



Parenting Children With Special Needs - Without Losing Your Mind

By Kim Pillow Williams

That got your attention, right? It doesn't matter whether you are parenting your special needs child as a couple, a single parent, a relative newlywed or a blended family, it's stressful, time consuming and takes its toll. I've done my parenting each of these ways, so with that experience behind me, I'd like to share some things I've learned along the way.

Parenting as a couple - Having a child with special needs will either tear you apart or pull you together, creating an unbreakable bond. In some cases, it may do both. Everyone handles stress differently, and that applies to even the most solid couple. It's not unusual for Dad to go to work every day out in "the real world" while Mom stays behind on "Planet Special Needs" coordinating doctor's appointments, therapy sessions, therapeutic recreation, IEP meetings, lab work, support group discussions, plus regular activities for the other children in the family like soccer, PTA, the orthodontist and Tae Kwon Do. She has to get the laundry done, grocery shop, have the oil changed, purchase a birthday gift for her mother-in-law, wrap it, and get it to UPS before they close. Dad comes home and collapses on the sofa, expecting a break, a kiss and a hot meal. Mom sees Dad and collapses into tears, desperate for some assistance with the child who's mid-tantrum and/or dinner that's about to burn into something unrecognizable on the stovetop. He snaps. She snaps. Suddenly they're not looking or feeling much like "the perfect couple."

Parenting as a single parent - This is the hardest job you'll ever do. It's difficult enough in "normal" circumstances, but when your child has special needs, there's a whole new level of difficulty. When your child has a fever in the middle of the night and you're out of Tylenol, you have to bundle him up and drag him with you to the all night pharmacy. When he's up all night you have to go to work the next day on twelve minutes of broken sleep. If behavioral issues are a problem, then maybe by the end of the day YOU are the one ready to lie down on the floor kicking and screaming. You depend on your older children far too much and feel guilty for it. You long for the days where you could "run to the market" for something and it didn't require two hours of intensive planning and accommodations for your child's behavior, mobility device, bus schedule, therapy session and in-home counselor. A night out away from it all? Not unless you've waded through the years long Waiver waiting list, have respite services written into your Consumer Service Plan, located a qualified provider and coordinated carefully with a friend who will understand if you get a phone call in the middle of dinner and have to leap up and run out. "Running away from home" ceases to be an activity you only associate with teenagers.

Parenting as a relative newlywed- The bloom has fallen off the rose. The dreams of wine, roses and soft music by candlelight have quickly turned into hovering by the crib of your little patient in ICU and being plunged into a world where you don't even understand the language. The medical terms alone are enough to frighten you, and when the early intervention people show up, they've got a whole new set of words you don't understand. They spit them out quickly like you're supposed to be able to keep up. No one offers a glossary, much less an interpreter. As you watch their lips moving, you feel your eyes glaze over as you're nodding because you know your child needs these "services", whatever that involves. You don't have time to shower, much less remember you have a spouse, and while Mom sits at home shell-shocked and trying to function, Dad has gone to work to stare at his computer and try to remember what he's being paid to do while his mind is back home wondering if his child will ever walk, talk, read, or throw a ball.

Parenting as a blended family - One of you was placed unwittingly in this situation and the other of you chose to participate. For those who believe no one can love a child as much as their parent, let's review quickly what love is. If it involves being patient and kind, there may be times the stepparent finds this easier than the biological parent. As biological parents, we are preprogrammed to love our children intensely, but with that comes preprogramming to be passionate, intensely disappointed, devastated when something doesn't go "right" and more than devastated when a new diagnosis occurs. The emotion we have for our children can be productive, yes, but it can also be disruptive and even destructive if channeled incorrectly. Sometimes we need to let the stepparent "step" in and help because they are able to be neutral. There are times when that's a huge plus. Events that drive us to tears and emotional turmoil might be handled by the stepparent in a logical, reasonable fashion. They can talk the parent off a ledge and see the whole picture instead of focusing on one event. They are a handy set of ears when the specialist is telling us something new and our head has gone numb with the latest diagnosis.

Okay, that's us. Now explain what you meant about not losing our minds...?

If you're a part of "the perfect couple" the first thing to do is forgive each other for the differences in the way you each cope with stress.. Dad may throw himself into work and Mom might be on the Internet searching for answers every minute she's not reading about the latest techniques, methods, devices and therapies. She's deep in information and Dad is just hoping it will all go away. Mom says "Be careful at the playground. He doesn't like vestibular movement activities. We don't want to create any post-traumatic stress response and trigger the adrenal system into... you know what? I'll just come along with you...." Dad says "I just wanted to put him on the swings like the other Dads... why is that a problem?"

