

# Me and my epilepsy

## Chelsea Leyland

Like her sister Tamsin, Chelsea Leyland has epilepsy, but they lead very different lives. Tamsin has complex epilepsy with learning difficulties. Chelsea has junior myoclonic epilepsy and is a model, DJ and actor. Chelsea talks to Olivia Rzadkiewicz about their lives

### Early childhood

Epilepsy has always been a part of my life. People used to say I was a great little helper because from the age of about four or five I was picking Tamsin up after a seizure or calling an ambulance. I had fun in hospital – we spent so much time in A&E for Tamsin that it became normal. I even had my hair braided by the nurses. It was still quite hard though, because I remember numerous occasions just waiting in hospital with our parents to see whether Tamsin would make it through the night.

### School days

I was at the same primary school as Tamsin in Wandsworth. It accepted children with special needs so we were exposed to people with all sorts of conditions.

### Role reversal

There was a time when our roles inverted. I remember us both playing with Polly Pockets. Tamsin stayed at that level, but I moved on and sort of became her big sister. Tamsin left home at seven and went to live at Lingfield and then moved up north to Cheshire. We had to keep family Christmases quiet because we had so many Christmases of opening stockings and then spending the rest of the day in hospital because Tamsin became over excited and had a seizure.

### Boarding school

I went to Bedales boarding school when I was 13. It was quite a tough time. I just wanted a 'normal' sibling, and felt that I was missing out. It was quite painful if people asked me whether or not I had any siblings.

I didn't really talk about Tamsin, even though some of my friends were aware of her epilepsy and they would have awkward conversations about it.

### My diagnosis

I'd had myoclonic jerks for a long time, when the light was dappled, and it got worse when I was tired. I would drop





things too. Even so, my diagnosis with epilepsy came as a shock. I was 15 and had been to the doctor at school, who said my symptoms were as a result of my paranoia around Tamsin's epilepsy. He told me 'just to let go of it'. The third time I saw him, he sent me to a neurologist to put my mind at ease. But I was diagnosed with juvenile myoclonic epilepsy instead.

### Family worries

My parents felt quite let down by the doctor, and my mum especially took the diagnosis really badly. She blamed herself for having two daughters with epilepsy. It was hell on earth for my parents who had seen Tamsin's epilepsy, which was uncontrolled by medication. There was a lot of asking why it had happened to our family.

### Side effects from medication

I was put on lamotrigine for the first two years, and then levetiracetam and zonisamide. I became very frustrated with levetiracetam because I had rage and was very irritable. It was a relief to read a blog that explained that these were side-effects of the drugs.

### DJ-ing and drama

When I was 19 I moved to New York to go to the Lee Strasberg Theatre & Film Institute to study drama. A fashion photographer got me to DJ. There were not many female DJs, but there was a lot of demand for them. My heart still lies more with acting, but DJ-ing has opened a lot of doors for me. I'm collaborating to design a bag, and casting for a TV show, all thanks to that first break.

### Photosensitive epilepsy and gigs

I have photosensitivity so I have to make sure the gigs I play use lasers instead of strobe lights. I'm very lucky in that I live a normal life for the most part. I haven't had a seizure for a couple of years, but epilepsy is always there even when I'm having a good day – I'm always conscious of it. I can't drink if I haven't had enough sleep, and I have terrible anxiety around catching early flights for the same reason.

### Finding the positive

Epilepsy has given me more drive, more hop in my step to succeed where it made me feel so weak before. I once told a journalist about my epilepsy without quite meaning to, and that was the beginning of my new journey.

The epilepsy world back at home had felt very real, and then I entered the ridiculously chichi world of fashion, beauty and acting in New York. I realised I didn't have to turn my back on either one of those worlds, so I went back to my roots, being honest to my truth and my experience of epilepsy. As soon as I did that I started to feel better, and strangely, I was able to enjoy the glamorous side of life much more freely.

### Making some noise about epilepsy

I have been through a time when it was a challenge to talk about my epilepsy and now talking about it with power is really different. I'm trying to make it positive and upbeat, so I'm trying to use my position as an 'influencer' to make an impact. I had a voice but I wasn't using it – now I want to make some noise and help people understand what epilepsy is. I want to give people strength by telling my own story. When I was first diagnosed, I would have loved to meet



someone who understood. I have so many reasons to speak out – I want to do it for Tamsin, I owe it to her, and also to empower other young people.

### American dream

Tamsin has always had an obsession with America. Sadly, she can't fly to come and visit me – the journey would be too disruptive and would put her at too much risk of seizures.

She has lived at Epilepsy Society since she was 18, and absolutely loves it. She's the happiest she's ever been. Some people think she'd rather be at home, but that's wrong – there's a big part of her that's very independent, like any adult. She knows exactly what she wants, and she wouldn't have that same freedom if she was at home.

### The strength of my family

My family has always had a great sense of humour around our epilepsy, in spite of the pain. We like to keep it light, even when people are staring at us in a restaurant because Tamsin's had a seizure and fallen into her food. We just laugh and have great fun.

- Chelsea designed a unitard with lifestyle brand Live The Process and raised £10,000 for Epilepsy Society.

## Tell us your story

Would you like to share your story about how epilepsy impacts on your life. You might also like to talk about the effect it has on those around you. Or you might like to talk about how you get on with your life in spite of your epilepsy. To share your story in *Epilepsy Review*, please:

- Fill in our online form at [epilepsysociety.org.uk/become-media-contact](http://epilepsysociety.org.uk/become-media-contact)
- Download the form at [epilepsysociety.org.uk/yourstoryresearch](http://epilepsysociety.org.uk/yourstoryresearch) and send to: Press Office, Epilepsy Society, Chesham Lane, Chalfont St Peter, Buckinghamshire SL9 0RJ.
- email [pressoffice@epilepsysociety.org.uk](mailto:pressoffice@epilepsysociety.org.uk) for a copy of the form to send to us at the above address.