



Axial SpA
works silently
We don't.

Twenty twenty- done

Our impact in 2020



Our story

Axial SpA is an inflammatory disease of the spine and joints. Inflammation where muscles attach to the bones causes extreme pain. If left untreated, it can permanently fuse bones together.

We are the National Axial Spondyloarthritis Society (NASS) and we seek to transform the diagnosis and care of people living with axial SpA. It's an invisible and misdiagnosed condition, often leaving people feeling powerless, in increasing pain and extreme exhaustion.

So we campaign policy makers for early diagnosis and better services. We work with the NHS to get axial SpA identified and diagnosed quickly. We're determined that everyone receives effective care.

We make sure people with axial SpA get the latest information and the support they need to tackle living with this condition.

And we build an active community, online and through our local branches across the UK. We're with you all the way.

Join us. Help us raise our voices and raise funds.

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Raising our voices for axial SpA

The Covid-19 pandemic may have over-shadowed 2020, but thanks to the support of everyone in our community, our work to deliver our new five-year strategy didn't stop. This included tackling the unacceptable eight-year delay to diagnosis and driving improvements in the quality of care for people living with axial "spondyloarthritis".

Despite significant challenges, we continued to campaign policy makers for better services, worked with the NHS to improve care and made sure people got the latest information and support they needed to tackle the challenges of life with the condition.

Since our inception in 1976, NASS has been determined to ensure that no one is locked out of life because of axial SpA. We know with the right information, guidance and support, anyone can develop the skills and confidence they need to live well with the condition.

During 2020, as access to rheumatology services became harder and, simultaneously, we had evidence that the pandemic was affecting people's emotional well-being, we knew that our support was more important than ever.

We responded with longer Helpline opening hours and additional staff, as well as weekly Facebook Live sessions that kept people moving and helped many feel less isolated. We created a new online resource, *My AS, My Life*, with videos, guides and advice to help people tackle the challenges of living with axial SpA. Our national branch network provided regular virtual physiotherapy sessions. Demand for support from our Helpline rose by 300% in the early stages of the pandemic which we were fully able to support.

Our campaigning work didn't stop. We built pressure at a national level to ensure effective and wide spread implementation of the NICE Guideline and Quality Standard for axial spondyloarthritis through the All Party Parliamentary Group (APPG) for Axial Spondyloarthritis. The APPG also convened a special meeting to look at the impact of Covid-19 on axial SpA services and examined the key role that hydrotherapy services play in helping people stay well.

Diagnosis of axial SpA is still taking too long and, while people wait, they live with significant amounts of uncertainty, anxiety and pain. We undertook a national consultation with healthcare professionals and people with axial SpA to identify ways to reduce the time to diagnosis. We also published our proposal for a Gold Standard diagnosis time of one year.

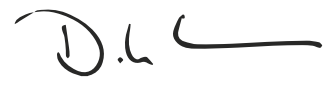
We supported rheumatology services to test approaches to improving diagnosis and treatment through our *Aspiring to Excellence* programme. Despite the demands of the pandemic, we're really pleased that our first six hospitals stayed the course and developed their expertise in Quality Improvement methodologies.

We're proud of the work NASS and its community did in 2020. Our committed networks of branch volunteers, healthcare professionals, donors and funders, Parliamentarians and policy makers were unfailing in their support.

We want to thank everyone for helping us to make great strides towards achieving our new five-year strategy during an unprecedented time.



Raj Mahapatra
Chair



Dr Dale Webb
CEO

Our impact in 2020



Our Helpline supported
5,600 people



We helped people obtain
£852,000
in disability benefits



Called 500
members during lockdown
to combat isolation



863 people
supported our campaign to ensure
people got access to vital healthcare
services during the pandemic



Produced videos that
were viewed over
135,000 times

By Your Side in 2020

As the Covid-19 pandemic hit, people needed our support more than ever.

Across the UK, rheumatology departments closed or were left with a skeleton service. The advice on shielding and enhanced social distancing was confusing. Many people were left feeling isolated and anxious, and turned to NASS more than ever for information, support and to hear a voice they could trust.