Dad should respect Mom's concerns and trust that she's not overreacting. She's with the child all day, sees more, might know a bit more and has invested more in what affects the child's overall condition, in great detail. Mom needs to step back and allow Dad to parent on his own. Sometimes Dads can show Moms just how "normal" our kids can be. While it's true they often learn just how "normal" our kids are not, it's just as likely that the cracker they offer won't choke the child to death, they'll survive the germs at Chuck E. Cheese and they might even enjoy mini-golf even though we were certain they'd use the club as a weapon to strike another child.

Respect each others' need for a break. Support each other even if you don't understand what the other is feeling. Talk about your feelings and never be judgmental. You're a couple and a team. You will have differences in coping and parenting styles. With few exceptions, neither is better or worse or more right or wrong. Spend as much time together as you can without the children. If you can't get a sitter, make time for wine, cheese and a board game after they go to bed. Watch a movie and order Chinese food. Commit to taking a day off once a month to spend the day together while Junior is in school. Go to lunch, go for a walk, visit a flea market or craft show, tour a winery, take a lunch cruise, or just crawl back into bed together with the newspaper, a pot of coffee and a basket of muffins. Remember the things that brought you together as a couple.

Single parents have it the toughest. Their support system must often come from outside of the home. If you have older children, use them, but not too much. Accept help from neighbors, family, the teenager down the street, friends from church, and local social service agencies. Make chunks of time for yourself when you can. Take a day off and soak in a tub, go shopping, make a lunch date with a friend, clean your house if it will make you feel more organized, splurge on a new pair of shoes, work in the garden, sit in the bookstore or library and read in total peace and quiet, get up 30 minutes early or back your child's bedtime up 30 minutes for a little extra time each day to read, organize, meditate or pray. Some parents "barter" with a neighborhood teen. "You have a day in my house away from your parents. Do all the laundry and in between you can watch TV and eat Doritos. If you clean the kitchen while you're there, I'll give you money to order pizza. Dust and vacuum, it's \$10 cash." You'd be amazed how many 15 year old girls will snap up a deal like that and love being able to try what they learned in Home Ec and MTV for an afternoon. Pamper yourself when you can. Don't feel guilty about indulging occasionally. It'll help you to fill up your own vessel so you won't run dry from constantly pouring yourself out for other people.

The Newlyweds can follow some of the same advice as the "perfect couple." Make a commitment early on that you will remove divorce as an option. For many couples, the stress becomes so great that divorce begins to look like an easy solution because you haven't been married that long and you haven't become but so entwined, right? Wrong. No matter how short a time you've been together, you are bound together by the blood of your child. Divorce won't stop you from having to co-parent your children. It will only make you do it from different locations.

Established couples may already understand that, having been through many trials, tribulations and stresses during years of marriage, but when the first real stress you have is the birth of a special needs child, walking away can look pretty tempting. After all, isn't it enough that you have to deal with the child's issues? Now we have to deal with the spouse's issues too?

Respect your spouse if they are plunged into a depression. Encourage them to get professional help if necessary. Don't forget how to be playful. Make time for yourselves. Try to squeeze in as much romance as you can. Remember that if you pull together and get through this stress, it will only strengthen your marriage. Seek counseling services. Join a support group, different ones if possible, so you can each feel free to discuss ALL the aspects of your stress, as a parent and as a partner. Give each other space, but hold hands, stick together, show appreciation for one another and say it all out loud. while watching soap operas

For blended and step families just allow for plenty of time together. You're mature newlyweds and you knew what you were getting into better than anyone. Don't give up on romance, but remember that you have to plan it out instead of relying on spontaneity. Biological parents should be open-minded about allowing stepparents a space in the child's life. They've become a part of the team. Have them join you at IEP, medical appointments, school meetings, and include them in everything. You're not doing this alone any longer, so don't try to shoulder it all yourself. It's time to relax and say "Now I've got a partner to support me." Let them handle bedtime routine if they have more patience by the day's end. Teach them medicine/medical procedures so you are replaceable. Appreciate the stepparent for volunteering for this position, even if they do things differently. Children can thrive on having a caretaker with a different approach. This is how they learn to be flexible.

Finally, and most importantly, we are only capable of good quality parenting if we've first taken care of ourselves. This is why, on an airplane, you are instructed to first place the mask over your own face, then assist your child or other passengers. If you have no oxygen, you are of no use to anyone. You will suffocate. First, breathe deeply, take care of yourself, then you will be able to provide the best assistance to your child and others you love. Your family will thank you because you'll be there for them for many years to come.