

Communicating Emotions, Needs & Concerns

Having a child with a serious medical condition can put a strain on your relationships. Family and friends can have different reactions; some may be openly upset while others may become quiet and keep their distance. It helps to stay in touch with family, friends, and other important people in your life, although it can be difficult at times. Here are some ideas to renew your relationships:



- **Share.** Talk about your thoughts and feelings. Let others know what worries you and what you need from them.
- **Listen.** Be open to what others in your family are thinking and feeling. Be aware that their feelings may be different from yours, but they may value talking with you.
- **Be patient.** During times of stress, conflicts and fights may happen more often. Let people cool off, and then try to discuss the issues again.
- **Reach out to others.** If you feel alone, reach out to someone you trust, even just to say "hello." Arrange to spend time with a close friend or family member.
- **Make an effort to stay in touch.** If someone in your life has become quiet or distant, reach out to him or her, and try to reconnect.
- **Relax and take your mind off things.** Set aside some time to get together with family and friends to do fun or relaxing activities.

What about siblings? Your other children will need time to adjust to their brother's or sister's medical needs and treatment. Most siblings will react in very positive ways, with love, caring, and support. Some children might feel confused, upset, or afraid. Siblings can feel worried but also jealous, and may not want to talk about their feelings. All of this is very normal, but it can still be stressful for you and your family.

Some things that might be happening with your other children:

1. They miss you and their brother or sister
2. They only partly understand the situation
3. They want to help out, but aren't sure how
4. They feel angry, jealous, or guilty and aren't sure if that is OK

In younger children, you might see:

- Clinginess to parents or other caregivers
- Temper tantrums
- Doing things again that they had grown out of, like bed wetting
- Trouble sleeping, having nightmares or being afraid of the dark

In older children and teens, you might see:

- Wanting to be alone or to be with you all the time
- Being easily overwhelmed, jumpy or irritable
- Changes in behavior, more sensitive or quiet, or talking back or getting into fights
- Trouble sleeping or having nightmares
- Missing friends or feeling left out
- Problems in school

8 Tips for Helping Siblings Cope

- 1 Help your family understand what is happening.** Diagnosis and treatment of Dravet syndrome can be confusing and scary for children. Remember children have active imaginations. They can tell when others are upset or not telling them things. Without the facts, they can easily misunderstand and “fill in the blanks” with their imagination. Use words appropriate for your child's age that they can understand.
- 2 Set limits as usual.** It can be tempting to relax family rules to help siblings feel special or to make up for hard times. However, it is often better to keep most of your family rules and expectations the same.
- 3 Allow children to talk about their feelings and worries if they want to.** Let them know that being scared and upset is normal. If they don't want to talk, they could tell a story or draw a picture.
- 4 Spend time with your other children.** It is important to care for your ill child. But remember that your other children miss you. Try to make plans to spend one-on-one time with your other children. If you are away, call regularly so you can keep in touch.
- 5 Help siblings feel involved.** Allow them to be a part of their sibling's care. Plan a visit to the hospital or clinic and introduce them to the healthcare team. Let them choose which toys and games to take to the hospital. Make sure you let them know how much you appreciate the extra things they do to help.
- 6 Help them keep in touch.** If their ill sibling is away, find ways to help your other children keep in touch. Make cards, write letters, draw pictures, make videos or arrange for video chats, or record a sibling reading a bedtime story. If possible, let them visit their brother or sister in the hospital.
- 7 Encourage siblings to have fun.** Often siblings feel guilty about wanting to have fun. Remind them that it is okay for them to do the things they enjoy, like spending time with friends, or hobbies and extra-curricular activities.
- 8 Seek help.** If your other children seem to be struggling, talk to your child's doctor about seeking help from a mental health professional, such as a psychologist or social worker.

Sibling Resources: Explore resources created based on research and inspiration from the community, with guidance from health care providers specializing in Dravet syndrome and mental health experts. Visit www.dsfsupersibs.org for more information.

Please visit www.dravetfoundation.org for more information on the Dravet Syndrome Foundation.