

Respite & Self-Care^{2,3}



Caregiver Mental Health

Being a caregiver can be equally rewarding and overwhelming at the same time – it is completely normal to feel this way. Many caregivers start this journey as parents, yet others might be relatives (grandparents, siblings, etc.) or close family friends who are all essential parts of the “village” that cares for someone with a rare epilepsy. Western society often considers the village as solely for the loved one who needs assistance; however, the reality is the village is the support system for the primary caregiver in addition to the loved one with a rare epilepsy.

Caring for a loved one with a rare epilepsy means having to work especially hard at finding balance. It is all too common for caregivers in our community to find themselves without a sense of balance in their lives. Too often, caregivers can find themselves exhausting their minds and bodies in an effort to provide the absolute best care for their loved ones while neglecting their own basic needs.

Mary Anne Meskis, Executive Director of the Dravet Syndrome Foundation reminds us in the *Decoding Dravet* Blog, that “Self-Care is Not Selfish.”⁵

“Caring for a child or adult with a rare epilepsy is challenging. It is a lot of work, mentally and physically. Our caregiver community frequently talks about feelings of isolation, depression about the diagnosis, and anxiety over what their child’s future looks like. On top of that they are overworked and exhausted from managing their child’s medical, educational, and emotional needs. They are left with little or no down time when they can relax, rest, or have fun.

I understand how it feels to try to keep up this pace day after day, hour after hour, with no real break in sight. While love is a limitless resource, energy is not. I have looked around some days, wondering how this chaos became my life. I have felt my nerves fraying and I have fought the urge to walk out the door and keep going. Those are not feelings that we as parents are comfortable with or want to admit to ourselves. We feel guilty thinking them and want to fight them off. But we should recognize that these are signs that we are in desperate need of self-care.

The extremes in your day-to-day lives as a caregiver for someone with a rare epilepsy can and will wear you down. It is important to remember to take care of yourself. You need to focus on eating well, moving your body, and taking time for things that bring you joy. Caregivers typically don’t get to just “turn off,” so it is important to realize when you’re overwhelmed and to establish coping mechanisms and a plan. Whatever you need to do, prioritize yourself and make it happen. Let go of the idea that good caregivers don’t need breaks. **It is regular breaks that will keep you from breaking.**

Prioritize yourself

I realize that me telling you to take care of yourself feels like one more thing on your never-ending To Do list. But, here is the good news – it sometimes doesn’t take much to make a huge difference. Purposely doing something that brings you joy will be restorative – get in a workout, indulge in a hobby, take a nap, schedule a spa day – whatever you need. No one is going to force you to take a break, so you have to give yourself permission and make yourself a priority. Only you can shape the life you want to live, even with the many challenges you face as a caregiver. I know it’s hard, but you will be amazed that a little bit of time to yourself can significantly change your outlook.

- **Say no.** With the additional needs of your child your time is extremely limited. If something adds stress to your life, say no. Say yes to those things you find fulfilling.
- **Consider counseling.** It is never too early or too late to get counseling. This is a lifelong condition you will be dealing with, and it is important to maintain your mental health.
- **Do something that brings you joy.** Give yourself permission to make time for something you enjoy. Take a class, go to a museum, meet up with a friend – just do something that makes you happy.
- **Take alone time for yourself.** Whether it’s just in your own home for an hour or it’s an entire weekend away, mark it on your calendar. Consider setting a long-term goal that forces you to make time for yourself. For instance, training for a 5K or committing to a weekly class.”

That being said, we understand that in the midst of being overwhelmed, it can also be challenging to even know where to start, how to recognize if you are close to “burning out” and what action steps you can take to create healthy boundaries so you can live your fullest life. The information below covers some signs and symptoms of caregiver burnout. If you or another caregiver is experiencing these symptoms, we recommend reaching out to your local provider or therapist to work through your unique situation and provide you with a plan that meets your needs.

TIP: Take time to listen to this [Raring to Listen](#) podcast episode that focuses on the importance of self care. The TSC Alliance's [TSC Navigator](#) also offers a wide range of great resources

Signs and symptoms of caregiver burnout

If you find yourself identifying with a lot of these feelings, please bring the following information to your local primary healthcare provider (PCP) or mental health provider.

- **Physical**
 - No energy, “run down” feeling
 - Changes in your body weight
 - Chronic or acute pain and fatigue
 - Sleep cycle disturbances
 - Nausea (with or without vomiting)
 - Changes in bowel movements (diarrhea or constipation)
 - Frequent cold-like illness or congestion
- **Emotional**
 - Mood swings and/or stronger-than-usual emotions (anger, crying, etc.)
 - Emotional numbness
 - Lack of focus/concentration
 - Constant state of feeling overwhelmed or worried
 - Frequent emotions of guilt and/or resentment
- **Behavioral**
 - Neglecting your own basic health needs (appointments, screenings, hygiene)
 - Not enjoying the things that you used to
 - Avoiding your friends and family
 - Detachment from loved ones
 - Increased use of alcohol, drugs, and/or prescription medications

If you feel an immediate threat to yourself or others, please call 911 for immediate assistance.

If you are having suicidal thoughts, please call the National Suicide Prevention Lifeline at 1-800-273-8255.

Respite care

For families of a loved one with a rare epilepsy, respite care is a support service that may be required from time to time. Several types of respite care exist, but the two main models of respite care are in-home and out-of-home options. Some community-based programs offer respite care that may be as simple as providing a substitute caregiver for a few hours each week. Others provide more major interventions, like temporarily placing your loved one in a special respite home that can accommodate their needs. The [National Respite Locator Service](#) helps individuals, parents and caregivers find respite services in their state and local area. Please note: Respite care and services vary by state and region.