In response, we redesigned our frontline services to ensure that everyone was able to get the support and advice they needed to live well with axial SpA.

Our Helpline was a lifeline

During 2020, we doubled our Helpline opening hours and increased the number of staff on the Helpline.

The number of enquiries that we responded to rose by 300% in the first six months of the pandemic and over 12 months we helped 5,600 people who were struggling with issues related to axial SpA. Calls were often long and complex and we did our utmost to support every single caller.

More people than ever faced financial difficulties and we helped people obtain more than £852,000 in disability benefits that they were entitled to.

Whether we were helping with benefits or work issues, Blue Badge applications or housing issues, despite the increase in demand, we were more determined than ever to ensure that people could tackle the challenges of living with axial SpA.

We were concerned that older people in our community might be struggling with loneliness and isolation. So NASS staff and trustees took the time to call 500 members to offer a friendly voice and time to chat.

Keeping people moving and connected, even when we couldn't go outside

Exercise is crucial for people living with axial SpA. We worked tirelessly to provide new ways to motivate people to move, even when going outside was tough.

We ran 33 innovative Facebook Live sessions and produced videos that were viewed 135,000 times.

Covering themes from Pilates to yoga, and emotional wellbeing to managing night-time pain, we created a new section of our website, *My AS My Life*, with advice, blogs, guides and videos to empower people to tackle the challenges of living with axial SpA.

Thanks to funding from the National Lottery, we offered 65 people three online physiotherapy sessions with an expert axial SpA physiotherapist, to ensure that those who urgently needed support were able to get it.

Providing clarity, in a confusing and changing world

A new Covid-19 section on our website was visited almost 50,000 times and provided clarity at a time when official information could be confusing.

It was updated regularly and covered issues such as shielding, enhanced social distancing and even shopping. We also provided advice on medical issues, such as blood tests and medication.

Our influence



Called for the first **Gold Standard** to end the delay to diagnosis of axial SpA



Built political pressure to get people access to vital NHS services during the pandemic and beyond



Secured a **landmark parliamentary debate** on the delay to diagnosis of axial SpA



Delivered the largest UK programme to **improve the quality of care** for axial SpA patients

Campaigning in Parliament to transform diagnosis and treatment

Our work to ensure that policy makers and politicians hear the voice of people with axial SpA didn't stop during the Covid-19 pandemic.

We were very grateful that the members of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis continued to share our commitment to drive change despite facing considerable challenges.

Calling for faster diagnosis and improvements in care

In January, we worked with the APPG to launch a landmark report calling for urgent improvements in the care available to patients with axial spondyloarthritis.

The report *Assessing variation in axial spondyloarthritis services in England* was based on a freedom of information request and revealed worrying gaps in the care and diagnosis of people living with axial SpA.

Its launch was covered by *Channel 5 News* and it was sent to all Clinical Care Commissioning Groups and NHS Trusts in England with individualised key recommendations based on the answers received.

Ensuring people got access to services during the pandemic and beyond

We convened a special virtual meeting of the APPG in July, to undertake a national review of the impact of the Covid-19 pandemic on axial SpA services.

We found that thousands of people were being left in limbo and struggling to access appointments with healthcare teams. The results were published in a report, *Minimum Services Specification Recommendation Paper*, which called for axial SpA services to be maintained during the pandemic and beyond.

The findings were also published in an editorial in *Lancet Rheumatology* and discussed with the National Clinical Director for Musculoskeletal Conditions for NHS England.

Campaigning for Ministers to support measures to end the delay to diagnosis

In September, Tom Randall MP hosted a landmark parliamentary debate on the delay to diagnosis of axial SpA and we were immensely grateful to him for sharing his personal story of life with the condition.

During the debate, the Minister of State for Care, Helen Whatley, gave her commitment to greater public awareness of axial SpA. During the debate she said:

"I want to pick up on my hon. friend's point about the importance of awareness and the call for an awareness campaign by the APPG, and I should of course commend the National Axial Spondyloarthritis Society for its work in this area. My hon. friend mentioned that there is clearly a huge amount of public health messaging going out at the moment, but I hope the time will come when we can gain more airtime for this particular condition."

