

A person wearing a blue and white plaid shirt and jeans is holding the hand of a young child with blonde hair. They are standing in a field of tall, golden-brown grass. The background is a soft-focus landscape with rolling hills under a bright sky. The overall mood is warm and hopeful.

our beautiful
H · O · P · E

SUPPORT FOR
THE SPECIAL
NEEDS PARENT

five tips

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I know you are tired.

Tired of the appointments. The trips to the ER. Switching therapists. Mounds of paperwork (seriously, does the paperwork EVER end)? Begging insurance to cover your most recent hospital stay. Getting low on medication, then rushing to get it ordered and find a pharmacy in town that will fill it quickly. More paperwork...

But, you're not alone.

When my son was first diagnosed, my world flipped completely upside down. Friends and family rallied in support, and it was then I realized the true meaning of "it takes a village."

Here are some ways to stay connected, feel part of a community, and not lose yourself in the process.



Christine



1. BUILD A BRIDGE

No, not in the literal sense (like you have time for that)! This means that if, right now, you feel like you are on an island, treading water or possibly drowning, grab the net that has been cast out for you and save yourself. Build a bridge over this troubled water and rise above the waves. This is not the time to isolate yourself. Don't ignore the people that want to be there for you! It's likely that these people have been there with you for years, and they love you – your best friend, your cousin, your sister, your parents, your uncle – it doesn't matter who it is, just know they really DO want to help you.

They will be the people who drop off a meal, do your laundry, or drive you to an appointment when your car breaks down. There is so much to do, especially at first, that it's easy to feel overwhelmed and alone. Don't create distance with those around you – build a bridge. Let them in and accept the help right now! It doesn't make you weak, inadequate, or difficult – it makes you human.

2. FIND OTHERS LIKE YOU

Do you have a local support group in town with other parents whose children have similar diagnoses? How about an online Facebook support group? Connect with other parents who know exactly what you are going through and can help you with the ins and outs of your child's disability.

I've found online communities to be extremely beneficial – whether it's recommending the best hospital or surgeon, or simply the best pair of shoes to fit my son's ankle-foot orthotic (AFO). No one gets you like these people, because they literally have been, or currently are, in the exact same situation as you. Find them and connect with them. Request to be a part of these groups online or in your community and be open to forming new friendships. Keep an open heart, as some of the most beautiful people I know are the people I have met on this journey.

3. BE GRACIOUS WITH YOURSELF AND ALLOW THE HELP

This is so important! I know we so often push people away because most of the time it's just easier to do things ourselves than ask for someone to help! There was a time where I had so much to do, I couldn't even think of what I needed help with because my sole focus was just executing and trying not to get too far behind. The thing is, though, your child needs you, and that means he/she needs your best self.

This means allowing a babysitter to come and watch your child for a few hours so you can go run errands or take a shower. It means having a little bit of time to catch up with your friend at dinner or go to a yoga class. It means sitting for five minutes and not having to think about your child's development or therapies. Be still occasionally and allow those around you to help. Have some grace with yourself – you are doing the best you can.

4. BECOME FRIENDS WITH YOUR CHILD'S THERAPISTS

These are the people who you will see on a regular basis. They will be in and out of your home weekly, if not more frequently, and they are instrumental in helping your child reach his/her fullest potential. Don't be afraid to talk to them and ask questions.

If you don't feel like they are the right fit for your family, find a new one (yes, you really can do that)! It doesn't make you a bad person, it's just that sometimes personalities don't mix or you need a therapist with a different style. This is OK! Adjust your schedule to find the right fit for your child (and for you)!





5. SEEK PROFESSIONAL HELP

If you're finding the burden you're carrying to be too great to bear, it's OK to ask for professional help. Some parents may be battling with anxiety, depression, and/or PTSD, and there are professionals who can help you sort out your feelings, as well as give you advice and tips for moving forward.

After my son's initial diagnosis, and prior to his brain surgery, I found myself really needing tangible advice from a professional to help me get through the hardest times of my life. She was able to give me actionable items to focus on and this time with her gave me a safe space to share my honest thoughts and feelings without judgement.

* BONUS! SPEND TIME WITH YOUR SIGNIFICANT OTHER

I know it's easier to fall asleep after the crazy routine of the day than to find your way back downstairs to your spouse. In the past, it has been easier to close my eyes and drift off to sleep than re-connect with my husband after a long day. There are some nights where this will just be the case, and it happens. But try, at least a few nights a week, to open your eyes back up and talk with your significant other.

Talk about your day, share your fears, and discuss ways to carry the load together so that you both can find space in your days for your marriage as well. And please, once in a while, have a date night!

I'm interested in hearing the other ways you've built community on your journey as a special needs parent! Please connect with me at www.ourbeautifulhope.com.



RESOURCES

The Brain Recovery Project: <https://www.brainrecoveryproject.org/>

Children's Hemiplegia and Stroke Association: <https://chasa.org/>

Pediatric Stroke Warriors: <http://pediatricstrokewarriors.org/index.html>

Facebook Groups I'd recommend connecting with to help meet other parents, based on your situation:

The Brain Recovery Project

CHASA Hemiplegia Parent Support

Pediatric Epilepsy Surgery Support

KISS Pediatric Stroke Support

Pediatric Stroke Warriors

Pediatric Stroke - CHASA Babies

Pregnancy After Perinatal Stroke

Parents of Kids with Orthotics

Christine Knapp



CHRISTINE KNAPP

Writer, blogger and digital marketing specialist, Christine is the mama of her amazing perinatal stroke survivor. Her “why” is to continue to provide support and make sure no parent ever feels alone on his/her journey, and she began writing to give hope to other parents of children with special needs.

Her son continues to grow and thrive, and you can follow their story on her blog, www.ourbeautifulhope.com.