Caregiver Zone Guide

The rare epilepsy journey can often bring ups and downs given the uncertainties that exist during non-conflict or non-crisis times, so understanding your caregiver zone can help you gauge the amount of stress you are currently under. Stress levels constantly ebb and flow – you may have seasons where you fluctuate between the different **Caregiver Zones**. This is normal and to be expected. Once you have had time to implement this you can start to uncover trends in your life and start proactively empowering strategies that work for you and your family dynamic. It is not about surviving this life; it is about uniquely thriving the best you can with the resources you have.

Finding Your Caregiver Zone^{2,3}

This chart can help you identify where you need help. You'll find yourself moving between zones, which is completely normal. Try to track this monthly and share with close friends and family so they, too, can help you to recognize signs of burnout.

	Thriving	Surviving	Struggling	Crisis
Emotion	Emotions are steady with only minor swings.	Increased emotional fluctuations – nervous, sad, anxious, etc.	Constant thoughts of intense emotions – fear, panic, sadness, anger, hopelessness, etc.	Unable to regulate any emotions. Numbness, complete loss of control, easily aggressive or emotional.
Focus	Able to focus on and execute plans.	Inconsistent focus but still able to execute plans.	Decision fatigue, unable to focus or make decisions.	Extreme inability to focus on any decisions for yourself or others.
Social	Able to communicate effectively and adjust to changes within reason.	Difficult to communicate and adjust plans, easily overwhelmed, irritated, or emotional.	Increased difficulty with communication and adaptation. Avoidance of friends, family, work, etc.	Unable to communicate or adapt. Frequent isolation from others – emotionally and/or physically.
Appetite	Normal appetite.	Inconsistent appetite.	Emotional eating or restriction.	Out of control eating/restriction.
Sleep	Normal sleep habits.	Trouble falling asleep or staying asleep.	Frequent restlessness and disruption of sleep (more often than not).	Complete inability to sleep, with restlessness and disrupted sleep nightly.
Daily Activities	Feeling consistent with daily performances.	Inconsistent with daily performances but still able to achieve most on your “to-do” list. No time for hobbies.	Increased inconsistency, more frequently unable to achieve daily tasks, no time for hobbies.	Complete inability to get any daily tasks done. Withdrawn from friends/family and tasks/hobbies.
Self-Care	Providing daily self-care.	Inconsistent, but still providing self-care a few days a week.	Increased inability for self-care, except for very randomly throughout a month.	Inability to perform any self-care or meet basic needs for oneself or others. Self-medicating with drugs, alcohol, prescription medications, food, and other stimuli.

References:

- <https://www.caregiver.org/resource/taking-care-you-self-care-family-caregivers/>
- <http://www.njni.org/programs/njni-supporting-stress-first-aid-for-nurses/>
- <https://www.firefightermentalhealth.org/system/files/Stress%20First%20Aid%20Student%20Manual.pdf>

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How to Help Me Guide^{2,3}

Another resource is the **How to Help Me Guide** where you will find a list of examples that you can customize to fit your own needs. As caregivers going through challenging times, you often get asked, “How can I help you?” Yet, you might not even know that because you are already in a crisis and decision fatigue is setting in. Having a go-to list you can show to others not only helps you, but it also helps those in your inner circle to know how to truly help you.

	Thriving	Surviving	Struggling
Emotion	Reach out to someone close to schedule a regular phone call or lunch. (A person you feel safe with in case you need to discuss life situations.)	Reach out to someone close to discuss. (Counselors, clergy, primary care providers are also helpful resources.)	Reach out for immediate assistance. Develop a crisis plan with a friend for this type of scenario. (Counselor, clergy, Suicide Hotline, or seeking emergency care.)
Focus	Set a daily goal to stay focused. (There are apps for that!)	Can you help me make a task list and prioritize my tasks?	Can you help me by making a plan for daily check-ins with myself or someone else?
Social	Participate in organization groups or focus groups. Plan one event per week that is for YOU.	Can you watch my loved one with rare epilepsy so I can take my other kid(s) out to do something fun?	Discuss strategies and resources with a close friend or group to help examine priorities. Do not overcommit. Prioritize.
Appetite	Can you come grocery shopping with me this week?	Can you help me plan my meals/grocery shop for me?	Can you help me make sure I have dinners made for the next few nights?
Sleep	Can you provide respite care by watching my child on this night so I can stay at a local hotel and get a much-needed break?	Take a shower or try to meditate.	Have friends clear your nighttime responsibilities for you for a few nights so you can sleep.
Daily Activities	Create a list of grounding activities like walking, painting, music, etc.	Ask a friend to help with a chore or task to help focus on priorities. Ask for help with laundry. Ask a friend, “Can you pick up these prescriptions at this pharmacy?”	Can you please help me run a few errands? (The more specific you are, the better – would a clean kitchen help clear your mind? Or picking up groceries? Taking another kid to the dentist?)
Self-Care	Can we do an at-home spa day?	Can you absorb some of my responsibilities for 20 minutes, 3 days a week so I can take a luxurious shower, attend a workout class, meditate?	Can you come over at ____ time and do ____ so I can take a shower, meditate, take a nice walk, etc.?

References:

1. <https://www.caregiver.org/resource/taking-care-you-self-care-family-caregivers/>
2. <http://www.njni.org/programs/njni-supporting-stress-first-aid-for-nurses/>
3. <https://www.firefightermentalhealth.org/system/files/Stress%20First%20Aid%20Student%20Manual.pdf>

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Make Your Own How to Help Me Guide^{2,3}

We gave you some suggestions for your **How to Help Me Guide**. You can also use the template below if you would like to create your own How to Help Me worksheet based on your individual needs.

	Thriving	Surviving	Struggling
Emotion			
Focus			
Social			
Appetite			
Sleep			
Daily Activities			
Self-Care			