



Amy's story

11-year-old Amy O'Neill has been in and out of hospital much of her young life.

At three years old she developed CAD or hypoglycaemia. "She went into a hypoglycaemic fit and we nearly lost her," says Amy's gran, Gwen, who looks after her.

Four years later, Amy started having another kind of seizure. Doctors realised something was wrong when she started taking what are known as petit mals. Within a year, these had progressed to tonic-clonic grand mal seizures and, following an EEG (electroencephalogram), Amy was formally diagnosed with epilepsy.

Despite the relatively rapid diagnosis, specialists haven't been able to do everything they would like for Amy. Her hypoglycaemia affects her liver, as do the better drugs for epilepsy. This means that "Amy can never go on to the better drugs," explains Gwen.

Amy's current medication has been upped four times in as many months, but she's still taking constant petit mals – up to 15 a day. As a result, she is not aware of what's going on a lot of the time. Amy is also displaying many of the behavioural problems that can go hand in hand with epilepsy.

"Amy's mum finds it particularly hard to cope with her," says Gwen who looks after Amy most of the time. A manic depressive, Amy's mum already has enough on her hands looking after Amy's older and younger brothers. Which is why Gwen took over the role with Amy from day one.

The Muir Maxwell Trust has been able to help with an epilepsy alarm, which stays at Amy's mum's where she has her own room. What seems to work best at Amy's gran's is if Amy sleeps in beside Gwen. Amy is now having the kind of night-time seizures where there is no movement whatsoever, so she wouldn't trigger an epilepsy alarm. "She'll lie completely rigid for two minutes with her eyes wide open," says Gwen "so you have to be with her".

For Amy, there's no light at the end of the tunnel just yet. Right now, hopes rest on an imminent appointment with a neurologist