

How a Dad of 2 Teens with Cerebral Palsy Parents: 'Our Normal Is Very Different from Other Families'

[How I Parent](#) explores the ins and outs of modern day parenting with moms and dads from all over the world, who are raising their own unique families and sharing their best advice and most heartfelt lessons with PEOPLE.

By Diane J. Cho February 18, 2020 01:42 PM



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Name: Dr. Joe Niamtu

Location: Richmond, Virginia

Occupation: Cosmetic Facial Surgeon

Family situation: Our oldest son Joey is 19 and Evan is 17. They both have cerebral palsy and will always be in diapers. They cannot walk, talk, sit or stand without assistance and are tube-fed. We have a staff of 13 nurses who provide full-time care for both of our boys. My wife April is a supermom and also manages their care. She often becomes an “instant nurse” when a scheduled nurse calls out.

Parenting “philosophy” in a sentence: Our “normal” is very different than other families’, so our goal is to show our sons as much love as we can and make them as comfortable as possible.

What was your journey to having the family life you have today?

It took me a half a century to find the girl of my dreams, so I didn’t get married until I was 47. After I got married, like every father, I wanted to have a son. I had visions of throwing a football around and taking him fishing and buying him little camouflage clothes. My wife gave birth to our first son Joey, who was born with a normal birth score; it seemed like everything was going perfectly until about three months in, when he started having seizures.



I’ll never forget when my wife and I were in the pediatric ICU hospital and a doctor came out and said, “Your son’s brain stopped growing.” We were told he was never going to be normal, would have to be in diapers and totally dependent. If there was a word I could use to describe that moment in time, it would be “gutted.” It was like an atomic bomb was dropped on our lives. As a first-time special needs parent, I thought, If something happens to me and my wife, who will take care of our child?



Once April and I decided to try again for a second, we were told that the chances of Joey’s condition happening to our next child would be like winning the lottery twice. Then, we had our second son, Evan, who was also born with a normal birth score. Evan was going to be my savior. He was going to help us take care of Joey. But about three months in, Evan started to manifest the same symptoms as Joey’s. Now that we had two children who would always be totally dependent, we were faced with two tough choices: either put

them in an institution or bring the institution to our home. We were lucky enough to [be able to] do the latter and we outfitted our entire house with lifts and track systems, so the boys could move around in the shower and other parts of the house.

For most people who have children, their memories are of their first steps, first crawl, a school play, soccer games, prom. Our memories have to do with emergency rooms, doctor's offices and ICUs. Last year, one of my sons was in the hospital through Thanksgiving, Christmas and New Years. My wife has stayed overnight in the ICU so many times. Most days I get to go to work, but my wife stays in the trenches and manages all of our nurses.



As a cosmetic surgeon, I've had many patients come in for Botox injections. Some people think it's very frivolous, but what they don't know is that Botox can also be used on a therapeutic level.

Both of my boys have undergone Botox treatments for years to help with their limb spasticity. If everybody walked around the whole day flexing their biceps, they would be completely worn out by night.

My children's limbs are frequently stuck in a flexion or extension. Sometimes it's so severe that the bones in their hands and feet can actually pop through their skin. This has not happened to my boys, but their upper limbs can be flexed so tight that their palms sweat and they can have skin breakdown. There are a lot of problems that can go along with this. [Botox] may not help solve everything, but it has definitely given my kids a better quality of life.



How did your upbringing influence your parenting style?

I grew up in a very middle class family. We lived in a 800-square foot house with six people. My mother, who passed away when she was 61, always taught us to be compassionate. She would say, when you walk into a room and see somebody who is different, somebody who looks left out, go up to that person and make them feel welcome. That nurturing, caring attitude has a lot to do with why I've dedicated my life to trying to help people.



What's your favorite thing about parenting?

I had to reconfigure everything because all the things that I thought I was going to be able to do with them, I can't. Our family's "normal" is me coming home from work, working out and then spending the rest of my time with my boys. They love watching *The Voice*, so my wife and I will sit with them, hold them and I'll play guitar. They seem to enjoy that. It's my favorite thing to do because that's all I can really do. Our family time is just being with them, touching them, putting our arms

around them. My wife loves taking them trick or treating, to the mall and to the theater. They love the movie theater.

What is some advice you can give to families in a similar situation, but perhaps without the same access to resources?

We see it all the time and we try to reach out as much as we can to help them find doctors and proper equipment. What people need to remember is that many parents aren't prepared when they learn they have become a special needs parent. Most have zero experience in that area and they also need to account for the shock they may feel when they hear the news. For us, we've reached out to SOAR365, an organization in Richmond, Virginia that put us in touch with other parents, doctors and therapists we needed, because in the beginning, we had no idea where to start. We're so lucky to have the means to have our children at home with us, but that's not the case with everyone and it can be very taxing on a family.





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How have you coped with your experience emotionally?

People deal with things in different ways. I have friends that are very religious and they feel that this was God's plan. There's no instruction manual for this and relationships can be challenging, even in the

best situations. One thing that helps me is motivational speaking. I talk to a lot of young people, particularly high school students, to share our story and spread awareness.

Some days, my wife will tell me to pick my butt up and get out there when I'm feeling down. She always encourages me to be the best dad I can be. You can't control the wind, so you must adjust your sails – but there are days when I'm very happy and there are days when I'm very, very sad. Birthdays can be extremely sad for me because I think of what could have been... but you can't live in that world. Life is too short and you have to make the best of it. Our goal is to provide my sons with a loving, caring environment where they're safe and happy. That's all we can do.

We also talk to other parents, some of whom are still in the shock phase. They cry uncontrollably, but we encourage them to step up because it's their job to help their children. It's not always an easy conversation to have.



What's the best advice you can share with new parents?

I would say, love your children, kiss your children and try to be helpful to other families in need. A lot of special needs children end up abandoned or left in institutions... Do your best to try to help those who cannot help themselves.



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What would you want your kids to say about you as a parent?

I wish there was a way I could know what they were thinking. Maybe they understand a lot more than I think they do. In any case, I would want my sons to be proud of me and their mom. I wish they could say, "Dad, we are proud of you." I know it may sound self-serving but I wish I could hear it or at least know that they are. But in the mornings, when I hug them and when they are able to give me eye contact, and even a little smile, I think that's their way of saying they're proud.

By Diane J. Cho

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