

An AS course to change your life

by Stephen Dean, NASS trustee and chairman of the Brighton NASS group

So you have ankylosing spondylitis (AS) and it's making your life particularly difficult to cope with at the moment. Imagine that you could go on an NHS funded, residential based course at a location that enabled you to have daily access to physiotherapists who were among the most specialised in the field of AS in the country. Also at this location you could, on a daily basis, access a hydrotherapy pool and a gym plus a multitude of other health professionals.

Is this venue located up some inaccessible mountain goat track, and policed by some local health mafia? No, such a course can be found currently operating at the Royal National Hospital for Rheumatic Diseases, Bath.

I have been fortunate to go on the course, and it has enabled me to change my life, and the outcome of my life beyond my wildest imaginings.

The course, or courses, for there are different ones for different levels of flexibility and mobility, are available for anyone of whatever age, provided that you have an open mind and are willing to try to work and make the best use of the facilities available on the course.

Self management seemed to be the watch word of the course, to me. Spending time in the hydrotherapy pool and gym most days was a major factor in improving my flexibility and strength, but this was supplemented with talks and discussions from health professionals on a range of related subjects.

These included pain management, dealing with flare ups, foot care and footwear, medication, radiology and some alternative treatments like Pilates, reflexology and acupuncture.

A large part of the benefit of the course I found was actually living, for the duration of the course, with others who to have AS. The physical manifestations of AS in people were different, but the pain, the sleeplessness, the fatigue, the frustration, the anger, the difficulty interacting with others – they all seemed universal. This meant that there was no need to explain how one day you felt great and the next you didn't. It was part of the common understanding that prevailed between us all.

The AS course at Bath did not do the changing for me but it showed me and empowered me to make the changes for myself. It was far from easy or quick. Changes to my daily routines took a lot of mental and physical effort, but once I started seeing results in terms of reduced fatigue, better sleep, better body strength and flexibility and feeling that I had been more productive at the end of the day, then the results encouraged the changes to become permanent.

Once home I made part of my new regime of dealing with every day AS creating a better support network where I had access to the inherent expertise of the first hand kind, i.e. other people with AS. I had previously been a member of NASS and a latent member of the local support branch but now I endeavoured to go to the hydro and gym sessions, where again I could take comfort in the common understanding that exists between those with AS.

That in itself can be one of the most beneficial things to experience although it is often the least practiced and the least appreciated. The result is that I maintained the high level of well being that I felt on leaving the course at Bath for many months, and I now have more, and

better solutions for coping with whatever AS deals me in the future.

As Steve has so eloquently described, the course is 2 weeks long and residential: you stay in a slightly scruffy but comfortable Georgian house opposite the hospital in the centre of Bath. The course is focused on physical therapy and you will need to be assessed at Bath so that you slot in to the right level of course.

If you want to go on a course you will need to have a diagnosis of AS and to ask your GP or your consultant for a referral to a consultant at the RNHRD. If your GP has never heard of the course then you should say you think it is what you need and how successful it has been in helping other patients with AS – you can quote what Steve has written. The Government policy on Patient Choice and the introduction of "choose and book" in England means that patients can theoretically choose to go to the RNHRD for treatment, in practice it is not always that simple and some GPs and Primary Care Trusts (PCTs) may be resistant to funding the referral because they do not understand the benefits of attending the course. It is worth noting that 2 weeks at Bath costs less than a third of the cost of an anti-TNF for one year. The majority of people who go to Bath are from the South of England but anyone in England can attend and some Welsh LHBs will fund courses as well.

If you have a place on a course, it is important to attend and to let the organisers know promptly if you are unable to do so, otherwise the place and resources may be wasted.

If you cannot attend a Bath course, you should still ask what alternatives are on offer in your area for people with AS as in some places there is help available.

Jane Skerrett