

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

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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?**

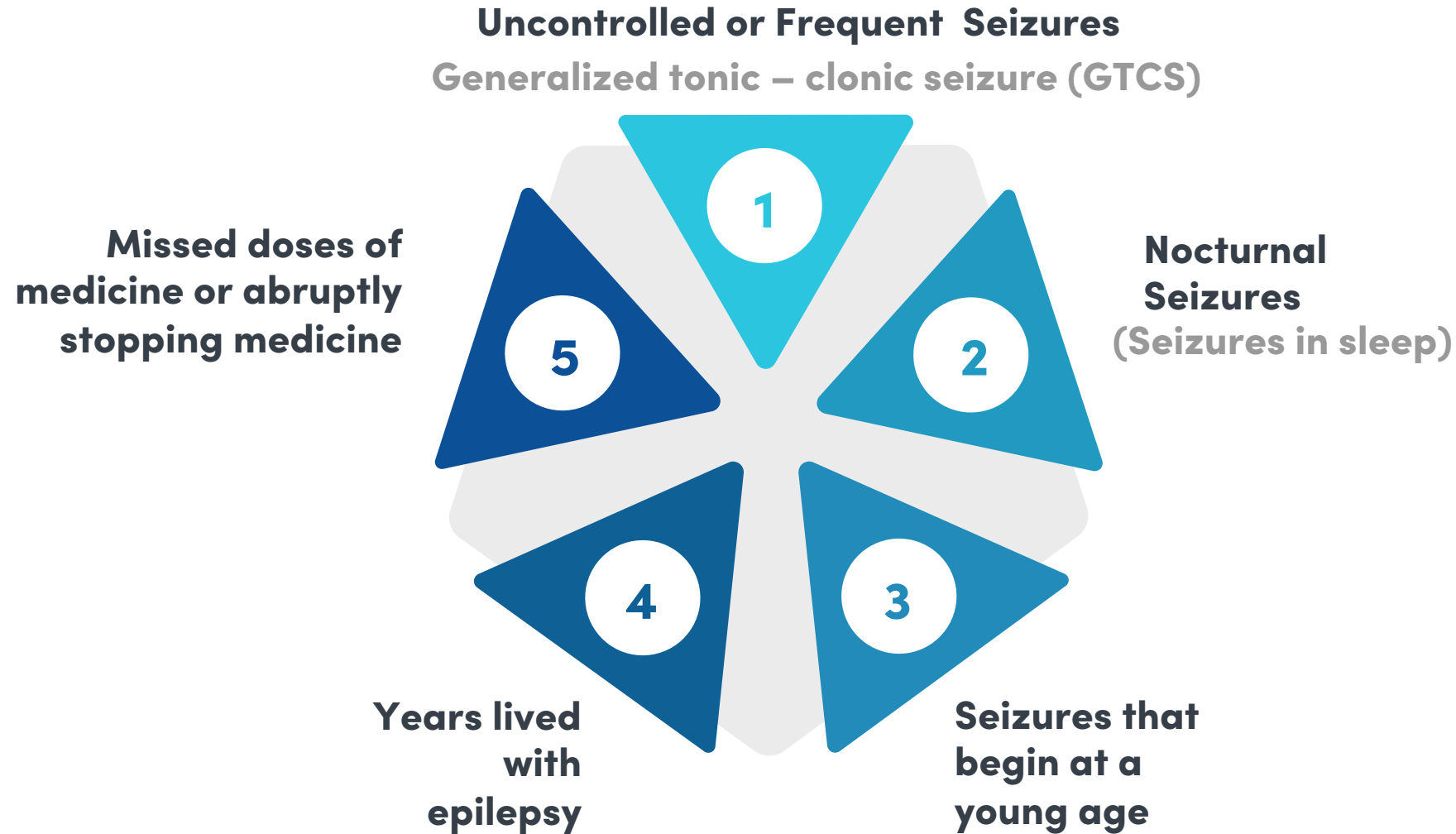
Question 2:
**When did you learn first about
SUDEP?**

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



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)**.

Post-Mortem Brain and Tissue Donation



UNIVERSITY of MARYLAND
SCHOOL OF MEDICINE
BRAIN AND TISSUE BANK



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.

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(800) 225-6872 | tscalliance.org | [@tscalliance](https://twitter.com/tscalliance)



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

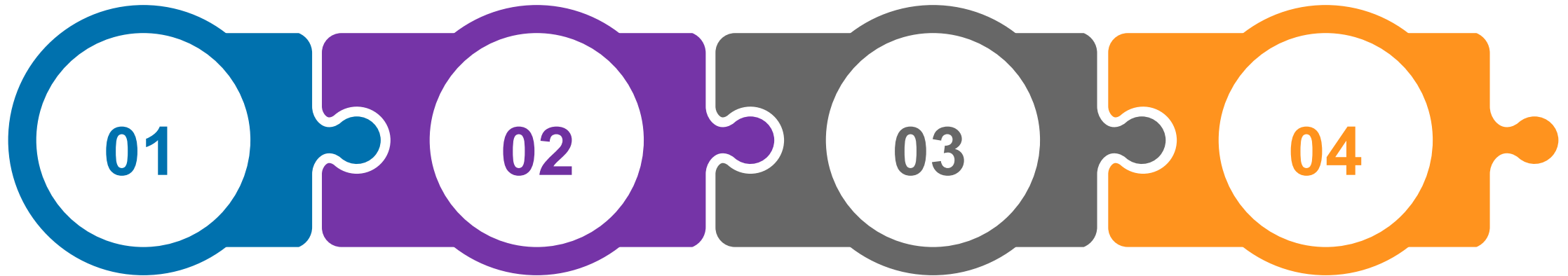
Strategies and Resources

- 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



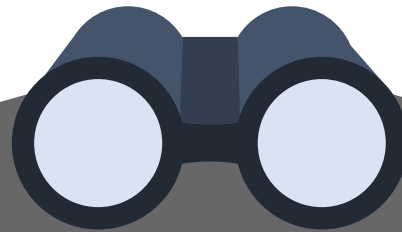
**Focus on
controlling
things within
your control**

**Challenge your
need for certainty**

**Focus on the
present**

**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

