

# Managing Caregiver Burnout



A serious medical condition like Dravet syndrome can be traumatic for you as parents or caregivers too. When your child has a serious illness or medical condition, it is normal to feel stressed and worried. Relationships with medical staff can take priority, and other important relationships and activities might get interrupted or put on hold. Having a child with a serious medical condition often challenges your core beliefs about the safety of your children.

You are not alone. Just as the medical team surrounds your child with care and support, there are people surrounding you — family, friends, and professionals in the hospital. Many times, people want to help but just don't know how until you tell them. Take the advice of other caregivers who have been in your shoes: by taking better care of yourself, you will be taking better care of your child.

## **Understand normal reactions and feelings:**

- After a diagnosis, it's normal to feel upset, worried, and more stressed
- Dealing with a new diagnosis is difficult and an unexpected disruption to day-to-day family life
- These feelings and reactions can get better with time and support from family and friends
- Know when you should ask for help
- While it's normal to feel upset, worried, and overwhelmed in the first few weeks following your child's diagnosis, continuing to feel this way may mean you need to seek out help

## **Signs to look out for include:**

- If your feelings make it hard to get back to (or enjoy) your usual activities
- If you find it hard to talk with others about what happened
- If you seem to be getting worse rather than better
- If your feelings and reactions that bother you last more than a month

## **Strategies for preventing and reducing the effects of stress reactions:**

- Eat sensibly and regularly every day
- Get adequate sleep and exercise regularly
- Be mindful of your own thoughts and feelings, allow yourself time to cope with your emotions
- Be aware of your stress level; know your own limits.
- Spend time with family and friends
- Stay connected with others through social and community events, religious groups, etc.
- Engage in pleasurable activities, especially those that allow for creative expression (writing, art, music, sports, etc.)

# What can you do to help yourself?

## 1 Be aware of your own feelings and reactions.

- Some parents may find it upsetting to talk with their children or family about what happened, or they feel anxious or overprotective of their child. If this is true for you, be sure to get support for yourself so that you can best help your child.

## 2 Take care of yourself.

- If you are worried, upset, not sleeping or eating, it will be harder to help your child
- Let other people help you and be sure to tell them what kind of help you need
- Make a list of things you might need — bringing a meal or taking care of your other children — you can refer to this when people call to ask how they can help you
- Do fun or meaningful things. Distract yourself from your reactions with hobbies, helping others, and other enjoyable activities
- Try calming strategies, such as breathing exercises, writing about your feelings, meditation, exercise, stretching, yoga, prayer, listening to music, or outdoor activities

## 3 Watch out for problematic ways of dealing with stress.

- Overeating or undereating
- Lashing out at others in emotional or physical outbursts
- Be especially careful not to increase smoking, alcohol, or other unhealthy ways of coping when you feel worried, upset, or stressed

## 4 Talk to your own doctor, your child's medical team, or others you trust to find additional help for yourself.

- If you find yourself very upset or worried and this does not seem to be getting better after a few weeks, be sure to talk with your own doctor about ways to help
- Consider talking with a counselor or therapist
- Talk with people you trust (family, friends, clergy, and your doctor) about how you are feeling
- Engage in rejuvenating activities such as meditation, prayer, or relaxation to renew your energy

Please visit [www.dravetfoundation.org](http://www.dravetfoundation.org) for more information on Caregiver Burnout and other topics and tips.