



Understanding Dravet Syndrome

Dravet syndrome is also called severe myoclonic epilepsy of infancy (SMEI). This epilepsy syndrome affects infants and usually begins with frequent, fever-related seizures that can be hard to control. In many cases, Dravet syndrome is linked to a defect in a gene that helps brain cells function. For more information about how genetics factor into Dravet syndrome, ask your doctor. After a Dravet syndrome diagnosis, ask your child's doctor about your goals for epilepsy treatment. In many cases, Dravet syndrome management is about finding the right balance between decreasing the number of seizures, minimizing the severity of seizures and reducing treatment-related side effects. It's important to understand what Dravet syndrome means for you and your child and to set clear expectations for the future.

As you plan for child's future, make sure to think about his or her education. Share your seizure management plan with your child's teachers, school nurse and other key people who will be involved with your child's care and education. Communication is an important way to make sure your child receives consistent care.

What is Life Like for Children with Dravet Syndrome?

Dravet syndrome is a lifelong condition that is often managed with epilepsy medications and lifestyle changes, such as a ketogenic diet. Children with Dravet syndrome often have other mental and physical challenges. In addition to seizures, children may have delayed speech and motor development, trouble sleeping, chronic infections and other growth deficiencies.

As children get older, their mental function may become more stable. In some cases, cognitive function may improve as the child matures. More frequent seizures or regular prolonged seizures tend to correspond with more severe mental impairment. Children with Dravet syndrome will likely need a caregiver throughout their lives. Seizures related to Dravet syndrome are often unpredictable and hard to control, which makes caregivers vitally important. Caregivers can help manage medications and prevent injuries from seizure episodes.





Your Team of Health Care Professionals

Raising a child with Dravet syndrome often has unique challenges. It can be beneficial to draw support from professionals who have experience managing the various aspects of this epilepsy condition. In addition to a team of epilepsy specialists, you may want to meet with people who can help with your child's developmental, pharmaceutical and nutritional needs.

It is important to monitor the development of a child with Dravet syndrome. A formal assessment of your child's physical and mental abilities is often recommended before he or she starts school. It can be beneficial to have professional help from a physical therapist, an occupational therapist and a speech therapist.

Dravet syndrome is often difficult to manage. Children with this diagnosis may be on several different medications. It's important to connect with your child's clinical pharmacist for help administering medications, managing side effects and avoiding potential drug interactions. Amber Specialty Pharmacy recommends filling all your child's prescriptions at one pharmacy to avoid errors and keep everyone on the same page.

The ketogenic diet and other specific meal plans may be beneficial for children with Dravet syndrome. These diets can be confusing and difficult to follow. Working with a registered dietitian to manage your child's diet can make it much easier. Even if your child is not on the ketogenic diet, children with Dravet syndrome often have trouble getting the nutrition they need. A registered dietitian can ensure your child get the best nutrition possible.

You may want to connect with a social worker or case manager to help you manage your child's Dravet syndrome. Case managers coordinate and build bridges between medical professionals, teachers and caregivers. This is important to help ensure that everyone works together to provide the best possible care. They can also help you find resources and connect with other families who are familiar with Dravet syndrome.

Dravet syndrome may also affect your child's behavior. If your child is having behavioral issues, a psychologist may be able to help. Other medical specialists may also be important members of your child's health care team. Your doctor will help you decide if other medical specialists, such as a gastroenterologist or a cardiologist, could be beneficial.



A physical therapist is someone who helps people affected by injury or disease with their movement and exercise therapy.



An occupational therapist helps people learn and participate in everyday activities.



Speech therapists offer training for people with speech or language difficulties.

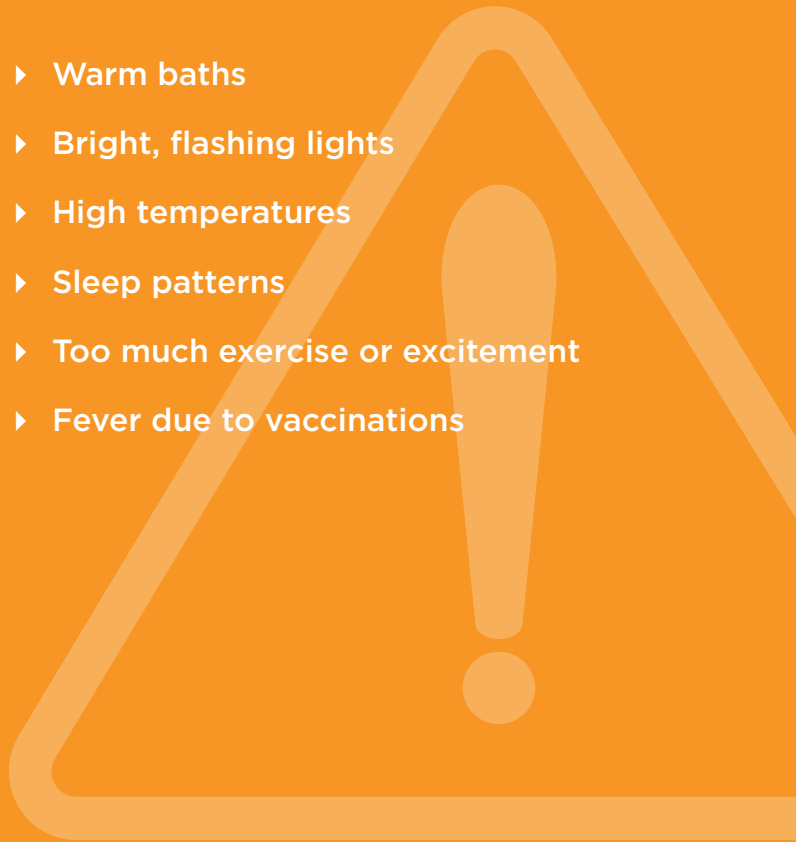


A registered dietitian can ensure your child get the best nutrition possible.

