



SPIKES

A GUIDE FOR DISCUSSING SUDEP WITH FAMILIES

SETTING

Set the stage for a collaborative discussion by preparing a comfortable, private space and ensuring that all parties whom the patient wishes to involve are present.

- Introduce SUDEP in the outpatient setting when possible, either in person or via a face-to-face telemedicine visit
- Ensure that a neurology and/or primary care clinician with whom the caregiver and patient have an established, trusting relationship with leads the conversation when possible
- Turn off pagers to vibrate and hold non-emergent calls
- Discuss SUDEP at the time of diagnosis, and revisit iteratively with changes in risk
- Integrate SUDEP risk disclosure into the broader discussion of epilepsy risks
- Attend to the developmental age and stage of child
- Demonstrate active listening skills, centering your attention on the needs of the patient

PERCEPTION

Assess the caregiver and/or patient's baseline knowledge about SUDEP using open-ended inquiry.

- *What worries do you have about your child's epilepsy diagnosis?*
- *What have you heard about the risks that can come along with seizures?*
- *Have you ever heard of something called SUDEP? [If yes], Tell me about what you've heard.*

INVITATION

Ask caregivers and/or patients directly about how much and what kind of information will be helpful to them. If a child is present, ask permission before proceeding with the conversation.

- *Some parents prefer to have conversations about serious risks of seizures without their child present; others prefer to include their child in these conversations. Which do you prefer?*
- *Would you like to learn more about your child's risk of SUDEP?*
- *Is it ok if we discuss SUDEP today?*

KNOWLEDGE

Share your knowledge about SUDEP in a clear, direct, and comprehensive manner.

- Provide information about SUDEP in direct terms
- Deliver information in small segments, allowing caregivers and/or patients time to process
- Use simple, non-medical language matching the caregiver's and/or patient's education level(s)
- Acknowledge any uncertainty that may exist

- Conversations about SUDEP should include the following information:
 - **Definition:** *SUDEP is the sudden unexpected death of a person or child with epilepsy. We do not yet know the cause of SUDEP, but we do know that SUDEP happens most often at night. SUDEP in children is rare.*
 - **Risk factors:** *There are a few things that can increase a child's risk of SUDEP. Those risk factors include having seizures that are not well controlled, having generalized tonic-clonic seizures where the whole body stiffens and shakes, and having seizures at night.*
 - **Patient's risk level:** *Based on everything we know about [name]'s seizures, his risk of SUDEP is [insert risk level].*
 - **Risk mitigation strategies:** *The best way to prevent SUDEP is to have as few seizures as possible. Things we can do to reduce your child's risk of SUDEP include making sure that he continues taking his medication every day, keeping a seizure diary, learning your child's seizure triggers, and creating a Seizure Action Plan. Let's talk more about [insert risk factor]....*
 - **Resources to find additional information:** *There are many good resources where you can learn more about SUDEP. Would you like to go over some of those today?*
- Check the understanding of caregivers and/or patients, and ask if they need additional clarification: *This was a lot of information. What questions do you have?*

EMPATHY

Acknowledge and respond to caregiver and patient emotions.

- Name emotions when present: *It sounds like you are worried about...*
- Assess and explore the emotions in the room: *Tell me more about your concerns....*
- Normalize the emotions that caregivers may be experiencing: *Some parents describe feeling overwhelmed when learning about SUDEP. How do you feel?*
- Validate the efforts of caregivers: *You are such a strong advocate for [name].*
- Share resources for further support: *Our team will be here to support you. Would you like to hear about organizations and resources that can help you learn more about SUDEP?*

SUMMARIZE

Summarize the information that has been presented using lay language and present a plan for next steps, including referrals to further resources.

- Ask questions to verify that the caregiver and/or patient understands the key information and proposed plan
- *We've reviewed a lot of information today; can you tell me what you understand about SUDEP and your child's risk?*
- *To summarize, all children with epilepsy have a risk of SUDEP and your child's risk of SUDEP is [insert risk level]. You can reduce your child's risk by....*

HELPFUL RESOURCES TO REFER FAMILIES TO FOR FURTHER INFORMATION:

- **Epilepsy Foundation:** www.epilepsy.com
- **Child Neurology Foundation:** www.childneurologyfoundation.org
- **Danny Did:** www.dannydid.org
- **Partners Against Mortality in Epilepsy (PAME):** www.pameonline.org