

Carpe Diem – Seize the Day Blog

Editor's Note: Content presented in the Carpe Diem – Seize the Day Blog is for awareness and informational purposes only, and it is not meant to be a diagnostic tool.

In an article written by Mary K. Talbot she talks about getting the best care for your child with Dravet or Lennox-Gastaut Syndrome.

Your child has been having prolonged seizures. You have been hoping for answers that will bring a cure, but today you have received the diagnosis of Dravet syndrome or Lennox-Gastaut syndrome — progressive conditions with no cure at this time.

Your picture of your child's future has suddenly become clouded with many questions:

- What kind of quality of life will they have?
- Will they be able to go to school?
- How will you manage their care?
- Will you be able to work and pay the medical bills?

Take the Time to Create an Action Plan

It is important to take a deep breath and know that others have received the same diagnosis. Acknowledge that your life will change. Your child's future may not be taking the course you had wished, but there will be joy and celebrations, smiles, and family memories made. A specialist will become a valuable resource for your family as you navigate these uncharted waters.

Both Dravet syndrome and Lennox-Gastaut syndromes are extremely uncommon. In fact, it is estimated that only 1 in every 20,000 to 40,000 children has Dravet syndrome and only 3 percent to 4 percent of those children who have epilepsy receive the Lennox-Gastaut diagnosis. Because of the rarity of these conditions, finding an expert may take some research and involve travel.

You can begin by looking to the organizations that focus their resources on these rare diseases. The Dravet Syndrome Foundation has an online list of professionals recommended by patients' families.¹ Because Dravet syndrome has a genetic component, it will be important to identify specialists who work at epilepsy centers where you can also receive assistance creating a ketogenic diet for your child. The LGS Foundation also offers a comprehensive list of neurologists and epilepsy centers. Your own neurologist may also have some recommendations.²

Daily Life

Getting into a routine for you and your child will require discipline and resources. Good sleep hygiene, routine medications, and following a recommended diet will be important to maximizing your child's quality of life.

Do not forget to use a seizure-tracking app or a written log on a daily basis to record sleep, food, triggers, medications, and other key indicators. This information will become critical in assisting your doctors to identify and refine the optimal medications and dosage for your child, to reduce the number of seizures and minimize side effects.

As your child's daily caregiver, your careful observations will be highly valued. However, you must follow your doctor's recommendations, keep medications consistent (and as prescribed), and attend routine medical appointments. Have an adequate supply of both regular medication and rescue medications on hand. The doctor-parent partnership is key to successful seizure management for children with Dravet syndrome or Lennox-Gastaut syndrome.

Leaving Your Child With a Caregiver

As a parent (and perhaps a spouse), it will be important for you to take care of yourself and to leave your child in the care of someone else on occasion. Family, friends, and other qualified caregivers will need to know about your child's needs, routines, medications, special diet, and what to do in the event of a seizure. The Dravet Syndrome Foundation recommends working with your doctor to put together a written plan to leave with your caregiver in the event of a seizure.

Before you leave your child alone with a caregiver, have that trusted provider spend time with you and your child. Let them observe how you care for your child. The Epilepsy Foundation recommends letting them witness a seizure and see how it affects your child.⁸

A helpful first aid for seizures poster is available from Epilepsy Alliance Ohio. Hang in a visible location for a caregiver's quick reference. It highlights the need to stay with a person (and time the seizure), keep the person safe (move them or guide them away from harm), and turn the person onto their side (make sure their airway is clear and their head is cushioned).

A special caution should be given to caregivers for children with Dravet syndrome. "Children with DS will often elope, placing themselves in unsupervised, potentially dangerous situations," according to the Dravet Syndrome Foundation.¹⁰ They may not be able to sense danger and might put themselves in hazardous situations. They also may not be able to provide their name or address if they wander off. Consequently, it is important that caregivers be vigilant and always provide supervision.

Here are some other ways to prepare:

- Purchase and place a medical identification bracelet or other piece of jewelry embedded with a QR code on your child. Make sure they wear it at all times.
- Consider purchasing a GPS-enabled tracking device for your child.
- Notify your neighbors about your child's condition and provide them with your contact information in case they wander.
- Compile and annually update a special needs information profile (SNIP) for your child and provide it to local police and fire departments in your town.¹⁰ Include these items:
 - A current photo of your child
 - Identifying information, such as height, weight, hair color, and birthmarks
 - Pertinent medical information, including diagnosis and medications

- Emergency contact information
- Suggestions on how to calm your child
- Major hazards that your child may be attracted to, including lakes, swimming pools, and train tracks

Preparing for an Emergency

In the event of an unexpected hospital stay or a disaster, it is also helpful to be prepared with a “grab and go” kit. This kit should include medications (regular and rescue), dosing information, and emergency phone numbers for your child’s neurologist.

If your child has an emergency at home, CHOC Children’s Neuroscience Institute provides these helpful guidelines for when you should call 911:

- The seizure lasts longer than five minutes and there is no Diastat (Diazepam rectal gel) available.
- The seizure is followed by more seizures and your child does not wake up in between seizures.
- Your child has trouble breathing, seems hurt, or is in pain.
- Your child’s color appears bluish or gray during or after the seizure.
- Your child has diabetes.
- The seizure occurred in the water.

Self-Care for Caregivers

The emotional toll of living with a child who has Dravet syndrome or Lennox-Gastaut syndrome can sometimes be overwhelming. The physical challenge of caring for a child with a disability can also be exhausting. Knowing that your child is relying on you, it is important to take good care of yourself too.

- Exercise — Maintain an exercise routine, even if you have to complete it at home. Exercise with a professional online, ride a stationary bike, or take regular walks with your child. You need to keep the blood pumping, your heart strong, and your endorphins flowing.
- Mental Health — Care for your mental health. Make an appointment with a therapist to get a baseline on your stress and keep a schedule of regular visits to monitor your levels of anxiety and depression.
- Spiritual and Mindfulness Practice — Prayer and meditation can be powerful coping tools. Keep up your participation in your faith community if you have one.
- Connection — Reach out to friends regularly. Whether it is a text, an email, a phone call or a visit, human connections can be restorative.
- Online Support — Through these electronic connections, such as the Epilepsy Alliance Ohio’s Mom’s FB page, you will be able to talk about disease-specific challenges and learn coping strategies from other families that have experienced these hurdles.

For more information about Dravet syndrome or Lennox-Gastaut syndrome consult with your neurologist or epileptologist.

Editor’s Note: The Carpe Diem – Seize the Day Blog will be distributed and posted weekly.
Always remember – **CARPE DIEM – SEIZE THE DAY!**

Steve.Hutton@epilepsy-ohio.org