I am number 17
Karen's experience

I have lived with hereditary angioedema (HAE) all my life, I was born with it, and was symptomatic from about 2 years old. Like many HAE patients, and people living with other rare conditions, I spent my childhood in and out of GP surgeries and hospital clinics. I was seen by many doctors and consultants, who all thought I had allergies & at least one implied I was attention seeking. I wasn't diagnosed with HAE until I was 14 years old. This was a difficult age to be diagnosed with a rare condition, as your body is already going through changes. Even though I was born with the condition, mine was due to a genetic mutation, not heredity, which is even more rare. When I was diagnosed, I didn't know anyone else with the same condition as me, which was rather challenging. However, I see myself as lucky. I was fortunate to grow up with a supportive family and friends. I have been able to work whilst living with HAE and hold down a job my whole life and I have many wonderful people in my life who I would never have met if I didn't have HAE.

My self-management regime is based on being mindful of the three possible scenarios I face every day: well days, hiccups/changes and emergency mode. I follow a healthy lifestyle, try to ensure I get enough sleep, eat well and have a good work/life balance. This does mean I have to make sacrifices from time to time, and it's important to pace myself by building downtime into my routines. However, I try to not let my condition stop me from being sociable with friends and family, I do however have to be realistic with what I can and can't do. I have lost count of the number of events and holidays I've had to miss or cancel at the last minute, and the pounds I've lost in deposits and tickets not used, but I still try to live my life to the full.

Due to having a compromised immune system, I do pick up more common illnesses and viruses than most people. I need to manage my own expectations of what I can achieve and those of family, friends and colleagues. I must also recognise when I need to ask for support or help, which isn't easy, but crucial.

A positive of living with HAE, is I know that my condition will not get progressively worse, unlike other rare conditions. However, the reality is, I could experience an attack at any moment, which could be life threatening. This means I must be constantly mindful of my state of well-being, make sure I take my medication appropriately, and always keep my emergency treatments where they can be accessed quickly, for example, I always have a dose in my handbag. My friends and family know what condition I live with; however, it can be hard explaining it to new people, and can affect how I'm treated, so sometimes I don't. Wherever I go, I carry out risk assessments, to see if it is worth putting myself and my health in these different situations. I have become my own expert on my rare condition, you have to be.

I'm passionate about peer support because I didn't meet another person living with HAE until I was 50, when I attended my first HAE UK patient conference. My ability to manage changed exponentially with that support and I wonder how different my life would have been if I, and my family, had that from birth? As a result, I changed my career and now work in the NHS as a HealthMakers Peer Support and Volunteer Coordinator, which is a programme I started in East Berkshire back in 2014. In order to help anyone living with health issues to take more control of their condition and improve their quality of life. I believe patient involvement in research and health and care service delivery is vital and key to improving the care we receive. I hope by being a part of the I am Number 17 campaign it can continue to raise awareness for HAE and all the rare conditions and ensure those who live with these conditions receive the peer support they may require.

I like to share what I can on social media and within the national and local health arena, raising general awareness of the number of people who contend with rare conditions daily. In addition to this I also like to help those living with a rare condition, their families and carers to have more understanding of the importance of gaining self-management skills and building appropriate peer support networks.

It's vital to have hope when living with rare diseases such as HAE. Things have changed a great deal in my lifetime and I know that people are devoting their lives to improving the lives of those living with the HAE and other rare conditions, which gives hope to improved quality of life and potentially a cure. I hope that the advocacy and volunteer work I carry out continues to make a difference.

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