NCMD

National Child Mortality Database

Knowledge, understanding and learning to improve young lives

Sudden Unexpected Deaths in Epilepsy in Children in England: What can we learn?

Deaths between 1 April 2019 and 31 March 2024

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HQIP

Healthcare Quality Improvement Partnership

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We thank all Child Death Overview Panels (CDOPs) who submitted data for the purposes of this report and all child death review professionals for submitting data and providing additional information when asked.

Background

Epilepsy is one of the most common long-term conditions affecting approximately 112,000 children and young people (CYP) under 18 years of age in the UK. When someone with epilepsy dies suddenly and unexpectedly, without any alternative cause identified, it is called Sudden Unexpected Death in Epilepsy (SUDEP).

Potentially modifiable risk factors for SUDEP include non-adherence to medication, alcohol and drug misuse, having focal to bilateral tonic-clonic seizures or generalised tonic-clonic seizures, having uncontrolled seizures, living alone and sleeping alone without supervision (see NICE guidance NG217).

The aim of this briefing is to describe the characteristics of the children who died of SUDEP and the learning from the national themes identified from the child death reviews.

Characteristics of the children

- There were 111 deaths identified as being due to definite or probable SUDEP.
- The number of deaths increased with age, with a sharp increase in 14- to 17-year-olds. 49% (n=54) of the deaths were of children aged 14 to 17 years.
- There was a higher proportion of males (57%, n=63) than females (43%, n=48).
- 64% (n=69/108) of the children had a physical disability, and for children aged 4 to 17 years, 69% (n=66/95) had a learning disability.
- There was a higher proportion of deaths of children living in the most deprived neighbourhoods (31%, n=34), compared to the least deprived neighbourhoods (16%, n=18). This pattern of this variation followed the pattern seen in the incidence of epilepsy over one year across the deprivation quintiles in the Epilepsy12 national audit.
- 25 (23%) children were not on regular antiseizure medications at the time of death; 19 of whom were aged 10 to 17 years. Out of this 25, 19 were awaiting a formal diagnosis of epilepsy (for example, waiting to see a specialist, awaiting EEG, or awaiting commencement of medications after tests), and a small number (fewer than 5) had a family history of SUDEP. It was not possible to determine to what extent safety netting, for example using RCPCH first seizure leaflets, was in place in this group.
- 26% (n=29) had a genetic diagnosis: SCN1A (n=5), STXBP1 (n=2), KCNQ2 (n=2), Angelman's Syndrome (n=2), and 18 cases had other genes identified.
- 40 cases were identified as having drug resistant epilepsy (DRE); this information could be ascertained in 82 cases. Of those 40 cases, 6 (15%) children had been referred to the Children's Epilepsy Surgery Service (CESS) and 9 (23%) were offered the ketogenic diet.
- Out of 28 deaths of children aged 16 and 17 years, 10 (36%) had evidence of issues with adherence to treatment, 4 (14%) had significant events leading to sleep deprivation on the night before death, and 10 (36%) had generalised convulsive seizures.

- Out of the 16- and 17-years-old children with generalised convulsive seizures (n=10), 4 were male and 6 were female. In the male children, 2 were not on any antiseizure medications, and 2 were prescribed sodium valproate but had issues with adherence to treatment. In the 6 female children, 3 had therapeutic lamotrigine levels post-mortem, 2 had been weaned off sodium valproate, and there were issues with adherence to treatment in 1 child.

Themes identified from the national qualitative analysis of the Child Death Overview Panel reviews

Communication

Communication between services

- There was evidence of a lack of clear understanding of whether the responsibility for providing prescriptions for medications for the treatment of epilepsy sat with secondary or primary care. This caused confusion to the families and lack of timely medication for treatment of epilepsy.

- There were also instances where planned dosage changes had not been made due to lack of timely communication between the hospital and GP.

Communication with families and patients

- There were examples where families had not heard of SUDEP before it happened to them. Child Death Overview Panels (CDOPs) recorded the importance of improvements to information sharing with parents, to ensure understanding of risks and when to seek advice from a healthcare professional. It is important that children and their families feel empowered to escalate any concerns they may have. SUDEP Action provide information on what SUDEP is, including the causes and risk factors, and signposts to available support. They also have free leaflets for professionals, people with epilepsy and parents and carers, and the Paediatric SUDEP and Seizure Safety Checklist to support evidence-based epilepsy/SUDEP risk communication.

- CDOPs highlighted that young people should be allowed to have their voice heard regarding decisions about their epilepsy, associated risks and treatment options. There should be information on SUDEP specifically designed for children and young people.