Tom Randall was also interviewed by the *Daily Mail* about his life with axial SpA and his work to drive political change, alongside NASS member Dasha Karzunina.

Keeping hydrotherapy alive

In November, we took the first steps to ensure that hydrotherapy gets the attention it deserves, with an APPG focused specifically on this sometimes-overlooked form of treatment.

During 2021, we will continue to work with other patient organisations, professional bodies and health professionals to publish a Hydrotherapy Manifesto with the aim of ensuring that it is recognised as a vital treatment.

Transforming care.

Transforming diagnosis

Through our programmes we work with the NHS to ensure that everyone with axial SpA receives effective care and diagnosis.

Acting on the delay to diagnosis

In 2020, we established a ground-breaking five-year programme that aims to end the unacceptable average time to diagnosis of axial SpA of more than eight years.

NASS is the first organisation in the world to call for a gold standard time to diagnosis of one year and is leading the largest programme undertaken to act on the delay.

The programme will tackle the main causes of delay by:

- **increasing** public awareness of the signs and symptoms of the condition and encouraging people to see their GP quickly
- **supporting** GPs and other primary and community care professionals to ensure people with suspected axial SpA are identified earlier and referred to rheumatology faster
- **working** with secondary care services to ensure patients with suspected axial SpA are identified and referred to rheumatology
- **partnering** with rheumatologists and radiologists to ensure faster diagnosis once the patient gets to rheumatology.

During 2020 we led a national consultation process with patients and healthcare professionals to develop consensus on our proposed gold standard and national implementation plan which will be launched in June 2021.

By the end of the five-year programme, we want medical professionals to think axial SpA, refer to rheumatology and follow the NICE guideline. We also want more people to be empowered to spot the signs and symptoms of the condition, and book an appointment to see their GP without delay.

Working with rheumatology teams to drive quality improvement

In 2019 we launched *Aspiring to Excellence*, which supports rheumatology departments to improve their care of axial SpA patients. With the support of our external quality improvement experts at the NHS Transformation Unit, teams received training, coaching and shared their experiences of improving care.

During 2020 the first six teams faced considerable disruption, with many staff redeployed to the frontline to care for Covid-19 patients. This didn't deter them and the 31 people taking part made commendable strides in their Quality Improvement (QI) learning journey.

They began the design and implementation of 13 projects. One highlight was a new referral process that reduced the waiting time for diagnosis within rheumatology from four months to a staggering five days.

In 2021 the teams will complete existing projects and new ones are already being planned. They have reported that the QI techniques and processes they have developed are invaluable in helping them ensure continuity of care for axial SpA patients, operating under Covid-19 restrictions.

With five more rheumatology departments joining in 2021, this is the largest quality improvement initiative in axial SpA anywhere in the world. It is already making its mark as an epicentre for QI collaboration and best practice sharing that delivers better outcomes and experiences for patients.

Building communities and embracing new technologies

During 2020, it was more important than ever that NASS was here to make sure that no one with axial SpA felt alone. Despite the challenges of Covid-19, our community remained active and everyone's determination to join together and combat isolation shone through.

Our branches innovated and kept people positive

We have 90 volunteer-led branches around the UK, and they were determined to keep people connected during lockdown and help people stay active.

When our branches were unable to meet in person, over half ran virtual sessions, giving people a much-needed opportunity to exercise with a trained physiotherapist and connect with friends living with axial SpA.

Many also used WhatsApp groups to keep in touch with members, particularly those who were vulnerable or isolated.

We want to thank every single branch volunteer who worked tirelessly over the past year to help others living with axial SpA.

Membership connected people, even when we couldn't meet in person

By the end of 2020 we had 3,685 members.

Our members told us that during the pandemic, when people felt alone and isolated, NASS membership was more important than ever.

"NASS could be considered a lifeline to some with this chronic painful condition. You're not alone when you're a member of NASS, especially when you join one of the many local NASS exercise groups which are based all over the country."

