

My story

Mike Newbigin

When Mike Newbigin was eventually diagnosed with generalised dystonia in his early twenties, the chances of surviving past his 30th birthday weren't considered very likely. Now some thirty years later with a loving and sympathetic wife, together with two sons and a daughter, Mike leads the sort of life that most able-bodied men would envy.

Mike has never seen his condition as a drawback. He holds a BSc in microbiology and virology and is qualified as a chartered accountant. Not only is Mike honorary treasurer of the Dystonia Society but as a trustee also helps to plan the future development of the Society. He is also involved with several other charities including Comic Relief.

"I started to walk on the toes of my left foot when I was aged nine which led to me undergoing an orthopaedic operation. I clearly remember being in plaster for a fortnight and that I was screaming for most of that time! I had another operation when aged 12 to lengthen my left foot tendons. I was in plaster for six months on that occasion. Although I can't say my life has been easy, I didn't seem to have any difficulty in passing examinations. Apart from my BSc degree from Warwick University, I managed to gain 11 O levels and 3 A levels at school.

I was also determined to stay active and as fit as possible. When I lived in Bath, I cycled everywhere. As I had only 4 gears, I often had to use all my effort to push my bike uphill. I had lots of sprained ankles but my left leg was getting stronger. By the time I was 16, I felt very fit and even walked unaided six miles on the Isle of Lundy from the south to the north, and back.



● In complete control...

"I know I am a prime candidate for DBS. However, having been through 13 operations, I really don't welcome another one..."

After university I came to London and worked for a firm of chartered accountants. It was at that time I ended up by accident living in the same flat as three recently qualified medical students. One of my housemates was dating a Professor of Neurology. One day at breakfast my housemate said: 'We think we know what your problem is. Come to the Royal Free Hospital for some tests'. I was diagnosed with spinal muscular atrophy and was referred to a neurologist. Eventually I was finally diagnosed by Dr Stern at University College Hospital when I was 22 years of age with Generalised Torsion dystonia.

One of my hobbies for 20 years (up to 1998) has been skiing. My theory of why skiing has helped me is that it's controlled falling! A former girlfriend of mine became a chalet girl at the resort of Val D'Isere where I met Jean-Claude Killy who promised that he would lend me his equipment free of charge for as long as I was trying to ski! Within two weeks I finished with the nursery slopes and was attempting the more difficult blue runs.

I know I am a prime candidate for DBS. However, having been through 13 operations, I really do not welcome another one. Also I do not feel I really need it at the moment – I can still drive, walk, get around, do the shopping and socialise. If I really could not control my movements, then I would have to think about it but I have no plans to at the moment.

With generalised dystonia, I always try and avoid infections because our bodies have enough to cope with rather than trying to fight other bugs. I always have a flu jab and so far have managed to avoid the virus.

Whatever time is left to me I will try and enjoy myself as much as possible. I have a very full and active life. Being busy helps keep my brain active and I still feel I have much to contribute to the Dystonia Society."



● Mike & AnnMarie