Understanding Your Child’s Risk for SUDEP

Your Child’s Current Risk is Low, But it is Important to Stay Informed

WHAT IS SUDEP?
SUDEP is Sudden Unexpected Death in Epilepsy. It is the most common epilepsy-related cause of death. SUDEP refers to the death of a mostly healthy person with epilepsy who dies unexpectedly and there is no clear reason for the death. Scientists and researchers are still learning about SUDEP and its causes. Current research is focused on problems with breathing, heartbeat and brain function after a seizure.

WHAT IS MY CHILD’S RISK FOR SUDEP?
Based on your child’s medical history, your doctor has determined that your child is currently at low risk for SUDEP.

Low risk is determined because your child:

• Does not have uncontrolled or treatment resistant epilepsy
• Has not had more than one seizure in the past year with stiffness and or jerking

HOW CAN WE STAY LOW RISK?
The best way to prevent SUDEP is to have as few seizures as possible. Low risk does not mean no risk. It is important to follow the recommendations below.

Take medication on time everyday—exactly as prescribed
Get enough sleep
Visit a neurologist or epileptologist (epilepsy specialist) at least once per year, and any time seizures change in type or frequency
Discuss additional treatments to reduce the risk of seizures—treatments include additional or alternate medications, surgery, ketogenic diet or devices
Know your child’s seizure triggers
Create and share a seizure response plan and seizure first aid
If your child has seizures at night, consider using a seizure alert device or other monitor to help alert family members if a seizure happens

WHERE CAN WE LEARN MORE?
Visit one of our patient-advocate partners:

childneurologyfoundation.org/sudep
dannydid.org
epiny.org/epilepsy/sudep