Guidelines for the discussion of SUDEP with children with epilepsy and their families.

SUDEP is defined as:
“The sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in patients with epilepsy, with or without evidence for a seizure and excluding convulsive status epilepticus in which post-mortem examination does not reveal a toxicological or anatomical cause for death.”

Nashef L. sudden unexpected death in epilepsy: terminology and definitions. EPILEPSIA 1997;38(suppl 11):S6-S8

Epilepsy is not a single disorder, rather a group of syndromes with different clinical phenotypes, causes and prognoses. This fact is of huge importance when discussing epilepsy and the risk of death with families. It is not appropriate to discuss epilepsy as though it were a single disorder. Diagnosing a child’s specific epilepsy syndrome and cause of the epilepsy may better inform doctors about the risks of premature death and SUDEP for individual children which can then be shared with the family.

Risk of SUDEP is known to be higher in those patients:
- with poorly controlled seizures;
- who are poorly compliant with treatment;
- who have symptomatic epilepsy;
- who have associated neurological comorbidity;
- who have associated significant learning difficulties.

SUDEP should always be discussed with families of children:
- With symptomatic epilepsy, (ie epilepsy in the context of a structural brain abnormality, metabolic disorder or neuro-degenerative disorder)
- With drug resistant tonic-clonic seizures;
- With associated severe neurological impairment;
- Who ask direct questions about death and epilepsy.

Discussion about SUDEP should be considered in children:
- With additional learning difficulties;
- With additional physical difficulties;
- Who are not complying with treatment;
- Who are resisting treatment.

SUDEP does not need to be routinely discussed with families of children:
- With benign familial infantile seizures;
- With childhood absence epilepsy;
- With benign partial epilepsy with centro-temporal spikes;
- With well controlled idiopathic generalised epilepsy.

Ideally, discussion regarding SUDEP should be done in the epilepsy clinic by a consultant.

The content of the discussion should be clearly documented in the patient’s hospital notes and included in the correspondence to the GP that is copied to the parents and child. The family should also be given a generic information sheet on “epilepsy and death”.