

# 10 Tips to Cope With Your Child's Chronic Illness

Learning your child has a chronic illness is a feeling you cannot prepare for.

The new and unfamiliar stresses can cause intense feelings of love, sadness, grief, panic, and guilt. All those feelings are completely normal and valid. However, there are ways to cope with these new emotions that both you and your child may be facing.

We share some tips for parents on how to cope with some of the stress post-diagnosis:

## Try to Keep from Comparing

"Chronic illness" can mean so many different things, such as highly publicized diseases like diabetes or cancer. But a chronic illness can manifest in different ways. It could be developmental – like a non-verbal learning disability, or neurological – like epilepsy.

Chronic illness can also include things we don't always associate with that term. Things like ADHD, depression, OCD, or even childhood obesity.

With so many conditions filed under "chronic illness," one family's progress can cause you to doubt your own. Even with similar diagnoses, your treatment plan, doctors, support system, and most importantly, your kids, are completely unique to you.

Try your best to not compare where your family is at with others. You'll find your own ways to adapt and adjust to meet your own needs, and that will differ from family to family. You will also experience emotions like grief, and sadness, and joy, much differently. So try to let yourself off the hook.

“Remember that every child and family journey is different. Do your best not to compare and to look at your own successes. You are an amazing family.” –Katie D.



## Research, but Know Your Limits

Research can be both a source of comfort, and a source of stress. On one hand, reading about your child's chronic illness can make you a better advocate for them, prepare for what to expect, and help you answer your child's questions.

On the other hand, information overload is a real thing, and can leave you feeling overwhelmed and helpless.

Sometimes it's okay to let go of the constant need to know more, and trust that one less Google search isn't going to make or break your child's future. It's okay to let yourself step back once in a while, if you're feeling burnt out.

Allow yourself a much-needed break by taking time to journal, go for a walk, or pop on your favorite TV show. Choose an activity that allows you to escape the vortex of information, even if only for a while.

## Lean On Your Support System

As a parent, it can be easy to feel like you can't ask for help. There can be a stigma attached to it, like you can't meet their needs or that you are neglecting your responsibilities. But no one was meant to tackle a chronic illness alone. Not you, as a parent, and not your child.

It's okay to look to your own parents, siblings, aunts and uncles, cousins, friends, and even colleagues. Don't be afraid or embarrassed to ask for what you, and your child, need.

This could mean financial assistance, caring for your other children during long hospital stays, or housework. We can all use a helping hand sometimes, and never more than in moments of hardship.

Most people in your circle will want to help. But keeping track of all these helping hands can be quite overwhelming. Consider forming a care team to coordinate and keep a schedule of what people can do. That way, you can focus on what's important: your child.



**Tip:** A free CaringBridge online health journal allows you to update everyone at once, so all your loved ones know what's happening in your child's health journey. You can receive heart-warming support on your journal entries, and our on-site Planner lets loved ones easily sign up for care needs.

To learn more or start a site today visit:  
[www.caringbridge.org/pediatric](http://www.caringbridge.org/pediatric)

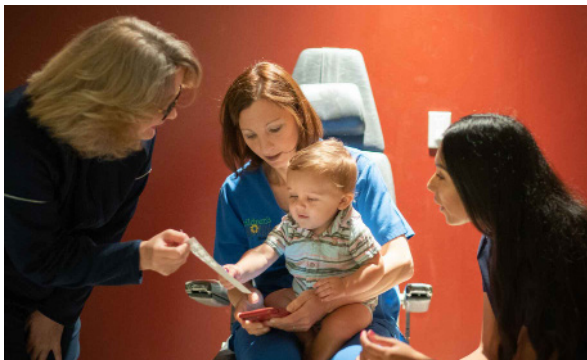
## See a Counselor

Children's health specialists are just one professional piece of your medical team. You can also see a regular counselor. It's up to you to determine if you want to include your child or the rest of your family in your sessions. It may be helpful to have a mix of both.

A trained mental health professional can help you navigate the emotional toll this illness has on your whole family. This might look like helping a parent work through feelings of guilt, or a sibling feeling jealous or neglected.

Prioritizing your family's mental health can give your family resilience, and protect your marriage and other relationships through this time.

