

I am number 17  
Rachel's experience

I received my diagnosis at the age of 21. I was diagnosed with Ehlers-Danlos syndromes (EDS) first and a couple of hours later I was diagnosed with mast cell disease. I had no idea what was going on, I just remember feeling very different to the people around me. I remember feeling ill all the time, experiencing a lot of pain, not being able to enjoy eating without being sick.

As I was getting older, it was consuming every part of my life. I lost nearly all my friends, as I was at home 24/7 and I didn't want to be ill at someone else's house. My parents didn't understand either, they had not heard of these conditions and it was hard for them, as they didn't understand how to help. However, the journey to receiving my diagnosis has made us stronger and closer as a family.

When I was 16, I kept passing out in public, which was quite scary, as you never know what could happen to you. After going to the doctor's multiple times, I kept getting turned away. They thought I had stomach bugs, or an eating disorder and I was told to get outside and enjoy the fresh air. I had to almost prove how poorly I was, which can be very unnatural and not the easiest thing to do. Not being believed can affect you and you begin to second guess, 'am I ill enough to need this?'

To not being believed by family and friends that's one thing, but to then meet a new consultant who doesn't believe you, that's a whole new battle. You finally have the guts to be there stripping back your façade – but you're being told "we have a CT – you're clear". I attended a neurologist appointment for my muscle pain and exhausted body. I always take someone with me not for support, but for back-up. To help relay the symptoms I experience, as my conditions cannot be seen on scans. The neurologist thought I was fine, when I was not.

My husband and I met at school and then reconnected 8 years ago. I explained my symptoms to him, and I said if you are going to be with me it's going to be a challenge, you may feel like a carer. We started this diagnosis journey together and the majority of the time he's been there whenever he can. It's been hard for him to see me go through some unbelievable downs.

Everyday can be very different, there can be lovely days, where I can feel on top of things and in control. Then other days it feels like I have taken a couple steps back, I have lost control and I am in a lot of pain. This can make me feel very deflated and frustrated. I question why my body has failed me today, I believe it is not fair and the reality is, my condition holds me back.

I have to be hard on myself, in order to compete with my mental battles. I remind myself of a really bad time or day and think hang on a minute, I still managed to cross the same finish line as everyone else. I manage to do the same as everyone else, I am just slightly different.

I feel every hospital and local doctors' surgery should have knowledge about rare conditions. The experts do and I am grateful to these people. However, more awareness needs to be done to inform the smaller hospitals and those who treat people on a day-to-day basis.

By sharing my story, I hope it helps just one person who may be like me at 16 and who felt alone at the start of a long medical journey. I am more than happy to make myself feel uncomfortable, if it means I help just one person. Misdiagnosis can have a massive effect on you and your life. This is the first time I've ever been this open and the reason I'm putting myself in this vulnerable position is, so awareness increases about rare conditions.

I feel a sense of achievement when someone messages me about a condition they live with and asks for my advice. By putting myself on the line, I have potentially helped them speak to someone about the symptoms they are experiencing. I would shout about my experience of rare diseases from the tops of buildings, if I knew it could help another person, because I wish someone would have done that for me.

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