Wendy, NASS member

"NASS Membership helped me connect with other young people with axial SpA and seeing them leading active and full lives whilst navigating axial SpA gave me such hope."

Fiona, NASS member

Our events went online

In June, NASS held its Members Day online which was attended by over 150 people.

This annual event is a highlight for our members, and we were determined not to let Covid-19 stop us from hosting a day where people could reconnect with friends and find out about new approaches to living well with axial SpA.

In November, we hosted Physio in Focus to help people keep moving when they were struggling to get access to physiotherapy appointments.

We worked in partnership with physiotherapist association AStretch to deliver the event for 100 people that motivated people to exercise and feel confident in managing their axial SpA, both in and out of lockdown.

Our income in 2020

Raising essential funds during a tough year

NASS receives no statutory funding and relies on the generosity of its community, but 2020 was a challenging year for fundraising.

Many events and fundraising activities were postponed or cancelled but our fundraisers were undeterred. We want to say a big thank you to everyone who found inventive ways to fundraise or gave a donation during the Covid-19 crisis.

Your generosity meant that we could carry on helping thousands of people live well with axial SpA. Despite challenging times, our fundraising didn't stop. We are grateful to our corporate sponsors, including UCB with whom we secured a five-year funding agreement that enabled us to bring the Gold Standard Time to Diagnosis programme to life. We also secured emergency Covid-19 funding from industry sponsors.

We are also grateful to everyone who gave a cash donation. The income from our Winter Appeal and our Covid-19 Emergency Appeal helped power us through the pandemic.

Together, our generous donors gave over £40,000, which made a significant difference during a very challenging year. Our growing number of regular givers, who collectively gave over £9,000 in 2020, are helping to ensure that our income is sustainable for the future.

And we want to say a big thank you to all our fundraisers who walked, ran and stretched their way to raising £58,000 for NASS. Highlights included our first virtual event Walk with Us, Walk for AS, with supporters from all over the country collectively raising £5,000!

"As I approached my 30th birthday I wanted to celebrate being as active as I can be whilst managing my diagnosis of ankylosing spondylitis. I decided to run 130 miles for NASS because they've been so supportive. My local NASS support group have been a source of encouragement and friendship and always remind me to keep moving even on those difficult days."

Becky Morley, who raised over £1,000 in 2020.

"Since my diagnosis, NASS has been a lifeline. It was nice giving a little bit back, just a small thank-you for the ongoing support".

Lindsay Halliday, who took part in a half marathon with her sister and raised over £500.

Leaving a gift in your will is a wonderful way to leave a lasting legacy for the care and support of people living with axial SpA. We are incredibly touched that we received £120,567 in legacies in 2020.

We would also like to thank the following trusts for their wonderful support in 2020.

Bernadette Charitable Trust, C M Lowe Charitable Trust, Charles Fairweather Charitable Trust, The Edith Florence Spencer Memorial Trust, The February Foundation, G C Gibson Charitable Settlement, John Coates Charitable Trust, The Mary Homfray Charitable Trust, PF Charitable Trust, Postcode Neighbourhood Trust, and The Simon Gibson Charitable Trust.

Finally, our grateful thanks to AbbVie, Biogen, Janssen, Eli Lilly, Novartis and UCB for grant support to NASS in 2020.

