

2015-2019 Strategic Plan



NASS - Our impact

During the course of the last 3 years the work of NASS has grown substantially. Our free Helpline has seen an increase in enquiries from 1,000 to over 5000 a year. Hits to our website have increased from 50,000 to 250,000 a year. Demand for all of the information we produce has trebled. NASS has worked hard to raise awareness about AS in the media and has run a very successful GP awareness programme which was Highly Commended by the British Society for Rheumatology.

The delay to diagnosis remains a key issue for NASS, as does the need for a consistent level of care across the UK. In 2013 NASS successfully campaigned for Clinical Guidelines to be produced by NICE and these should be published in 2016.

NASS membership has remained constant but we need to grow our membership to have a bigger voice and level of income.

Our Vision is for a healthcare system which recognises the signs of inflammatory back pain early and refers people swiftly for a diagnosis. We want to see people with AS having better access to physiotherapy and hydrotherapy, being supported to self-manage their condition.

NASS is the voice of the AS community in the UK. We will continue to listen to people with AS and their families to inform the provision of information, support and services they need. We will continue to work to grow our physiotherapy branch network and provide a hub for the AS community to connect and share experiences.

Our 5-year strategic plan helps us to address issues raised in our recent Patient Survey.

NASS continues to listen, work with patients and provide first-class support to the AS community.

Debbie Cook
Chief Executive

Raj Mahapatra
Chair of Trustees



2015-2019 Strategic Plan

About Ankylosing Spondylitis

Ankylosing Spondylitis (AS) is a painful, progressive form of inflammatory arthritis. It mainly affects the spine but can also affect other joints, tendons and ligaments.

Ankylosing means fusing together. Spondylitis means inflammation of the vertebrae. Both words come from Greek language. Ankylosing Spondylitis describes the condition where some or all of the joints and bones of the spine fuse together.

Entire fusing of the spine is unusual. Many people will only have partial fusion, sometimes limited to the pelvic bones.

Other areas such as eyes, bowel lungs and heart can also sometimes be involved with AS.

We know there is a strong association between AS and a gene called HLA B27. In white western Europeans about 8% carry this gene. Although HLA B27 is present in over 95% of people with AS, only about 1 in 15 people who are HLA B27 positive go on to develop AS. This means that this gene alone is not responsible for people developing AS but must contribute towards it.

A lot of genetic research is going on around the world and researchers have discovered that at least 20 other genes must be involved. We believe that if someone also carries enough of these linked genes, their susceptibility to developing AS will be higher. One gene of interest is called ERAP1 and some variants of this gene may even protect against developing AS.

About NASS

NASS is the only registered charity dedicated to the needs of people affected by ankylosing spondylitis (axial spondyloarthritis)(AS) in the UK.

Since April 1976 NASS has played a crucial role in providing accurate and up to date information. This allows people with AS to understand their condition and make more informed choices in the management of their symptoms.

We do this by:

- NASS [Helpline](#) open daily to talk about all things AS
- [Accurate and up to date](#) guidebooks, fact sheets, audio podcasts and videos
- [Back to Action](#) guide to exercising safely in the gym is available as a download and a free app
- 91 [local branches](#) offer regular supervised hydrotherapy and physiotherapy sessions.
- Keeping everyone updated with the all latest developments on the website, in E-News and in AS News
- Working alongside the National Institute for Health and Care Excellence (NICE), health service providers and policy makers to raise the profile of AS and, highlight the need for earlier diagnosis and access to appropriate care
- Actively encouraging participation into [research](#) into the cause, genetics, treatment and management of the disease.

NASS – Our next 5 years

In 2013 NASS conducted three large pieces of work to gather information about patients, rheumatology services and research across the UK. The results of these surveys helped us shape our key priorities:

- Early diagnosis
- Patient Empowerment - Support for self-management
- Access to physiotherapy and exercise
- Awareness

In order to rise to the challenges identified in this plan, NASS will continue to work hard to understand the AS community. We will stay aware of emerging treatments. NASS will continue to be dynamic and innovative, embrace technology and look for new ways to provide support. We will aim to grow our membership and supporter base as well as our income in order to continuously broaden our archives. NASS will continue to engage with politicians and policy-makers and is committed to working with partners, as appropriate to achieve our goals.

NASS remains as ever, committed to a world where AS is widely understood.

The work outlined in this Plan is in addition to the delivery of our core NASS services.

NASS Future goals ~ 2015-2019

GOAL 1

To reduce the delay to diagnosing

Ankylosing Spondylitis (Axial Spondyloarthritis)

This is important because ...

