

Zoë Clark, aged 28 years from Norfolk

I originally started working with the NASS in 2018 after being asked to write blog posts for their website for young people with axial spondylitis. From there I became involved with the NASS Allies campaign, a partnership between the NASS, the Institute of Osteopathy and the Royal College of Chiropractors. It's been exciting to be involved in a large project improving the knowledge of osteopaths and chiropractors, to hopefully contribute to reducing the delay to diagnosis for people with axial spondylitis and improve their care once diagnosed.

I have lived with some form of inflammatory arthritis since I was 20 years old. I was in my third year of my Masters degree in osteopathy when the symptoms started and through a combination of support from my university, family help and perseverance I managed to complete the four-year degree. Over the years I had a few different diagnoses, including rheumatoid arthritis and psoriatic arthritis, but the symptoms weren't very well managed.

Once I started working with the NASS I gained the confidence to get a second (well, third!) opinion and after scans, it was confirmed that I have ankylosing spondylitis (which falls under the umbrella of axial spondylitis). Having a seven-year delay to diagnosis as a healthcare professional under the care of rheumatologists shows just how difficult it can be to diagnose. This has encouraged me to continue working with NASS to update knowledge within the medical profession and raise public awareness.

Working with chronic pain

My job is quite physical when I'm in clinic treating patients, but I've adapted techniques so they're safe for me to use while still being effective for my patients. The main adaptation I make is limiting the number of patients I see in one day, so that I keep well and my last treatment of the day is the same quality as the first. Being self-employed can be difficult, but it allows me flexibility in when and how I work.

I practise what I preach with regular exercise and stretching! Although I do have to make accommodations, I feel that I can empathise with patients very well; helping people out of pain or finding ways to manage it is incredibly rewarding. With my own experience of chronic pain, I also have a real focus on empowering patients and giving them the tools to help manage their symptoms, rather than relying on treatments like osteopathy regularly.

Quality of life

Ankylosing spondylitis does have an impact on my daily life, but since getting the correct

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diagnosis and starting a new medication I've seen a marked improvement in my pain and fatigue. I have accepted that I have a lifelong condition and am encouraged to make adaptations. For example, I now use a stick if I'm walking long distances, which enables me to continue doing things I enjoy without aggravating my symptoms as much. For a naturally stubborn person, this is a big step!

Being part of the NASS team has helped me both professionally and personally. Before I started working on the NASS Allies project, I had no idea they were such a small organisation with no Government funding, because they do so much incredible work. Everyone in the organisation, as well as the many volunteers, are friendly and welcoming. They're so passionate about improving the lives of people with axial spondylitis and it shows in the work they do.

Helpful guidance offered by the NASS is free to access on their website. The reliable information explaining what axial spondylitis is, resources for people to give their employers and information about the different treatment options really empowers people living with axial spondylitis. The patient groups around the country provide a support for

members and the online information the physiotherapists share is fantastic.

As well as the help directly for people living with axial spondylitis, the NASS gets involved in lobbying at a high level, for example, helping with Employment and Benefits processes and the creation of the All-Party Parliamentary Group to ensure care across the UK is up to the right standard. I was privileged to speak at the January 2020 meeting focusing on the delay to diagnosis and was inspired by the plans NASS are forming for the years ahead.

It's been a real pleasure to work with NASS professionally and I owe a lot of thanks for the help they've given me personally when getting my own axial spondylitis diagnosis. I'm excited to see what lies ahead and hope that with greater awareness of axial spondylitis the charity will go from strength to strength.

