

Where Can I Get More Information On SUDEP?

You should discuss SUDEP with your loved one's neurologist or epileptologist. There are also many organizations available to help answer your questions on SUDEP:

- Danny Did Foundation - dannyydid.org
- Partners Against Mortality in Epilepsy - pame.aesnet.org
- SUDEP Aware - sudepaware.org

More About Safety

You may still have questions about safety and seizures. More safety tips and information on SUDEP can be found on our website at www.dravetfoundation.org.

Dravet Syndrome Foundation can also connect you with other families who are living with Dravet syndrome.



What Can I Do To Lower the Risk Of SUDEP?

There is a lot about SUDEP that we don't yet understand, including how to prevent it. We do know that the risk for SUDEP is higher in people with uncontrolled seizures. Until we better understand the mechanisms of SUDEP, one way to possibly lower the risk is by controlling seizures.

- Make sure that seizure medications are given consistently and at the correct doses.
- Attempt to find the best seizure control, with the fewest side effects. If medications are not working, consider other therapies such as dietary therapy or VNS (vagus nerve stimulator).
- Know your loved one's seizure triggers and adjust their environment accordingly.
- Make sure that family, friends, teachers, and caregivers know what to do in the event of a seizure.
- Keep your child's seizure action plan up-to-date and make sure everyone who may need it has a copy.
- Consider co-sleeping with the patient and/or monitoring the patient during sleep, both at night and during naps. Most cases of SUDEP occur during sleep in unmonitored patients. Options include movement monitors, video monitors, and baby monitors.

These guidelines have been reviewed and approved by the Dravet Syndrome Foundation's Medical Advisory Board



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Patient Safety & Mortality Risks



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Safety & Mortality

Patients with epilepsy have a mortality rate significantly higher than that of the general population. Seizures can sometimes be fatal for a variety of reasons. It is important to take appropriate precautions to make sure that your loved one is safe. Patients with DS are at an increased risk for entering into dangerous situations. They may not have the ability to sense danger and will frequently wander off if not properly supervised. Many are unable to articulate their name, address, and phone number if lost.

- Take extra precautions around water, including swimming and bathing.
- Make sure that anyone caring for your loved one has a copy of their seizure action plan.
- Make sure your loved one has appropriate supervision at all times to prevent accidents during a seizure (i.e., head trauma, drowning, burning, choking, falling, etc.)
- Have your loved one wear some type of identifying information at all times. If they won't tolerate a medical ID bracelet, necklaces, shoe tags, and wearable QR codes are available.
- Consider using a GPS-enabled tracking device or watch.
- Make sure neighbors know your loved one's special needs and concerns for their safety.
- Alert your local police and fire department of your loved one's special needs. Many cities keep a database of disabled individuals and many counties now offer a Yellow Dot Program that alerts first responders that vital medical information is stored in the glove compartment of your vehicle in case of an accident or other emergency.

School Safety

If your loved one has an individualized education plan (IEP) at school, you can ask to add safety to their learning goals. You can have the school work on teaching important skills like reciting parents' names, home address, phone number, crossing the street, etc. The school may devise strategies such as role playing or behavioral modeling to help to enforce these skills. Try to work on safety both at home and school. Your loved one will have a better chance at retaining information that is repeated and reinforced from multiple sources.

Home Safety

It is important to safety-proof your loved one's environment to keep them safe. Suggestions include:

- Hidden gas shut-off valves/appliances with special safety features.
- Install electrical outlet covers.
- Store sharp objects, medications, and other hazardous items in a locked drawer or cabinet
- Install code locks on interior and exterior doors where you want to prohibit access.
- Lower the temperature settings on your hot water tank to prevent burns.
- Bolt large pieces of furniture to the wall.
- Place padding around tables and other furniture with sharp edges.
- Remove potential choking hazards.
- Install gates or fencing around pools. Make sure your loved one is never left alone in the pool or bathtub.

Safety Equipment

Consider acquiring safety equipment that may help keep your loved one safe and/or alert you to seizures. Suggested equipment includes:

- Seizure alert/monitoring devices
- Video monitors
- Safety gates for stairways
- Protective helmet
- Cooling vest
- Bed rails or medical bed

Seizure Safety & Mortality

Mortality due to epilepsy is a significant concern for those with Dravet syndrome (DS), affecting 15-20% of patients. This is significantly higher than the mortality rate in people with epilepsy not classified as DS. Some patients may lose their lives due to accidents, status epilepticus, or illness. Another concern for our community is SUDEP, or Sudden Unexpected Death in Epilepsy, a fatal complication in epilepsy. It is not a cause of death, but rather a category of death. In SUDEP cases, a person with epilepsy dies unexpectedly, with no other clear cause of death found when a post-mortem examination is done. Notably, evidence of a recent seizure does not exclude the diagnosis of SUDEP as long as death did not occur during the seizure.

While this information may be frightening to read, it is imperative that families have the knowledge they need to do what they can to reduce risks and potentially prevent complications or death. DSF strongly recommends that families of those diagnosed with Dravet syndrome discuss SUDEP and ways to reduce the risk with their health care professional.