- CDOPs learning also highlighted the importance of professionals' support for facilitating discussions about SUDEP. A paediatric version of the SUDEP and Seizure Safety Checklist has been developed to aid the early identification of epilepsy-related risk factors in children, leading to more effective management and interventions. The Checklist also aims to improve the two-way discussions between clinicians and patients and their families.

Timely and appropriate management

Delayed diagnosis

- CDOPs recorded instances of delayed diagnosis and a lack of professional understanding in the diagnosis of epilepsy. Learning recorded that there is need for improved recognition of non-convulsion seizures presentations by emergency medical staff. Professionals were falsely reassured following normal investigations, despite the presence of video evidence of seizures.

Treatment changes

- There was also evidence in some reviews around issues with treatment changes, including where a change in medication was associated with seizures becoming less controlled. For example, being taken off sodium valproate and replacing it with levetiracetam, which resulted in seizures becoming less controlled. CDOPs recorded the need to ensure appropriate discussions take place between professionals, regarding the need to change medication.

Follow up

- Issues with follow up were also recorded, including issues with transition between paediatric and adult neurology services.

- Issues with being incorrectly discharged without follow up were also recorded by the CDOPs. Examples included cases where the child was discharged from both adult and paediatric services after they were not brought for their appointment with the adult epilepsy team.

  There is now clear guidance from the adult and paediatric neurologists' professional bodies that all patients who have ongoing seizures or who are on antiseizure medications need follow up in adult services.

Adherence to treatment

- CDOPs recorded learning around the importance of services supporting adherence to treatment, including GP monitoring of the number of prescriptions to ensure that medication is being taken regularly. CDOPs suggested automated alerts in primary care systems and shared care records which could help services to promptly respond.

Actions for local hospitals, community health services, commissioning bodies, national bodies and health professionals who work with families with children

Integrated Care Boards (ICBs), Trusts and neighbourhood services should:

1. Fully implement the National Institute for Health and Care Excellence (NICE) recommendations and Epilepsy12 metrics, including:

   - Referring children and young people (CYP) urgently (for an appointment within 2 weeks) for an assessment after a first suspected seizure.

- Empower CYP and families with ongoing SUDEP risk assessment. This should include information and education in an appropriate format, individualised planning to optimise risk of SUDEP, adherence to medications and safer sleep practices. The SUDEP Action Children's SUDEP and Seizure Safety Checklist is freely available to support these discussions and guide personalised risk management, and it can be embedded into patient record systems to support ease of access and completion.
- Children and young people with epilepsies should have early and ongoing access to specialist paediatricians and nurses, who ensure ongoing shared decision making to optimise treatment and care planning for the child. This should balance risks and benefits of different treatment options and should avoid withholding sodium valproate where that becomes the appropriate treatment.
- Ensure pathways facilitate the timely referral of all suitable children with a complex epilepsy for consideration of epilepsy surgery, vagal nerve stimulation (VNS) and ketogenic diet.

2. Review the design, capacity, timeliness and effectiveness of early pathways towards specialist epilepsy services, and opportunities for ensuring early safety-netting, seizure first aid and safety advice and communication channels whilst awaiting or between investigations and appointments.

For example, through:

- Ensuring timely clinical reviews and investigations as indicated, including timely electroencephalogram (EEG), so that children do not die while awaiting diagnosis and treatment for epilepsy.
- National review towards inclusion of EEG within the NHS Diagnostics waiting times and activity guidance to facilitate timely EEG.
- Early provision of RCPCH first seizure leaflets, for example from primary care, which provide information to parents and carers, and to children and young people who have had a first seizure that was not considered to be a 'febrile convulsion'. These leaflets should be completed and individualised to confirm ongoing contact details for the paediatric service and follow up details.
- RCPCH to oversee the review and continuing updates and dissemination for the RCPCH first seizure leaflets, including making them available in formats to suit different needs within the whole population.

3. There should be robust Was Not Brought (WNB) policies across the NHS, as detailed in the NICE Transition Guideline. This should include the transition process between adult and paediatric care such that children and young adults with suspected epilepsy are not automatically discharged from specialist care.

4. Ensure robust systems are developed for identifying and communicating issues with prescriptions and dispensing, between pharmacies, primary, secondary and tertiary care. This will enable children with evidence of issues with adherence to treatment to be routinely highlighted to the epilepsy service.

5. Missed opportunities for monitoring outcomes after medication changes should be avoided, with clear pre-emptive written plans communicated to families and all healthcare providers on what to do if seizures get worse following medication changes.

6. There should be mandated, ongoing, competency-assured paediatric epilepsy training for all professionals who may care for a child with epilepsy across primary and secondary care, including emergency services.

