

National Axial Spondyloarthritis Society Our Story in 2023



Axial SpA
works silently.
We don't.

Axial spondyloarthritis is an inflammatory disease of the spine and joints.

If left untreated, it can permanently fuse bones together.

We are the National Axial Spondyloarthritis Society (NASS) and we 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, and are 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 active communities, online and through our local branches across the UK. We're with you all the way.

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Our impact in 2023



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A challenging external operating environment

2023 was a very challenging year for NASS, for healthcare charities, and for the sector overall.

The continued impact of Covid-19 on rheumatology departments, the ongoing workforce shortage in the NHS and the cost-of-living crisis had a significant impact on our work.

Demand for our services remained exceptionally high, while the income raised through fundraising to deliver them reduced considerably.

Adapting NASS to meet the challenges

We put in place numerous cost reduction measures, and adapted our ways of working to ensure that, as best as possible, we were able to deliver on our core objectives.

Our staff responded with an incredibly positive and co-operative approach to the financial circumstances in which we found ourselves, demonstrating tenacity, flexibility, and absolute loyalty to our mission and vision.

Despite the challenges we have faced, our activities, visibility and influence have been greater than ever.

Impact Snapshot

5,000

People living with axial SpA supported by our Helpline

800,000

A reach of over 800,000 with our social media adverts on diagnostic delay

68

NASS branches running weekly physiotherapy and hydrotherapy sessions

£1.3m

Helped people access £1.3million in welfare benefits

57

Events for people living with axial SpA and healthcare professionals



Reducing diagnostic delay



8.5

Years to diagnosis is NOT OK. Time to act.

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In June 2021 we launched our act on Axial SpA campaign to implement a Gold Standard Time to Diagnosis of one year. In 2023 we continued to make the case for change, raising public awareness, engaging healthcare professionals and seeing local reductions in time to diagnosis.

act on Axial SpA



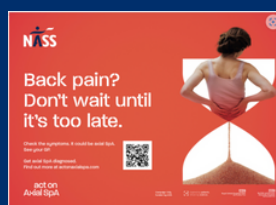
Over 33,000 people have visited our campaign website www.actonaxialspa.com and viewed content 77,000 times

Public Awareness

A reach of over 800,000 from our social media content



170,000 engagements with our social media content such as likes, comments, views

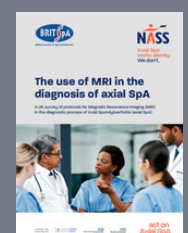


Nearly 25,000 visits to our symptom checker

Over 8,000 people completing the symptom checker

Healthcare professionals

3 key NASS policy publications released



10 Champions in Primary Care, with over 280 hours of training and development time



129 healthcare professionals signed up to the peer to peer network with

23 NASS Changemaker awards given out to healthcare professionals

Improving healthcare quality across the patient pathway



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Aspiring to Excellence was established to ensure that every patient gets the best care, every time.

Working with the NHS Transformation Unit, we partner with rheumatology teams to catalyse improvements in their departments and the wider NHS.

We welcomed four more rheumatology departments into the programme.

We held a celebration day to reflect on progress from the first and second cohorts and to share data from the teams from their improvement work.

We continued to promote the existing podcast series and launched a blog series asking teams to reflect on their experiences and learning.

We created a toolkit to support healthcare professionals in applying values-based quality standards to their services.

We began work on establishing a Gold Standard in Treatment and Care.

We continued to recruit rheumatology teams and patients in the NASS time to diagnosis audit with 54 teams signed up and over 500 patients' data submitted.



onset to diagnosis. We also would like some basic demographic information, this does not include anything that could personally identify you. If you are unsure about how to answer a question, please consider asking a member of the rheumatology team.

for AS or axial SpA. The National Axial Spondyloarthritis Society (NASS) are working to reduce this time from 8.5 years to one. Our rheumatology teams are working with NASS to understand whether measures being taken to reduce diagnosis times are working.



Scan the QR code to access the survey

By completing the survey you are giving your consent for the use of the information supplied

What is axial SpA?

- Axial SpA is an inflammatory condition of the spine and joints. Inflammation where muscles attach to the bones causes extreme pain. If left untreated it can permanently fuse bones together. It works silently, leaving people in

How will we use your data?

- NASS and the hospital will use the information you give to campaign to transform diagnosis and treatment of axial SpA.
- The data will help us measure if we are

Providing vital support to people living with axial SpA

Our helpline, guides and website



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Helpline The numbers contacting the NASS helpline reduced since the unprecedented levels seen during COVID

5,000

People living with axial SpA supported by our helpline

80%

We responded to 80% of queries within one working day

324

We supported 324 people to claim disability benefits

£1.3m

We helped people access £1.3m of welfare benefits



"Everything about [axial SpA] is a battle, it doesn't end here, but the funds will help me put in place coping mechanisms to allow me to stay in work full time and be a contributing member of society. I wanted to express my thanks to you and NASS, without your help I'm not sure it would have been possible."

Female, 41, North – joined as a result of assistance

"The supporting letter is perfect and so accurately written. I can't tell you how grateful I am for your support with this."

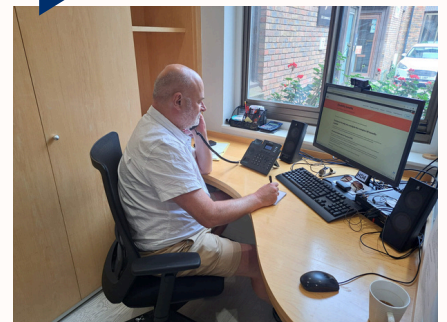
Female, 47, North – joined as a result

"Massive thanks for all you help- it is really appreciated! Your letter definitely helped articulate my condition and was very impactful"

Female, 40, N.Ireland - joined as a result

"You've been such a support and it was validating to have your letter to explain the symptoms which are incredibly difficult to describe when put on the spot by someone on the phone."