Common Seizure Triggers

Your child's seizures may be tied to certain triggers. A seizure trigger is something that causes a seizure event. There are many different kinds of seizure triggers and each one can affect your child differently. Take note of what happens leading up to a seizure and monitor your child's environment to learn more about his or her specific triggers. If a potential trigger can't be avoided, take extra precautions to avoid seizures.

- ▶ Warm baths
- ▶ Bright, flashing lights
- ▶ High temperatures
- ▶ Sleep patterns
- ▶ Too much exercise or excitement
- ▶ Fever due to vaccinations



Seek medical attention right away if...

A child with Dravet syndrome may experience status epilepticus. Status epilepticus is when a child has multiple seizures right after each other or a seizure lasts longer than five minutes. If a child is in status epilepticus, you should seek emergency medical help right away.

Service Dogs

People with epilepsy and their caregivers have found that seizure alert service dogs may be helpful. Service dogs can be specially trained to detect seizure episodes, protect your child and alert you during a seizure. Parents and caregivers often have greater peace of mind knowing their child is protected by a professional seizure response dog and a furry friend. Talk with your case manager or your child's epilepsy specialist to learn more about epilepsy service dogs.



Prioritize Naptime

Allowing your child to rest if he or she is feeling tired may help prevent seizures. Fatigue and exhaustion can be seizure triggers for children with Dravet syndrome.

Stay Cool

Heat can be a seizure trigger in some children with Dravet syndrome. Stay inside when temperatures are high and be careful with the water temperature during bath time. Cooling vests or cooling towels may help your child stay cool.

Avoid Overexertion and Overexcitement

Overexertion can happen when people are using too much effort or pushing their bodies too hard. It often happens on hot days, during exercise or when lifting heavy objects. Overexertion and overexcitement can trigger seizures in a child with Dravet syndrome. As a caregiver, make sure your child's environment is stable. Help them avoid stress while still offering fun and engaging activities.

Ask About Preventative Medicine

Talk to your child's doctor about preventative medications to help your child avoid seizures triggered by fever due to vaccinations or other illnesses.

Develop a Sleep Schedule

Dravet syndrome is sometimes linked to sleep disorders. Both too much sleep and too little sleep can be seizure triggers. In some cases, seizures occur during the night or right when a child wakes up. It may be helpful for your child to develop a consistent sleep schedule to reduce their sleep-related seizures.

Get vaccinated

It's generally recommended that you vaccinate your child. Ask your doctor about specific vaccinations and how they affect your child with Dravet syndrome. There may be preventative medications to help avoid seizure episodes.

Make a Dravet Syndrome Management Plan

Together with your epilepsy medical team, develop a thorough Dravet syndrome management plan. This should include your goals for treatment, other specialists who can help your child's development, a seizure response plan, and a list of your child's potential seizure triggers. Since children with Dravet syndrome are not able to care for themselves, you may want to consult an attorney and develop a plan that outlines who will care for your child if anything should happen to you as the primary caregiver.

Keep a Journal

A Dravet syndrome journal is a great way to track your child's condition. In your seizure journal, you could include potential seizure triggers, the dates and times of your child's seizures, which medications were given and how your child responded to them, among other things.

Create a Balanced Lifestyle

It's easy to get wrapped in doctor's appointments, medication schedules and everything else it takes to care for a child with Dravet syndrome. While it's important to care for your child's medical needs, remember to prioritize your child, not the epilepsy condition. Try to find balance between meeting both the physical and emotional needs of your child. Children with Dravet syndrome need to be loved and cared for, just like any other kid.

Developing a Seizure Response Plan

Developing a seizure response plan is a fundamental part of caring for a child with Dravet syndrome. Dravet syndrome seizures are often difficult to control, so it's important to be prepared. It's generally recommended that you have rescue medication at your home. Talk to your doctor or pharmacist about how to properly administer rescue seizure medications.

Work with your child's epilepsy specialist to develop a seizure response plan that you can share with your local hospital and your child's school. An epilepsy specialist

Seizure Response Plan continued...

may not be available to treat seizure emergencies in your hometown. Sharing your child's seizure response plan with your local physicians can help make sure your child gets consistent treatment for his or her Dravet syndrome. Make sure your child's school or caregiver has a copy of the seizure response plan in case you are not around during your child's seizure event. Consider adding a brief explanation of Dravet syndrome to your seizure response plan to make sure responders understand the condition.



Seizure Response Checklist

- ✓ Your child's name
- ✓ Date of birth
- ✓ Name of epilepsy condition
- ✓ Detailed medication list
- ✓ Emergency contact information
- ✓ Allergies
- ✓ Other medical conditions
- ✓ Contact information for your child's epilepsy specialist
- ✓ General hospital treatment procedures



Amber Specialty Pharmacy is here to help.

We offer guidance and support through our dedicated team of healthcare experts. From the beginning, we help you with the enrollment process and review your insurance coverage. We explore financial assistance opportunities to help you lower your medication costs whenever possible. Our pharmacists review your prescriptions with you - including how to take your medication and manage any side effects. Pharmacists are available 24/7 to assist you when you have questions. Our Registered Nurse and Registered Dietitian offer personalized consultations to assist you with any medically-based questions and nutritional care. We stay in touch with you regularly to remind you when it is time to refill your prescriptions. We are always here to help.

This information is intended for educational purposes only. The material is not a substitute for professional help or medical diagnosis. It is important that you consult a medical professional if this information leads you to believe there is a concern for you or your patient(s). The diagnosis and treatment of all physical and/or psychological disorders requires a trained professional.