NATIONAL
ANKYLOSING
SPONDYLITIS
SOCIETY
NASS UK

Annual Review 2017

Supporting people with axial spondyloarthritis including ankylosing spondylitis

> NASS are always there to support and give advice. For an incredibly small team they do an absolutely astounding job! They really do care about what we're all going though and always do their utmost to help. Thank you so much to all the team for being such an amazing charity.
>
> Kathy, NASS Member

> **Thank you NASS for keeping all of us AS sufferers 'in the loop' about current and upcoming legislation, drugs and information. Without you, we would definitely be in the dark about our condition and how it can affect us. It's good to feel that someone has our back in the 'professional' world.**
>
> David, NASS member

Message from the Chair and Chief Executive

Raj Mahapatra

Dr Dale Webb

Welcome to the annual review of NASS. We are the only UK charity dedicated to supporting people with axial spondyloarthritis including ankylosing spondylitis (AS). Around 200,000 people in the UK have AS and we're determined to make sure that we're here for everyone who needs our support.

2017 was a great year. We continued to provide vital support through our Helpline and information resources, and we supported our 90+ branches across the UK. We worked in partnership to raise awareness of AS among a range of clinical communities and to develop new national clinical guidelines for AS.

The end of this year saw us say farewell to Debbie Cook who was CEO at NASS for over 6 years. We would like to take this opportunity to thank Debbie for her work in raising the profile of the charity and AS.

The challenges ahead are considerable. It is still taking on average 8.5 years before someone with AS is diagnosed. By this time irreversible and life changing damage to the spine may well already have occurred. This is not acceptable, and we will be redoubling our efforts to help reduce the time it takes to get a diagnosis. We're a small organisation but we are determined to grow so that we can take on this challenge, and to do that we need to develop our income. As a charity we receive no government funding, so we must raise the funds necessary to achieve our goals.

We now look forward with great anticipation to the exciting projects we have in the pipeline for 2018 and beyond – and a better future for those living with AS.

Raj Mahapatra, Chair

Dr Dale Webb, Chief Executive

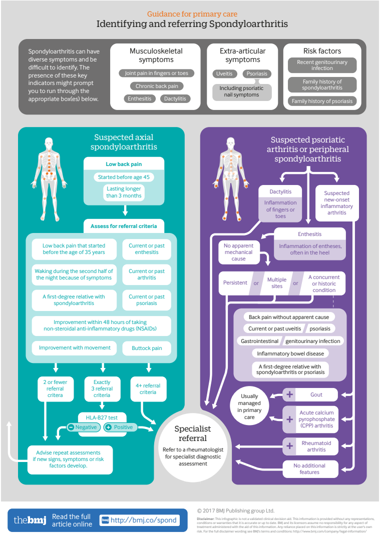
200,000 people in the UK have AS, the average age of onset is 24 and the current average delay to diagnosis is 8.5 years

2017: A year in numbers

Goal One:

Reducing the delay to diagnosing AS

Infographic of National Institute for Health and Care Excellence Guideline for Spondyloarthritis sent to **78,600 hospital doctors** and **28,000 GPs.**



Guidance for primary care

Identifying and referring Spondyloarthritis

Spondyloarthritis can have diverse symptoms and be difficult to identify. The presence of these key indicators might prompt you to run through the appropriate box(es) below.

Musculoskeletal symptoms: Joint pain in fingers or toes; Chronic back pain; Enthesitis; Dactylitis

Extra-articular symptoms: Uveitis; Psoriasis; Including psoriatic nail symptoms

Risk factors: Recent genitourinary infection; Family history of spondyloarthritis; Family history of psoriasis

Suspected axial spondyloarthritis

Low back pain: Started before age 45; Lasting longer than 3 months

Assess for referral criteria

- Low back pain that started before the age of 35 years
- Current or past enthesitis
- Waking during the second half of the night because of symptoms
- Current or past arthritis
- A first-degree relative with spondyloarthritis
- Current or past psoriasis
- Improvement within 48 hours of taking non-steroidal anti-inflammatory drugs (NSAIDs)
- Improvement with movement
- Buttock pain

2 or fewer referral critera

Exactly 3 referral criteria

4+ referral criteria

HLA-B27 test: Negative; Positive

Advise repeat assessments if new signs, symptoms or risk factors develop.

