Living with Drug-Resistant Epilepsy

I have lived with epilepsy since the age of eight. My epilepsy is drug-resistant, meaning medications alone have not been able to control my seizures. My medical journey began with surgery to remove a brain tumour that was initially believed to be the cause of my seizures. However, seizures continued even after the tumour was removed.

At the age of twelve, I underwent epilepsy surgery to remove residual tumour tissue or scar tissue that doctors believed was responsible for the abnormal epileptogenic activity in my brain. Following this procedure, I experienced a long period of stability and was both seizure-free and medication-free for many years.

Nearly ten years later, new episodes began to appear. These episodes initially presented differently from my previous seizures and often resembled panic attacks. Because of this, it took some time before they were confirmed to be seizures. Over the past four years, my medical team and I have tried numerous medications through a process of trial and error, but unfortunately none have successfully controlled my seizures.

My seizures originate in the frontal lobe and can rapidly propagate throughout the brain. This can result in tonic-clonic seizures as well as focal seizures that impair awareness. During these episodes I can lose my sense of identity, become unable to recognise familiar people such as my daughter or my mother, and have no awareness of what is happening around me.

After exhausting many medication options, I underwent another procedure called a stereo-EEG. This investigation helped identify that my seizures originate in areas of the brain where I previously had surgery, forming a network that also involves other regions such as the temporal lobe.

Because my seizures occur daily, my ability to work is extremely limited. I was eventually approved for the Disability Support Pension, a process that required extensive documentation and evidence from medical specialists. The results of my most recent surgical investigations showed that further surgery would be too risky, as the affected areas are heavily involved in speech and memory.

Through a special access scheme at the hospital, I was able to begin treatment with a medication called cenobamate. So far, this medication has produced the most positive response I have experienced.

Support through the NDIS, including access to transport, drivers, or other services that are affordable and accessible, would make an enormous difference to my daily life. My mother is currently unable to work because she is my full-time carer.

During the long seizure■free period earlier in my life, I had my daughter, who is now seven years old. Living with drug■resistant epilepsy does not only affect the person with the condition; it impacts the entire family.

Greater recognition and education around drug■resistant epilepsy are essential. It is a debilitating condition that can affect every aspect of a person’s life.

I am 27 years old. This should be the prime of my life, yet my circumstances look very different. Still, if sharing my story and advocating for better understanding and support can make even a small difference for others living with epilepsy, then it is something I am proud to do.