and try not to take your break at your desk. Having a break during the day is beneficial for your mental health and wellbeing, and it's a good opportunity to get active. Instead of eating at your desk or sitting down in the kitchen area for your whole lunchbreak, make a point to get up and move for at least part of the time. Maybe go outside for a walk and enjoy the change of scenery.

ASone
BRINGING YOUNG PEOPLE WITH AXIAL SPA (AS) TOGETHER

For more articles like this and a chance to share your own experiences visit ASone.nass.co.uk

Walk AS One

Walk AS One has been running every May since 2012.

Every May people with axial SpA (AS) join an online team and record their steps every day. It helps you focus on getting moving with the help and encouragement of team members.

Not everyone can walk long distances so it's about focussing on what you are able to do and seeing if you are able to improve on that over the month. It's also about raising awareness of axial SpA (AS) and participants have kindly used it to raise funds for NASS too.

It's an international effort with teams joining from around the world and this year the teams reached a combined step total of over 100 million steps!

There are two teams in the UK, the AS Buzzers run by team captains Kathy Miller and Gerry Dance, and the Orange Apples run by team captains Gillian Eames and Jean Morton.

Huge congratulations to the Orange Apples, who walked an extraordinary 16,758,404 steps to top the table in this year's challenge.

I join the team Orange Apples every year to raise the profile of axial SpA (AS). Through increased awareness we can reduce the delays to diagnosis which will allow patients to access modern treatment. So, every year I hope I can do my little bit by joining hands with friends across the ASIF network to walk the steps, run the extra mile, climb that flight of stairs to improve care for patients with axial SpA (AS).

Dr. Antoni Chan, Royal Berkshire Hospital

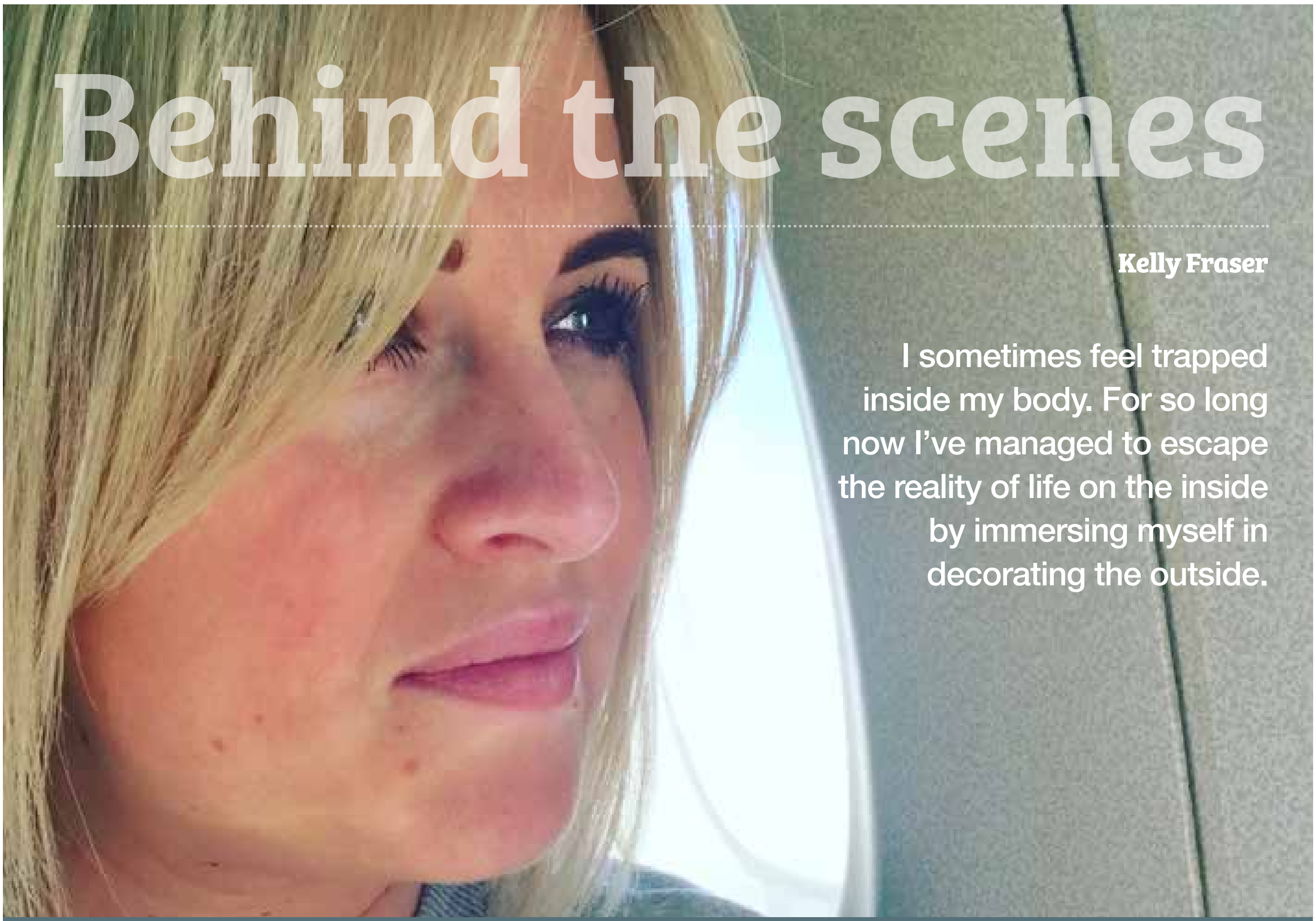
I am a mum of a daughter who has axial SpA (AS) and fibromyalgia. I am a regular walker but in May my efforts are doubled as it brings me closer to understanding what my daughter is going through. She is amazing, never complains although she always has pain. Gillian is our leader and gets us all going, she deserves a star or perhaps an MBE! Go for it Orange Apples! I hope one day my daughter will be pain free.

