

Taking Care of the Caregiver

Feeling distressed or having strong emotional reactions is common with the diagnosis of Dravet syndrome. Even though it is your child who has Dravet, your whole family – parents, brothers, sisters, other relatives – can feel overwhelmed. You may feel unprepared to cope with new demands and uncertainty that Dravet syndrome brings.



What should I expect after a diagnosis of Dravet syndrome?

No one expects their child to have a serious medical condition. It is common for parents and other family members to feel upset, scared, or worried. Most people need time to adjust to the illness and to treatment. Some people will experience medical conditions and their treatments as traumatic. Your reactions may include thoughts, feelings, and actions that are upsetting or get in the way of work, school, or life at home.

Strong feelings are expected after a diagnosis and can include:

- Having trouble keeping your mind off the diagnosis and what will happen in the future
- Wanting to avoid places (such as the clinic or hospital) and things that are reminders of the medical condition
- Feeling confused, upset, frustrated, worried, or numb

Other common reactions after diagnosis:

THOUGHTS

Memories you cannot stop/control

Thinking you have failed as a parent

Thoughts of your child suffering or dying

FEELINGS

Worrying about your child's safety

Feeling jumpy or on edge

Feeling helpless, scared, or angry

ACTIONS

Being more protective of your child

Avoiding reminders of Dravet

Not eating, sleeping, or taking care of yourself

When and where to get extra help? Even though treatment can be difficult and overwhelming, most families manage to adjust over time. Be sure to talk with a member of your child's medical or psychosocial (social work, child life, etc.) team about changes in behavior. If your family's reactions seem to get worse, a team member can help. Also, for helpful hints on ways to cope after the diagnosis, read the tips on the other side of this handout or go to www.dravetfoundation.org for more information.

8 Ways You Can Help Your Family Cope with Dravet Syndrome

- 1 Be patient and give everyone time to adjust.** Keep in mind that members of the same family often react in different ways. Siblings and other children can feel upset and may have questions. Most family members need time to adjust to and cope with the changes. It can be helpful to talk as a family about how Dravet affects everyone.
- 2 Get to know your child's healthcare team.** Don't be afraid to talk to the doctors, nurses, or other staff if you are confused or need more information. Make sure your child's condition or treatment has been explained in a way that you understand. See a specialist who understands Dravet syndrome. Our Find a Doctor tool at www.dravetdoctors.org can help.
- 3 Encourage your family to share feelings.** This can happen in different ways (talking, drawing, story-telling, hugging), times (dinnertime, bedtime), and places (in the car, home, hospital). Help your children name their feelings, such as being sad, scared, or angry. Sometimes sharing your feelings can show children that it's okay to do the same. When children or other family members do talk, accept their feelings and be a good listener, even if what they say is hard to hear.
- 4 Keep as many everyday routines as possible.** Many aspects of Dravet syndrome can be unpredictable. Regular routines help children and teens feel safer. Having regular routines (e.g., meals and bedtimes) and activities give family members things to expect and look forward to.
- 5 Ask for practical help if you need it.** Let others know how they can best be of help to you and your family. Suggest ways that family and friends can help. They want to help but might not know how to support you. Create and share your list of needs. Do you need meals? Child care?
- 6 Help family members stay connected with friends and family.** After the diagnosis, people can feel "different" and alone. You and your children may wonder how others will react. If possible, plan a few fun activities and encourage visitors. Talk ahead of time about how to explain the illness and respond to questions.
- 7 Take care of yourself.** Feeling worried or upset are common reactions in parents and caregivers. You can more easily care for your family by taking care of your own needs and dealing with worries when they arise. Try calming strategies, such as breathing exercises, writing about your feelings, meditation, exercise, stretching, yoga, prayer, listening to music, or outdoor activities.
- 8 Take breaks.** Time away from your child allows you to take care of yourself and other family members. It also gives your child the chance to feel safe without you. When you leave your child with a family member or familiar adult, be sure to let them know when you are leaving, how to reach you in an emergency, and when you will be back.

