



The reach of volunteers

In celebration of Volunteers' Week (1-7 June), *Epilepsy Today* looks at what volunteering is like for volunteers and the people they support

Kenny Borland is an Epilepsy Action volunteer based in Manchester. He works for the University of Manchester managing the administration of the first two years of the medical degree programme. Kenny's interest in volunteering came from his experience with epilepsy and a desire to develop his skills.

"I was diagnosed at the age of 10 and started having tonic-clonic seizures around once or twice a year until I hit my late teens. When I was in my second or third year of university I started to get more anxious about exams. I started having intermittent insomnia (sleeplessness) which, in turn, triggered more seizures.

"By the time I graduated, I was probably having tonic-clonic seizures around once a month and I had to go on incapacity benefit (which is now replaced by the Employment and Support Allowance (ESA)) for a few months. I was taking carbamazepine for years but then my parents paid for me to see a specialist who switched me over to a combination of levetiracetam and lamotrigine. I had some partial seizures for a year or so, but I have now been seizure free for about eight years.

"I don't really remember epilepsy being a big problem in my early teens, because I didn't have seizures very often. But it was still a bit scary. As a child I had to go to hospital for some tests, including an EEG during which they stuck a strobe light right in my face!

"It was really only as I got a bit older that the seizures became more frequent and I had to take care of myself. At its worst, I felt nervous about taking any kind of

long trip on my own so my girlfriend or one of my family members would have to be with me in case anything happened. I wasn't able to learn to drive until I was about 27 either, so it generally affected my sense of independence. The worst part was feeling like I was depending too much on other people and making the people around me anxious.

"At my current job, my manager knows that I am always looking for opportunities to develop myself. She pointed out a scheme that the University of Manchester was running (Volunteering

The worst part was feeling like I was **depending too much on other people**

for Development). This allowed staff members to take a maximum of one day a month paid leave to work for a non-profit organisation. As I have epilepsy and I had written for *Epilepsy Today* a few times, Epilepsy Action seemed like a natural fit for me. I got in touch with the volunteering team and they sent me a list of possible roles. There were no project management roles, which I was initially interested in, but they encouraged me to become an Accredited Volunteer (AV).

"To do this, I attended a training day back in 2013 and I was accredited at the end of it. This means I can deliver awareness sessions to organisations across the North West of England. I have since attended three AV update meetings.



From the other side

Anthony Williams is a mechanical technician at the University of Manchester. He went along to Kenny's Volunteers' Week presentation at the university.

"I am a member of the university's disabled staff network, which I joined when I started working there. It was announced by email that Kenny was doing an awareness session and I responded saying I'd like to go.

"I'd only had contact with Kenny by email before, but as soon as I arrived, I was made to feel very welcome. Most of his talk was music to my ears and I think it's fantastic that presentations like these are being delivered at my place of work. It's good to see that some support is available and that members of staff are being educated about epilepsy. I was pleased to see other members of staff were interested. I think it's a good way to make people aware of what they can do in the event of witnessing a seizure.

Kenny being interviewed for BBC Radio Manchester during Volunteers' Week

"I like it when I get a real sense that the people who have attended one of my epilepsy awareness sessions have come away with a better understanding. Thankfully for me there haven't been many challenges to face with volunteering. The only occasional problems have been with the technology in some places. It's frustrating when I can't show the videos. I've also come across one or two difficult audience members. One lady said she refused to watch a video of a person having a seizure, which worked out nicely because the videos wouldn't play!

"Before doing these sessions, I had done some presentations at university and at work, but I wouldn't say that I was confident. I think most people (including me) are usually a bit nervous, but it gets easier the more I do it. When I was first looking into volunteering opportunities, my girlfriend and I had just got engaged. I was already nervous about doing a wedding speech, so I wanted to get as much experience of public speaking as possible. Volunteering has definitely made me more confident when speaking to groups of people, which transfers into my job and even my personal life. On top of that I take pleasure in knowing that I'm playing a small part in helping a really worthwhile cause.

"For Volunteers' Week I put a presentation together for the University of Manchester. First aiders seemed to be a good target group, but I quickly found out that there are around 700 first aiders across the university! I had to narrow it down to the ones in the Faculty of Biology, Medicine & Health. We ended up with around 10 people, which is ideal for the awareness presentations.

