

## NHSE E-learning for healthcare

### Video transcript:

#### Louise's experience of living with ME/CFS

"When I was a teenager, I began experiencing confusing symptoms. I felt incredibly lethargic day to day, there was a constant, sharp pain in my head and my swollen glands and sore throat meant that sometimes it was hard to speak.

"Before this point, I'd always been a very active person. I didn't know it until many years later, but it's likely that my undiagnosed glandular fever led to my body's dysfunction.

"I saw my GP many times over the next few years. I tried to explain that I felt tired and weak all the time, but I just couldn't properly articulate just how disabling my symptoms were becoming. The GP would order blood tests that would always come back clear, reassure me that I was fine and send me on my way with no further follow up.

"In my head there was no reason not to trust a medical professional who presumably understood what was happening to me better than I could. However, years passed, and my symptoms only got worse. Whenever I tried to vocalise how much I was struggling, I was told that it was probably just teenage hormones or perhaps stress over upcoming exams.

"During one appointment, the GP advised my mum and I that it was my stamina that needed improving. Even though they knew I'd been very active and even in pre-professional ballet training as a child, they recommended that I go for an hour long walk every day after school.

"Coming out of that appointment, I felt utterly humiliated. I began to think that all the pain and fatigue I was experiencing was in my head, and maybe I was just a weak person. I also wondered if everybody else secretly felt the same way about me. I was around 16 at this time and I felt like a failure.

"For the next few years, I kept my pain and struggles to myself and avoided seeing a GP unless it was absolutely necessary. I put everything into finishing my exams and starting university. I told myself that if I could just grit my teeth and ignore the symptoms then maybe the doctor was right, and they would go away.

"There were so many warning signs that I ignored until, at the age of 19, I experienced a huge relapse and my whole way of life had to change. From that point onward my condition was impossible to ignore.

"For the first few months I spent most of the day lying down in a darkened room wearing ear plugs and headphones, because even the noise of the door closing caused pain to reverberate through my body. I couldn't stand or walk for more than a few moments at a time. And any trip out the house - no matter how short - took days to recover from.

"It was only then that my GP referred me to a local clinic specialising in myalgic encephalomyelitis/chronic fatigue syndrome, or ME/CFS for short. Before then I had no idea that such a clinic even existed.

"At the clinic it only took one initial appointment before I was diagnosed with ME/CFS. Although it was an overwhelming time, I remember feeling a sense of relief that I was finally being listened to and had some answers.

"Although there was very little they could do for me at the time, it helped me to begin to realise that what I was going through was a very real thing, that my feelings were valid and that I wasn't a failure.

"I believe that if healthcare professionals had a greater understanding of ME/CFS' early warning signs and they were equipped to ask the right questions to understand how a patient was feeling, they could make that referral sooner and avoid crises like mine. However, trust and empathy are the most important qualities of all.

"An understanding and empathetic relationship with my GP means I can use my limited energy to find meaningful ways forward."