

My continuing journey for change

Before the symptoms

As a teacher, my work life was devoted to helping others. Alongside work, I was living life to the fullest. I travelled, camped, and, most of all, I gardened.

That is, until February 2009, when my life was uprooted. A rash on both legs alongside a growing instability, and a sudden pain behind my right knee became too severe to ignore. I had the realisation that I couldn't drive safely any longer due to the pain. As a healthy 48 year old, I had rarely seen my GP, but this forced me to them.

This one visit has turned into a 17-and-a-half-year journey of undiagnosed chronic pain and a growing understanding of the shortfalls of the UK healthcare system.

Many appointments, no answers

Pain has slowly infiltrated every part of my life, like a stubborn weed whose roots have grown and spread throughout my body.

My first encounter with a healthcare professional (HCP) who didn't understand life with chronic pain was my first referral. It was an appointment with a specialist, a rheumatologist. During that first visit to my GP, they suspected Henoch-Schönlein purpura (HSP), which explained the rash and pain. I was hoping the specialist would give me the direction that I needed for a diagnosis in this complex health care system. Unfortunately this experience gave me the realisation that I would need to learn to steer myself through the healthcare maze.

Going into this appointment I was surprised, nervous and hoping for some guidance. My medical history up till that point in my life had been relatively uninteresting, and I did not know what to expect. After the initial greetings, the rheumatologist asked why I had been sent to him. I explained my GP's suggestion of HSP. However, the rheumatologist did not agree, as the pain had endured many months, too long for HSP. After what developed into an argument with no progress, I was dismissed and sent for blood tests and physiotherapy.

My initial expectation for this appointment was to be given direction. I was unable to convince the rheumatologist that I had a problem. I said I was unable to extend my leg. To show that it could, he pulled my leg till it straightened. The potential cause of my problems was never discussed with me. To this day I still don't know if my GP's initial suggestion of HSP was correct. Later, upon asking for my records, I discovered that the specialist's notes taken during the appointment had been labelled by others as largely illegible.

This experience taught me the importance of communication. Communication, from patient to doctor, from doctor to patient, and between doctors. My GP's notes were not detailed enough to convince the rheumatologist that I had a problem. I lacked the experience to explain my problem to a sceptical specialist. And he lacked the ability to ask the questions to a novice patient in a way that would uncover the clues. By the end of the appointment I had no idea what the blood tests were for, or the aim of physiotherapy.

The prescribed physiotherapy consisted of exercises, hydrotherapy and massage. Unfortunately, my pain did not respond. I began to walk differently under the fear of my knee collapsing, this caused further pain. I began to sit differently because of the pain, and this caused further pain.

By September 2009 I was sent to an extended-scope physiotherapist (ESP). They prescribed MRI's of my knee and spine. A minor tear was found on my right knee's anterior cruciate ligament. This was never mentioned to me, instead I was told that everything looked normal. I was again prescribed a few further sessions of physiotherapy and a walking cane (as a 49 year old!).

Later, upon receiving my notes from the ESP, I discovered that they believed my pain had begun in August 2009, instead of February. Only one month of a changed gait had been taken into consideration, as opposed to the reality of six months of accumulated instability. I don't know if this would have changed the physiotherapist's decision, but now after 17 and a half years, I can't help but wonder. After being discharged I was cast adrift with my symptoms as severe as ever. It began dawning on me that this was the beginning of a battle to prove that I had a problem.

My collection of appointments and procedures has included; another rheumatologist; a variety of physiotherapists; and even a gastroenterologist, after being referred by another specialist declaring that I was a Not Our Department (NOD). I had a spinal cord simulator fitted during COVID to reduce the pain. This needed to be removed as it caused more problems than it solved. This was put down to the lockdown restrictions interrupting the usual trial period and the follow-up appointments not being readily accessible and months apart.