Specialist referral

Refer to a rheumatologist for specialist diagnostic assessment

Suspected psoriatic arthritis or peripheral spondyloarthritis

Dactylitis: Inflammation of fingers or toes

Suspected new-onset inflammatory arthritis

Enthesitis: Inflammation of entheses, often in the heel

No apparent mechanical cause

Persistent or Multiple sites or A concurrent or historic condition

- Back pain without apparent cause
- Current or past uveitis / psoriasis
- Gastrointestinal / genitourinary infection
- Inflammatory bowel disease
- A first-degree relative with spondyloarthritis or psoriasis

Usually managed in primary care

+ Gout

+ Acute calcium pyrophosphate (CPP) arthritis

+ Rheumatoid arthritis

No additional features

thebmj Read the full article online http://bmj.co/spond

> It was 12 years before I was diagnosed and effectively treated for AS. Severe symptoms started in 2001 when I was 21 years old, suffering flare-ups until 2013 when I finally got a diagnosis and access to anti TNF - no problems since. Something like this infographic would have flagged it much earlier I'm certain.
>
> **Rob, Facebook Follower**

Goal Two:

Ensuring that people with AS have the support they need

5,480

calls, emails and Facebook messages

seeking information from the helpline

301,900

unique visitors

to our website

> All the staff and trustees do a fantastic job, always at the end of the phone or email. As a person with AS and member of NASS, I have benefited hugely from your help.
>
> **Gareth, NASS member**

ASone

BRINGING young people WITH AS together

3,200

unique visitors

to our newly launched ASone website

30,000

patient guides

distributed via hospitals

Goal Three:

Empowering patients to self-manage their condition

75 AS clinics
advertised on the website

800 attendees each week taking part in **559 hours** of physiotherapy each month with **savings of £1.3 million to the NHS** this year at our **94 local branches**

An award for our branch network from Patients as Partners Sustainable Healthcare

150
attendees at Members Day

> I regularly attend the branch because I enjoy the companionship, sharing of experiences and support of other people with AS. The exercises and stretching help to control the disease and, along with access to a physiotherapist, keep me positive about the future.
>
> **Peter, NASS Grimsby**

Goal Four:

Raising awareness of AS

1.82 million people
reached over **3 Twitter accounts**

2.28 million people
reached over **2 Facebook accounts**

23,350
views on 3 brand new YouTube videos

> Another awesome video! AS is not just back pain and a lot of people don't understand that. Your work is amazing, keep it up!
>
> **Commando Squeak, YouTube channel subscriber**

Stronger Together

Thank you to all our supporters – we couldn't exist without you

> 'I am so grateful for the advice NASS gave on their website and to the support on the NASS Facebook page. Raising money for them is the least I can do. Thank you, NASS, for helping me get my hiking, fun loving and bonkers husband back.'

Teona, who ran the Oxford Half Marathon in support of her husband, Ian.

119 Fundraisers;

£36,8

raised

66

94 Branches

220 volunteers

9,253
Twitter followers

433
Instagram ASone followers

14,191
Facebook followers

595
YouTube followers

£682,291
received in legacies

Goal One:

Reducing the delay to diagnosing AS

Awareness of AS amongst health care professionals outside rheumatology is low. But we want to ensure that every AS patient gets high quality care every time.

That's why it is so important to have nationally agreed guidelines for clinicians on how AS should be managed. We worked with a group led by the National Institute for Health and Care Excellence (NICE) to develop the Guideline for Spondyloarthritis, published in March 2017. Subsequently, we worked with industry partners to develop this into an infographic which was sent to 78,600 hospital doctors and 28,000 GPs. We are delighted that this will be followed up with a Quality Standard, due for publication in June 2018 and we are contributing to the development group. This Quality Standard will help ensure that high-quality AS services are being commissioned and help to avoid inequalities in the standard of care provided around the country.

We have continued to work hard to raise awareness of AS among health professionals. The Back Pain Plus project targeted hospital doctors and nurses in ophthalmology, gastroenterology and dermatology, requesting that they ask patients with uveitis, inflammatory bowel disease and psoriasis if they also have back pain. We embarked on two projects with the Royal College of GPs (RCGP) – two accredited modules on diagnosis and treatment of AS were written by NASS with the British Society for Spondyloarthritis and advertised by the RCGP. A new Inflammatory Arthritis Toolkit was also launched in partnership with the British Society for Rheumatology and the National Rheumatoid Arthritis Society.

Goal Two:

Ensuring that people with AS have the support they need

Providing information and support has been a key part of our activity since we were founded in 1976. NASS is seen as a world-leader in terms of the quality and depth of information that we produce; societies from around the world have often asked to reproduce our information in other languages to share with their members.