**Tip:** Health insurance may cover the costs of counseling, so check with your provider to see if your family is covered.



## Work with Your Medical Team

Depending on the specific chronic illness, your child may spend a lot of time in and out of the hospital. Your medical team is here for you, and is dedicated to supporting you through this.

Take time to get to know your child's team, which could consist of doctors, nurses, social workers and child life specialists. They can share helpful tools with you, like referring you to support groups for your child or family, and answering any questions you may have. They may also have resources to help you best care for your child at home.

Getting to know your medical team will help you feel more comfortable and confident when asking questions about your child's treatment or condition. Better yet, it will make your child more comfortable to know the people helping them are not strangers.

## Speak to Other Parents with Similar Experiences

There is strength in community. Even if you feel alone, there are people out there who can empathize with what you're going through.

Parents who have been there, or are going through it, can become a support system that can guide you through what to expect during your child's health journey.

If you don't know anyone personally, your social workers may be able to connect you with some other families in the area who have gone through a similar diagnosis.

**“**Make friends with other parents on the ward and spend time with them while the children are asleep, rather than sitting alone with your thoughts. I did this 20 years ago and we are still friends to this day and one is my daughter's Godmother.” –Lena W.

## Get Organized

Taking steps to get organized is a great way to help you keep all your ducks in a row. Try making a health binder where you can keep all the information in one place. This could include:

- Pamphlets
- Papers
- Referrals
- Medication history
- Treatment notes
- Health portal passwords
- Contact information

Having one place to keep all this information makes it easier for you to be an active participant in your child's treatment. You can really advocate for them, with all the information to back you up, and hold your doctors accountable.

If binders aren't your thing, as an alternative, you could keep everything in a cloud-based drive on your computer and smartphone, or add everything into a planner, complete with contacts and calendar.

Organization is work though, so make sure to share the effort between parents or your care team if you need help. Hopefully, having all of the information together in one spot will speed up appointments, ease worries, and create a better quality of life for you and your child.



## Make a Hospital Stay More Comfortable

If your child will be hospitalized for some longer stretches, make the room feel more like home. Bring in comforting items like their favorite stuffed animal, snuggly pillows and blankets, and some of their own books and toys. Some hospitals may let you hang things on the wall like drawings or cards or posters.

Another idea is to try to do fun activities around hospital visits, like going out to eat afterward, ordering food in for longer stays, or getting an ice cream cone. It may sound silly, but this makes hospital visits more manageable. It can also feel normalizing after a scary visit, and is extra time you get to spend together.

“One day at a time. Try to add something fun to the days full of doc appointments. Maybe try to visit different restaurants near the hospital. Or order food when admitted for a change of pace. The cafeteria gets old!” –Becki D.

## Accept the New Normal

It's okay to take time to mourn the life you lost, and the dreams you had for the future. But don't forget to embrace the present. Your child is still your child, not their illness. Find ways to celebrate who they are, and the little moments of success.

One way of accepting the new normal of your lives is to create new traditions, like going to a favorite restaurant after their treatment. Another way is to treat all your children the same, to the extent that you can. Keep the rules consistent, and give your child age-appropriate levels of responsibility, so they can feel like their peers.

This is who your child is. Love them up and enjoy all the precious moments together.

## Practice Self-Care

And finally, try to make self-care part of your new normal. Taking care of yourself is truly one of the best ways you can help your family. Self-care can look like:

- **Exercise** – Process your frustration and release endorphins
- **Eat well** – Eat foods that fuel your body through the hard days
- **Rest up** – Try to get 7-9 hours of sleep each night
- **Read a book** – Let your mind wander to far off worlds for a while
- **Journal** – Writing can help you process all these new emotions
- **Pray** – Prayer can be a source of comfort and healing when you need it most

And if finding the time just doesn't seem possible, we understand. Even finding a moment to close your eyes and take a few deep breaths can help you reset.

CaringBridge is a global, nonprofit social network dedicated to helping family and friends communicate with and support loved ones during a health journey. We offer free, personal, protected websites for people to easily share updates and receive strength and encouragement from their community. This article was pulled from our families' insights in collaboration with experts.

To learn more or start a site today visit: [www.caringbridge.org/pediatric](http://www.caringbridge.org/pediatric)

