

Raising a child who requires extra support and advocacy can wear down even the most resilient person. It is well known that caregiving professionals such as social workers, nurses, and first-responders can develop compassion fatigue – and even caregiver burnout. The same is true for people caring for elderly family members. But it's important to acknowledge that parents raising children with high needs are also vulnerable to these problems. Parents are the ultimate caregivers, after all!

## What is Compassion Fatigue?

Compassion Fatigue is a "state experienced by those helping people or animals in distress; it is an extreme state of tension and preoccupation with the suffering of those being helped to the degree that it can create a secondary traumatic stress for the helper." - *Dr. Charles Figley, Tulane University Trauma Institute*

As social worker Eileen Devine explains: "It results from an ongoing, snowballing process that occurs in a demanding relationship with a needy individual. In addition to relational stress, compassion fatigue brings with it the weight of frustration, emotional depletion, exhaustion and depression. It also might encompass negative elements driven by concern for the person being cared for, such as hyper-vigilance, avoidance, fear, and intrusive thoughts."

## Common Symptoms of Compassion Fatigue <sup>1</sup>

COGNITIVE	EMOTIONAL	BEHAVIORAL	PHYSICAL
Lowered concentration	Guilt	Withdrawal	Increased heart rate
Apathy	Anger	Sleep disturbance	Difficulty breathing
Rigid thinking	Numbness	Appetite changes	Muscle and joint pain
Perfectionism	Sadness	Hyper-vigilance	Impaired immune system
Trauma fixation	Helplessness	Elevated startle response	Increased severity of medical concerns

## **What is Caregiver Burnout?**

It's not surprising that repeated exposure to stress over time can also lead to burnout. Caregiver burnout is defined as the demoralization, disillusionment, cynicism, and physical, mental and emotional exhaustion that frequently occurs among individuals responsible for the constant care of another.

Burnout is not just a mental and emotional phenomenon it has physiological implications as well. Under chronic stress, our cortisol levels become greatly diminished, which can lead to fatigue, low blood pressure, lack of sex drive, and gastrointestinal effects. This manifestation of stress and burnout often occurs in parents who have children with special needs. The same presentation of stress (reduced cortisol levels) is found in soldiers assigned to combat zones who have become desensitized to danger due to chronic stress exposure.

## **Parents Like Us Are Vulnerable**

Studies show that parents of children with developmental differences and psychiatric issues experience more stress, illness, disrupted sleep, depression and anxiety than other parents. We need to protect ourselves, so we can give our kids our best - not just what's left.

## **HOW FATIGUE - AND BURNOUT - CAN HAPPEN:**

### **Not Seeing Progress**

We put all our emotional resources into helping our kids because we love them more than anything and we want them to thrive. But sometimes it can seem like all our efforts aren't yielding any progress, or we get stuck in parenting patterns that aren't effective.

### **Lack of Support or Validation**

Many of us don't have enough support and we're hesitant to ask for help. We place impossible expectations on ourselves. Some of us try to keep our struggles private because we don't want people to judge - or we isolate because we feel like we're under siege. Going for days without a break or having our efforts acknowledged is draining.

### **Ignoring the Signs**

Parents like us often put everyone else's needs before our own. Remember Shel Silverstein's book about the Giving Tree? The tree gave the boy everything she had - apples, branches, trunk - until all that was left was a stump. Some of us feel guilty about taking care of ourselves when we could be doing "more" for our kids. We figure we'll be fine "for now." But the stress creeps up.

It can be difficult to recognize compassion fatigue in yourself. When we, as parents, are in a state of repeated, constant exposure to stress (in this case, our child's behavior and its ramifications), we can quickly become desensitized to its intensity. Often, we don't realize how depleted we are until problems surface.

## STRATEGIES FOR MANAGING THE STRESS

### **Recognize What You're Experiencing**

We put all our emotional resources into helping our kids because we love them more than anything and we want them to thrive. But sometimes it can seem like all our efforts aren't yielding any progress, or we get stuck in parenting patterns that aren't effective.

### **Be Kind to Yourself**

We all experience more than our share of grief and guilt on this journey. No one is a "perfect" caregiver, so allow yourself to be perfectly imperfect. Remind yourself that you are doing the best you can and making the best decisions you can with what you know at any given time.

### **Take Steps (Even Tiny Ones) to Replenish**

Lots of self-care advice can seem out of reach to parents like us. Daily micro actions such as drinking enough water, taking deep breaths, finding things to be grateful for, and getting outside are practical steps you can take that will make a difference. If something brings you joy or is restorative, it's not a luxury, it's essential. Examine your routine and identify some time each week to do something that brings you joy. When you fill your own cup, you will have more to give.

### **Prioritize / Set Realistic Goals**

Move things off your plate. Delegate anything that can be delegated. Someone else may not do it as well as you—or do it exactly the same way—but that's okay. If you have the means, pay someone to do a task for you that would otherwise hang over your head. Say no to requests that are draining. Let go of the feeling that you should be able to "do it all." Create distance from toxic friendships. If you've been deemed eligible for respite hours from a state or local agency, use them.

### **Seek Positive Support**

Finding other people who understand your experience can provide validation and encouragement and offer problem-solving strategies for difficult situations. Look for another parent on a similar path and/or join a support group. Make an effort to stay connected with family and friends who can offer nonjudgmental emotional support.

You may need professional support to heal. If you as the parent are not well (physically and emotionally), it will be harder to help your child with the challenges they are experiencing. In fact, [one 2008 study](#) by psychologists at Swansea University in Wales noted that high levels of parent stress reduced the effectiveness of interventions for the child.

### **Don't Suffer Alone / Ask for Help**

Don't assume that those around you, even your partner or closest friends, understand the full impact of your experience. Find the space and time to let them know how you are truly doing. And then tell them what you need

from them. Most of the time those who care about us really do want to help, but they either don't know we need it (because we are so good at pretending and hiding it) or they don't know how to provide it. Be direct and clear, and then step aside to let them help.

## **Maintain Perspective**

Sometimes we get so absorbed in the day-to-day, we forget to take a step back and consider the big picture. Parenting can be challenging, but it can also be transformational. What our kids need most is love and connection.

---

## **Notes:**

Much of this guide, including the descriptions of compassion fatigue and caregiver burnout and some suggested strategies are based on an article, *Managing the Toll of Caregiver Trauma* by Eileen Devine, a licensed social worker in Portland Oregon who specializes in supporting parents of children with a range of special needs that include behavioral challenges.

## **Related Articles:**

1 "Secondary Traumatic Stress." Children's Bureau | Administration for Children and Families, [www.acf.hhs.gov/trauma-toolkit/secondary-traumatic-stress](http://www.acf.hhs.gov/trauma-toolkit/secondary-traumatic-stress).

Administration for Children & Families - [Secondary Traumatic Stress](#)

Mayo Clinic - [Caregiver Stress: Tips for Taking Care of Yourself](#)