In 2017 we assisted with 5,480 helpline enquiries, a 3% increase on 2016; saw over 300,000 unique visitors on our website, up 72% on the previous year and distributed 30,000 publications via hospitals and individuals. The Guide to Anti TNF therapy was updated to include the new class of biologic medications and renamed Guide to Biologics, with 3,000 copies distributed.

2017 also saw the launch of ASone – a new platform directed at younger people with AS. The website was launched in June and has a distinctly different feel to the main NASS website, allowing young people to share their experiences of living with AS via an online community rather than providing a source of information.

Some of the less visible complications of AS can be the most debilitating – many people will suffer from severe fatigue and most will have a flare at some point which can make socialising, work and exercising problematic. The overwhelming feeling of not being able to be 'normal' when suffering from fatigue or in a flare also leads to people developing stress, anxiety and other related disorders. The invisibility of this condition means it is often difficult to communicate its impact to loved ones, leading to a profound effect on relationships.

Being able to provide a listening ear, an understanding of the complexities of the condition, as well as credible information, is a vital part of the service that the charity provides to people with AS. This will continue to be a major component of the work that we do in 2018 and beyond.

Goal Three:

To empower patients to self-manage their condition better

AS is a long term condition and so there is only a limited amount of impact an annual or bi-annual appointment with a rheumatologist or rheumatology team can have on a person's overall wellbeing. This means that outside one or two appointments with their rheumatology team every year, people have to learn to manage their own condition. We continued in 2017 to help patients manage their AS.

Exercise is the most important thing anyone with AS can do to manage their AS, a message that NASS shares on a daily basis. NASS branches provide weekly or fortnightly exercise and /or hydrotherapy sessions which are supervised by a fully qualified physiotherapist with a special interest in AS. All of our branches are run by dedicated volunteers who give a huge commitment to the charity. In 2017 we were very pleased that our branch network remained strong, with 94 active branches by the end of the year. We were also thrilled to receive a Patients as Partners Sustainable Healthcare award, recognising the value of the branch network in the category 'Supporting Individuals to Take Control of their Care'.

In 2017 we visited Sheffield where we saw 150 people attend talks and workshops, including a 2-hour workshop dedicated to building a first aid kit when in a flare – a time when pain and fatigue is at its peak, which is often completely debilitating for people with AS. This workshop is now being developed into an online module to ensure that all of our members benefit from this resource, which is in addition to our freely available to all guidebook, 'Managing your AS flares'.

Living with AS can feel like a very lonely life. By regularly forming new branches, holding events and sharing experiences, we ensure that people with AS have the opportunity not only to effectively self-manage, but also meet with others who understand how AS affects them.

Goal Four:

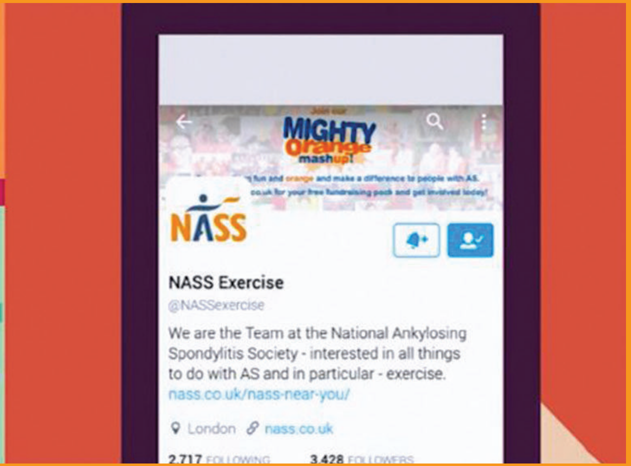
To raise awareness of AS

AS is not a rare condition with prevalence estimated at 1 in 200 of the UK adult population. Despite this, few people have heard of AS unless they or a loved one has a diagnosis, and knowledge is often much weaker than other conditions with a similar or even lower prevalence.

We want to change this so that when someone says they have AS those around them will understand the impact that this will have on their life.

The launch of our three videos 'What is AS', 'Not Just Back Pain' and 'Managing Your AS' saw 23,350 views on You Tube, 800 likes and 1,024 shares on Facebook, plus 268 retweets and 265 likes on Twitter. We used World AS Day and World Arthritis Day to launch these videos to maximise the impact and reach. The hashtag #BackingYou was used to reflect our promise to support those with the condition.

