Fifty years on, the UK's only axial SpA charity says 2 in 3 people with the condition still don't know why they are in pain

Thursday 5 November, 2026

NASS marks its 50th birthday today by launching an appeal to raise £50,000 for people like David, whose axial SpA is difficult to manage.

London, 5 November 2026. The National Axial Spondyloarthritis Society (NASS), founded in 1976 and still the UK's only axial SpA charity, marks its 50th birthday today, Thursday 5 November, by launching an appeal. It aims to raise £50,000 to keep NASS here for everyone with axial SpA and, in 2027, launch a new initiative for people whose axial SpA is difficult to manage.

Axial SpA, an inflammatory arthritis mainly of the spine, affects 1 in 200 people in the UK. A typical cinema screen seats around 200 people: one of them is likely to have axial SpA. Around 220,000 people live with the condition, yet only 60,000 have been diagnosed, so 2 out of 3 still don't know why they are in pain. The average wait from first symptoms to a diagnosis is still as high as 7.5 years.

David was a national junior cycling champion at 15 when the back pain began. For ten years, he searched for an explanation for the pain. A biologic medication gave him seven good years, but it stopped working, and nothing he has tried since has helped. Parts of his neck, spine and ribs have now fused, making it difficult for him to take a full breath.

“They don’t know what to give me,” David said. “There’s no such thing as a pain-free day anymore. I want to tell my story so other people won’t be left waiting in pain.”

Dr Dale Webb, Chief Executive of NASS, said: “No one with axial SpA should have to wait in pain. Fifty years on, NASS is here for everyone with axial SpA. But I believe we can and we must do more to help people like David, whose axial SpA is hard to manage. That is why, in 2027, we will launch a new initiative to focus on them: talking to them, working with researchers, rheumatologists and NHS professionals, finding out what they need and helping them to access it.”

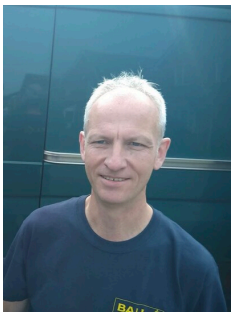
NASS began in 1976 when a small group of patients, rheumatologists and physiotherapists met at a hospital in Bath. In 2013 it took the voices of people with axial SpA to Parliament; four years later the NHS had its first national clinical guideline for the condition. In 2025 NHS England adopted NASS's Axial SpA Playbook. Last year alone, NASS supported 5,053 people through its Helpline.

£25 could get the right support and trusted advice to someone who is newly diagnosed; £100 could give the next person who calls the Helpline a listening ear; £250 could help NASS be there for someone with axial SpA for a whole year.

Those who wish to support the ‘end the wait’ campaign are invited to give a donation at nass.co.uk/donate.

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