# **"Is It When They Have 'Man' Hands?"** Asking For A Friend

By Debra O'FEE

## A MOM PENS A HEARTWARMING ACCOUNT OF HER JOURNEY THROUGH LIFE WITH HER AUTISTIC SON.

ast year my son Ryan had a seizure the day before his 11th birthday. After a few tests, they released him from the hospital calling it "an isolated event." They believed it was a "one-off." The more I talked to other parents; I found that some kids did just have one seizure and never another one.

As parents, we really do just listen to what we want to hear sometimes, don't we? Ten days later Ryan had another seizure. After more tests in the hospital, they diagnosed him with "epilepsy related to his autism."

## **Growing up fast**

Epilepsy sounded so scary, and they seemed so blasé delivering this news. I pummeled them with questions. They said this sometimes happens in children with autism when they are at the on-set of puberty.

I laughed and laughed. Ryan just turned 11. I literally just shared a gurney in the ER with his little body overnight. The thought of my son being at the "on-set of puberty" was ridiculous!

Within days, my son came down the stairs in the morning and I swear he was 3 inches taller than he was when he went to sleep the night before. He had developed a little faint mustache, and all of a sudden also had a deep voice.

While most kids his age have moved on to "Mom" or "Ma"—and Ry refers to me as these at times



as well—he will many times revert to "Mommy." Hearing "Mommy" in a deeper voice is just a little contradicting...it goes with the bigger picture of raising Ry: the recurring feelings of heartbreak and heart-melt all at the same time.

### No longer a little boy's hand

I have another son, named JT who is 13 and does not have autism. In these cases, for distinguishing purposes, families like ours refer to them as our "neurotypical" children in conversation. Thank God, I have a neurotypical child, for multiple reasons, but in this particular case because otherwise, I might not have that "reference" timeline and barometer of when events should happen outside of autism.

I try to give Ryan his independence as he grows, but inevitably, there will be times where I can't do that. The other day we got out of the car in a parking lot; I got out of the driver's seat, he exited from the backseat behind the passenger side door. Ryan usually knows not to walk beyond our car's edge until I am next to him and we can proceed together.

Before I reached him, he started to shoot out into the traffic of passing cars. I yelled: "Ryan...wait!" and he jolted to a stop. I think he got a little scared because he then extended his hand to reach and hold mine. In that moment, I couldn't remember the last time we held hands, but I realized he no longer had the hands of a little boy.

He has "man" hands now. Instead of him softly slipping his into the palm of mine, he must have felt the difference too and instead, instinctively, for comfort purposes, decided to envelope mine with his on the outside.

66 He will always be my baby, on some level. My baby with 'man' hands.

**99** 

Mine was in the palm of his hand; not the other way around as it had been his whole life. His hand was so strong. He was not doing anything to make it strong; this is just the way his hands are now.

It also felt different, even a little rough. I considered looking for calluses or hair on it, but I don't know if my emotions could've handled much more in that moment, had I found any evidence of adult hand afflictions. Again the feeling of heartbreak.

### Always be my baby

He is growing, but he grabbed my hand because he can't walk in the parking lot independently. Noticing this melted my heart. He will always be my baby, on some level. My baby with "man" hands.

I am a person who tries to stay in the moment. Especially in my journey with Ryan, I try not to project too much into the future.

Through the years, I have received notifications from our special ed department in our school district about workshops being given; subjects titled: Transition, Guardianship, Social Security benefits, etc. All of these informational presentations on the issues that have always seemed so far off in the distance for us; for him.

When do parents start paying attention to these? When do you start to make the decision to actually face the heartbreak and the heart melt of these topics—instead of being caught off guard by them in unexpected moments?

Is it when they have "Man" hands?...Asking for a friend.

**Debra J. O'Fee** is the author of the book <u>I'm Sorry Jimmy</u> <u>Muscle: Why My Son With</u>

<u>Autism Wanders</u>. She is a former Vice President at Citigroup and now works as a Secretary in Plainedge High School. She lives in Massapequa Park with her husband and two children and serves on her school district's SEPTA board.