

Twenty Years as a NASS Group Physio

By Heather Harrison



Last year our NASS group celebrated it's 20 years anniversary. This gave me time to reflect on what changes have happened in this time. In 1998 Tony Blair was at No 10, Bill Clinton was in the White House, Britney Spears was in the charts and Titanic was in the cinemas. In the world of Ankylosing Spondylitis, exercise and anti-inflammatories were the mainstay of treatment, anti- TNF treatment was a whisper and anti IL-17 treatment unheard of. NASS was run almost single handily by Fergus Rogers. And X-ray was the main diagnostic tool.

So where are we now? Well as I write I'm unsure who will be at No 10 and Donald Trump is the president of America. As with the world of politics the world of ankylosing spondylitis has totally transformed. Axial Spondyloarthritis (Ax SpA) is now the more favourable, inclusive terminology, with NASS voting to become the National Axial Spondyloarthritis Society last month. Diagnosis, although still taking too long, has been aided by the easy access to MRI and we are now able to identify people at much earlier stages of disease. In May BRITSpA set out new recommendations on acquisition and interpretation of the MRI to help in diagnosis of spondyloarthritis. This will hopefully aid clinicians, as well as standardising practice and ensuring a consistent approach to diagnosis.

Biologics have totally revolutionised the medical management of the disease and should be offered to patients who haven't responded adequately to anti-inflammatories. I saw my first patient on biologics in 2000 who was taking part in an infliximab trial. I was amazed how her life had been transformed. After the treatment she could sleep through the night, had minimal morning stiffness and could manage to live an active life without constant fatigue. Having seen people suffer with Ax SpA for years I was amazed how this new treatment gave her a normal life. In the 2017 NICE Guidelines for Spondyloarthritis, 6 biologics are recommended treatment for adults over 16 years. This gives people with the disease more treatment options to improve their condition.

NASS has matured. It now has 11 staff and over 3,400 members. It provides support to people via Twitter, Facebook and Instagram as well as a website and a helpline. They have a Back to Action exercise App and they have numerous information video clips on YouTube. It is involved in NICE guidelines, Parliamentary lobbying and it's new Aspiring to Excellence Programme.

So, what has happened to our NASS group. It has been run at 6 different venues including the physiotherapy gym, school swimming pool and now a school gym. We have tried lots of different types of exercises as well as the more traditional gym and pool work including Nordic Walking, pilates, tai chi, walking football and netball. We've done sponsored walks, had educational talks and recently held our first 'gig night' that raised over £800. Our membership has peaked and toughed over the years. There was a low point about 10 years ago when we only got 3 or 4 members a session and struggled with finances. Whether this was due to dawn of biologics, an increase in gyms and local exercise facilities it's difficult to know. In the last 5 years however, the number have slowly increased and we have gone from being predominantly a male group to now being more or less 50:50 male to female, with an age range from 25-81 years. The group is now bigger than it's been for many years. We have fun, lively sessions with members pushing themselves hard to exercise and enjoying some healthy competition playing walking netball or football. About 1/3 of the group take biologics.

Before I wrote this blog I asked the members a few questions about the group, here are some of the responses:

How long have you been attending the NASS group?

Range from 3 month to 20 years

How long was this after you were diagnosed?

Range from Immediately to 20 years

What was the main reason you started attending at that time?

Encouraged to do so by another member. Plus an unavoidable sense that my stiffness etc was getting more pronounced.

Heather suggested it again and there was the opportunity to do Hydrotherapy and try pilates

Was told about the group by the physio who did my initial assessment. He told me it was pretty much vital to managing the condition that I attend; he pushed me to it before denial could set in!

To help my condition, to exercise and to be with other people who have AS

Were there any reasons why you didn't attend before?

Laziness. Denial. Pathological fear/dislike of "gyms". Not sure I would get on with the others who attended. But laziness above all else.

Difficulty of getting there for an 18.15 start.

Child care and out of comfort zone

Didn't know about the NASS branch

What are the main things you get from attending the group?

Huge variety of exercises and activities, some of which can be re-used at home. On-the-spot advice in relation to any particular aches and pains. And a great bunch of people – really nice to chat to others who're in the same place, right across the age range. I generally feel a bit fitter and brighter.

It means I get out of the house and I don't have to cook tea!

Stretching exercises; a fixed definite weekly exercise session – I'm much better at keeping to an external commitment than doing exercise at home.

Targeted exercise on a regular basis to help manage the condition. Social interaction with other members and sharing of experiences. Having fun together.

Meeting others with a similar medical problem and seeing how they cope

The reasons for not attending the group are varied but the reasons for attending are very similar: exercising, with people who share the same experience and having fun

while doing it. I never imagined I would still be running the same group 20 years on, but I still love my Tuesday evening sessions for the same reasons the members enjoy coming. There are more things we can still achieve in the world on Ax SpA, a reduction in time to diagnosis, more biologic options and equality of service throughout the country. Here's to the next 20 years.



Heather