

PE2038/F: Commission suitable NHS services for people with hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders

Emma Roddick MSP written submission, 13 September 2024

I'm sorry that I couldn't be there in person today due to a committee clash, but I am glad to be able to share some thoughts regardless on an issue very close to my heart.

Over the last three years, I've had the pleasure of meeting many others who struggle daily with normal tasks, like walking, sitting, typing, and living. I know that too many struggle also to get the help that they need with their pain and other symptoms due to a lack of diagnosis or available treatment.

When we meet each other, we will often get excited when the other mentions something like neck headaches, the difference in pain between crisp packet crepitus and everyday joint clicking, or getting toothache in your hip. Nobody is happy that others feel these things, but most patients with chronic pain will experience a type of gaslighting by the world; being told over and over that the bizarre is normal, the exhausting is routine, and the excruciating is mild. The joy of hearing someone else acknowledge and validate your experience is so extreme because of the dismissal we've experienced before.

Doctors cannot be expected to know everything all the time. There are so many so-called rare conditions which affect many thousands of people in Scotland. I do not expect every GP to look at hypermobile joints, migraines, gastro issues, and chronic pain and think "EDS". I do not expect them to see chronic pain and know exactly what the cause is. But there should be a nationally agreed standard for pain pathways to ensure that people do not fall through the cracks, left to suffer.

We know that earlier diagnosis and earlier treatment for EDS mean you are less likely to develop more severe symptoms. We know that quality of life can increase drastically, and the cost to the NHS should, therefore, also be lower.

Living with chronic pain can seem impossible. I have had times where I can barely move, barely think through the pain, but the receptionist at the end of the phone simply asks me to try paracetamol and ibuprofen for a few days. I've been taken to hospital with medication-induced hepatitis because I have relied on too much of the wrong medication for too long. These are very common situations, and it is very common for people with chronic pain to end up suicidal.

EDS Support UK has been clear in its calls for a pain pathway and formally commissioned services for people with EDS – with input from lived experience. Many people giving evidence and energy to this committee have been clear why this is necessary.

I hope that the committee will progress this petition, which gives voice and hope to many of our constituents who are suffering unnecessarily.