June Sexton

Gillian's been really encouraging. Joining the Orange Apples has made me feel less alone.

Beth Shaw

Congratulations to everyone who took part this year and hopefully we'll see you in Team Orange Apples and the AS Buzzers in 2020.



Behind the scenes

Kelly Fraser

I sometimes feel trapped inside my body. For so long now I've managed to escape the reality of life on the inside by immersing myself in decorating the outside.

I can barely remember what life felt like back then before my arthritis gripped. I struggle with that. I mourn that loss in small ways everyday.

I miss waking up in the morning feeling refreshed and awake in my body and mind. I miss going to the cinema or a restaurant with friends and sitting for hours in stillness and complete comfort. I feel a compelling resistance to accept that loss and to be in my body as it is today.

How do I settle here? How do I find peace in this discomfort? What's more, I know that this tug of war is inadvertently causing me more distress.

When I was 15 I sang at the London Palladium for the first time. I was so excited to set foot on that beautiful stage, and when I arrived that day, in the summer of 2000, the theatre was every bit as magnificent as I had imagined. As I stood there, my mind catalogued the stars whose footsteps had graced the very floor I was standing on. I was cuddled by what felt like a never-ending sea of red seats with beautiful golden architecture surrounding me and I couldn't have felt more grateful.

After we had sound checked I was taken back stage to settle into my dressing room. No sooner had I walked fifteen steps then the lights and sparkle vanished. All I could see in front of me was cold, dark corridors and lots of concrete. To this day I can remember the dismay I felt, learning that life behind the scenes of this glorious theatre was a stark contrast to the outer shell of its auditorium.

My imagination hadn't factored in grubby hallways and dirty toilets. I couldn't help but wonder if Julie Andrews or Judy Garland felt as surprised as I did that day? The paradox of one of those big superstars shivering in a cold, darkened corridor waiting to perform on this grand stage bemused me even more.

