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Why is fibromyalgia so misunderstood?

Fibromyalgia is a chronic widespread pain disorder, estimated to affect roughly one in 25 people. But, despite being relatively common, fibromyalgia remains a seriously misunderstood condition, surrounded by stigma, confusion and long delays in diagnosis. So what is it really like to live with fibromyalgia, and why do we still understand so little about it?

Anywhere between 2% and 6.8% of the population will suffer from fibromyalgia at some point in their lives. "It is typified mainly by pain, but patients report that in a variety of different ways. It can include pain generally, as an ache. It can be described as a sharp, burning, pins and needles type pain. It can be funny sensations," explains Dr Attam Singh, a consultant in Pain Medicine from [The Fibro Clinic](#).

"We see the whole gamut, and I think it's important to note that one person's pain may well be different to another's. Generally the pain tends to flit around the body, and may change from day to day, or possibly from hour to hour, and that's the problem - patients generally aren't able to predict where the pain's going to be next, and treating pain that moves is extremely difficult," he adds.

Besides pain, Singh explains, fibromyalgia is associated with two other main symptoms: [fatigue](#) and [brain fog](#) or difficulty concentrating (sometimes referred to as 'fibro fog'). "The fatigue might be mild fatigue towards the end of the day, or it might be something that renders the patient bedbound. Likewise, difficulty concentrating and processing things can have a major impact on patients' work and family lives," he says.

While neuropathic painkillers are an option, to "turn down the hypersensitive nerves within the brain", Singh explains, treatment largely involves looking at lifestyle changes and tracking triggers to help patients better manage the highs and lows of living with constant pain and fatigue.

Difficult diagnoses

Part of the reason fibromyalgia remains so misunderstood is because very little is definitively known about what causes the condition. "It's likely to be multifactorial," says Dr Raj Sharma from UCLH's Royal London Hospital for Integrated Medicine. "It may be triggered after an accident or some sort of medical intervention, but there will be various factors for each individual," he explains.

Fibromyalgia is also commonly associated with mental health problems, Singh says, and there's a suggestion that people who've been exposed to abuse or high levels of [stress](#) during their early lives are more predisposed to developing the condition - but that's not to say that the pain is all in sufferers' heads.

"Historically it's a chronic pain condition that's been poorly understood. Often the notion is that there must be some sort of underlying pathology, and if we can't see it on a blood test or a scan then it must be psychological. However, we know the pain these patients are perceiving is 100% absolutely real," Sharma explains.

Because there isn't a straightforward test or scan for fibromyalgia, Singh adds, there's often a long delay in diagnosing the condition, partly because doctors have to rule out other possible causes of these varied and unpredictable symptoms.

Other reasons for the delay, according to Sharma, include symptoms being picked up late, and patients being referred by their GP to the wrong type of specialist - for example, to a neurologist instead of a rheumatologist. "The diagnosis can take, on average, two to six years, and a lot of that comes down to how patients are picked up and referred on," he says.

41-year-old Jagroop waited nearly nine years for a diagnosis, after her fibromyalgia symptoms were initially put down to her existing [chronic depression](#). "I was really lethargic, struggling to get out of bed, and just not functioning at all. I had a constant headache that was just there all the time," she says.

"This started in my late twenties, and was a constant all the way through my thirties. Doctors just kept telling me it was one thing after another, after another, after another, and trying me on different medications."

It was only through doing her own research online that Jagroop found out about fibromyalgia, suggested it to her doctor, and eventually got a diagnosis in summer 2018.

Out of sight, out of mind

In the most severe cases, fibromyalgia can have a debilitating impact on sufferers' lives, shutting them off from their careers, social lives, and even families." Basically I've gone from being a perfectly active, normal person to being stuck in bed 20 hours a day, and being exhausted and in pain 24/7," says 56-year-old Ruth.

"My husband of 31 years is my carer and does everything now as I can't manage - my personal care, all the cooking, cleaning, laundry, shopping, gardening, driving me around, and pushing me in my wheelchair. He's done this for many years while also running his own business and, until our children were grown up, also doing the majority of childcare," she adds.

Most painfully, Ruth adds: "I've lost a ton of friends through it, because I just don't feel able to go out. With an [invisible illness](#) like that, that you can't see, you're very much out of sight, out of mind.

"When I do go out," she says, "I'm obviously feeling well enough, so I put on my nice clothes and makeup, do my hair, and I look fine. Apart from the fact I've got a wheelchair or a walking stick, you wouldn't know there's anything wrong. But then when I'm not feeling well there's this attitude of 'shut up moaning'. There's been a real lack of understanding from some people, and many of my closest friends have distanced themselves. It's very lonely and isolating."

For Jagroop, who began a PhD around the time of her diagnosis, there's been a similar lack of understanding about the need to pace herself. "I feel like I have to put on a front sometimes at the university, because people don't understand. I'll socialise and act like I'm functioning, but then I'll just go home and collapse," she says.

"There's also a real cultural misunderstanding within the Asian community," Jagroop adds. "People just don't understand chronic illness. Unless you've got [cancer](#), the attitude is, 'you're fine, just be strong!'"

Not just a 'women's condition'

Fibromyalgia has had a similarly devastating impact on 35-year-old Steven's hopes and dreams. "The last time I felt well was in my teens. I had career plans, I was very sociable, but I've lost pretty much all of that," he says. "Life is very difficult. I can't think clearly, I'm in a lot of pain, my legs ache, I'm clumsy, I fall, I mix words up, I'm forgetful, and I sweat easily. It's a massive struggle."

For him, stigma and misunderstanding about the condition are made worse by the perception of fibromyalgia as a 'women's condition'. According to Singh, fibromyalgia clinics typically see a distribution of one male patient to seven women, although this may be partly down to under-reporting and under-diagnosis among men.

"It's such a lonely world being male with fibromyalgia, and there's not much in the media about men's experiences, which drives me mad," says Steven. It's an issue that Des Quinn, chair of Fibromyalgia Action UK ([FMAUK](#)) - who himself lives with the condition - says he sees coming up "time and time again". "As a charity we're continuing to make a point of representing the male aspect of fibromyalgia, as well as the female experience," he adds.

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