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 happens, rather than get offended I try to openly 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.

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 0342 832243 ext 296 or email epilepsytraining@youngepilepsy.org.uk for more information.

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