

Anna Wilson

Leading a creative life

Anna Wilson has generalised dystonia. She has tried a variety of treatments but unfortunately none have managed to stop her regular muscle spasms and dystonic storms. However, she has not let that prevent her from leading a creative life and helping others. Here's her story:

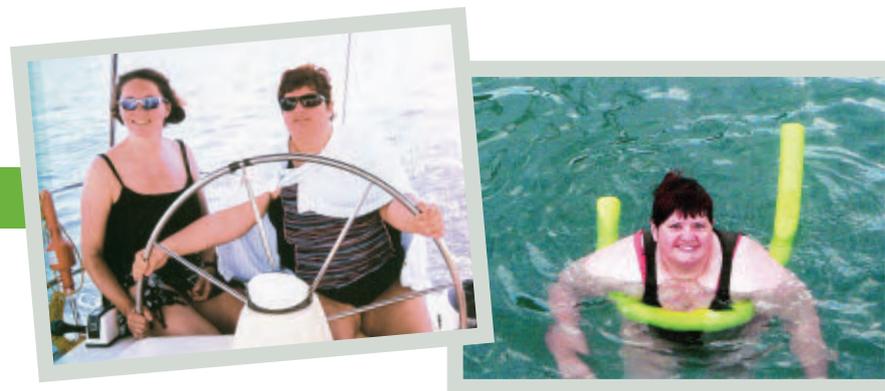
"My dystonia appeared when I was 21 and working as a chef. I started walking on tiptoes and couldn't put my feet down. The symptoms started to spread to the rest of my body and eventually the day came when I could no longer go to work.

I spent the next 18 months going in and out of hospital weekly until my condition was finally diagnosed as generalised dystonia at the Queen Elizabeth Hospital in Birmingham. The first treatments they tried were botulinum toxin and some drugs – but these didn't really help so, after discussion with my doctors, I decided to try deep brain stimulation (DBS). DBS doesn't work for everyone – and unfortunately I was one of the minority where it didn't help. I still experience severe muscle spasms – which I find get more violent if I'm stressed. Sometimes, my dystonic storms mean I need to go to hospital in an ambulance.

Currently, my doctors are reducing my medication as I've been on it for so long it no longer seems to be making a difference – so they are going to try something new. Despite the fact the treatments didn't work, the people responsible for my care have been brilliant – really kind and supportive. However, I do come across medical professionals who don't know about dystonia – ambulance drivers often think my dystonic storms are epilepsy and one weekend I was in hospital and none of the doctors knew about dystonia.



● *At a fancy dress party*



● *Enjoying my holiday!*

I have a cheerful attitude to life and like doing art. I enjoy making ceramics and painting them – I find this very therapeutic and I think it relaxes me and reduces my spasms. Unfortunately, the ceramic sessions have been stopped due to the cuts. I've done courses on cake-making and sugar-craft, I completed an NVQ in art and also paint watercolours. I'm still an enthusiastic cook, even if I can no longer cook professionally, and I'm working towards independent living – which I'm really looking forward to although it's quite stressful.

Once or twice a week, I volunteer my services helping disabled children to do art which I really enjoy. A particularly successful project we made was a collage of musical instruments which was put on the wall.

I haven't let the dystonia stop me travelling – and my family have been really supportive to help me do this. Over the last few years, I've been to Tenerife and on Mediterranean cruises. One highlight was a sailing holiday. All the week before I'd been having muscle spasms, perhaps due to the stress of going but thankfully after a couple of days of the holiday they eased off. After that I found the motion of the boat incredibly relaxing and it was wonderful."

● *One of my watercolours*

