

Living with epilepsy – my invisible shadow



Yasmin Belgrave

Yasmin was diagnosed with epilepsy in 2004 and until recently, her tonic-clonic seizures were uncontrolled. She is currently looking for work in the not-for-profit sector and hopes to one day return to university to do a Master's degree in Art Psychotherapy.

Young Epilepsy is the national charity working exclusively for the 112,000 children and young people aged 25 and under with epilepsy and associated conditions. The charity exists to improve the lives of children and young people with the condition to enable them to fulfil their potential and ensure they have the best quality of life. Young Epilepsy provides world-class diagnosis, assessment and rehabilitation for children and young people with epilepsy. Young Epilepsy's campus is also home to St Piers School and College as well as The Neville Childhood Epilepsy Centre, the only rehabilitation unit in the UK that specialises in young people with epilepsy.

How Young Epilepsy works with healthcare professionals

It is important for professionals to understand the many issues that epilepsy can cause families including diagnosis, treatment, emotional impact and living with epilepsy.

For families whose child has complex epilepsy there will be many other issues to deal with. Certain co-morbidities quite commonly occur and families may need help managing behaviour, language and communication, and other multisensory impairments. Young Epilepsy provides training to all professionals as well as organising conferences and workshops to further understanding around epilepsy and associated conditions. We also offer bespoke packages for individual organisations.

Training courses cover topics including:

- Understanding children with epilepsy and how to administer emergency medication
- Epilepsy and autism in children
- Complex childhood epilepsy and managing challenging behaviour
- Epilepsy and education
- Intro into epilepsy

Please call 01342 832243 ext 296
or email epilepsytraining@youngepilepsy.org.uk for more information.

Twelve years ago, at the age of thirteen, I was formally diagnosed with epilepsy. I had been having quite severe headaches for about a year, when I had my first seizure at a friend's birthday party. We'd been doing karaoke and whilst I was in the middle of a song, I fell backwards and began to convulse. Unlike other seizures that I have had since then, I maintained some level of consciousness that meant I could hear my friends' screams. My mother has since said that she didn't believe them when she got their panicked phone call that night. In fact, it wasn't until she actually witnessed me having a seizure a few months later that she could truly accept what was going on.

Unlike everyone else around me, I adjusted to having epilepsy fairly quickly. As teenagers, most of us are quite malleable and I suppose it was this that allowed me to wake up, bruised and confused, and wholly accept that this was now a part of me. It is however very important to note the difference between having a seizure and witnessing one. I've only ever seen one other person have a seizure before and it terrified me. It was whilst I was in Sixth Form – without warning, a friend of mine dropped to the ground in our crowded common room and began fitting. I stood frozen, just watching over her before running away. The helplessness that I felt in that moment was magnified by the knowledge that that was how it felt for my friends and family. Although it was jarring, the experience of watching someone else have a seizure gave me a fresh perspective on my condition which was something I really benefited from.

Since my diagnosis, I've had well over 100 seizures – the vast majority of which have been tonic-clonic (although I've also had partial and myoclonic). Whilst they are undeniably disruptive and dangerous, it is indirect aspects of the condition such as medication side effects, headaches, lethargy and memory loss that I have found to be most challenging. I think it is easy for people to forget about the multi-faceted nature of epilepsy, and unfortunately this lack of awareness can sometimes leave you feeling misunderstood.

As with most things, I have found being able to talk about epilepsy and how it has affected (and continues to affect) my life to be one of the most important and effective therapies. I am very lucky to have an extremely strong support system in my family and friends. However, due to the subjective nature of the condition, attempting to explain epilepsy to new acquaintances can be particularly difficult. Many people who are unfamiliar with it often default to 'flashing lights' as photosensitivity does tend to dominate the public understanding of the condition. Others react with fear (which can sometimes read as aversion), worried that I'm going to start fitting right then and there. When this happens, rather than get offended I try to openly inform people of the complexities and diversities present within epilepsy.

At the beginning of 2015, my epilepsy nurse recommended that I get in contact with Janine

Palm from the charity Young Epilepsy. Initially, my meetings with her were one-on-one: we would meet for a coffee in central London and discuss my admittedly turbulent transition from student to working adult. Despite having a close network of family and friends, I found it surprisingly comforting and helpful to have someone who was removed from my personal life to be able to talk to. I suppose it afforded me a level of honesty that, as a proud and independent person, came as a great relief.

Since meeting Janine, I have been introduced to lots of young people coping with epilepsy through volunteering at various focus groups and events run by the charity – something that I have found to be therapeutic, educational and inspiring. Volunteering has allowed me to share my experiences of living with epilepsy whilst simultaneously learning from others about theirs. The scope of disability and the way in which different individuals experience it cannot be underestimated, and I think this is only something I truly realised having spent more time with other disabled people.

Schemes such as those run by Young Epilepsy are unfortunately rare due to a lack of funding. However, I feel that there is a great deal to be gained from encouraging communal activities within disability – particularly for younger people. It is all too easy to become isolated when you are labelled by society as being different, so time spent socialising with others who have an acute understanding of your circumstance can provide great respite.

Thankfully, after over a decade of more medications than I'm able to remember, I finally found a combination that seemingly controls my condition in September 2015. Prior to that, I'd had my worst year ever seizure-wise so it's hard to overstate the relief this brought not only to my body, but to my mind also. Despite this, I initially struggled when the 'what if' of epilepsy became 'what now'. After living with it for so long and growing accustomed to the unpredictability of it, factoring epilepsy out of my life seemed to be a much harder task than factoring it in had been. For a while, I felt like I was in epilepsy limbo – it was almost as if I was waiting to have another seizure. Although I'm a natural optimist, I suppose I just wanted to manage my expectations and prevent any disappointment further down the line. Having had some time to adjust, I've finally allowed myself to feel excited about a seizure-free future and all of the possibilities that that entails.

Essentially, I see my condition as a mark of strength, not one of weakness. I am proud to count myself as one of the millions of disabled people living in this country, for the resilience that I have discovered within myself and witnessed in countless others along the way has given me motivation and a level of awareness that I wouldn't otherwise have. I only hope that in time this attitude will become a universal one, for the existing stigmas surrounding disability are harmful not only to the affected individuals but ultimately to society too.