So often my expectations demand that things should be more than what they seem in any given moment. But maybe we all have a grubby backstage? Maybe I'm not alone in ploughing through the mess hidden behind my own scenes? As I grow older I am starting to accept my life for what it is right now - not what it was, or what I expect it to be. My disease may be hidden, but today I am choosing to share openly so that I can be fully seen.

What it's like to: Be a sculptor with axial SpA (AS)

Hazel Reeves is an award-winning figurative sculptor who lives with axial SpA (AS). I visited her studio in the depth of the Sussex countryside to find out more.

Even as a child, Hazel wanted to become an artist, but initially followed an academic route. Her love of politics, campaigning and feminist issues led her to a career promoting women's rights internationally, including working with the United Nations in the Dominican Republic. It was there she started to get back in touch with her passion for art, music, and dance.

She discovered that sculpting was:

'My way of understanding the world around me and enabled me to tell important stories.'

Bronze public commissions Hazel has undertaken include her:

- Sculpture of Sadako Sasaki, a young Japanese girl who died from the impacts of the Horoshima bomb (1945). This is in a peace garden in Wales.
- Statue of Sir Nigel Gresley, Britain's most famous steam locomotive engineers, for King's Cross Station, London.
- The Cracker Packers sculpture to celebrate the lives of these women biscuit factory workers, for Carlisle.
- The 'Rise up, women' bronze of suffragette Emmeline Pankhurst, unveiled in 2018 in Manchester.

I wanted to understand how having axial SpA (AS) affects Hazel's work as a sculptor. Hazel's symptoms started in her late 20's but she didn't get her diagnosis until 15 years later.

She explains that in her previous career she was largely desk-bound. Now she works standing up and this has really helped reduce her pain and stiffness and improve her balance and strength.

'Overall having a physical job is better for my AS. It does lead to problems but there are ways of dealing with it.'

Hazel particularly enjoys the flexibility of being self-employed. Rather than working 9 to 5 she can fit her work around her need to exercise. Working at a studio deep in the countryside means she can head out for a walk at lunchtime. Most days she takes lunch with her to eat outside. At the end of the day Hazel takes another walk before setting off on the drive home.

> **'I can just get up and go for a meditative walk whenever I want. I'm not stuck in town'**

Hazel also finds a lunchtime walk helps stave off fatigue. She has pain and stiffness in her ribs and a tendency to take shallow breaths. When she walks outside in the fresh air Hazel makes a conscious effort to breathe deeply which helps with her rib mobility and ensures she is getting a good supply of oxygen into her lungs. She also notes that walking out in the sunshine means she gets a good dose of vitamin D.

> **'My work has to absorb all I need to manage my AS. It has to become part of it. So walking is my work and exercise is my work.'**

One downside of flexible working can be the time pressure to get commissions finished. Deadlines can change and she can end up working on more than one commission at the same time. Under these conditions Hazel will be working long hours with few breaks and finds her axial SpA (AS) can really start to flare.

Sculpting is very hard, physical work, especially when working on some of her larger sculptures (her bronze of Sir Nigel Gresley is 7ft 4 inches tall). With her bigger sculptures she has no choice but to go up and down ladders. Some days she may be crouched on the floor to sculpt feet or skirt hems.

To ensure she had all the support she needs, Hazel turned to Access to Work, the government scheme which can offer grants for special equipment, adaptations or support workers.

Access to Work helped Hazel buy equipment such as hydraulic tables. These are very useful for her smaller sculptures so she can work at a comfortable height. She also uses a hydraulic table as an adjustable desk so she can stand or sit to draw. Access to Work has also helped her employ support workers to tackle difficult tasks such as taking in a heavy delivery of clay, cutting steel and bending wires.

Hazel finds delivering sculptures to exhibitions and driving to see clients very difficult as she quickly develops back pain and stiffness when driving. Access to Work has meant that she is able to use a specialist art delivery service.

