

Coping with Loss and Grief and Seeking Help

Every child with Dravet syndrome is affected differently and every family copes differently. You will be working to adjust to your “new normal,” and you may experience many different emotions.

Many parents report a sense of loss or grief when their child is diagnosed. Your life may look quite different than what you expected.

You may grieve the life that you and your family had before the diagnosis, or you may think about “what could have been.” This does not mean that you don’t love or appreciate your child as they are. These feelings are normal and can be a healthy part of the adjustment process.



Parents experiencing loss and grief may:

- Have trouble accepting the diagnosis or new reality
- Feel guilt for being sad about your child's condition or limitations
- Feel overwhelmed with loss and change, sadness, fear, or anxiety
- Struggle to talk or spend time with friends and family
- Feel unsure about what, and how much, to share with others
- Face physical symptoms of stress and grief, such as: fatigue, sleeplessness, brain fog, restlessness, pain, headaches, nausea and more

Adjusting to life as a parent of a child with Dravet syndrome

The goal of working through ambiguous grief is not “how do I get over this” or “how do I stop being sad,” rather, it can help to ask “how do I carry this and build my life around it?” There is no one right way to adjust to Dravet syndrome, but there are some things that you may find useful during the process:

- **Acknowledge the “ands.”** Complex emotions can be hard, especially when you have more than one at the same time. Give yourself permission to experience a range of feelings without judgement. For example, you love your child and feel sad about their complex needs at the same time.
- **You are the expert on your child.** Let others on your child's medical, school, and caregiving teams know how to comfort and put your child at ease. Tell them about your child's favorite things, strengths, skills, and personality.
- **Remember, support comes in many forms and may change over time.** Consider joining the DSF Family Network at www.dsffamilynetwork.org to connect with other families. DSF has programs and resources, including private parent support groups.

Finding help for your family

While doctors and nurses treat your child's medical condition, a mental health professional's job is to help your child (and family) recover emotionally. These professionals can be psychologists, psychiatrists, social workers, counselors, or psychotherapists. When choosing a mental health professional, it is important to find a provider who has the right training and experience in working with children and teens with serious medical conditions and their families. Also, it is important that your children (and you) feel comfortable with their therapist.

Finding the right therapist can take time. It's an important relationship, and like any relationship, success depends on a good fit. Don't hesitate to ask questions of prospective therapists. Things like:

- What can I expect each time we come for a session?
- Do you work with families who have experienced medical trauma?
- Do you have experience working with children? Children with medical issues?
- Do you see people in person, virtually, or both?

What is the "right help" for your family?

Different types of treatment may be used to help your children and family with medical traumatic stress, and the difficulties and challenges of your child's medical condition. The details of treatment (like what kind, how long, by whom) will vary for each child and family. Generally, treatment for medical traumatic stress should:

- **directly address the traumatic experiences** related to illness or hospitalization, and your **child's reactions** to them,
- **include you as parent** in the treatment,
- **support family needs so you can best help your child**, and
- **focus on reducing traumatic stress symptoms** for the long run, but also help you and your child cope and function better with current challenges.

Therapy will also differ depending on the type of therapist and the child's age. For that reason, it's best to talk with your therapist about the details of treatment. However, some things that kids could expect from therapy are: talking, doing activities, and learning and practicing new skills. Therapy for younger children may focus on drawing, playing, and talking. Older children may focus on talking through their feelings and problem-solving.

Please visit www.dravetfoundation.org for more information and tips.