7. The British Paediatric Neurology Association (BPNA) should ensure there is ongoing development of professional training and educational programmes, such as the BPNA Paediatric Epilepsy Training (PET) courses, to ensure that professionals continue to develop and improve their approaches to ensure timely and appropriate management of epilepsy, and minimise all modifiable risk factors for SUDEP.

Data tables

Table 1. Number of Sudden Unexpected Deaths in Epilepsy between 1 April 2019 and 31 March 2024, by sex, age, ethnicity, disability and learning disability

	Number (%) of Sudden Unexpected Deaths in Epilepsy
Total	**111**
Age group	**111**
Under 1 year	0 (0%)
1 – 4 years	18 (16%)
5 – 9 years	18 (16%)
10 – 13 years	21 (19%)
14 – 17 years	54 (49%)
Sex	**111**
Female	48 (43%)
Male	63 (57%)
Ethnic group	**109**
Asian or Asian British	14 (13%)
Black or Black British	10 (9%)
Mixed	3 (3%)
White	81 (74%)
Other	1 (1%)
Disability	**108**
Yes	69 (64%)
No	39 (36%)
Learning disability (4 – 17 years)	**95**
Yes	66 (69%)
Suspected but not confirmed	1 (1%)
No	28 (29%)

Table 2. Number of Sudden Unexpected Deaths in Epilepsy between 1 April 2019 and 31 March 2024, by region and social deprivation

	Number (%) of Sudden Unexpected Deaths in Epilepsy
Region	**111**
North East	5 (5%)
North West	16 (14%)
Yorkshire and The Humber	11 (10%)
East Midlands	7 (6%)
West Midlands	18 (16%)
East of England	10 (9%)
London	13 (12%)
South East	23 (21%)
South West	8 (7%)
Social deprivation	**110**
1 (most deprived)	34 (31%)
2	26 (24%)
3	16 (15%)
4	16 (15%)
5 (least deprived)	18 (16%)

Table 3. Number of Sudden Unexpected Deaths in Epilepsy between 1 April 2019 and 31 March 2024, by genetic diagnosis and Epilepsy classification

	Number (%) of Sudden Unexpected Deaths in Epilepsy
Total	**111**
Genetic diagnosis	**29 (26%)**
SCN1A	5
STXBP1	2
KCNQ2	2
Angelman's Syndrome	2
Other	18
Epilepsy classification	**82**
Drug resistant epilepsy	40 (49%)

Methodology and limitations

Cohort identification

NCMD is commissioned by the National Health Service England to collect and analyse data on all children who die in England before their 18th birthday. The main source of information for NCMD is statutory data from various agencies gathered by 58 Child Death Overview Panels (CDOPs).

All child (0 – 17 years, inclusive) deaths between 1 April 2019 and 31 March 2024 were identified, where they were notified to the National Child Mortality Database by a Child Death Overview Panel (CDOP) in England. This was then restricted to deaths that had been reviewed by a CDOP before 1 January 2025.

Deaths occurring due to SUDEP were identified by searching the medical certificate cause of death or the cause of death within the statutory analysis form completed by the CDOP, for one of the following term combinations: 'SUDEP'; or 'epilep*' AND 'sudden'.

Deaths were identified through this initial search strategy. The cases were then clinically validated retrospectively to ensure appropriate case inclusion of deaths.

Essential information extracted included structured demographic and patient-specific information (for example whether the child had a learning disability), and free text derived information on details such as medical history and learning points from the child death review process. The supplementary form for epilepsy provided specific information on epilepsy-related risk factors for SUDEP. Further free text information variably included minutes of child death review meetings, post-mortem examination reports and clinic letters.

Trends, patterns, and potential risk factors associated with child deaths were explored through tabulation of demographic information, and correlation with known risk factors for SUDEP.

Exclusions

Cases identified where SUDEP was not the cause of death (e.g., status epilepticus, infection) were excluded.

Data extraction

The data used for deaths that occurred between 1 April 2019 and 31 March 2024 within this briefing was extracted on 14 January 2025.

Limitations

This work is based on statutory data reported to NCMD, and previous work has shown good validation and coverage. However, this work relied on the completion of the medical certificate cause of death or the cause of death within the statutory analysis form completed by the CDOP to identify the cases, meaning that child deaths that had not yet been reviewed by a CDOP would not be included in this work. In total, 82% of all child deaths between 1 April 2019 and 31 March 2024 had been reviewed before 1 January 2025. This means that there would be an underestimation of the total number of deaths that occurred during the time period, particularly in the later years. The identification of deaths for this work is dependent on the key words being recorded in the cause of death fields.

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