No appointment has resulted in a clue, and no procedure or treatment has resulted in reduced pain. My only refuge from the pain is painkillers, which are becoming less and less effective.

A voiceless teacher

In 2012 my voice failed me. I once held a proud teacher's voice, able to command a rowdy room of children. I was unable to speak for a period of months. I couldn't remember how to vocalise certain sounds. There seemed to be no reason why. Perhaps it was the accumulation of laryngitis, stress and the death of my father. With the help of two generous speech therapists, I slowly recovered my voice, only to lose it several times again over the next few years.

Finally, complications after an operation in January 2025 seem to have robbed me permanently of my voice. All I can manage is a hoarse whisper. I feel that my medically unexplained symptoms (MUS) have taken away my voice literally and figuratively.

Green shoots of hope

My journey through the healthcare system has included moments of positivity. These can be sorted into two groups: The well intentioned but poorly executed treatments, and the occasional green shoot of hope and understanding.

An example of the former; a few years after that initial appointment, a physiotherapist referred me to a podiatrist, thinking that a leg imbalance might be a reason for my pain. I was prescribed a raised insole to ameliorate what she thought was the problem, but she neglected to continue physiotherapy after the insole seriously affected my balance. That one oversight led to developing enduring nerve pain in both legs, long after I stopped wearing the insole.

Throughout the many appointments that I have attended with the many HCPs, there have been a handful of occasions that have given me hope for this system: A nurse who double-masked and gowned-up to give me a hug after a long, presurgery isolation during COVID; a doctor who undertook a surgery after a refusal from his colleagues whilst expressing the desire that new doctors should also learn to think outside the box; and a counsellor who, unlike his colleagues, guided me with understanding and empathy.

This pain counsellor let me cry, rant without judgement, and gave me time to process each disappointment. Once he had learnt my story, he took the dual role of counsellor/coach. We strategised for each upcoming appointment to get the best possible outcome. Afterward, he was there for me when the appointment inevitably went belly up. Realising my reliance on him, he kept me on for months longer than what I should have been allowed.

My 17 and a half year journey has proved to me that change is needed in the current UK healthcare system. These reaffirming moments have equally proved to me that change is attainable. These HCPs were sunflowers standing tall, willing to make one deviation from the norm: to empathise with the person asking for help.

After 17 and a half years

My life has changed drastically. From an able, active person, I now feel trapped in a body unwilling to perform the meanest of physical feats without pain. Walking hurts, sitting hurts, talking hurts. It is the worst form of distraction from focusing on anything different. Pain is my new constant companion.

Sleep is an elusive necessity. My pain increases as I sleep, which in turn disrupts my sleep. I have not had a good night of sleep for 17 and a half years. My mornings consist of attempting to reduce my pain to a manageable level to allow me to make it through a day of organising medical appointments and chasing up referrals.

For many of my family and former friends, this has turned me into a person that is challenging to be around. For some it has proved to be too challenging. My reality is too uncomfortable for people, they prefer for me to tell them I'm fine. The pool of people that I can turn to for support has shrunk to a few friends, my sister and an increasingly understanding GP.

At the beginning of my journey, the school principal where I taught was patient and encouraging. I was given the freedom to attend appointments and practise my physio exercises in-between lessons. Eventually their patience wore thin. During my ordeal, a colleague also had a painful health event with a long recovery. Others could not understand why, when she had recovered as expected, I had not improved. Their empathy slowly turned to indifference to my stress for appointments and lack of results.

I loved my work. I was not going to let the pain defeat me. However, the accumulation of pain, other health issues, and my struggling voice made work conditions unmanageable. In late 2018, a period of severe pain pushed me to take time off work. I reluctantly surrendered. In May 2019, I stopped full-time work and took an early retirement. The pain had won.

I still work occasionally as a supply (replacement) teacher. I began this in September 2019. I refused to accept that my working life was over. The pain and my hoarse voice make each new assignment more and more of a struggle. I fear that I only have a few more jobs left in me.

