Epilepsy and sudden death: what nurses need to know

Better access to services and information can improve outcomes among young people with epilepsy

SUdden unexpected death in epileptic people (SUDEP) is thought to be the highest cause of epilepsy-related death in children and adults. However, research suggests that up to 80% of epilepsy-related deaths could be avoided with improved access to services and information.

How common is SUDEP in children and young people with epilepsy?

It had been thought that rates in children and young people were lower, but a review, Sudden Unexpected Death in Epilepsy in Children, published earlier in 2023 challenges this assumption, says the charity SUDEP Action. The review suggests figures are comparable to those in adults – at 1.2 per 1,000 people each year.

What are the key risks?

According to the National Institute for Health and Care Excellence (NICE), potentially modifiable risk factors include:

- Non-adherence to medication.
- Drug and alcohol misuse.
- Having focal to bilateral tonic-clonic seizures or generalised tonic-clonic seizures.
- Having uncontrolled seizures.
- Sleeping without supervision.

The NICE guidance states that the risk of epilepsy-related death increases in those with previous brain injury, previous central nervous system infection, metastatic cancer, previous stroke or abnormal findings in neurological examination.

Neville Childhood Epilepsy Centre epilepsy nurse consultant Kirsten McHale says: ‘We need to be mindful that risk factors are individual.’

‘The generic SUDEP and Seizure Safety Checklist is brilliant and gives us a structure to guide discussions with patients and their families, but it must always be individualised.’

Those at particular risk may include older teenagers, with young men having a slightly higher risk, and those with complex epilepsies that cannot be controlled well with medication, she adds.

What kinds of interventions can help reduce the risk of SUDEP?

NICE suggests discussing the use of a night-time monitor for those with epilepsy who have seizures when they sleep and are assessed to be at a higher risk of SUDEP. Children and young people should also be supported and encouraged to take their medications as prescribed.

‘My rule of thumb is eat well, drink well and sleep well,’ says Ms McHale. ‘It’s about lifestyle: not going to bed late and taking your medication.’

How can nurses raise awareness of SUDEP without creating unnecessary distress?

For young people and their families, having a diagnosis of epilepsy can be frightening, says Ms McHale.

‘Families search Google, which can be to their detriment,’ she says. ‘They may read about SUDEP and ask what are the chances of their child dying from a seizure. Some parents don’t sleep properly for months because they are so worried.’

Part of her role is to reassure families that while the risks are there, they are small.

‘We take everything into consideration holistically. This includes the young person’s mental and physical health,’ says Ms McHale.

‘We have to talk about SUDEP, as we have a duty of care to our families. We need to give them the tools to look after themselves.’

How can nurses support their young patients with epilepsy and their families?

‘Epilepsy is not well understood,’ says Ms McHale. She suggests contacting your local epilepsy nurse specialists for up-to-date advice.

‘We are such a font of information,’ she says.

‘We can provide training, resources and emergency care plans. We are a resource to tap into.’

Further information

NICE (2022) Epilepsies in Children, Young People and Adults. www.nice.org.uk/guidance/ng217


Lynne Pearce is a health journalist