It is currently estimated that Ankylosing Spondylitis affects 200,000 in the UK population. The average delay to diagnosis is currently approximately 8.5 years. An early diagnosis usually leads to better outcomes.

NASS will

Continue to raise awareness with GPs, physiotherapists, osteopaths, chiropractors, dermatologists, gastroenterologists, ophthalmologists and rheumatologists

Work with the National Institute for Health and Care Excellence (NICE), supporting the development of Clinical Guidelines and subsequently promote such Guidelines.

NASS Future goals ~ 2015-2019

GOAL 2

To ensure that people with Ankylosing Spondylitis (Axial Spondyloarthritis) have the support they need to help them manage their condition

This is important because...

Currently a large number of people with AS do not have access to physiotherapy*

People with AS need more support during a 'flare' of their condition.

NASS will

- Campaign for better access to physiotherapy and hydrotherapy
- Campaign for better support for people during a flare
- Redevelop and improve the Back to Action free App.
- Work with the private gymnasium and health club industry to seek improved access + support for people with AS.

*NASS patient survey 2013

NASS Future goals ~ 2015-2019

GOAL3

To empower patients to better self manage their condition

This is important because...

People with AS want a recognised self-management programme**. Patients would benefit from a care plan to help facilitate the joining-up of their care which may be undertaken by numerous specialists. People newly diagnosed with AS need support at this critical time of diagnosis.

NASS will

Continue to run 'AS and you' events for people newly diagnosed with AS
Seek to develop a UK-wide recognised self-management programme (including a Care Plan) for people with AS.

** NASS research priorities consultation 2013

NASS Future goals ~ 2015-2019

GOAL 4

To raise awareness of Ankylosing Spondylitis (Axial Spondyloarthritis)

This is important because...

Awareness about AS is needed at many different levels, from GPs to the general public. AS can be an invisible condition; for people with AS to be better understood, the pain, stiffness, fatigue and daily challenges associated with the condition needs to be recognised widely.

NASS will

- Continue to seek features about AS, the patient experience and NASS in the media
- Continue to work on and develop campaigns aimed at recognising Inflammatory Back Pain
- Continue to raise awareness and seek improvements in care with parliamentarians and policy-makers.
- Expand our use of social media and digital campaigns to reach a wider audience.

NASS Future goals ~ 2015-2019

Goal 5

Seek improved support for people with Ankylosing Spondylitis (Axial Spondyloarthritis) of working age to stay in work whenever possible

This is important because...

People with AS are currently not receiving sufficient support to stay in work. A large proportion of people with AS feel that their work is effected by their condition*

NASS will

- Continue to promote the NASS Guide to AS and Work
- Invest in providing additional Helpline support for people needing support with employment and benefit issues
- Campaign for people with AS to have improved access to an Occupational Therapist
- Continue to work with the Fit for Work (UK) coalition and other arthritis organizations to campaign for work as a health outcome.

* NASS patient survey 2013

The Impact of the NASS Plan

Through the delivery of this plan NASS will ensure that:-

- People with AS in the UK are not waiting years for a diagnosis.
- People with AS in the UK have access to regular physiotherapy and (where possible) hydrotherapy.
- People with AS have better, more easily accessible support during a 'flare up' of their condition.
- People with AS wanting to use technology to manage their condition will have such access to information and practical advice about self management, including exercise and physiotherapy advice.
- People with AS will have wider and more affordable access to private sector gymnasiums in order to help them exercise to manage their condition.
- An approved self management programme is in place for people with AS to follow.
- People with AS have access to a Care Plan and their care is better co-ordinated.
- The general public understand what it means to suffer with AS.
- People with AS have the right support to enable them to stay in work wherever possible.

Delivering the Plan

NASS is supported by a small team of seven members of staff and a wide volunteer network. In order to deliver this plan NASS will rely on an increasing membership and income stream. We will continue to explore new opportunities to increase our fundraising and non-fundraised income. We will continue to aim to grow our supporter base.

In addition to delivering this Plan the Team will continue to deliver the core services that NASS provides :-

- Continue to support patients, their friends and families, provide free information and a free Helpline
- Continue to support our Physiotherapy Branches (91 at November 2014)
- Continue to raise funds to deliver the work of the charity
- Continue to support Health Professionals
- Continue to support research into AS
- Continue to improve our understanding of AS and patient needs. We will work within and recognise the changing health landscape and adapt our response in accordance with political and policy changes.
- Work with collaborators.
- NASS will continue to be the voice of the AS Community in the UK, ensuring that it is an innovative and dynamic organisation.

