Sudden Unexpected Death in Epilepsy (SUDEP) Awareness and Grief Support

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May 3, 2023
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Today’s Presenters:

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Objectives

- Education you on the FACTS
- Acknowledge fears and worries
- Give hope to future research on how to best prevent
- Shift focus on controlling things that are under your control
- Build patient – provider trust and reduce anxiety and stress levels

01 What is SUDEP
Understanding the facts while breaking down myths

02 SUDEP Research
Exploring knowledge gaps and path forward

03 Strategies and Resources
Actionable advice to reduce SUDEP risk factors

04 Grief
Ways to process and cope
Question 1: Is this your first discussion about SUDEP?
Question 2: When did you learn first about SUDEP?
What is SUDEP?

Sudden Unexpected Death in Epilepsy (SUDEP) refers to a category of deaths in people with epilepsy in which there is no other clear cause of death (for example, cancer, stroke, known heart disease, or an accident related to a seizure).

• 1/1000 people with epilepsy die each year from SUDEP
• Full known causes are still largely unknown
• Rare occurrence...but ALL people with epilepsy are at risk
Most Common Risk Factors for SUDEP

1. Uncontrolled or Frequent Seizures
   Generalized tonic – clonic seizure (GTCS)

2. Nocturnal Seizures
   (Seizures in sleep)

3. Seizures that begin at a young age

4. Years lived with epilepsy

5. Missed doses of medicine or abruptly stopping medicine
Future Research

• Improve clinician driven discussion about SUDEP.
• Broader understanding on how social determinants of health impact SUDEP risk factors.
• Improve education to clinicians, medical examiners, coroners, and forensic pathologist for accurate diagnosis and risks.
• Advocate for public policy on SUDEP legislation.
• Identifying potential biomarkers for SUDEP.
• Referring families for donate whole brain tissue after death to the Maryland Brain and Tissue Bank (MBTB).
The University of Maryland Brain and Tissue Bank (MBTB) gratefully accepts brain and other tissue donations from individuals with neurologic, development, movement, and psychiatric disorders as well as from individuals with none of these underlying diseases to serve as unaffected controls. There is no cost to the family to donate. Anyone, regardless of age, is invited to donate. The MBTB generously supports the TSC Alliance® by sharing tissues from individuals affected by tuberous sclerosis complex (TSC) with the TSC Biosample Repository.

Preregistration is not required but simplifies and speeds the process of tissue recovery when death occurs. **Scan the QR code for instructions on how to register in advance for postmortem donation.** If death is imminent and you would like to donate brain tissue, please call the MBTB as soon as possible at 1-800-847-1539.

Successful donation rests on swift and thorough communication between family members, healthcare professionals, and the MBTB. Although the MBTB will make every effort to retrieve tissue in an emergency, tissue recovery may be impossible if there is no advance notice.
Question 3: How did you learn first about SUDEP?
Why isn’t my provider talking about it?

• Fears of worsening fears and anxiety
• Lack of personal knowledge of risk.
• Minimizing discussion because of the “low risk”
• Clinic time constraints
• Lack of guidance and training – including best strategies to reduce the risks when there is not a lot of evidence of value
So, Let’s Talk about “it”

The “Who”
98.6% of families want their epileptologist / neurologist!

The “When”
Frequency of when the discussion should occur.

The “How”
What do we as a team need to effectively communicate?
Strategies and Resources

- Take medication as prescribed
- Avoid seizure triggers
- Seizure monitor or devices
- Discuss with your healthcare team
- Seizure Action Plan
- Advocate for further SUDEP research
Question 4: How often do you think of SUDEP?
Grief is a continuum
Coping with difficult circumstances and confidently facing the unknown

01 Focus on controlling things within your control
02 Challenge your need for certainty
03 Focus on the present
04 Reduce your anxiety and stress levels
Confidently facing the unknown

Understanding your SUDEP Risks

Proactively using resources

Advocating for SUDEP research
SUDEP Resources

• Epilepsy Foundation: https://www.epilepsy.com/programs/sudep-program

• PAME (Partners Against Mortality in Epilepsy): https://pameonline.org/

• Preventing Epilepsy Deaths: Clinician Toolkit https://preventingepilepsydeaths.org/death-facts/

• TSC Navigator https://www.tscalliance.org/tscnavigator/
Discussion & Feedback