> **'I would prefer to do everything myself. We all want to be completely independent but I do love to work with other people. I only work with people who positively add to the experience'.**

While Access to Work has provided Hazel with invaluable help, she notes that anyone seeking support should be aware that it requires an administrative burden in working out costs and getting a range of quotations. It also doesn't run on from one year to another. Each year Hazel has to put in a fresh claim and it can take a long time to be approved, leading to the delay or cancellation of activities that need this support.

HAZEL'S TOP TIPS

Try a NASS branch

Hazel regularly attends NASS Brighton physiotherapy and hydrotherapy sessions. She loves the ongoing support from both the physiotherapists and the other branch members.

'I love the hydrotherapy. It doesn't feel so much like exercise. We can do more because we are all warmed up'

Get a referral to the RNHRD Rehabilitation Course

It was from local members at NASS Brighton that Hazel heard about the rehabilitation course at the RNHRD. She's since attended the course 3 times and describes it as 'life-changing'.

Hazel finds that each rehabilitation course she attends renews her commitment to exercising, which makes such a difference to her axial SpA (AS). Just knowing that she can improve her flexibility is very empowering.

'I know that the more I do my neck exercises, the better my neck mobility will be'

Mix it up

Hazel started running 2 years ago. She runs on the South Downs on very 'springy' ground and will sometimes stop and lie down mid-run to enjoy the sunshine and bird-song.

She does Pilates classes each week, sometimes down on the beach, and still loves to dance. Ballet classes help her with balance and posture and she looks forward to her Gyrokinesis dance class which includes seated exercises and a whole range of different types of dance including Salsa and Charleston.

Perspective. Division and Harmony

Andy Cutler

This story starts early one Monday morning in February, with me sitting in a Starbucks literally and figuratively scratching my head. The reason for the head-scratching was that I had to come up with a proposal of ideas for my final major project on my part-time Art and Design course I was attending, and to be honest I was stumped.

What on earth could I create/design that would be remotely interesting or attractive with no direction, and just using my own life experiences as inspiration?

Miraculously a couple of ideas started to form in my coffee fuelled early morning brain and very stiff and painful body. First, I decided I would keep a blog of the project, this seemed like a good idea at the time as I hoped it help reduce my workload somewhat – by the way, not true. Second, my tutor had said, 'Work on projects that you care about, know about and have a passion for'.

There and then my project was born, and for the next 10 weeks I got stuck into bringing something to life. You can look at my progress through the project if you're interested at my 'work-saving' blog at www.mistercdesign.com.

So, over the next few days I began to consider topics including:

- Different perspectives
- Living in your own bubble
- Invisible parts of society, for example, people with disabilities, refugees
- Bipartisanship

All the while my tutor's words about passion, caring and knowledge kept buzzing around in my head, and seemed inexorably to be directing me towards my axial SpA (AS) journey.

In fact, my axial SpA (AS) brought me onto this course in the first place. That journey had started 5 years earlier, at a follow up consultation with a Chest specialist after recovering from multiple blood clots in both of my lungs. He asked me how I felt. I replied, 'Absolutely fine, but boy do my legs hurt deep in my bones', which to be honest stumped him.

To cut a long story short, I was properly diagnosed with axial SpA (AS) about one year later, and the next five years have been a rollercoaster ride, culminating in me having to take early retirement autumn 2017. This led to my part-time course, which I viewed as a form of therapy, keeping my mind active and me sane.

Over the next couple of weeks in February, my thoughts started to solidify, and I decided to call my project 'Perspective, Division and Harmony'. My objective was to create a piece of work that brought together axial SpA (AS), the idea of how easy it is to NOT see things from another person's perspective, how we and society create real and perceived barriers between us, and finally the somewhat idealistic idea that if we tried to remove and break down those barriers, life would be more far more harmonious. Lofty ideals maybe, but ones I hoped I could aspire to.

My one and only piece of real insight during the project, was to use my own words that described my feelings about my axial SpA (AS) in the project as I felt this could be powerful. Then one day I suddenly thought, 'Stop! My own words are not interesting but I bet the words of other people living with axial SpA (AS) would be.

