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LIVING WITH EPILEPSY

One person in 120 has epilepsy. But our knowledge about it remains “primitive” claims one expert. Denny Rosey reports.

Carlie's eight year old son was playing soccer when she first noticed him acting in an unaccountable fashion. Like many keen young players Angus ran around furiously, and a bit aimlessly, kicking up more clods of earth than the ball, but a few times he stopped and let the ball dribble past him. Carlie supposed at first that Angus wasn't concentrating except he was curiously listless and spaced out. Each episode was over in seconds.

She paid closer attention to her son's behaviour at home and observed the same strange lapses that had been easy to overlook in the mild chaos of three children negotiating disparate needs.

As it turned out, Angus has childhood absence epilepsy. The age of onset is generally three to ten years of age and his neurologist predicts he will probably outgrow the condition once he reaches puberty – 65 per cent of children do. While childhood absence seizures tend to last less than half a minute they can occur anywhere from once to 50 times a day.

Childhood absence epilepsy is just one of 40 or more different varieties of epilepsy. And, as with Angus, epilepsy does not always entail someone collapsing unconscious to the floor with arms and legs flailing. In reality, medication has made this most dramatic form of seizure – once termed *grand mal*, now *tonic-clonic* – the exception.

Epileptic seizures come in two main forms – generalised and focal or partial seizures (see box). Doctors use an electro-encephalogram or EEG to map patients' brainwave activity to see whether there are any abnormalities. When someone is having an epileptic seizure, the EEG shows rapid, steep peaks which indicate violent, synchronised discharge of neurons in one part of the brain.

Seizures do not automatically point to epilepsy. Babies sometimes have febrile (meaning fever) seizures when they are ill or overheated. Seizures can occur also as the result of cardiac arrhythmia, and in pregnant women who develop eclampsia. Edgar Allen Poe, Truman Capote and Richard Burton had seizures after alcohol withdrawal.

Epilepsy affects around one in 120 people and it is three times more common than Parkinson's disease, cerebral palsy or multiple sclerosis.

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Generalised seizures

Generalised seizures include *absent* seizures (previously titled *petite mal*) and as the name suggests, the person stares vacantly into space; sometimes their muscles twitch.

Tonic-clonic seizures, and their various sub-groups, are the kind most often associated with epilepsy. The person loses consciousness and often falls, their body stiffens and their arms and legs jerk repeatedly – these used to be called grand mal seizures.

Focal seizures

Around 60 per cent of people with epilepsy have *focal* or *partial* seizures; these occur in one part of the brain. In *simple focal seizures*, the person may be over-whelmed by sudden inexplicable feelings of joy, sadness, anger, or nausea, and experience sounds, visions, smells and tastes that are not real.

Complex focal (sometimes called *partial*) *seizures* cause a change in or loss of consciousness and people often feel they are in a dreamlike state. Sometimes they blink or smack their lips repeatedly or walk in circles: this is called automatism. Other more complicated actions look deliberate but are in fact involuntary. Some people continue to do things they had started before the seizure began, like washing dishes, except their movements during the seizure are repetitive and ineffective.

Historical curiosity

In the Middle Ages many executioners combined their head-lobbing roles with that of healer. Conveniently, some of their remedies were very close to hand. Imbibing ground human skulls was said to be a most efficacious cure for epilepsy, although much the same result could be obtained by drinking wine from the skulls of hanged men; it was not unlike the Church sanctioned practice of sipping wine from the noggins of saints.

David Silke was 20 when he went to his doctor to find out why he was blanking out occasionally and discovered these episodes were in fact complex partial seizures. “Sometimes you get a euphoric feeling over your body and images become a little bit distorted and you can't quite work out what they are. I can get a little dizzy and disorientated and if I'm holding something I might forget and drop it. I've been drinking a glass of water and I've not been aware I had water in my mouth and it's dribbled out, because I can't feel it there – it's a very odd feeling.”

His seizures sound minor but they exert a huge impact on David's ability to work and travel. “I find it very difficult to travel on buses as their size and suspension means they bounce up and down a fair bit and that brings on attacks. Trains are much smoother but I've had one or two attacks on trains too,” he explains.

Travelling to his part-time job requires two changes of train or bus each way and if the journey has been rough, he can arrive feeling much the worse for wear. Problems arise sometimes at his workplace where he is employed as a computer programmer.

“An episode can be set off if the office is hot or if I focus on the computer screen for too long. The old cathode ray tube screens had a more obvious refresh rate and were more of a problem than LCD (liquid crystal display) screens but staring at graphics or data for a long time and having to concentrate sets your brain moving and electrical signals go off and set off an episode.

“I can't go to the cinema as the flickering sets it off too. Films run at 30 frames a second and most people wouldn't notice any flickering but there's enough of a flicker to spark an epileptic attack.”

However, his wife and 16 month old daughter Caitlin more than compensate for missing out on trips to the cinema. David can't think of any drawbacks to parenthood except getting up three or four times a night – but the ramifications for him go beyond feeling stale the next day. And there are likely to be more disturbed nights after their second child is born in a few weeks.

“Sleep deprivation triggers episodes and that can stop me from going to work the following day. Sometimes my wife stays with her mother overnight so I can get a full night's sleep,” David explains. “Thankfully I work at a place which is very understanding, friendly and helpful.”

A new finding by scientists in Canada earlier this year has challenged traditional understanding of epilepsy. Using EEGs in combination with functional magnetic resonance imaging, researchers discovered that many patients display epileptic activity in large areas of the brain between seizures and in areas that have never been suspected. Patients are unaware anything is happening and the activity cannot be detected by observers.

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Jean Gotman, professor of neurology at McGill University in Montreal, suggests that this brainwave activity is very likely to affect thought and behaviour as the neurons involved in these brief but very intense brainwave spikes cannot do their designated tasks.

Professor Gotman says doctors “have a quite primitive level of knowledge when it comes to treatment” and despite a plethora of new medications, 30 per cent of people with

epilepsy find their condition cannot be controlled by drugs, either because they need very high doses that cause intolerable side-effects or they continue to have seizures at lower doses.

People whose epilepsy does not respond to drugs have a few alternatives. Surgery is one. Some experts estimate that several thousand patients in Australia could be helped with surgery – but it requires knowing which area of the brain the seizures arise from and if the area can be removed safely, although Prof Gotman’s findings are likely to assist doctors locate areas where electrical activity is happening.

Other options are vagus nerve stimulation – which involves implanting a lead under the skin and sending electrical impulses to the left vagus nerve in the neck via a stimulator – and a ketogenic diet. These diets (very high in fats and low in carbohydrates) are effective for some but the majority of those who’ve tried it say they dislike being on a highly restricted diet; others cannot put up with common side-effects, such as vomiting, diarrhoea and nausea. 