We also had our very own fundraising campaign called the 'Mighty Orange Mashup!'. Although its primary aim is to raise money for NASS through a variety of activities, it is certainly an ideal opportunity to spread the word about AS and NASS. The campaign was specifically designed with the consideration that AS can be extremely variable, and so any activity from a coffee morning to an ultra-marathon would be considered as a 'Mighty Orange Mashup!'.



NASS Exercise

@NASSexercise

We are the Team at the National Ankylosing Spondylitis Society - interested in all things to do with AS and in particular - exercise.
nass.co.uk/nass-near-you/

London nass.co.uk

2,717 FOLLOWING 3,428 FOLLOWERS

The AS it is Campaign - Lobbying for Change

2017 saw the publication of the National Institute of Health and Care Excellence (NICE) Guideline for Spondyloarthritis. The development of this Guideline did not happen by chance; from 2013, NASS played a key role, launching our *AS it is* campaign at the Houses of Parliament, asking MPs to sign a charter calling for NICE to issue a national standard of care, with the support of Huw Irranca Davies MP.

NASS followed the launch with persistent lobbying of the Department of Health, meeting with Norman Lamb MP who was the Minister for State of Care and Support when our campaign began, Professor Peter Kay, National Clinical Director for Musculoskeletal (MSK) Conditions and Professor Charles Greenough, National Clinical Director for the Spine as well as meetings with the Director for the Centre for Guidelines at NICE, Mark Baker. In 2014, NICE announced that work on a Clinical Guideline for Spondyloarthritis would commence.

Our success continued following this announcement; Debbie Cook served as a patient representative on the Guideline Development Group for two and a half years, ensuring that the voice of those living with the condition was heard. From the very beginning until publication in March 2017, NASS has played a key role in the Guideline development.

Beyond this, NASS has begun work to ensure that the Guideline, is in the first instance, distributed widely, with 78,000 hospital doctors mailed with an infographic via the BMJ, and 28,000 GPs in the same manner. We will continue to promote the guideline and hope to push for wider implementation, working with other organisations and professional bodies

As a patient organisation, we strive to ensure that any such clinical documents are understood and utilised by people with AS. We are in the process of developing an interactive guide to the Guideline which will sit on the NASS website, linking to current NASS materials and a set of new videos.

The AS it is campaign has now reached its goal, with the NICE Quality Standard in progress, due for publication in June 2018. The Guideline and Quality Standard are only the beginning in our quest for better care, providing a solid foundation upon which NASS can build.

Dr Carol McCrum is a Consultant Physiotherapist at East Sussex Healthcare NHS Trust. Dr McCrum worked with NASS on the NICE Clinical Guideline for Spondyloarthritis as the physiotherapy advisor and is also a member of the group developing the Quality Standard:

“NASS has been inspiring to work with and absolutely key in helping raise awareness, targeting the breadth of specialities who are also key in earlier recognition, taking up education opportunities with health professionals and championing for better access to and quality of care.

The guideline group was passionate about improving care and championing for earlier diagnosis and reducing variation in care, and the NICE team were invaluable in ensuring the guideline was developed using a robust evaluation of the evidence as well as recognising the research that still needs to be done to help further improve care.”

Society money

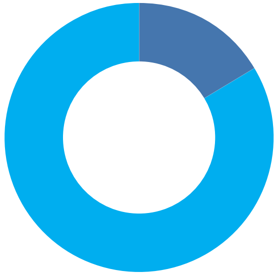
From every £1 of expenditure, 83p was spent on improving the lives of people with AS.

Income

Donations & legacies: 76%
Other trading activities: 0%
Investments: 3.4%
Charitable activities: 20.6%
Other: 0%

Expenditure

Raising funds:16.4%
Charitable activities: 83.6%
Other: 0%



More in depth information is available in our Trustees Report and Annual Accounts at **www.nass.co.uk**

NATIONAL ANKYLOSING SPONDYLITIS SOCIETY NASS UK

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National Ankylosing Spondylitis Society (NASS) is a registered charity in England and Wales (272258) and Scotland (SC041347)

With thanks to our major donors and corporate partners

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From funding vital research to providing life-changing services, leaving a gift in your will can make an enormous difference to the lives of future generations affected by AS. If you would like to know more about how you can leave a lasting legacy of support, **please call Amardeep on 020 8741 1515 or email amardeep@nass.co.uk.**