

I am number 17
Alan's experience

Around 25 years old I was diagnosed with ataxia, which is a long time ago now. I first realised something was wrong when I was making a sandwich for work, and I couldn't navigate the butter on the bread. I found this hard to communicate with the GP, who thought I was just tired. This went on for 7 or 8 years and every time I was diagnosed with something new. I knew that something wasn't right.

Finally, after further testing and seeing a consultant, my GP said I had a rare condition called ataxia and that I wouldn't meet anyone with this condition in my lifetime. After researching ataxia on the internet, I found out there was someone living with the same condition within five miles of me.

Once I knew I had a rare condition, I wanted to reach out to the people who were in the same position as me and help them feel less isolated. I started my own patient group to help spread awareness and provide people with information about ataxia. I wanted to let everyone who has ataxia know that there are other people out there with the same condition.

I believe the patient voice needs to be heard. Advocating for the patient's voice and their experiences is something that everyone will pay attention to and this will help people who are going through the same thing.

Ataxia is a rather complex condition; the main characteristics is lack of co-ordination and lack of speech. People often think we are drunk, when we are not, we might just be slower than everyone.

After living with your condition for 54 years, you learn how to live with it. I am always thinking one step ahead, you learn how to compensate for the slowness of your body messages. You shouldn't dwell on what you should be like, you need to adapt and get on with your life.

I don't expect change to happen overnight. However, you may speak to someone about ataxia and they might spread awareness of the condition. So, I think even if you don't receive a direct result on the day, in weeks, months, years to come you will.

The statistic 1 in 17, is so simple. I live in a very small village of 17 people, so I am that 1 person out of 17 who lives or affected by a rare condition. I hope the public in general become more mindful about my condition and other rare diseases and to not jump to conclusions.

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