"As first aiders, I primarily wanted them to be able to recognise an epileptic seizure and know what they should do. As with any group I speak to, I also wanted

I like it when I get a sense that people have **come away with a better understanding**

them to get a wider picture of how epilepsy works and how it affects people socially as well as physically. The lady I share an office with actually had a seizure the day after my session, so I was able to put the first aid advice into action myself! I would encourage anybody to do some volunteering if they felt so inclined."

"I think raising awareness of different types of epilepsy in workplaces is very important. As a result of misunderstandings, my employment really suffered in my 20s. I feel more still needs to be done to engage staff generally. I feel, as a whole, awareness needs to get to those who know least about the condition, and not just those with an interest. Delivering sessions to managers would be a good start.

"What also struck me about Kenny's presentation was that the size of the presentation was perfect for me. I often get uncomfortable and overwhelmed when there are too many people.

"I attended because I always want to help raise positive awareness about epilepsy. Epilepsy is still a very misunderstood condition because we don't talk enough about it. So, I always hope that stories like mine can engage people and start conversations about it in a more positive way.

"I was born in Manchester. My school days were quite miserable. Good friends were hard to find as I was seen as a nuisance because of my unusual behaviour – which was probably down to seizures. This made



Anthony (left) with the rest of the founders of the Epilepsy Surgery Friends network

me feel frustrated and made me quite aggressive. However, I later started going to college to study engineering, which I really enjoyed. This led to an advanced certificate in mechanical engineering.

“After this, I was offered an apprenticeship with a large pump manufacturing firm. However, only six months into my apprenticeship, my career in engineering stalled when I was diagnosed with temporal lobe epilepsy. I started at the company in June 1994 and by August, my workmates knew there was something wrong. I had started staring into space on two occasions in as many weeks. I was referred to a specialist and by November, I was fully diagnosed.

“There were many clues leading up to my diagnosis. I had a febrile convulsion at two months old, behavioural problems at school, and episodes of staring into space at school and during my apprenticeship. There was also an unexplained car accident shortly after passing my driving test.

“Some of my seizures were mild and only lasted a few moments. But they usually came in a cluster, as many as 20 a day. I also had the odd more severe seizure, where I fell to the ground. This usually

took a long time to recover from because of my aching muscles.

“Epilepsy hit me hardest with employment. The moment I told my employer at the pump manufacturing firm that I had epilepsy, I was sacked on the spot. Understandably, there were some things I couldn’t do, like drive or use machinery. But I was still able to do most

It’s fantastic that presentations like these are being delivered at my place of work

everyday tasks, and yet the moment I mentioned my condition at interviews, the door was slammed in my face. In the nine years leading up to my epilepsy surgery, I never managed to find employment even though I tried everything. The whole of my 20s were completely destroyed.

“I got my job six months after I had my epilepsy surgery. The journey through surgery was very uncertain and frustrating. But I was lucky that I met someone first,

who had had surgery, who supported me through it. I met Carl and I was relieved to be able to speak to someone who understood what I was going through. Following surgery, I am now seizure free and I am really enjoying life.

“A few of us who had been through surgery set up a group network called the Epilepsy Surgery Friends, which we also do on a voluntary basis. The network aims to support people all over the world who are going through the process of surgery. People can speak to others who have been through epilepsy surgery and we can try to answer their questions. The group is run by all its members and we try to make it really positive.

“Volunteering is great because you realise people appreciate what you do for them and you can see it making a difference for them.”

The difference it makes

Kenny and Anthony have both faced some of the challenges that epilepsy can create in a person’s life. They have both had ups and downs with their conditions and have both been able to use their experiences to support others who may need help.

Volunteering can be done in many different ways. It can be anything from raising some money for charity, to sharing your epilepsy story to help raise awareness. It can be presenting to workplaces to improve staff understanding of the condition and how to manage seizures. Or it can be creating a network for people who need to talk to someone who understands. It’s a great way to boost your skillset and experience, while also knowing you’re making a difference to people’s lives.

And all this work can be really far-reaching. It could be helping your next-door neighbour or someone on the other side of the world. It could be ensuring a person is safe if they have a seizure. It could be helping someone have a better time at work. It could be making someone feel less alone.

This Volunteers’ Week, Epilepsy Action celebrated all the people who share their skills and their time to support others. If you are interested in volunteering, there is more information at: epilepsy.org.uk/volunteer.