This form is used in the child death review process to gather detailed information about children who die as the result of epilepsy. Its primary purpose is to enable CDOP to review all children's deaths in this category in their area in order to understand patterns and factors contributing to children's deaths. Please complete those questions on which you hold information. If you do not have information for a particular item, please tick “Not known”.

Information on this form will be shared with other professionals for the purposes of the child death review process. All professionals are entitled to share this information without contravening laws on data protection. All information gathered will be stored securely and statutory safeguards (s251) are in place to allow the legal transfer, storage, analysis of identifiable data.

**Identifying details** **- to be removed for the purposes of anonymisation prior to discussion at the CDOP:**

|  |  |  |  |
| --- | --- | --- | --- |
| Name |  | Date of birth  (dd/mm/yyyy) | / / |
| URN |  | Date and time of death | Date: / /  Time: **:** (24hr) |
| Postcode |  | | |

|  |  |
| --- | --- |
| Which subcategory does this child’s death fall into? Please choose from the following options: *(tick* ***ALL*** *that apply)* | ☐ Seizures  ☐ Status Epilepticus  ☐ Epilepsy Syndrome  ☐ Sudden unexpected death in Epilepsy (SUDEP)  ☐ Other *(please specify)* |
| **Family history of epilepsy**  *(Please answer for all subcategories)* | |
| Was there a family history of seizures or epilepsy? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| **Aetiology of the epilepsy**  *(Please answer for all subcategories)* | |
| Was there an identified underlying aetiology for the epilepsy? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Had the child had a gene panel test or whole-genome sequencing for potential causes of epilepsy? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Were there genes with identified pathogenic variants, probably pathogenic variants, or variants of unknown significance (VUSs) that might have been the cause, or a contributory cause, of the epilepsy? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Had the child had an MRI head scan or other form of neuroimaging (such as CT head or USS head)? Please give dates and findings: |  |
| Had there been an appropriate screen of investigations for potential metabolic causes of epilepsy? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Were any of these investigations abnormal, and if so, what did the reports state? |  |
| **Medical and nursing management of the epilepsy**  *(Please answer for all subcategories)* | |
| Had the child been reviewed by a consultant paediatrician with special expertise in epilepsy? | ☐ Yes *(please give the date of the most recent*  *review)*  ☐ No  ☐ Not known  ☐ Not applicable |
| Had the child been reviewed by a consultant paediatric neurologist? | ☐ Yes *(please give the date of the most recent*  *review)*  ☐ No  ☐ Not known  ☐ Not applicable |
| Had the child been reviewed by a paediatric epilepsy nurse? | ☐ Yes *(please give the date of the most recent*  *review)*  ☐ No  ☐ Not known  ☐ Not applicable |
| Had the child had a clinic review of their epilepsy by one of the above doctors or an appropriately trained clinical nurse specialist within the preceding 12 months? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Was there a seizure-management care plan (SMCP)? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Did the SMCP include a rescue antiepileptic drug (such as buccal midazolam)? If so, please specify which drug: |  |
| Which rescue medications were administered during any seizure episode on the day of death? |  |
| **EEG features**  *(Please answer for all subcategories)* | |
| Had the child had an EEG? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| If **yes**, which of the following applies? *(Tick* ***ALL*** *that apply)* | ☐ Awake-state  ☐ Sleep-state  ☐ Video-EEG monitoring  ☐ Ambulatory EEG monitoring |
| Did any of the EEGs report the following? *(Tick* ***ALL*** *that apply)* | ☐ An abnormality of background (such as  asymmetry or focal slowing)  ☐ An interictal (between-attack) pattern that was  interpreted as being epileptiform and  indicating a liability to seizures  ☐ An ictal (during-attack) pattern showing an  electrographic seizure  ☐ Generalised epileptiform abnormalities  ☐ Focal epileptiform abnormalities  ☐ Multifocal epileptiform abnormalities  ☐ Periods of frequent, repetitive epileptiform  discharges in sleep consistent with a  diagnosis of CSWS/ESES (continuous spike-  waves in sleep or electrical status epilepticus  in sleep)  ☐ Periods of frequent, repetitive epileptiform  discharges in wakefulness consistent with a  diagnosis of convulsive or non-convulsive  status epilepticus |
| **Treatment of the epilepsy — drugs**  *(Please answer for all subcategories)* | |
| Were there documented concerns about adherence to the AED regimen? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Were there undocumented (at the time of death) but subsequently reported concerns about adherence to the AED regimen? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |

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| **Treatment of the epilepsy — ketogenic diet**  *(Please answer for all subcategories)* | |
| Was the child treated with a form of ketogenic diet? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| If on a ketogenic diet, was there evidence of recent problems with maintaining ketosis? |  |
| During the final illness, had a medication or fluids been administered that would have compromised the ketosis? |  |
| **Treatment of the epilepsy — surgery**  *(Please answer for all subcategories)* | |
| Had there been a referral to the Children’s Epilepsy Surgery Service (CESS)? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Had there been an assessment by the CESS? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Which surgical procedures did this child undergo? *(tick* ***ALL*** *that apply)* | ☐ Lesionectomy  ☐ Lobectomy  ☐ Hemispherotomy  ☐ Hemispherectomy  ☐ Corpus callosotomy (partial)  ☐ Corpus callosotomy (complete)  ☐ Multiple subpial transection  ☐ An implanted device (such as deep-brain  stimulator)  ☐ Vagus nerve stimulator (please state the form of  the VNS)  ☐ Other *(please specify)*  ☐ No surgical procedure performed |
| For any device, were there any concerns about the functioning and maintenance of the device? |  |
| **Seizures**  *(Please only answer these questions if you selected the Seizures subcategory)* | |
| Was there a history of seizures? |  |
| Was there an underlying cardiac cause for this child's seizures? |  |
| Were there seizures due to an acute illness? |  |
| Was there a history of seizures with fever? |  |
| Was there a prior diagnosis of febrile seizures? |  |
| Were there recurrent unprovoked seizures? |  |
| Was there a diagnosis of epilepsy? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| What were the documented type(s) of seizure [with reference to the International League Against Epilepsy (ILAE) classification]? |  |
| At what age did the first seizure occur? |  |
| What was the initial seizure type? |  |
| Were there seizures with onset in the awake state? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Were there seizures with onset from the sleep state? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| When was the most recent documented and witnessed seizure prior to the day of death? |  |
| Was a seizure witnessed on the day of death? |  |
| What were the types of the most recent reported or witnessed seizure(s)? |  |
| **Status Epilepticus**  *(Please only answer these questions if you selected the Status Epilepticus subcategory)* | |
| Were the documented episodes of status epilepticus: | ☐ Convulsive status epilepticus  ☐ Non-convulsive |
| What was the longest documented period of CSE/NCSE? |  |
| Had there been prior hospital admissions because of prolonged seizures or status epilepticus? | ☐ PICU  ☐ PHDU  ☐ Paediatric Ward  ☐ ED  ☐ Other (*please specify)* |
| **Epilepsy Syndrome**  *(Please only answer these questions if you selected the Epilepsy Syndrome subcategory)* | |
| Was there the diagnosis of a specific epilepsy syndrome (for example, Lennox-Gastaut syndrome)? Please refer to the ILAE classification. |  |
| Were there previous diagnoses of different epilepsy syndromes? |  |
| **SUDEP**  *(Please only answer these questions if you selected the SUDEP subcategory)* | |
| Was this considered to be a case of sudden unexpected death in epilepsy (SUDEP)? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Was the child thought to have been asleep at the time of death? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |
| Was there any evidence that a seizure had occurred just prior to death? If **yes**, please specify specific features, e.g. injury, incontinence of urine, etc: |  |
| Was there any form of epilepsy monitoring device? | ☐ Alarm  ☐ Listening device  ☐ No device used  ☐ Not known |
| If **yes**, was the device used: | ☐ Under Medical/nursing supervision  ☐ Acquired informally by parents  ☐ Other *(please specify)* |
| Were any other safety devices employed? | ☐ Positioning system  ☐ Anti-suffocation pillow  ☐ Other *(please specify)* |
| Were the parents counselled about the possibility of sudden death? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable |