

WHEN PARENTS NEED A GAME CHANGER

There is a saying: *Sometimes we're tested, not to show our weaknesses but to discover our strengths.*

Many parents of special needs children must feel that way. Because while every parent expects and hopes for a perfect child at birth, the truth is that many are given a child who will test their strength and endurance on a grand scale.

When Anne gave birth to Christopher, she remembers being surrounded by an indescribable feeling of love, joy, and peace. In fact, she kept asking her husband, Dave, if he could feel it.

“It was so euphoric,” she says, “that I thought if I could bottle this the world would be full of love. There would be no more wars, no more differences, no more pain and suffering!”

The nurses, however, told her the feeling had been generated by going through labor. Yet, while Anne gave birth to two more children, she never experienced that sense of euphoria again and often wonders what it was about Christopher that inspired such a strong feeling.

What Anne didn't know at the time was that Christopher was born with the umbilical cord wrapped around his neck. Because of this, Christopher's Apgar score, the score by which a baby's health is measured at birth, was also very low.

All of this contributed to putting Christopher on the Autism Spectrum and changing his life, and that of his family, forever.

For those of us who aren't challenged with a child with Autism, it can be an eye-opening experience. Imagine discovering that your child is so sensitive to light, loud noise, or a change in routine that it sends them into a physical and emotional meltdown. Imagine that your child won't make eye contact or has trouble speaking. Imagine that your presence or the presence of his siblings or his peers has no impact or significance to him. Or, that he/she sits in a corner repeating the same movement over and over.

These are just a few of the many symptoms that parents of autistic children experience. And like any child, children with Autism don't come with a play book. Parents are left to figure out not only how to emotionally deal with the fact that their child is different than other children, but how to find the right services that will help them to live a safe and productive life.

Anne knows that only too well. She spent much of Christopher's childhood arguing with school personnel and state programs trying to get the services he needed.

“By the time he hit high school I was so burned out, I thought I would melt down,” she says. And yet, she got up every day just to do it all over again.

When asked how she has dealt with all of this emotionally, Anne was honest. “I had a lot of anger. In fact, sometimes it felt like anger ran my life. I was angry at doctors, psychologists, psychiatrists, and therapists,” she says. “I'd wonder why I was being ignored, why I couldn't get the services I needed, and why I had to fight for everything.”

Then there was the criticism. Teachers and school administrators would call her a helicopter mom because she was hovering over Christopher so much. Never mind that he needed it. And other parents made comments that perhaps she was the problem and not Christopher.

“My husband traveled for work a lot, and I was the primary caregiver. Even he would occasionally criticize me because he just didn’t see what I had to deal with every day.”

The good news is that Anne’s tenacity and resourcefulness paid off. Today Christopher lives on his own and works full-time as a Dietary Aide for a senior assisted home. He loves the people living there and loves what he does.

But that doesn’t mean Christopher doesn’t require support. His parents pay for someone to come in twice a month to clean his apartment, review his mail, and do his laundry. And even though they live in North Carolina and Christopher in Philadelphia, Anne and her husband are still an everyday part of his life. They continue to update his records, change his address, update his medical insurance, and make medical and counseling appointments, as well appointments for things like oil changes and tire rotations for his car.

When asked what will happen when she and Dave are gone, Anne said, “We have a trust set up to handle Christopher’s finances. But who is going to handle his emotional, social, and physical well-being? Who will check his mail? Who will make sure his medications are being filled? Who will accept him and support him?”

That’s where Front Porch Cohousing by NDL comes in. FPC’s neuro-inclusive co-housing communities will give people like Christopher the opportunity to live as independently as possible while being safe and secure. And their built-in amenities and natural support systems will give parents like Anne and Dave peace of mind that they will never have to worry about their child being alone or isolated once they are gone.

“Christopher wants to fall in love one day and have children,” Anne says. “He is just as deserving of that as you or I.”

Professional educator, Rita Pierson said it best, “Every child deserves a champion – an adult who will never give up on them, who understands the power of connection, and insists that they become the best that they can possibly be.”

In the end, Anne and Dave are Christopher’s champions, but he will need an organization like NDL to help him live independently in the long-term. Unfortunately, few communities such as those proposed by NDL exist. This leaves an open-ended question for parents of adult children with autism - what happens when they are gone?

When I’m gone,” Anne says, “I hope Christopher has someone who cares enough about him to help him live up to his ability. That would be a game changer.”

Jim Richardson, Founder and CEO of Front Porch Cohousing by NDL added, “We are working hard to ensure Christopher has the right environment to live the life both of his parents envision – to live the life all parents want for their children.”

With any luck, FPC will be the game changer the world of Autism needs.