

Learning from Lives and Deaths of People with Learning Disabilities and Autistic People (LeDeR)

Learning Brief no 4 - SUDEP

(Sudden Unexpected Death in Epilepsy)



The LeDeR programme aims to improve care, reduce health inequalities and prevent early deaths of people with a learning disability and autistic people. Email us at somicb.leder@nhs.net for further information.

In the UK, three people die from Epilepsy every day. People with a Learning Disability are at a significant increased risk of SUDEP as it has been found that Epilepsy is the second most common cause of death for this group of people. Studies show that in the majority of cases the individuals or their carers had not been informed about the risk of SUDEP or how to minimise those risks. <https://sudep.org/article/raising-awareness-epilepsy>

SUDEP is the Sudden Unexpected Death in Epilepsy which is the term used for a person with Epilepsy who dies without warning and where the post-mortem fails to establish any other cause of death. SUDEP is only associated with tonic clonic seizures.

Key risk factors for Epilepsy related deaths

- Learning Disability
- Depression or psychiatric illness
- Active seizures
- Frequent generalised tonic-clonic seizures
- Nocturnal seizures and lack of night-time monitoring
- Not taking medication as prescribed, or medication changes
- Infrequent Epilepsy reviews and engagement with an Epilepsy clinician
- Pregnancy
- Alcohol or substance abuse

Research has shown the factors below are also linked to SUDEP

- Having had Epilepsy for over 15 years
- Epilepsy starting before the age of 16
- Male gender
- Younger adult age

How to reduce the risks of SUDEP

- Take prescribed Epilepsy medication regularly
- Seizure alarms or monitors during the night
- Reduce alcohol intake
- Have a healthy amount of sleep
- Keep active as much as possible
- Keep the brain stimulated throughout the day with activities
- Reduce medications – polypharmacy can increase risk
- Avoid seizure triggers as much as possible. Common triggers include missing a dose of Epilepsy medicines, lack of sleep, stress and drinking too much alcohol

Case Study

This learning brief looks at a coroner's report of a person in their 30s who had epilepsy and Rett's syndrome as well as multiple and profound learning disabilities. This person was found faced down on the floor, staff and the paramedics attempted cardiopulmonary resuscitation (CPR) with no success. The cause of death, after a post-mortem, was identified as SUDEP. The family commented that they were not informed of the risk of SUDEP or how to reduce the risks.

Reporting the death of a person with a Learning Disability

<https://leder.nhs.uk/report>

Reporting the death of someone with Epilepsy

https://sudep.org/sites/default/files/sudep_postcard_21-11-19.pdf

Easy Read guide for SUDEP

[https://sudep.org/sites/default/files/epilepsy - make your risk smaller - easy read for pwe.pdf](https://sudep.org/sites/default/files/epilepsy_-_make_your_risk_smaller_-_easy_read_for_pwe.pdf)

NICE information about Epilepsy

Includes guidance on referral protocol following a first seizure.

<https://cks.nice.org.uk/topics/epilepsy/management/suspected-epilepsy/>

Epilepsy Specialist Nurses contacts

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Knowledge

Two commonly used medications for Epilepsy are sodium valproate and carbamazepine. These medications can cause long term effects if taken over an extended period. Long-term use of sodium valproate can cause osteoporosis and osteopenia which can cause the bones to be more fragile and more likely to break. Sodium valproate can also cause issues with fertility and can make hair either fall out, go curly or become very thick. Carbamazepine is a narrow therapeutic drug which means the therapeutic window is small; it can become toxic if the levels within the blood are too high which will be fatal. Both drugs are sodium channel blockers which results in a drop in sodium levels. Long term exposure to both drugs can also cause issues with bone density, liver damage, serious rashes or burns, high risk of weight gain and significant cognitive dampening.