



Complex Child E-Magazine

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Caregiving: 12 Years of Lessons We Learned by Cathie

Our 12-year-old son, Randy, was diagnosed at nine months with Cerebral Palsy, Sensory Integration Dysfunction and a few other issues. Over the past twelve years of his life, we have learned many lessons. Here are just a few.

Relationships

As we all know, as parents of children with special needs, it is hard to find the time and energy it takes to make a marriage or even friendships work. It has taken a long time for my husband and me to realize our feelings are important to each other. We needed to respect those feelings, and communicate instead of feeling like one is taking the other for granted, not understanding or just fighting about everything and not getting anywhere.

Avoidance was a big issue for us. If we didn't talk about it, we didn't have to face it. That went for everything in our lives. It wasn't until our son Randy started having different GI issues two and a half years ago that I admitted to myself we were in such a mess.

I think it was when we had to go back to a hospital we didn't like and Randy was misdiagnosed several times that we realized we needed to stick together to be the best advocates for our son. It was hard to find time to talk rationally when we weren't so exhausted from work and taking care of Randy full time, but we managed.

We started making that time for each other to get our feelings out without fighting. The other things fell into place. Communication was our weakest link. Now it's our strongest.

Acceptance

Acceptance is a hard pill to swallow and at times it's harder than others. Some days I'm not sure if I have accepted or grieved for all the things I dreamed of for my son. I keep a journal, call my mom or my husband, just take a little time to drink a cup of decaf, or get outside in the sun for a while with Randy. Staying focused on things that are positive helps me. Looking at where Randy was when he was born and where he is now and

knowing somewhere there is a child who is much worse than he is makes me realize how lucky we are at the moment.

When I feel like crying I do. When I feel like having a pity party I do, but for only a short time. When I feel like "why my son?" I remember God gave him to me because He has faith I can handle my very special child.

To accept my son has differences and challenges and needs me more than anything has been a process, one I go through daily. To grieve for the things he won't do or have is a double-edged sword. I try very hard to encourage him to try new things and succeed at whatever he is doing. I encourage him not to focus on "I can't," but rather "I can." Like a friend of mine always reminds me, "Your umbilical cord will stretch without breaking."

Stress

I'm not sure I'm the best person to give advice about handling stress. I know that I had to let go of a lot of control issues to be able to handle things in a way that is productive.

Stress is a major issue we all deal with in our own way. I can remember many times being so angry at my husband because he would tell me to relax even though I couldn't change being so upset or stressed. I would respond back to him that it was easy for him because he didn't deal with what I had dealt with in the situation. Then he would find a way to make me laugh or rationally talk me through it. I have a real issue of running away when things get stressful, to just get away for a while.

We've had a place at a camp ground on a lake for all of Randy's life. I've tried to talk my husband into selling it many times for financial reasons, but he won't because it's a place to go to be around friends who love us unconditionally, to get away from the farm we live on, or just to "defrag." He tells me as long as he is able to work we will keep "your" get-away. Who is he kidding? He loves it just as much as I do. Plus, when Randy and I go in the summer, it gives him some relaxation time after working in the heat 13 hours a day. When we can't go I try really hard to keep things in perspective by finding a few minutes to myself to calm down. I crochet or knit when I am by his bed or in the hospital.

Support

Randy has a sister who is 21. After Randy was born, I was very fortunate to have family help take care of her. I still have guilt about missing so much in her life because Randy needed me more than she did at the time. I knew she was getting all the love she needed, but it wasn't from me. I made one-on-one time for her at the hospital, after school, or whenever I could. I involved her in Randy's care as much as she wanted to help.

It makes me smile now to remember her telling him she was his second mom and he would sign to her "no, sister." Then she'd tickle him. I don't know how I would have survived without the support system I had or her being a great daughter, both then and now.

Support comes in many ways: emotional, financial, physical, etc. We have many friends that give all kinds of support to all of us. Last summer everyone got together and did a benefit for Randy so we wouldn't have to sell the place at the lake due to his rising medical bills. There were a lot of tears, laughs, hugs and love pouring out on that day.

They are there for us on a daily basis as well. I think my biggest supporters are my husband, my mom and my daughter. Believe it or not, I get a boost from all the animals on the farm, too. If Randy is having a really bad day, I will wait until my husband gets home from work to feed up the animals. He knows before he walks in the house because all of them are calling out to be fed. He hugs and kisses me, asks if I want help or company and respects that I need a half hour to myself with the animals.

As far as outside help, Randy doesn't qualify financially for Medicaid or SSI because my husband gets up every morning and works to pay our bills. We have just gotten him into a state-funded program that will help with developmental therapy. He is on the waiting list for CAP, another assistance program. Hindsight is always 20/20, and had I known about these programs when he was born I would have gone after them then. We also did private therapy when he was younger.

Life Lessons We've Learned

My best advice is to take a little time for yourself and communicate with those that are closest to you. Know and realize that even though your husband may not be at your side every minute, go to every doctor visit, or see all you go through in a day, that he also experiences emotions such as grief and loss just like you do.

Respect each other and make time to talk about how you feel and really listen. HUG each other. Be his support and let him be yours. Know in your heart you are just one person and you can't be all to everyone all of the time. That doesn't mean you are failing. It means you are human.

Let others help with anything they are willing to do. Finally, know God gave you your special children because He has faith you will love and care for them better than anyone else. When you feel like you can't take one more thing, know we are all there with you, to support, to listen, to cry, to laugh, to share.

Cathie Marshall is mom to Randy, 12, with Cerebral Palsy, Sensory Integration Disorder, Pelvic Floor Dysfunction, and GI Motility Problems. She is also mom to Lindsey, 21, one very special daughter, and wife to her best friend, Spencer. You may

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