

Caring for Yourself While Caring for a Child with a Disability

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My whole life changed in an instant when I was told that my sweet 10-month-old baby boy had a rare genetic disorder, one so rare that, at the time, he was only one of 60 diagnosed cases worldwide. In a matter of moments, I was thrown into a world I never expected to enter, a world full of unfamiliar words, uncertainty, and questions no parent wants to ask. Since that day I have spent countless hours, reading, listening, and talking to parents who have found themselves in similar situations. Despite the shared love for our children and the unexpected beauty that can emerge from these experiences, one common theme that has emerged again and again is *grief*. As I've reflected on my own feelings, I realize grief is also the word that best describes so much of what I have felt beginning this journey.

It sounds odd to say you are grieving when you haven't actually experienced a loss of life. However, when you find out your child has a disability, you have lost something: the loss of the life you had imagined for your child and the loss of the life you imagined for your family. Everything has changed, and suddenly, doctors' appointments and constant stress fill your days, and you may feel a sense of grief. Grief, among many other stressors, can create a heavy burden on parents or caretakers.

There are good days and hard days, and more often than not, they are woven together into the same day. So what can parents and caregivers do to help themselves cope when those hard moments arise? Here are five research-informed suggestions.

Get Support

It can be hard for a parent to reach out to others and ask for help. Often, you don't know where to start or even what kind of support you need. It can take time, especially when navigating a new world, but studies show that caregivers can cope better when they use the support they have available to them (Tümlü, 2026 & Yau, 2001).

There are so many different types of support that can help when trying to take care of a child with special needs, and each can provide support in a unique way. For example:

- Family and friends can often help with childcare, a listening ear, or emotional support.
- Healthcare providers are another great place to get medical support, and they can also help point you to other resources available, including social workers.
- Social workers are a great resource for connecting families with financial assistance and support services.
- Support groups or other individuals in similar situations can help provide information, experience, and a unique perspective that helps caregivers feel they are not alone (CDC, 2025).
- Social media and nonprofits can also help you get connected with these individuals as well as other helpful resources.

Educate Yourself

The more informed you are, the more empowered you become. Educating yourself helps you make deliberate decisions for your child as well as better prepare you for what lies ahead (CDC, 2025). Reaching out to your pediatrician or other healthcare professionals is a great place to start. Additionally, other parents or online groups can be helpful (Help Guide, 2026). They can help connect you to other resources as well as provide unique experiences.

However, as important as it is to educate yourself, taking in too much information at once can be harmful or discouraging. Thus, it is important to know yourself and what you can handle. Sometimes this is discovered through trial and error. Also, each child is unique, even those who share the same diagnosis. This is why it is so important to come to know your child and the things that work and don't work for them (Reid, 2026).

Practice Acceptance

Acceptance is not necessarily a destination you reach at once and stay forever. Accepting your child's disability and your new reality is a journey. It will ebb and flow. However, your resilience will increase as you experience moments of acceptance of your new life (Tümlü, 2026).

How do you practice acceptance?

- Remember who your child is, including both their strengths and their challenges, and then focus on building upon those strengths (Reid, 2026).
- Try to be flexible, especially when it comes to your expectations (Tümlü, 2026).
- Celebrate your child's success no matter how small or trivial it might seem (Yau, 2001).
- Be patient with yourself. This is a learning process, and you will not navigate everything perfectly.
- Try to look forward and recognize there will be many beautiful moments you and your family will get to experience (Reid, 2026).

Take Care of Yourself

It can be easy to lose yourself while you are taking care of someone else, especially a child with special needs. It can wear you down fast. Because of that, it is vital to take care of yourself. Try to maintain your hobbies even if that means adjusting what they look like. For example, if you love to read, you may find it difficult to be able to sit and read a book, so consider listening to audiobooks instead. You also may need to adjust the expectations you have for yourself. Sometimes you will need to take a break or reach out to others for help (CDC, 2025). Be kind to yourself. Taking care of yourself does not mean you are a failure or selfish. Rather, it means you are ensuring you will have the energy to continue taking care of your loved ones.

Be an Advocate

This is the natural next step once you have become educated and informed. Being an advocate for your child doesn't have to be doing big things. Rather, you can be an advocate in many small ways. This can be as simple as sharing what you've learned with other parents either online or in a simple conversation (Help Guide, 2026). Don't be afraid to ask questions, particularly about what accommodations will be made to help your child (CDC, 2025). By advocating for your child, you in turn will become an advocate for others in similar situations.

Parenting and taking care of a child with a disability can be physically and emotionally exhausting, increasing the risk of burnout, particularly for mothers (Monnier, 2026). Thus, it is vital to find ways to cope with your new life. Be patient with yourself and try to do your best to live in the present (Yau, 2001). Despite the hardship, I have seen many beautiful moments and have seen myself become a more empathetic and loving person.

To quote Disney's *Mulan* (1998), "The flower that blooms in adversity is the most rare and beautiful of all."

References

- Centers for Disease Control and Prevention. (2025, April 2). *Disability and health information for family caregivers*. <https://www.cdc.gov/disability-and-health/about/information-for-family-caregivers.html>
- Monnier, M., Michelon, C., Rattaz, C., Redlinger, F., Peyre, H., Baghdaldi, A., & Elena Study Group. (2026). Coping profiles of parents at the time of their child's autism diagnosis: Differences between mothers and fathers, and associations with family mental health. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-026-07345-w>
- Reid, S. (2026, February 19). *Parenting a child with a disability*. Help Guide. <https://www.helpguide.org/family/parenting/parenting-a-child-with-a-disability>
- Tumlu, C., Kara, E., & Ulker Tumlu, G. The mediating role of psychological inflexibility in the relationship between resilience and marriage satisfaction among parents of children with developmental disabilities: A multigroup bayesian structural equation modeling approach. *Hammill Institute on Disabilities*, 1-14. <https://doi.org/10.1177/00343552261442957>
- Yau, M. (2001). *Success in parenting children with developmental disabilities: Some characteristics, attitudes and adaptive coping skills*. The British Journal of Development Disabilities. <https://doi.org/10.1179/096979501799155594>

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