



Oxford University Hospitals
NHS Foundation Trust

Children's Hospital, Oxford University Hospitals NHS Trust

Improving Care for Children with Epilepsy

Talking about SUDEP

Results: SUDEP example Content

- We discussed the risk of Sudden Unexpected Death in Epilepsy (SUDEP). Here are some key points:
- SUDEP is when someone with epilepsy dies suddenly, and prematurely & no cause of death can be found. It is not a condition itself, but a way to categorise these sudden deaths.
- Overall, people living with epilepsy are at a 1 in a 1000 risk of SUDEP per year, but risk is specific to each individual and ways to reduce risks are person-centred too. People with learning disability, other physical conditions or rare epilepsies may be at higher risks.
- Different types of epilepsy carry their own level of risk, some higher, some lower.
- Epilepsy with generalised tonic-clonic seizures has a higher risk. This is especially if these happen at night or when asleep.
- Increased number of seizures also increases the risk.
- People with absence or myoclonic seizures are not known to have an increased risk for SUDEP.
- Epilepsy risks (linked to dying prematurely) can change over time. However, steps can be taken to reduce some of these risks.

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- We discussed things we can do to help reduce the risk of SUDEP. These could include:
- Getting better control of your epilepsy, to reduce number of seizures where possible
- Taking your epilepsy medication regularly and as prescribed
- Following safety advice and lifestyle measures
- Using epilepsy monitors, that may help to better detect night-time seizures – however these should be one part of a wider safety plan to reduce epilepsy/SUDEP risks.
- How girls of childbearing age will need to have pre-conception counselling to help understand the risks related to this, and how if you take certain medications they may need to be reviewed/changed as you get older.
- That the EpSMon app can help people 16+ to monitor and manage their epilepsy risks (www.sudep.org/epsmon)
- Additional helpful information is available below.
- <https://sudep.org/sudden-unexpected-death-epilepsy-sudep>
- <https://sudep.org/childhood-adolescence-and-risk> (Free leaflets from SUDEP Action on reducing Epilepsy risks and SUDEP for children with epilepsy are available here: <https://sudep.org/leaflets-and-downloadable-information>)
- <https://www.epilepsy.org.uk/info/daily-life/safety/practical-guidance>
- <https://www.epilepsy.org.uk/info/daily-life/safety-aids-equipment/alarms-monitors>
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