Male, 57, Scotland - non-member



Guides and website



122

We sent guides to 122 rheumatology and physiotherapy departments, GP practices, osteopath & chiropractor clinics

124,416

The NASS website had 124,416 visitors in 2023



Supported Self-management Programme

Regional online support sessions, My AS, My Life and Your SpAce



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Regional online support sessions

12

We ran 12 online sessions

26

In partnership with 26 NHS rheumatology departments

450

We reached nearly 450 people living with axial SpA



Your SpAce

We launched Your SpAce, our online programme to support people to manage their axial SpA and the impact it has on their life.

12,000

Views of the 14 videos

22,000

Views of the webpages

120

Promo packs sent to rheumatology departments



12

We ran 12 online peer support meetups

297

With 297 attendees

My AS, My Life

Live-streamed webinars with expert speakers

20

We ran 20 live webinars

121,000

Views of our video library

20,000

Visits to the My AS, My Life webpages

Raising axial SpA awareness

Raising the profile of axial SpA within government



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- The All Party Parliamentary Group (APPG) on axial SpA met twice in 2023 on women and axial SpA and the new healthcare structure in England
- We responded to a call for evidence for the Major Conditions Strategy
- We met with the Secretary of State for Health and Social Care representing the wider musculoskeletal community
- In Wales we continued to develop our relationship with the Musculoskeletal (MSK) Clinical Leads within the Welsh Government
- We collaborated with the British Society for Rheumatology (BSR) campaign on homecare services and House of Lords inquiry



 All-Party Parliamentary Group for **Axial Spondyloarthritis**
Reducing the delay to diagnosis and improving services in axial SpA

Raising public awareness through social media

2.3m

Our organic activity via the NASS Facebook page reached 2.3 million people

588k

Our Instagram activity / posts reached 588,800 people / profiles

1,397

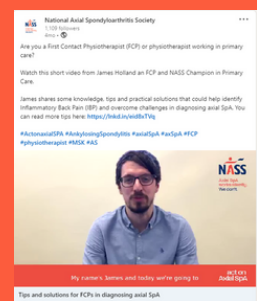
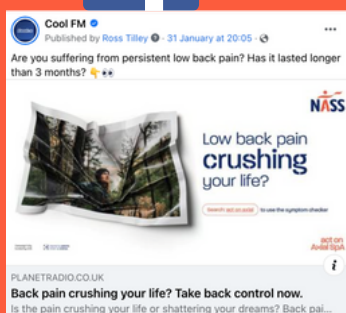
The NASS YouTube channel increased subscribers by 1,397 our videos received 127,269 views and had 1.4m impressions

454k

The NASS Twitter (X) page had 453,568 total reach across our tweets

62k

The NASS LinkedIn page had a reach of 62,306 with our content with an engagement rate of 23%



Supporting a vibrant axial SpA community



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Members are the lifeblood of the society

“Without the helpline, information and support, I would have been lost. Just £10 helps to maintain this support. I am so grateful to the whole NASS team.” - Sarah, 2023

- Membership numbers remained constant at around 4,100 which was encouraging in light of the economic environment and its impact on people's disposable income.
- We held another successful Members' Day, but did so online only due to budget constraints, and held NASS Voices events in Glasgow and Cardiff.
- We welcomed 576 new members across 2023.



NASS Branches

Our extensive branch network offers regular physiotherapist-led sessions across the UK. All our branches are run by local volunteers and our thanks go to them for their hard work. 2023 saw branches make a strong return to pre-COVID activity.



58

58 branches met face to face for group physiotherapy sessions

36

36 of these branches were able to offer hydrotherapy

10

10 branches operated online, including our new NASS online branch



Raising funds for NASS



Fundraising enables us to operate and provide vital services to those living with axial SpA

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Thank you to everyone who supported us in 2023 by donating or fundraising. We didn't receive public funding in 2023 and couldn't do our work without the generosity of our supporters.

Fundraising activities



694 donors

Despite the cost-of-living crisis, 246 people gave a one-off cash gift, 122 people gave a regular donation, 96 people donated in memory of someone, and 230 people - including 14 branches - donated to the Winter Appeal

93

fundraisers

38 people took on a running, trekking, swimming, cycling or rowing challenge, and 55 people joined Gaming for AS, Walk Your AS Off, Stretch-Tember or the Winter Walks Challenge

"Axial SpA can be genetic, and my children could well inherit this condition from me. If that is the case, I don't want them to have to go through the same experience that I did. That's why I have left a gift in my Will to NASS."

Danny McFarlane



I'm so grateful for the support NASS has given me over the years. They are a wonderful organisation and provide vital support and advice to people living with axial SpA.

Gillian Eames, NASS Member



£79,443

We are extremely grateful to everyone who leaves a gift in their Will. In 2023 we received income from five legacies totalling £79,443

515

450 people took part in a raffle, 46 people made a bid in the online Christmas auction and 19 people bought a card from Making a Difference Cards. We want to thank everyone for taking part and supporting our work

£421,294

We were successful in securing funds from pharmaceutical companies for ringfenced work

£63,200

We would like to thank all the charitable Trusts that supported us, collectively giving £63,200

Fundraising ratio £1 : £7.10

Every £1 spent on income generation activities raised £7.10 in income





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National Axial Spondyloarthritis Society

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Facebook: @NationalAxialSpondyloarthritisSociety
Instagram: @NASS_exercise

NASS is a registered charity in England and Wales (1183175) and Scotland
(SC049746)