Ashford and St. Peter's Hospitals
NHS Foundation Trust

SUDEP

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Guideline History		
Date	**Comments**	**Approved By**
2007	Developed by K. Irwin	General paediatric consultants
2014	Reviewed and approved	General paediatric team
2022	Reviewed and approved	General paediatric team

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1.

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."

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".

2. Supporting References

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

2. Guideline Governance

a. Scope

This guideline is relevant to all staff caring for all children from 0-18 years old across the emergency department, inpatient ward and outpatient department.

b. Purpose

i. This guidelines aims to facilitate a common approach to the management of children. At times deviation from the guideline may be necessary, this should be documented and is the responsibility of the attending consultant.

ii. This guideline is subject to regular review to ensure ongoing evidence based practice.

c. Duties and Responsibilities

All healthcare professionals responsible for the care of all children 0-18years should be aware of practice according to this guideline.

d. Approval and Ratification

This guideline will be approved and ratified by the Paediatric Guidelines Group.

e. Dissemination and Implementation

i. This guideline will be uploaded to the trust intranet 'Paediatric Guidelines' page and thus available for common use.
ii. This guideline will be shared as part of ongoing education within the Paediatric Department for both medical and nursing staff.
iii. All members of staff are invited to attend and give comments on the guideline as part of the ratification process.

f. Review and Revision Arrangements

a. This policy will be reviewed on a 3 yearly basis by the appropriate persons.
b. If new information comes to light prior to the review date, an earlier review will be prompted.
c. Amendments to the document shall be clearly marked on the document control sheet and the updated version uploaded to the intranet. Minor amendments will be ratified through the Paediatric Guidelines Group. A minor amendment would consist of no major change in process, and includes but is not limited to, amendments to documents within the appendices.

g. Equality Impact Assessment

Background • Who was involved in the Equality Impact Assessment
Author and the supervising consultants.
Methodology • A brief account of how the likely effects of the policy was assessed (to include race and ethnic origin, disability, gender, culture, religion or belief, sexual orientation, age) • The data sources and any other information used • The consultation that was carried out (who, why and how?)
All groups of staff and patients were taken into consideration and there is no bias towards or against any particular group.
Key Findings • Describe the results of the assessment • Identify if there is adverse or a potentially adverse impacts for any equalities groups
There is no evidence of discrimination.
Conclusion • Provide a summary of the overall conclusions
There is no evidence of discrimination.
Recommendations • State recommended changes to the proposed policy as a result of the impact assessment • Where it has not been possible to amend the policy, provide the detail of any actions that have been identified • Describe the plans for reviewing the assessment
This guideline is appropriate for use.

h. Document Checklist

To be completed (electronically) and attached to any document which guides practice when submitted to the appropriate committee for approval or ratification.

Title of the document:

Policy (document) Author:

Executive Director: N/A

		Yes/No/ Unsure/NA	Comments
1.	**Title**		
	Is the title clear and unambiguous?		
	Is it clear whether the document is a guideline, policy, protocol or standard?		
2.	**Scope/Purpose**		
	Is the target population clear and unambiguous?		
	Is the purpose of the document clear?		
	Are the intended outcomes described?		
	Are the statements clear and unambiguous?		
3.	**Development Process**		
	Is there evidence of engagement with stakeholders and users?		
	Who was engaged in a review of the document (list committees/ individuals)?		
	Has the policy template been followed (i.e. is the format correct)?		
4.	**Evidence Base**		
	Is the type of evidence to support the document identified explicitly?		

		Yes/No/ Unsure/NA	Comments
	Are local/organisational supporting documents referenced?		
5.	**Approval**		
	Does the document identify which committee/group will approve/ratify it?		
	If appropriate, have the joint human resources/staff side committee (or equivalent) approved the document?		
6.	**Dissemination and Implementation**		
	Is there an outline/plan to identify how this will be done?		
	Does the plan include the necessary training/support to ensure compliance?		
7.	**Process for Monitoring Compliance**		
	Are there measurable standards or KPIs to support monitoring compliance of the document?		
8.	**Review Date**		
	Is the review date identified and is this acceptable?		
9.	**Overall Responsibility for the Document**		
	Is it clear who will be responsible for coordinating the dissemination, implementation and review of the documentation?		
10.	**Equality Impact Assessment (EIA)**		
	Has a suitable EIA been completed?		

Committee Approval (Paediatric Guidelines Group)			
If the committee is happy to approve this document, please complete the section below, date it and return it to the Policy (document) Owner			
Name of Chair	**Claire Mitchell**	**Date**	**21/02/2022**
Ratification by Management Executive (if appropriate)			
If the Management Executive is happy to ratify this document, please complete the date of ratification below and advise the Policy (document) Owner			
Date: n/a			