Could I collect thoughts, feelings, and words from other people living with axial SpA (AS)?

Of course, the answer was yes, and maybe some of you reading this article may have taken part in my online survey, which was made successful largely by the support of the admins of the Real AS Facebook group and Jenny at NASS who was incredibly helpful in promoting the survey. The survey results were invaluable and formed the central part of my final piece.

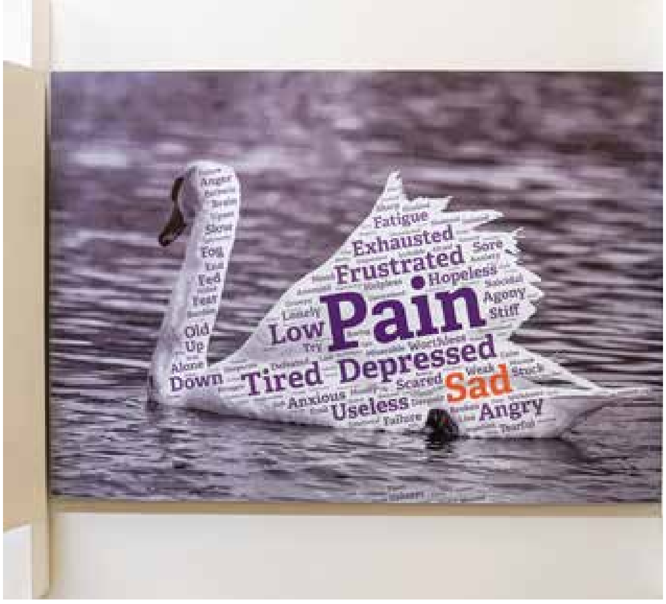
It attempts to capture the feelings of people with axial SpA (AS) during the tough times.

I used a swan as the central image to capture those feelings because they look incredibly serene floating on the water but are busily paddling like mad under the water to maintain that serenity. I wonder whether that sounds familiar?

I hid the swan with a set of gates that contained the feelings of how people living with axial SpA (AS) think the world views them. These gates or barriers can easily be moved out of the way, by the viewer leaning forward and opening the gates to see the reality of axial SpA (AS).

Please judge for yourself, whether I was successful or not.

My project helped me on my journey with axial SpA (AS). I was also helped by the brilliant NASS Members day in the summer, which really galvanised my wife and I to try and turn my axial SpA (AS) into an advantage and to lead a happier life. That journey continues with its ups and downs, but thanks to NASS, I now recognise I am on my own personal axial SpA (AS) journey and I embrace it.



Celebrating SUCCESS

Since the last edition of AS News, lots of incredible people have decided to fundraise for NASS, raising nearly £40,000 between them. Also since the last edition of AS News, we have said goodbye to our fundraising manager Amardeep, and have been joined by two new fundraising staff – Katie and Fareen.

If when reading these pages, you're inspired to do some fundraising of your own, please do contact us at fundraising@nass.co.uk and we can help and support you every step of the way. Whether you like your challenges full of adrenaline (skydive anyone?) or prefer to take things more sedately with a sponsored walk or a Christmas coffee morning, we'd love to hear from you.

Running for NASS

Since March, 24 fab runners have donned their NASS running vests and their running shoes and between them have covered a total distance of 691 miles and raised over £13,500 for NASS! Here are some of their stories:

Our first marathon runner of the year was **Daniel Whelan**, who took on the Barcelona Marathon in March and chose to support NASS as his sister has axial SpA. He says, *'It is an extremely unpleasant condition that not many people know about and it is my aim – by putting my willing body through 26.2 miles of misery – to raise money and awareness for those whose bodies are unwilling as a result of AS'*. Huge thanks to Daniel for raising £1,433.

Noel Fleming chose to support NASS after seeing the effect AS has on a family member. He ran the Rock 'N' Roll half marathon in Liverpool in May raising £605.

Arran Nicholson completed the Torbay Half Marathon to raise awareness of the importance of reducing the 8.5-year diagnosis, in honour of his dad. He raised an incredible £600 for NASS.

LONDON MARATHON

In April, **Peter Mallam** (left) , **Sarah Llanwarne** and **Jonathan Bremner** (right) flew the flag for NASS at the legendary London Marathon raising over £5,000 between them.

Peter ran in support of his sister: *'NASS offers support to people who do not have a support network. Invisible illnesses suck. I want to do my part!'* Thank you to all three of these impressive runners for your amazing efforts.

Our youngest supporter this year was 10-year-old **Jake Bamber**, who wanted to raise money in support of his mum who has axial SpA. Jake did an incredible job, raising a whopping £97 and completing the Liverpool Big Fun Run.

Eleni Keutsogeorgiou took on a Big Fun Run 5k in Brighton in August.

NASS Chair, **Raj Mahapatra**, along with long-term NASS supporter **Gerry Dance** took on an epic challenge this Summer – the aptly named Spine Fusion race, which is a 268-mile race across the Pennines. Both Raj and Gerry trained incredibly hard, mixed their running with stretching to control their axial SpA, and did an incredible job both with their running and their fundraising – raising £914 for NASS.

NASS was also represented in the Northampton 10K in May where **Calvin Lewis** raised a brilliant £240 to help NASS change and improve the lives of people affected by axial SpA (AS).

In Belfast, **Kirsty McLaughlin** teamed up with 5 friends to run the Deep RiverRock Belfast City Marathon. Kirsty's husband Niall was diagnosed with AS 6 years ago, inspiring her and the team to take on a run for NASS. Congratulations and thank you to all of you.

MANCHESTER MADNESS

Lots of runners have taken to the streets of Manchester for us this year, and we're so grateful to all of them.

In April **Ben Devall** and **Kay Savile** completed the Manchester Marathon. For Kay it was her first marathon and she ran to support NASS as her mum was diagnosed in 2015. Kay wrote, *'Running a marathon has been something I've dreamed of doing for a long time and being able to do it whilst raising money for a charity that's supported my mum so much, was an amazing experience.'* Kay's hard work and determination to raise awareness has raised an outstanding £2,265!

In May, **Joseph Cullen**, mum and son **Sheila and James Schofield** and **Sarah Cain** completed the Great Manchester Run 10K. Huge thanks to all of these runners!

Having been diagnosed with in 2017, Sarah chose to run for NASS to raise awareness and to continue to do one of the many things she loves, which she says she has found a new freedom in, since her diagnosis. She says that at times, her body says she can't - so she's proving she can.

Branch Fundraisers

Throughout the year, some branch members or their friends and family choose to take on a fundraising challenge to raise funds for their branch. If you or someone you know would like to do the same, do let us know and we'll be happy to support you.

In July **Lesley Higgins** completed the Glencoe Challenge, raising £200 for the Gartnaval branch which her brother-in-law attends.

In August, **Jess Provost** climbed Mount Snowdon, along with her sister and husband, and her two gorgeous companion dogs, Harley and Quinn. They battled some horrific weather to get to the top. Jess raised a fantastic £610 for the Woking Branch which has had some really tough times recently with their pool and gym getting closed down. The money will help the branch to hold hydro sessions in a private pool.

In April, **Martin Rabbetts** and his daughter **Lisa** ran the Brighton 10K raising £285 for their branch in Brighton.

Other Challenges

It's not only our runners who have been out flying the flag for NASS. People have been taking on all sorts of other challenges…

In May NASS trustee **Danny McFarlane** teamed up with two friends to conquer the Ironman Mallorca with Danny taking the 112-mile cycle leg, raising £1,975.

Amy Bowler, **Louise Dance**, **Nela Knight**, **Melisa Kupaza** completed the 'Samworth Charity Challenge' – a 3 hour hike, 3 hour canoe and 3 hour cycle raising £1,036 – well done girls!

James Kinsey completed the Thames Marathon 14km Swim raising £100 – thank you!

