

I am number 17  
Shona's experience

My mother knew when she was pregnant with me, that I would have Marfan syndrome. My grandfather passed away from the condition when my mother was a child and I was showing signs of being a long baby (a trait of Marfan syndrome). It wasn't until I was two, they performed a heart echo, and confirmed my official diagnosis as Marfan syndrome.

Until I was about 14, I was doing okay and then I was diagnosed with scoliosis, the curvature of the spine, which affected me more at school. When going through GCSE's, I had to have an operation and experienced a complication, which led to me eventually having to drop out from school during my A levels. I found this quite difficult and felt I did not get the support I needed from my school.

During my GSCE's, I had to fight to get the support I needed to be able to take my exams. I remember turning up for my first exam and none of the requirements being in place. There is no guidebook on how you handle these things. This was first time I was conscious of how my condition would affect my life.

I started my blog when I was 14, after my scoliosis diagnosis, and at the time was blogging about different subjects compared to what I blog about now.

When I knew I was having my scoliosis operation, I had a lot of questions and couldn't find the answers to these online. So, I thought I would document my own experiences and hope this would help other people to get the answers they needed. I received a positive response, lots of messages and emails. It was kind of like therapy, it was helpful for other people, but also helpful to me. It is great to have this safe space to share all this information.

From then on if anything significant happened, I would blog about it. Gradually, as I became a wheelchair user, I moved on to disability rights and blogging about accessibility information. I wanted to blog about these areas, as it is something people don't think about, unless it affects them directly.

I would like to see a change in how rare diseases are portrayed in the media. Some conditions receive more attention than others. However, there is such a variety of rare diseases out there. I want people to understand we are human; we have jobs and social lives and we are not just our conditions.

For me, I also want to inspire other people living with a rare disease to speak out and use their voice. It is important to have as many voices out there as possible. Not one person is the same. People underestimate the value of using their own voice. Raising awareness is how we fight the stigma surrounding rare diseases.

-END-

---