

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

Learning Brief no 3 - 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. Around 1 in 3 people (32%) who have a mild to moderate learning disability will also have Epilepsy. The more severe the learning disability, the more likely that the person will also have Epilepsy. <https://epilepsysociety.org.uk/learning-disabilities>

Case Study

This learning brief learns from a coroner report about a person in their 40s with a severe learning disability, cerebral palsy and Epilepsy. This person had been declining for 18 months and had been in and out of hospital during this time, an end of life pathway and a TEP (Treatment Escalation Plan) was implemented. Their family and care staff wanted them to pass away at home where it would be more comfortable for them, staff worked very hard to ensure they were appropriately trained, and the equipment was in place. Sadly, they passed away in hospital due to prolonged, uncontrollable seizure activity. Their Epilepsy had been particularly problematic and hard to control during their deterioration.

Following a seizure

- Maintain dignity and respect
- Support the person if they experience anxiety, sadness, confusion or forgetfulness
- Allow them time to recover
- Check on the person regularly during recovery period
- Ensure airway is clear and breathing is no longer compromised

Seizure triggers

- Stress
- Lack of sleep or tiredness
- Missed medication
- Alcohol
- Flashing or flickering lights
- Menstrual periods
- Missing meals
- Having an illness or high temperature

How can seizures present differently in a person with a Learning Disability?

- The seizures may be more regular
- The seizures may last longer
- The seizures may be too complex to put into a seizure category
- They might have more than one type of seizure, and could have a type of seizure closely followed by a different type of seizure
- The seizures may be small movements or behaviours that are difficult to recognise as a seizure which can sometimes be described as atypical

Reporting the death of someone with Epilepsy

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

NICE Epilepsy information

Includes guidance on referral protocol following a first seizure.

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

Support when someone with Epilepsy has died

<https://www.epilepsy.org.uk/info/sud-ep-sudden-unexpected-death-in-epilepsy/support-when-someone-with-epilepsy-has-died>

Epilepsy Specialist Nurses contacts

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Vagus Nerve Stimulation (VNS) The VNS is a stimulator that is connected to the left vagus nerve in the neck which sends regular electrical stimulations through this nerve to then control the irregular electrical brain activity that leads to seizures. A small magnet can be used to give stronger simulation for a short amount of time to stop an aura developing into another seizure or reduce the recovery time after a seizure. This is a physical magnet that can be swiped over the area where the VNS is fitted.

Guide to Epilepsy for Carers

<https://www.epilepsy.org.uk/living/for-carers>

Easy Read guide to Epilepsy

<https://phw.nhs.wales/services-and-teams/improvement-cymru/our-work/learning-disability-health-improvement-programme/resourses-learning-disability-health-improvement-programme/annual-health-check/easy-read-health-leaflets/epilepsy-different-epileptic-fits/>