Risks to Plan Delivery

- NASS will only be able to deliver this plan if funding is increased and project funding for specific projects is generated.
- NASS is a small team and so any unpredicted staff changes can have a big impact on project delivery.
- NASS will require co-operation and engagement from key partners in order to deliver many projects within the plan.
- NASS is a membership organisation. The more members we have, the bigger our voice. The more members we have, the more we are able to spend on delivering services to the AS community.

(Annexe A details the specific projects NASS is aiming to deliver in accordance with our key priorities and in addition to our core services. Annexe A will be revised yearly to reflect budgetary considerations and external influential factors)

Annexe A - NASS Project work (to be reviewed every year)

Time Scale	Early Diagnosis	Patient Empowerment - Self Management	Access to physiotherapy/ exercise	Awareness
2015	<ul style="list-style-type: none"> • GP awareness project to continue • Contribute to NICE Clinical Guideline Development • Back Pain Plus project (Gastroenterology / Ophthalmology / Dermatology) • Work with Clinical Commissioning Groups (CCGs) 	<ul style="list-style-type: none"> • NASS Near You project- Working to develop/increase number of physiotherapy branches (including new Friends & Family sessions). • AS Care Plan • AS & You – Newly diagnosed conferences to continue 	<ul style="list-style-type: none"> • Back to Action App re-development and launch • AS it is physiotherapy campaign to continue. 	<ul style="list-style-type: none"> • AS it is parliamentary event (newly elected Government) • Social media strategy further development • Develop & launch Young NASS. • Northern Ireland – Patient conference and branch development. • Work with Clinical Commissioning Groups (CCGs)

Annexe A - NASS Project work (to be reviewed every year)

Time Scale	Early Diagnosis	Patient Empowerment - Self Management	Access to physiotherapy/ exercise	Awareness
2016	<ul style="list-style-type: none"> • GP awareness project to continue – RCGP on-line E-learning tool • Contribute to NICE Clinical Guideline Development Group • Back Pain Plus project (Gastroenterology / Ophthalmology / Dermatology) • Work with Clinical Commissioning Groups (CCGs) 	<ul style="list-style-type: none"> • NASS Near You Branch Development project- Working to develop/increase number of physiotherapy branches (including new Friends & Family sessions) • AS & You – Newly diagnosed conferences to continue • Patient Survey (plus Unit Survey if possible) • Well-being Project – fact-sheet, videos for website & social media channels 	<ul style="list-style-type: none"> • Launch of Care Plan (developed in conjunction with partners) • AS it is campaign to continue • Launch of Back to Action revised App (early 2016) 	<ul style="list-style-type: none"> • AS it is parliamentary event – based on Patient Survey 2016 data • Launch Young NASS • NASS ‘Fab@40’ celebration events • Work with Clinical Commissioning Groups (CCGs)

Annexe A - NASS Project work (to be reviewed every year)

Time Scale	Early Diagnosis	Patient Empowerment - Self Management	Access to physiotherapy/ exercise	Awareness
2017	<ul style="list-style-type: none"> Continuation of Back Pain Plus project (Gastroenterology / Ophthalmology / Dermatology) Promotion of new Clinical Guidelines for Spondyloarthritis 	<ul style="list-style-type: none"> NASS Near You Branch Development Project (including training for branch contacts) Develop NASS self management programme 	<ul style="list-style-type: none"> Develop relationships with gymnasium chains - seeking discounts for AS patients / MSK programme. 	<ul style="list-style-type: none"> Promote new Clinical Guidelines Family and friends events to continue

Annexe A - NASS Project work (to be reviewed every year)

Time Scale	Early Diagnosis	Patient Empowerment - Self Management	Access to physiotherapy/ exercise	Awareness
2018	<ul style="list-style-type: none"> • Extension of Back Pain Plus Project (nurses, physiotherapists, pain clinics). • Promotion of Clinical Guidelines and (from June 2018) Quality Standards. Guideline poster to GPs. • E-Learning advert • Continuation of work raising awareness with chiropractors and osteopaths. 	<ul style="list-style-type: none"> • Development of Self-Management Programme. • Further development of ASOne (growth of the network, two pilot events). • Flares programme – development of on-line content • Members' Day 2018 • AS & You events 	<ul style="list-style-type: none"> • Continuation of NASS Near You Branch Development Project. • AS Clinic Near You (further promotion & development). 	<ul style="list-style-type: none"> • General AS Awareness Campaign. • Membership Campaign. • Website re-development and launch. • Campaign on 'Living With AS'. • Research Event