

## Richard's story

My story of blackouts began just after I graduated from university in 2001. Looking back I now understand how a rugby injury and an uncomfortable work chair were likely triggers for the story I'm writing now.

Just as I'd started full time work I also picked up a neck injury which caused me a lot of pain. I didn't manage the injury very well and persisted exercising, training and playing sports and as a result kept making my injury worse. To compound the injury I found sitting at a desk for eight hours a day to be torturous. My only relief was hot showers.

This is when my blackouts started. They would mainly occur in the same two situations: The first was in the shower and the second was at work. At their most frequent, my blackouts were happening once or twice a week and at the worst three times in one day.

As a result I went to see a neurologist. I described my feeling prior to my blackouts and my history. The doctor opted to investigate for epilepsy. I had all sorts of test including MRI's, sleep deprivation and strobe light EEG. All tests came back normal but my blackouts continued – as did my neck pain.

Despite the test results the neurologist started me on epilepsy medication. I was put on 25 mg of carbamazepine a day. During the time I was taking my medication I reported back that they were not working. The neurologist's course of action was to double the dosage and he also added sodium valproate. This loop continued until I was on 1.6 grams of carbamazepine and 1.2 grams of sodium valproate. Many years later I learned from another neurologist that he didn't have any patients on this high a dosage.

I really didn't like taking such large amounts of drugs especially as the frequency of my blackouts stayed the same if not got worse. I did something I wouldn't recommend. I decided to gradually reduce my dosage until I was not taking any drugs and I also decided to stop seeing the NHS about my condition. Looking back I had lost hope in the NHS and assumed their fix would always be 'double the dosage'.



Just after this decision, in 2004, my life went through other changes. I gave up rugby, moved jobs and found a physiotherapist to help me with my neck. My blackouts started to reduce in frequency. My friends and family tried to guess the connection but we were clueless.

Between 2004 to the end of 2011 I considered myself to be healthy and accepted that I would probably still have one or two blackouts a year – now mostly occurring in the shower. I was content despite not being able to drive due to my epilepsy diagnosis.

In August 2008 I met Elaine. During our relationship she witnessed my blackouts. Elaine encouraged me to go back to a neurologist to see what options were available; I was very reluctant. I felt I had been through the process before and did not want to end up taking medication which did not help and seemed to dull my life.

In 2011, I decided to go back to my neurologist. If I'm honest I only did it to show Elaine I was prepared to try but I was not prepared to go back onto the same medication I was on before. My expectations of the NHS were quite low and I was not expecting anything life changing to happen as a result of my visit.

Those 30 minutes with the neurologist were life changing. He seemed genuinely interested and took on board my belief that my epilepsy was somehow related to showers or hot water. After listening to my story, looking at my history, listening to Elaine's experiences of my blackouts and asking a few questions he told me he did not think I had epilepsy. He ordered two tests: A EEG and a tilt table test.

I had the EEG setup at Aberdeen Royal Infirmary. The technician was excellent. He did another strobe test and setup the equipment to also record my heart rate over the 72 hours. As he was monitoring my heart rate he noted it was very low and asked how active I was. At the time I was playing 5 a-side football once a week but I didn't consider myself fit. While being setup my heart rate was 42 beats per minute. He told me a professional sports persons resting heart rate would likely be higher than that!

Next came the tilt table test. I was quite excited about this test because I had read on the internet that if I got a positive reaction I would likely have some type of syncope. This is when I stumbled across the STARS website. It blew my mind reading all the information and for the first time in years I was reading about a condition I actually related to. I had never related to epilepsy and used to joke that I was a fake-ileptic.

The tilt table did have a positive effect. My heart stopped for around 30 seconds and when I was lowered back to the horizontal position I eventually woke up again. As always I was exhausted after my blackout for the next 24 hours but I was so excited that finally I had got the correct diagnosis.

Shortly after I saw the cardiologist I was diagnosed with vasovagal syncope. He started me on new medicine and told me to keep hydrated and to add more salt to my food to increase my blood pressure.

I'm not 100% free of blackouts but when they happen I now understand why. I now understand that chronic pain can be a trigger as can standing in hot environments – like a shower. I've also become aware of situations that make me squeamish. In fact my last blackout was on the phone as my brother told me about my sister-in-law breaking her leg in three places.

Elaine and I are now married and I'll always be grateful she managed to persuade me to get a second opinion. I have been very impressed with the NHS and I believe that when they get the diagnosis correct the treatment and advice they provide is very effective.

I hope neurologists are more aware of other reasons for loss of consciousness and use other investigative techniques such as the tilt table before diagnosing patients with epilepsy. I also wish I had found STARS back in 2001 so that I would have been armed with information to question some of the medical decisions made but I am very pleased it's available now.

**Richard Bowie, Aberdeen**