

Claire's Story

Hi, My name is Claire and I was diagnosed with NEAD when i was 19yrs old and I am now 29

I was 17 when i first started with "black-outs" and my GP put it down to hormones/Period problems etc. As 6 months went by it then developed into seizures - I have no recollection of what happened during them at all (Only what my family told me - Jerking limbs, Collapsing and rolling eyes) and to begin with I had no warning at all.

It was really scary - I was working in a hospital at the time and had to go on long term sick as I was having anything from 5 fits a week to 5 fits per day. I went through a whole host of tests and backwards and forwards to A & E after particularly nasty episodes and injuries and was eventually diagnosed with epilepsy and given medication.

However the medication didn't work - I then had a CT scan - Which came back normal and then an EEG - Again normal and I had now been in hospital a week. The Neurologist came and told me that there was no evidence of epilepsy and to stop the medication immediately and he had no idea what was going on as there was nothing medically wrong with me!! I felt like I'd been punched - Everyone looking at me as if I was mad and making it up - I don't think I've ever felt so vulnerable and alone.

My family and friends were fantastic and still very supportive but I felt like I was letting everyone down but didn't know how to stop it. The neurologist suggested a referral to a Psychiatrist (I thought great - Just to prove I'm mad!!) but when i got there - he was brilliant!!!

It was like he totally understood what was going on - he involved my family in treatment and made sure they understood this was not just something I was "putting on" and of course i finally got my diagnosis of NEAD. It felt wonderful just to know that I wasn't insane and this was a recognised problem.

It took a while and some hard going sessions but eventually we got to where it had all started from (I was abused as a child by family friend) and with the help from the Psychiatrist and my family and friends I got much better and in time even stopped fitting!

I do realise how lucky I am and that not everyone is as fortunate as I have been and I hope that by writing this it wil help someone else who is going through a similar situation. I am now happily married with two children - The therapy has now stopped however I have open access should i need it

Websites like this are fantastic for bringing issues like this into focus - Most people have never even heard of NEAD and that is something that needs to change - More training for Neurologists and GP's would be a good start as their treatments have a lasting impact both physically and emotionally.