

## Where Can I Get More Information On SUDEP?

Discuss with your Neurologist or Epileptologist. There are also many patient organizations available to help answer your questions on SUDEP:

- Danny Did - <http://www.dannydid.org/>
- Partners Against Mortality in Epilepsy - <http://pame.aesnet.org/>
- SUDEP Aware - <http://www.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, [www.dravetfoundation.org](http://www.dravetfoundation.org)

Dravet Syndrome Foundation can also connect you with other families who are living with Dravet syndrome. Email [info@dravetfoundation.org](mailto:info@dravetfoundation.org), or call us at 203-392-1955 for more information.

## Contact Us

Dravet Syndrome Foundation  
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## What Can I Do To Lower My Child's 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 child's seizure triggers and adjust their environment accordingly.
- Make sure that family, friends, teachers and caregivers know what to do if your child has a seizure.
- Keep your child's emergency seizure protocol up to date and make sure those who may need it have 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 seizure monitors, video monitors, and baby monitors.**



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# SAFETY & Mortality



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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 child with Dravet syndrome (DS) is safe. Children and adults 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 from their home or school if not properly supervised. Most children with DS may not be able to articulate their name, address and phone number.



Thinking about these potential issues ahead of time may help keep your child safe. Safety suggestions include:

- Be aware that children with DS will often elope, placing themselves in unsupervised, potentially dangerous situations.
- Take extra precautions around water, including swimming and bathing.
- Make sure that anyone caring for your child has a copy of his/her emergency protocol for seizures.
- Make sure the child has appropriate supervision at all times to prevent accidents during a seizure (i.e., head trauma, drowning, burning, choking, falling, etc.)
- Have your child wear some type of identifying information at all times. If he or she 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 your neighbors know your child's special needs and your concerns for your child's safety.
- Alert your local police and fire department of your child and their special needs so your child is already in their system in case of emergency. Many cities keep a database of special needs children and many counties now offer the "Yellow Dot Program" which is a sticker that alerts first responders that a pamphlet with identification and medical information is stored in the glove compartment of your vehicle.

## School Safety

If your child 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 child 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 child'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 setting 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 from your child's environment.
- Install gates or fencing around pools. Make sure your child is never left alone in the pool or bathtub.

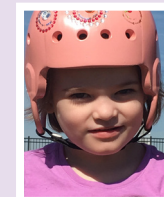
[dravetfoundation.org](http://dravetfoundation.org)

## Safety Equipment

Consider acquiring safety equipment that may help keep your child 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 place child's mattress on floor)



## Seizure Safety & Mortality

Mortality due to epilepsy is a significant concern for the families of those with Dravet syndrome (DS), affecting 15-20% of patients<sup>1</sup>. This is significantly higher than the mortality rate in people with epilepsy not classified as DS. Some children with DS 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 for a family to read, DSF is committed to making sure that families have the knowledge they need to do what they can to prevent complications and death. There may be some things families can do to avoid situations and reduce risks. DSF recommends that families of those diagnosed with Dravet syndrome be given information about SUDEP and ways to reduce the risk at the time of diagnosis.

