

Why Self-Care Is Essential to Parenting

childmind.org/article/fighting-caregiver-burnout-special-needs-kids

Caring for children with intense needs can take an emotional (and physical) toll on parents

Writer: Juliann Garey

Parenting can be stressful under the best of circumstances, but moms and dads of children with *developmental*

and mental health challenges often have to deal with strain of a different magnitude. Caring for a child with special needs can become a full-time job — and an overwhelming one at that, if you don't have adequate support. Without enough help, parents may be headed toward caregiver burnout, which negatively affects everyone.

The consequences of *chronic*

stress related to raising kids who have intense needs are real. Studies show that parents of children with developmental, psychiatric or learning disorders are far more likely than others to experience:

- Anxiety
- Depression
- Insomnia
- Fatigue
- Marital problems

According to one British study, chronic stress puts these parents at risk for medical issues as well. This study found that parents of children with either autism or ADHD had significantly higher levels of both cortisol, the stress hormone, and CRP, a biomarker linked to everything from colorectal cancer to diabetes to heart disease.

The risks, both emotional and physical, to caregivers of challenging children are important to address, for the children's sake as well as the parents'. Below, we look at common contributors to caregiver stress and offer some suggestions to help parents stay healthy, balanced *and* committed to their kids.

Accepting limits to what you can do

Experts agree that part of avoiding or lessening burnout is to challenge the idea that you are the only one who can help and there is no limit to what you need to do.

Wendy Blumenthal, PhD, an Atlanta-based *psychologist*,

says she sees mothers who reach a breaking point because they are driven to shoulder all the responsibility for their high-needs child. “These supermoms — they’re not sleeping, they’re constantly anxious, calling every doctor they can think of.”

“These parents feel like they should be able to do it all and the first thing to go is basic self-care,” says Elaine Taylor Klaus, the cofounder of ImpactADHD,

which offers training for parents of kids with ADHD and other disorders. “There are long-term risks of caring for these kids,” she says. “And one of them is that parents burn out.” Taylor Klaus urges parents to take seriously their own basic self-care including:

- Getting enough sleep every night
- Staying hydrated
- Getting regular exercise
- Spending time away from children

Isolation and exhaustion

When you have a child whose behavior is difficult or whose needs are challenging, feeling cut off from support and empathy can contribute to the stress. Colleagues, neighbors, friends, family — even your spouse can seem to be on another planet. “People cannot understand what you’re going through,” says Patricia Kandel, who has raised two children with serious mental illness. “There’s so much alienation.”

By the time her family decided their youngest daughter needed to go into a group home, Kandel says, “I was barely functioning.” She, her husband and her 20-year-old daughter were all diagnosed with PTSD “from all the years of living the way we did,” and her marriage had become unrecognizable. “It’s not a typical marriage. It’s survival.”

Outside assistance was nowhere to be found. “You can’t get a babysitter,” Kandel continues. “Our own family wouldn’t even help us. We never had any money. I had to be here 24 hours a day.”

High-stress and time-intensive situations like this one are also where respite care could play a role, says Jill Kagan, director of Access to Respite Care and Help (ARCH). “Respite care is temporary relief for the parent or the primary caregiver of the child so they can take a break from the responsibilities of their continuous caregiving,” she explains.

Many parents aren't aware of the existence of respite care, she says. "They're so focused on getting services for their child that they may not even stop to think that there are services out there for them as well. It seems out of the realm of possibility." But it isn't. ARCH's website includes an introduction to respite care and ways for parents to locate respite care by state as well as a list of funding sources. (*ABCs of Respite: A Consumer's Guide for Family Caregivers*)

It takes a village, but you need to ask

Another obstacle to getting help is that you may be afraid to ask. But in truth, people who genuinely want to help may not know how.

Parents need to be fairly direct. "Could you watch the kids on Wednesday so that I can get a haircut?" "If I give you a list, could you pick up the groceries?" These specific requests make it easier for family and friends to pitch in while not feeling out of their depth.

"People are often willing to help you in small ways," says Dr. Blumenthal. "Like watching your non-challenged child so you can take your special-needs child to therapy." Proposing babysitting exchanges with another parent (or even network of parents) of another special needs child is another way to get some time away, and some needed perspective.

Getting out and about

Many parents of kids with psychiatric and developmental challenges find that they lose touch with friends and activities outside the home. "Fifty percent of my sessions are just parent sessions" to help navigate that reality, says Matthew Rouse, PhD, a clinical psychologist.

Taking care of your emotional and social health is just as important as practicing more routine self-care. Several experts, including Dr. Rouse, emphasized the importance of reclaiming an adult-only social life. Dr. Rouse asks questions like:

- What are you doing for yourselves?
- What are you as a couple doing to support each other?
- When's the last time you had a date night?
- When did you last spend time with friends?

To mitigate feelings of isolation, Dr. Rouse recommends:

- Finding a support network outside the immediate family. There are online and in-person support groups for just about every *diagnosis* out there.
- Spending time with friends who have no connection to your child. "Support groups are great," Rouse says "but that's still doing something for your child."
- Planning social activities that put you among people who care about you.
- Time for activities that are purely pleasurable — reading, running, painting.

“The way I’ve framed it with parents who are resistant to this,” Dr. Rouse says, “is to tell them, ‘It’s like you’re depositing money into a bank and building up cash reserves. To have more to give your child, you have to build up those reserves.’”

Nurturing the marriage

Throughout, parents need to pay close attention to perhaps the most vulnerable relationship of all — the one between spouses. Experts suggest that parents make it a point of maintaining their relationship with small steps they can continue, *and* that they make it a point of letting the marriage exist outside of roles as caregivers.

“I encourage parents to take little breaks such as when their child is in a therapy session or in school,” says Cindy Ariel, PhD, a Philadelphia-based psychologist who specializes in working with families of special-needs children. Other small steps you can take might include an in-home break or “date.” Even if you don’t have help, there are still ways of finding time to devote to your relationship so that you and your partner don’t end up feeling like you’re merely tag teaming as caregivers.

Maintaining a healthy marriage and effective caregiving team is made much harder when parents disagree about treatment strategies and approaches. Andrea Weissman’s son Ethan, now 12, has learning, attention and social challenges. She and her husband often disagree on what is considered “normal” behavior.

“He thinks a lot of stuff is more normative than I do and tells me I’m ‘catastrophizing,’ ” she says. “We certainly don’t parent in a consistent manner — which is not good for Ethan.” Or for her—she feels she drinks too much as a result.

This is a common situation, according to Dr. Blumenthal. “There are information seekers and information deniers,” she says, “people who want to dismiss the diagnosis or write off their child’s symptoms as normal.” When one parent is a “seeker” and the other a “denier”— which she says is often, especially when a child is first being diagnosed — the conflict can put an enormous strain on the relationship.

“If you have differences around the child’s treatment, try to see things from the other person’s perspective,” Dr. Rouse suggests. “That will help you to reconnect.” And that’s easier if you’ve laid the groundwork with even something as simple as a “nightly check-in” that can help you and your partner stay close.

“Just making time before bed to tell each other about the highlight and lowlight of the day” is beneficial, he says. “So it’s focused more on the person’s emotional experience during these events, and less like a planning or logistics meeting. It can build intimacy and empathy just through sharing and listening.”

This article was last reviewed or updated on August 28, 2021.