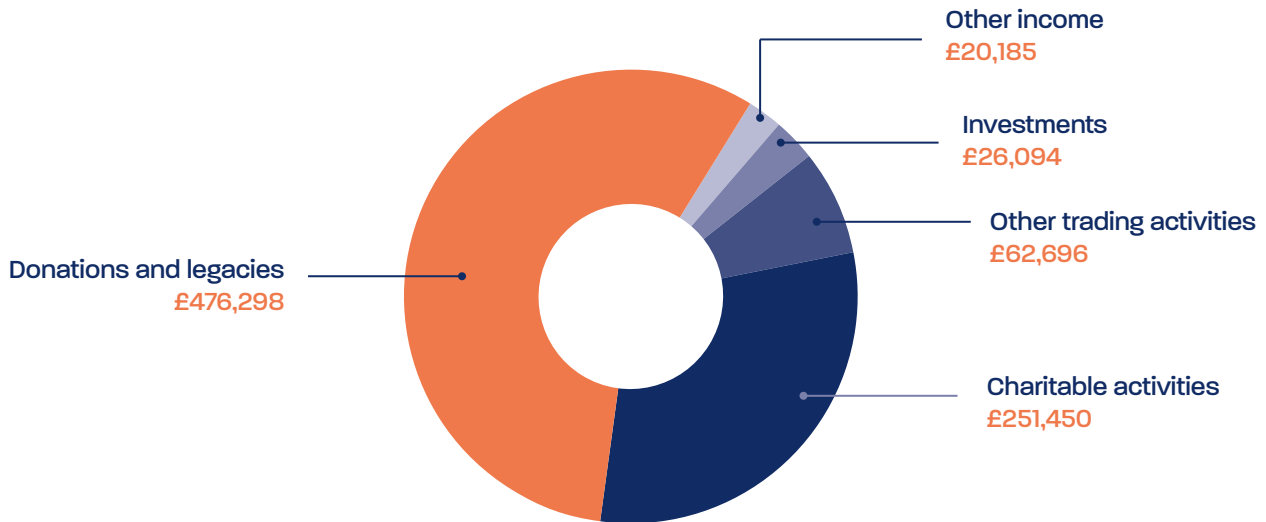


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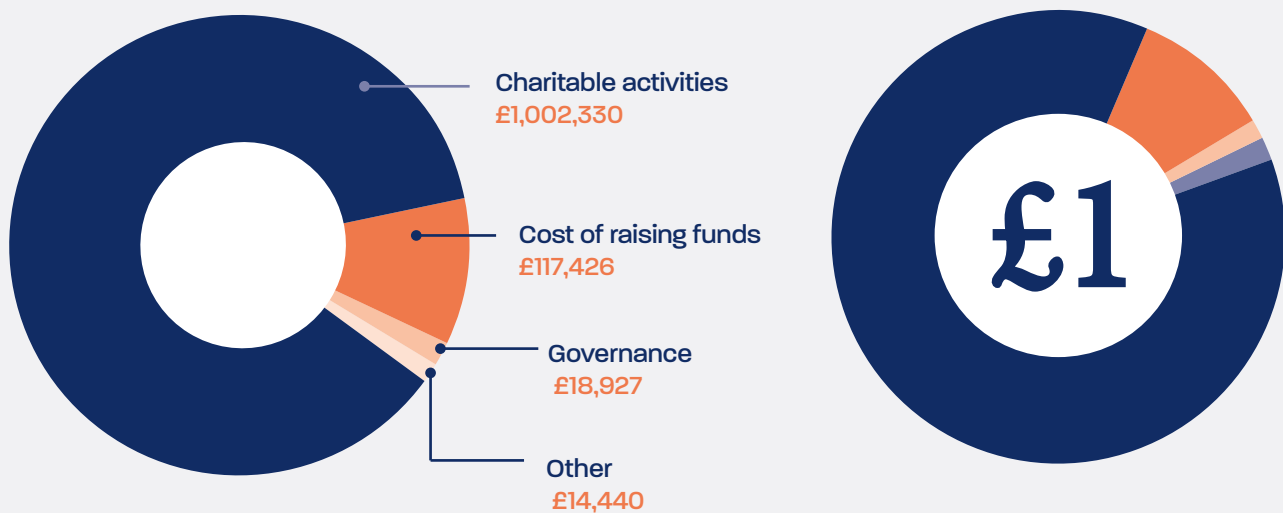
Our impact in 2020

Our year in numbers

Our income



Our expenditure



Of every £1 spent in 2020

- 87% was on charitable activities
- 10% was on raising funds
- 1.5% was on governance
- 1.5% was on other

The following information is provided as a summary.
Our full Annual Report & Accounts can be found at nass.co.uk



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