

## PRACTICE

## A PATIENT'S JOURNEY

## Juvenile myoclonic epilepsy

Diagnosed with epilepsy in her twenties, Nicola Morrison was told it was likely to be life long. She describes how she has grown up alongside the seizures

Nicola Morrison *patient*<sup>1</sup>, Rhys Thomas *clinical lecturer*<sup>2</sup>, Phil Smith *professor*<sup>3</sup>

<sup>1</sup>Inverness, UK; <sup>2</sup>Institute of Life Science, Swansea University, Swansea, UK; <sup>3</sup>Alan Richens Epilepsy Unit, Department of Neurology, University Hospital of Wales, Heath Park, Cardiff CF14 4XW, UK

This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (lapsley@bmj.com) for guidance.

To share more people's experience of epilepsy go to: [www.healthtalkonline.org/Nerves\\_and\\_brain/Epilepsy](http://www.healthtalkonline.org/Nerves_and_brain/Epilepsy)

I was 27 years old, had been married about a year, and was living in Inverness when I was diagnosed with epilepsy. I had moved to the area when we got married but didn't know anyone, and it was all very new to me. I was working in a school for children with special needs, which I loved, and was just beginning to find my feet and gain a little confidence. Although I had experienced a seizure when I was about 14, it was investigated with electroencephalography and doctors concluded that it was not epilepsy, highly likely to be a one off, and may even have been a reaction to a dose of antisickness medication following a minor knee operation. Several months into married life, I began to have more and more frequent jerks, predominantly in my right arm. I ignored them for a while but they became too regular and too disruptive to do so for long. I couldn't serve up food on to plates without spilling it and hot drinks were also dangerous. I recalled the jerks from stressful situations during my university days, but I had never put two and two together.

### Restriction

I have never really been one to talk about my epilepsy; I guess at times it has been my way of coping. I don't think I have been in denial but I just talk myself through things at my own pace over and over again in my head, coming to terms with the constraints the condition imposes on me. When I was diagnosed, I remember coming home from the hospital after seeing the consultant and being devastated because I would no longer be able to drive. My husband, John, worked away for two weeks at a time so I was going to have to sort out lifts for work and in an instant I felt like all my independence had been taken away from me. It wasn't so much the epilepsy as its practical

repercussions. I don't remember being given any information at the time about epilepsy in general. We weren't fortunate enough to have an epilepsy nurse specialist in Inverness ten years ago, so there really wasn't any support for me or my husband that we knew of. Since then I have used the Epilepsy Action website ([www.epilepsy.org.uk](http://www.epilepsy.org.uk)), watched related television programmes, and listened to radio programmes, and I guess I have just had more time to come to terms with my diagnosis.

### First and second pregnancies

A very low dose of sodium valproate controlled my myoclonic seizures for my first year but by then I was thinking of starting a family and so was taken off the drug by my general practitioner. I remained free of seizures throughout my first pregnancy but went back on to sodium valproate when my daughter was three months old because the seizures recurred. I didn't appear to suffer from any side effects but more drug changes were inevitable as I was planning another pregnancy. Also, I had my first tonic-clonic seizure a year or so later. Planning was the name of the game and so I was trialled on levetiracetam by yet another consultant. The dose for this increased dramatically throughout my pregnancy. I think I was on the highest dose the drug was licensed for—and still it did not control the seizures. With hindsight, I don't think anything would have controlled them, but looking back I can see how I became a different person. I lost a lot of confidence and became anxious about everything, to the point of really not wanting to do anything or go anywhere. That was just not like me. I was tired all the time and just wanted to sleep, but I was the sole carer for two weeks each month. Eventually we had to move closer to my family and friends. We managed to find two friends in particular who were willing to stay overnight and make sure I was OK with the two little ones when John was away working.

## Support and progress

Moving has been frustrating at times. First, we went from Inverness to Aberdeen where we received excellent care and advice with research projects on the go and nurse specialists available when I needed them. They were particularly supportive during my second pregnancy (a 24 hour answer phone was available) as drug treatment during pregnancy was a field they were researching. It made me feel like somebody knew what they were talking about and that gave me a feeling of security.