My dream of a diagnosis would return to me the dignity of peace of mind in my sanity. I have been told by doctors and physiotherapists to give up searching for answers and live my life. But what life is there to live? My response is 'There must be something wrong with me, or else I must be nutty!' (my exact words). I refuse to believe that my body could suddenly stop functioning properly and be in constant pain, with no explanation. Thankfully, my strong Christian faith has persevered, and I can safely say that this has been my saving grace.

Push for change

The soil in my garden is solid clay. I have worked and worked to improve it and now have a glorious, vibrant back garden with plants covering every square inch and many pots covering the driveway. But, hidden in the soil is an insidious problem; a vine weevil. The larvae of this insect eat at the roots of my plants, which can die, seemingly out of the blue. There is one clue to suggest their presence: the adults make tiny, horseshoe-shaped holes in the leaves.

At a friend's house I saw the same holes. Helping her, we started to empty out the infected pot. After we had removed the top layer of soil, she told me just to replace it with fresh mix and plant more plants, thinking this would fix the problem. But for a solution you need to dig deeper.

My friend's reaction to her plants reflects my experience with the UK healthcare system. Some practitioners have seen a problem, and like my friend, have taken the easiest route to a solution, such as prescribing painkillers. They do not consider looking for the small clues, the horseshoe-shaped holes, that will lead towards the underlying problem.

I have two goals: find a diagnosis, and to push for change. I feel like change in the UK healthcare system is required before I can be diagnosed. Each time a nurse, doctor or specialist says 'that's just the way it is' or 'I can't change the system', I question it. I ask 'why not?'. I don't expect this to change the entire NHS, but it might change some mindsets. This change could bloom through their practice, and maybe keep spreading.

At the political level, I have discussed with my local MP and councillor the changes required to better support pain patients. I have also worked through a complaints process at my local hospital after a difficult experience with post-surgery care, unprepared for people with chronic pain. I continue searching for any avenue to make change.

Achieving my two goals seems distant, but I will carry on pushing until I find a pain-free life again.

You are not alone

Telling my story is another front in my battle for change. My journey has been long, and it hasn't finished yet. Throughout this journey I have learnt many lessons and want to spread these to anybody who finds themselves in pain with no diagnosis:

1. Know that you are right, you know your body. Advocate for yourself.
2. Friends, colleagues, even doctors who have not experienced chronic pain or MUS will struggle to understand what you are going through.
3. Realise that the appointment, that you have waited months for, means more to you than to the doctor. They've only waited a few minutes since their last appointment.
4. Come prepared for that appointment, bring notes, questions and be prepared to defend them. This may be your one opportunity.
5. Try not to cry in the appointment, even though this may be hard, this can influence judgements. Wait until you are with someone you trust; a friend, a family member, then shout, cry, whatever. That emotional release is important.
6. Make sure that the doctor's notes are correct. You have a right to see what has been written about you. These notes are what all future appointments will be based on. Pay especial attention to this if your medical journey is long and complicated.
7. Give yourself time to mourn the life you had. Embrace your new life. Find time around the pain and appointments to rest and enjoy.

I hope equally that HCPs will read this story. Please consider the following:

1. Check that the person understands what you have said to them.
2. Check that you understand what they are telling you and how their life has been impacted.
3. Make sure they understand the purpose of any test, referral or treatment prescribed. You may be the link to their final diagnosis.
4. Please verify that there are no mistakes in letters or notes. Wrong information is difficult to change and can be a significant problem in the person's journey to diagnosis.
5. Please send referrals and notes as soon as possible. The patient's journey is already long enough.
6. Communicate everything to the new HCP when referring. They need to understand why you made this decision.
7. A negative test still leaves the person undiagnosed. This can be difficult for them. Ensure they know what this means, and consider what should come next.
8. Most importantly, listen and empathise.

If you find your life taken from you by undiagnosed pain, know you are not alone.