

I am number 17
Emma's experience

I have limb-girdle muscular dystrophy, which is a progressive muscle-wasting condition. It mainly affects my arms and legs (the shoulder and pelvic girdle muscles), but it can also lead to the weakening of my heart and breathing muscles. I was diagnosed with muscular dystrophy around the age of seven and since then, my muscles have gradually gotten weaker, losing most of my physical strength and ability to walk. This means I use a powerchair full-time and rely fully on the help and support of others for all aspects of my daily life.

When I was growing up, I didn't know many disabled people. Only a very small handful and that included my older sister, who has the same condition as me. So other than my sister, I personally didn't know or see anyone that was like me or had the same condition as me or used a wheelchair or even had the same experiences, struggles and thoughts about having a disability.

During my childhood and growing up with a disability, there was a severe lack of representation of disabled people in TV and media. This can add to the feeling of loneliness and insecurities. Nowadays, there is more positive representation across media which has been good for the disabled community, but there is still so much more that needs to be done. The music and TV/movie industries need to do more to represent disabled people. For example, we don't see many disabled musicians.

More awareness of disability and the barriers disabled people face day-to-day needs to be raised, in order to improve the normalisation of disabilities. I want to be part of representing disabled people, to help create inclusion and diversity. I want to be the role model I wish I had when I was growing up with my disability.

I feel there is somewhat of an outdated stigma towards disability, which has created barriers as well as negative attitudes and stereotypes of disabled people. We are often perceived to be helpless, unable to work, travel, live fulfilling lives or make our own decisions. I would like to see more understanding and general awareness of disability and rare conditions. I would love for disabled people to be better represented which would challenge the definition of what is currently considered "normal".

I would like the general public to be open-minded, understanding and empathetic when it comes to rare diseases. Putting themselves in someone else's situation and understanding that disability and rare conditions can happen to anyone at any time. Communication and being open-minded is so important. It would be great if the public got involved by sharing their own experiences of having a rare condition or someone they know or care for with a rare condition. They would be helping spread awareness which would change attitudes and in turn make society more inclusive.

Having a disability or rare condition doesn't make us inspirational or brave for managing to get out of bed in the morning or merely existing. We are not superhuman. We are just human.

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