We then moved to Cardiff where the most frustrating part was the delay in seeing a consultant; apparently my notes took almost nine months to appear. My general practitioner was great in understanding my situation and frustrations, helping me to balance it all with being careful as a busy mum. After my last change in medication we would speak over the phone to change doses as requested by the consultant. This saved her surgery time and saved me finding time to go to the surgery without the children in tow.

My job just now is at home with the children and it gives me so much flexibility in keeping my epilepsy under control. If I am tired, I can do less about the house or go to bed for an hour when the little one is at nursery and my seizures have been far less frequent. I had been having myoclonic jerks up to five or six times a day about a year ago (although this may have been a side effect of the drugs), but I haven't had any since being put on zonisamide. My last tonic-clonic seizure was in October 2010. It sounds like a cliché but I do feel I am getting my life and my old self back.

## Reflection

What do I know now that I wish I had been told at the time? That there is no quick fix. Everyone is different, I know, but personally I like to be told things straight. I might not like what I hear initially, but I am not someone who finds it easy to read between the lines. I wish someone could have told me at the beginning of my journey with epilepsy that there is often no quick and easy cure. It is often about "playing around" with drugs until doctors find the ones that suit you. Even then, there is no guarantee that you can remain on those drugs for the rest of your life. Depending on your type of epilepsy it may get worse at different stages in your life; it may not, but be as prepared for it as possible.

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### A doctor's perspective

450 000 people are estimated to have epilepsy within the UK and a further one in twenty people has a seizure in their life time. Epilepsy remains poorly understood (even within some medical circles) despite its high prevalence and its long term nature, and stigma is common. To many people a bigger cause of isolation, stress, and stigma than the diagnosis itself is the ineligibility to drive that accompanies epilepsy. There are only so many places a free bus pass can get you to in rural Scotland—particularly when trying to navigate a pram through the public transport system.

Nicola's story of a delayed diagnosis of juvenile myoclonic epilepsy is very typical, yet she has had her own difficulties to face. Myoclonic jerks are often not recognised for what they are, or are not sought by the consulting physician. Her type of epilepsy—despite starting in her teenage years—would not be expected to remit; therefore when choosing an antiepileptic drug, the clinician must consider the possibility of future pregnancy. In retrospect, Nicola was lucky not to be taking sodium valproate when she was pregnant, as we now know it to be not just physically but cognitively teratogenic. It is always a difficult decision to change antiepileptic medication to become pregnant—and one to be made (as far as possible) in close collaboration with the prospective mother, providing her with as much information as possible. We do not often counsel people to come off their drugs, but undoubtedly some people do and never let us know about it.

Epilepsy is not one condition but an umbrella of many disorders each with the same symptom: seizures. A consequence of this is that, even with an electroclinical syndromic diagnosis like juvenile myoclonic epilepsy, people respond differently to medication, making it very difficult to match the right person to the right drug. It can be enormously stressful when the drug control fails after a period of months or years and it is not clear what to do next. Uncertainty in the absence of good evidence often results in a variety of clinical approaches and patients can feel like the doctors are "experimenting" on them until either good seizure control is achieved, or either party loses enthusiasm for further drug changes.

Nicola's story is the description of a journey where she has overcome the shock of diagnosis, faced the trial of social restrictions (like driving), navigated the apparent inequalities of NHS care, and still remained a mother, wife, and teacher—rather than being labelled as a person with epilepsy.

Rhys Thomas and Phil Smith

### Further reading

#### *Web based resources for patients and health professionals*

Epilepsy Action ([www.epilepsy.org.uk](http://www.epilepsy.org.uk)) is the largest member led epilepsy organisation in the UK and has an active web forum as well as a helpline.

Epilepsy Society (formally the National Society for Epilepsy) ([www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)) is a medical charity focusing on research and awareness campaigns.

UK Epilepsy and Pregnancy Register ([www.epilepsyandpregnancy.co.uk](http://www.epilepsyandpregnancy.co.uk)) has a free helpline for clinicians and patients to discuss epilepsy drugs in pregnancy. Their registry is one of the first and one of the largest in the world and the source of much of what is known regarding the safety of antiepileptic drugs in pregnancy.

Epilepsy Bereaved ([www.sudep.org](http://www.sudep.org)) is a voluntary organisation that works to support bereaved families and prevent unnecessary deaths from sudden unexpected death in epilepsy (SUDEP) and other epilepsy deaths.