Since **Ben Kennedy's** wife **Rebekah** was diagnosed with AS, he has wanted to do something to raise awareness and show his support of NASS. As a heating engineer, he hit upon the idea to get sponsored to carry a 100kg boiler to the top of Mount Errigal (in County Donegal) and back down again! In August he completed this unique challenge and raised an incredible £2,694.

In January **Sandra Bull** made a New Year's Resolution to organise a sponsored walk/cycle and raise money for NASS. In July she did just that. Along with a team of 12 friends, she cycled 20 miles, just stopping for a 4 mile walk up and down Glastonbury Tor. She celebrated back home with a fundraising bbq and raised a fantastic £800. She says *'It was such a great day assisted by amazing British weather! I am extremely lucky to have had the support of family and friends both on this day but also on a day to day basis. I may even do another next year'.*

RIDE LONDON

Early August saw 5 cyclists take on the RideLondon-Surrey 100 race. Brothers **Chris and Rob Bartlett** cycled with friend **Jonathan Banks** raising £920. Making their team achievement all the greater is the fact that Chris has AS and had a hip replacement in 2018. **Rhys Tom** raised £640 and took on the challenge to celebrate his 40th year, and to honour his friend Ian who has AS and manages to keep up an impressive level of fitness. Our final team member was **Andy Henton** who rode for family members with AS and raised £795. A huge thank you to the whole team – we know those hills are tough, and we're so impressed with how well you all did.

In July, **Julie Shaw** completed the Blackpool Pier to Pier Swim with her husband. They completed the 1.6-mile route in just over an hour and didn't even wear wetsuits despite the sea temperature being a chilly 16 degrees! Not only did she complete the swim, but Julie has raised over £360 for NASS as well. Julie was diagnosed three years ago having had back and joint pain since her teens. She says *'I'm now on a biologic and that, plus my time on the Bath AS course in March, have made such a difference to my life. It's a challenge to consistently train for events between flares etc, but so far so good.'*

Sabrina Lamb and her mum **Heather** were triumphant in completing the Peak District 50k walk in July, in memory of her grandfather who had AS. They chose to take on a challenge they had never done before and raise money for a charity so close to their hearts. Together, Sabrina and Heather raised £205.

Community Fundraising

Fundraising doesn't have to see you take on a physical challenge to raise funds for NASS, you can have a more relaxed approach and fundraise with friends, colleagues or members of your community. Here are some great examples of what people have been up to in the past 6 months.

Chris Diamond saw a first for NASS - he decided to raise money by taking part in a 24 hour gaming marathon! Several members of Chris's family live with AS, so he decided to raise awareness of the condition and support NASS' work by live-streaming himself gaming for a solid 24 hours! Chris raised £120 for NASS.

After 8 years, **Robert Kiely** decided it was time to cut off his dreadlocks and raise money for a cause dear to his heart. He hopes that his donation will help further research into AS and possible treatments. Robert's goal was to raise £10 per dread (52) but he ended up raising an outstanding £770!

Huge thanks to the staff of **Northcutts Garden Centre** in Suffolk, who organised various fundraising events in support of NASS, raising a total of £500.

The guys from **Sheffield Hallam University Rugby Club** supported NASS again with their 2019 'naked calendar' and raised an impressive £1,300 – thanks boys!

Caroline Stevens is a yoga teacher with axial SpA, so in March, she performed an act of kindness and decided to teach a class with no fees but asking for donations to NASS and raised £100.

Fundraising in celebration

A big birthday, anniversary or even a wedding can be a wonderful opportunity for a celebration, and we're grateful to people who choose to ask for donations to be made to NASS in lieu of gifts…

In May **Edmund Hoare** celebrated his birthday and Golden Wedding Anniversary and raised over £480 for NASS – congratulations and thank you.

August saw **Ruth Bambage** celebrating her birthday and raising a staggering £860 in lieu of gifts, thank you!

