



## LIVING WITH ARTHRITIS

Journalist Juliette Wills has lived with inflammatory spinal arthritis for 18 years. In part three of a six-part series, she meets other people living with arthritis in order to challenge misconceptions and reveal the true impact of a condition that affects more than 10 million people in the UK

# My family never gave up on me

**L**iving with arthritis doesn't just affect a person's body. Pain can lead to depression and anxiety - which in turn makes the pain worse. It's a vicious circle, but many of us are afraid to tell our friends or family that we're unable to cope, so we miss out on the help we need.

My pain is invisible - I don't use a walking stick because it doesn't help, so cars don't slow down for me, people still push past me to get a seat on the train and even my friends are oblivious to the pain I'm in because I don't look like I'm suffering. I don't complain because I don't want to bore anyone with the truth, because, frankly, it bores me. According to research by the charity Arthritis Research UK, 81% of people with severe arthritis feel they're a nuisance to their family; hardly surprising when you can't do the simplest of tasks unaided, and all the more galling when this hits you in your mid to late 20s, as ankylosing spondylitis, also known as inflammatory spinal arthritis, generally does.

On a bad day, the pain is indescribable - for almost a decade, on and off, I could barely move my head due to the searing pain caused by the fused vertebrae in my neck, and the crushing ache around my ribs meant I had trouble drawing breath. Some days I could only crawl from room to room. The emotional impact of my disease on my family was enormous; they felt completely helpless and my dad was so worried about me he became ill. Even my brother's A-level results were affected. The ripple effect of a disease such as this is truly astonishing.

Arthritis can be a destructive beast of a condition at its worst, so little wonder that its devastating effects are felt not

only by the patient, but also by the people closest to them.

Liam O'Toole, chief executive officer at Arthritis Research UK, says: "Arthritis is a major public health issue, yet you rarely hear it talked about. We want wider society to understand the reality of the condition, so the needs of people with arthritis will be better understood."

**'The pain floored me and I couldn't work. The strain was immense ... We could no longer go on with our relationship'**

## Neil's story

Neil McDonald, 40, has suffered with arthritis for more than 20 years

In the mid-90s, I was working at sea in the merchant navy and training as a helicopter pilot when the lower back pain I'd had on and off for a few years suddenly became intolerable. Unable to continue flying, I took a junior deck officer's job on a cruise ship where I met Jill, who was part of the children's activity team. We came ashore together a month later.

I worked in IT for a while, but the pain completely floored me and eventually I couldn't work at all. The financial strain was immense; we had two young daughters and Jill was doing everything: running the house, looking after them and working. Eventually, we decided we could no longer go on with our relationship; I moved out of the family home in 2010 and sank into a deep depression. I would have done anything to end the pain. I felt like I was being skewered slowly through the hips with a red-hot poker, and even

lifting my foot off the floor would have me screaming in agony. I barely ate and couldn't even get dressed without help, but Jill never gave up on me. It took two years to find a treatment that worked; I wasn't pain-free, but I was a lot better. I embraced it by putting myself through law school and gaining a 2:1 degree last year. My tutors were very supportive, but it was the hardest thing I've ever done.

My relationship with Jill eventually got back on track and I moved back into the family home in 2015. There are times when I'm too tired, or in too much pain, to do all the things my daughters (aged nine and 12) want to do, and I'm often so exhausted I'm in bed before they are. I want them to have happy memories of their childhood and their dad, so I try my best for them. It's the least I can do - they never gave up on me, and they're the reason I'm here today.

To find out how arthritis affects us all and why Arthritis Research UK is raising awareness, visit: [theguardian.com/nations-joint-problem](https://theguardian.com/nations-joint-problem)

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