Understanding about SUDEP

Sudden Unexpected Death in Epilepsy is rare. For most people, the risk is very low. Dr Greg Rogers explains why talking about SUDEP with an epilepsy specialist can be reassuring and can help you to minimise your own risks.

SUDEP – or Sudden Unexpected Death in Epilepsy – it’s not an easy conversation to have. A diagnosis of epilepsy can be a lot to take in without having to consider the possibility that in rare cases, it has the potential to be life threatening.

SUDEP is a term used when a person with epilepsy dies suddenly with no known cause. It does not include those cases where a person may die through injury or drowning following a seizure or due to a prolonged and severe seizure as in status epilepticus.

Thankfully, SUDEP is very rare. Every year around 600 people in the UK die from SUDEP. Although initially this figure may seem quite high, when you consider there are over half a million people in the UK with epilepsy, you will see that actually the risk is very low. The risk of SUDEP for those with epilepsy is 1 in 1000. Significantly, every one of those deaths is from SUDEP.

SUDEP – or Sudden Unexpected Death in Epilepsy – can help to lessen its impact. ‘It was Christmas and I was in my fourth year of medical school, attached to a hospital. My girlfriend, Sue, came in to join me for the Christmas party which involved staff and patients. I’m afraid I was a little inattentive of those around me. I was very grateful. Two weeks later, the same young woman died of SUDEP. It was very poignant. She was only 22. It really brought it home to me just what a devastating effect a condition can have on a person.’

That experience sowed the seed for what has become a life-long interest for me in epilepsy and, as healthcare professionals, we can help to lessen its impact.’

Dr Rogers is GP clinical champion for epilepsy
and specialist nurses. But today we are as likely to go online to supplement our knowledge of health-related issues. Recent research showed that between 2004 and 2013, the volume of Google searches for the term ‘epilepsy SUDEP’ increased by 5,000 per cent. People want to know more, and indeed understanding about SUDEP and putting it into context can be reassuring.

A recent study in Cornwall, funded by SUDEP Action, looked at 93 epilepsy related deaths from 2004 to 2012. This included 48 cases of SUDEP. The study showed that many of the people who had died had not been in contact with their specialist team despite showing warning signs such as increased seizures before their death. Nor had a significant minority been in contact with their GP. Less than half the SUDEP cases had received an epilepsy medication review.

Researchers concluded that many of the SUDEP deaths might have been preventable with better screening in primary care to identify changes in seizure patterns and referral to specialist services when SUDEP risk factors are present.

In short, the report highlighted the need for healthcare professionals to talk more to their patients about SUDEP, particularly in the case of those thought to be at greatest risk. Currently we do not fully understand the causes of SUDEP. Evidence suggests that it seems to happen during or after a seizure, so it is possible that it may be due to a problem with a person’s heart or breathing during a seizure. Researchers at Epilepsy Society are trying to identify genes that may increase the risk of SUDEP in some individuals.

Although we are unsure why it happens, it seems that SUDEP is more likely in those with frequent generalised tonic clonic seizures. Young adults in this category seem to be more vulnerable. In people with severe epilepsy (frequent and severe tonic clonic seizures) the risk of SUDEP can rise to around 1 in 200.

Recognising that you may be at risk is a positive first step in minimising that risk. There are several things you can do to reduce your risk (see Minimising your risks of SUDEP below).

The important thing to remember is that SUDEP is very rare and the risks are very individual to each person. If you have concerns about your own risk, it is important that you talk them through with your epilepsy specialist, GP or epilepsy specialist nurse.

Minimising your risks of SUDEP

- maximising your seizure control is vital. Make sure you take your epilepsy medication as prescribed, on a daily basis and around the same time each day
- keeping a diary of your seizures will help to identify any changed patterns in your seizures and any avoidable triggers
- if you have active seizures, you might like to ask for a review of your epilepsy with your GP, neurologist or epilepsy specialist nurse
- SUDEP often happens when a person is asleep. If you have aseep (nocturnal) seizures, you might like to consider having a seizure alarm that will alert someone if you are having a seizure. You may also like to use an anti-suffocation pillow.

Caron Robinson lost her daughter Nik to SUDEP last year. She tells her story

‘Nik started having seizures two days before her seventh birthday. For eight years she went through 24 medications or combination of medications but nothing worked. At her poorest seizure control she had 200 tonic clonic and complex partial seizures per month.

In 2006 Nik had a final drug change. It was like someone had turned the light back on... her memory became sharper, she could follow simple instructions again. We flew to the US where she fulfilled a lifelong ambition to swim with dolphins.

Nik started to access life once more. She moved into her own bungalow. I was her night-time support and her PA joined her during the day for the gym, swimming, karaoke.

Nik went to bed at midnight on the 20 March 2013. She shouted through to tell me she had switched her bed alarm on and was doing a word search before going to sleep.

On the 21st at 8am her alarm clock rang. She didn’t switch it off. Nik was 23 when she passed to SUDEP. I knew she was at risk, hence she had an anti-suffocation pillow and bed alarm. Her seizure alarm was not triggered and no noise was made. I believe Nik fell asleep... her lights went out.

She was an amazingly brave young lady. We try not to mourn her death but celebrate her life. She leaves a big Nikey shaped hole in our lives. No one will fill it.

Since Nik passed away we have been raising awareness about SUDEP. It amazes me the amount of people who are not aware of SUDEP and whose healthcare professionals don’t mention it or say there is no risk. My own GP had never heard of it. She has now.’

For more information and support about SUDEP www.epilepsysociety.org.uk/sudep

You can also talk to someone on Epilepsy Society’s confidential helpline 01494 601 400 (Monday-Friday 9am-4pm, Wednesday 9am-8pm)

You can also talk to others with epilepsy at http://forum.epilepsysociety.org.uk