The end of August saw **Alex and Miriam** tie the knot – we are incredibly honoured that they chose to include NASS in their celebrations, raising £415. Congratulations, and we wish you a wonderful, happy life together.

In June, **Diane and John Faulkner** celebrated their Golden Wedding Anniversary, choosing to ask for gifts for NASS. We're so grateful for the £485 they raised. Huge thanks to Diane for also being our biggest raffle ticket seller for the Summer raffle, selling £180 worth of tickets!

Mary Lumby's mother celebrated her 90th birthday choosing to donate gifts to NASS, raising a total of £240. Thank you for including NASS in your celebration and supporting our work on this special day!

Fab Facebook fundraisers

In the past 6 months we have also seen 149 people choose to fundraise for NASS through Facebook fundraising on their birthday and have raised a staggering £9,916.70 between March and August this year – thank you.

MAKING A DIFFERENCE

Alongside our wonderful fundraisers, we are hugely grateful to generous people who give donations to NASS and to those who make donations in memory of a loved one. Since February these donations have totalled an incredible £14,163 - thank you!

We also receive donations from charitable trusts, and people who kindly decide to leave a gift in their Wills.

Charitable trust donations

We are truly grateful to the following Trusts for their continued support since February:

The John Coates Charitable Trust

The Mary Homfray Charitable Trust

Lord Leverhulme's Charitable Trust

The Simon Gibson Charitable Trust

Leaving a lasting legacy of support

Thank you to each of the following supporters, who generously left a gift in their Will to NASS:

Mrs Joyce Cartwright

Margaret Frenzel

Mrs Josephine Aicken

Mr Peter Saunders

To find out more about leaving a gift in your will, and how you can sign up to write or amend your Will for free, visit www.nass.co.uk/legacy

NASS BRANCH NETWORK

Our network of NASS Branches offer regular physiotherapy in over 90 locations across the UK. They provide regular hydrotherapy or gym sessions led by qualified physiotherapists.

Some branches get out and about, especially in the summer months, trying out different outdoor activities.

Our Derby branch recently celebrated 35 years by holding a dinner for 100 members and guests including Dr Marion Regan, Consultant Rheumatologist at the Royal Derby Hospital and the two health professionals who started the branch, Dr Christian Murray Leslie and Maggie Wylde.

It was a great evening, brilliantly organised by Guy Pearce the Branch Chair and a beautiful decanter was presented to Barbara Foster in recognition of her impressive 35 years of service as Branch Secretary.

Our branches provide a range of benefits to those attending including improved mobility and flexibility and a reduction in stiffness. They offer a place to seek advice and support from professionals and peers. They are a place where friendships are built in a fun environment with those who will understand you best.

If you think attending a NASS Branch is for you or a friend, you'll be able to find out more about branches near you on our 'In Your Area' page. Alternatively, do email any of the branches listed below for more information.

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Send a message that matters this festive season with NASS Christmas cards!

Choose from five designs and show your support for NASS this Christmas

(sold in packs of 10)

At the Haystack

Journey to Bethlehem

Christmas Socks

Painted Tree

Home by the Fire

To order, please visit www.nass.co.uk/shop. Alternatively complete the form below and send it with a cheque to NASS, 172 King Street, Hammersmith, London, W6 0QU.

Order Form

Payment: **Please make cheques payable to: NASS**

Title	Price per item	Quantity	Total cost
At the Haystack	£3.99		
Christmas Socks	£3.99		
Painted Tree	£3.99		
Journey to Bethlehem	£3.99		
Home by the Fire	£3.99		

Other items available in our shop

Back to Action 1	£15.00		
Back to Action 2	£12.00		
NASS wristbands	£1.50		
Mood Bands	£3.50		
		Donation (optional)	
		Postage and Packaging	£1.50
		Total Price £	

Please note :
We can only send Christmas cards to UK addresses

Delivery

Name ____________________

Address ____________________

Postcode ____________________

Tel ____________________

Email ____________________

Visit www.nass.co.uk/shop for more details or call 020 8741 1515