

**An honest, personal look at my experience with healthcare, and how being autistic has impacted my life with chronic illness. – an Anonymous Member**

A team of doctors and nurses had just run off with my baby to the NICU. They ran. I had stood up with the epidural still in and tried to follow them down the hall. I could do this because analgesics don't always work well on people with EDS. I wasn't stopped by being numb or paralyzed from the waist down, as a lot of people would have been. I was stopped by the fact that I was still attached to the epidural catheter which was still attached to the IV pole. There were lines everywhere. The nurse who had coached me through my labor unhooked me as quickly as she could while my baby's father followed the team rushing away down the hall with my baby.

I finally made it to the NICU, on foot, waddling, several minutes after my baby did. They were busy assessing her and getting her situated with her supplemental oxygen. There was not much use for me there -- after 9 months of this being only being alive because my body sheltered her, I suddenly was not much use. The delivery room nurse caught up to me with a wheelchair. She wheeled me to my postpartum room and introduced me to the shift nurse covering my room. My soul was on the floor, and my face was catatonic, and from miles away I heard the L&D nurse give my name and then say, with a modestly beaming voice, "Extremely high-functioning autism spectrum."

"Actually, in the neurodiversity movement, we've moved away from using functioning labels, both because it demeans people labeled 'low-functioning' -- you wouldn't call someone a low-functioning diabetic or say that Patty has low-functioning Down syndrome, would you? But also because it minimizes the actual struggles or support needs of people that are casually referred to as 'high-functioning;' and in fact, the concept of the 'high-functioning' autistic dates back to Hans Asperger in Vienna before World War II, who didn't actually name Asperger Syndrome after himself -- that wouldn't happen until half a century later -- but the guy himself, he built himself this little lab, or hothouse, with his 'little professors,' as he called them. When the Third Reich rose to power, he became head of the project tasked with sorting all the autistic people into two categories: the ones that could be put to use by the Reich, either for economic or military advantage -- and those that got sent to the gas chambers. So when you call me 'high-functioning' you're basically saying 'It was totally worth not sending you to the gas chambers!' And, you know, ummmm, thanks???"

...said the pretend version of me. The *actual* me just stared through the wall.

Clark Kent would pop into a telephone booth to quick-transform into Superman. It's a bit trickier being simultaneously an activist/ideologue/champion, and a mere patient at the same time. Superman would make his choice of which persona to tap into based on some pretty obvious criteria: a tornado about to kill thousands or outer-space villains invading Manhattan, for example. For us, it's a bit more subtle. I may decide to slip a bit of medical-provider education into a doc visit, reading the provider's body language and tone enough to know they might listen. But if I get too worn out from struggling to breathe while I sit in the emergency room, and the beeping heart monitor pushes my autistic brain over the edge, then I may back-off the throttle, and say nothing at all. I probably won't even say "I'm Autistic." I'll just put on my headphones, which I hopefully remembered to bring, and let them think I'm ill-mannered and b\*\*\*\*y.

Looking back into my time in the army, I'm reminded of the way, during a long ruck march, I would flip a switch in my head that connected to the part of the brain that actually reacts to the something causing the pain. Flipping the switch, I could just power through while the suede of my boots ripped holes in my feet and my rucksack ripped holes in my sides. I would feel it all happening, but I would just tell the pain that I couldn't attend to it now, it would have to wait. And the pain would obey. It would stop screaming. Now, in this memory of just having just given birth after pushing for five hours, of course I felt the pain. I was torn as well - badly - but didn't know it. I screamed from the restroom so loud the nurse came running. Through the tears and pain as I told her something was very wrong, she simply brought me a stack of witch hazel pads and said, "Yeah it really burns." And walked away.

The books will say that autistic people have a heightened sensitivity to pain, and the appearance of diminished sensitivity is only because the brain flips that same switch under extremes. To survive. I also think that over the years I've gotten so used to my pain being dismissed that I mostly don't bother to report it anymore. So, do I feel less pain than other people? Or do I just know how to suck it up? For autistic people needing medical care, we are at war to decide what to allow them to see and what to hide. Pain largely psycho-social, and disability performative. Do we stand outside the building and demand they build steps we can walk up? Or just find a building without them? For me, medical care is so often just a crap shoot. I never know what I'm going to get no matter how hard I work to improve the odds. Some days it feel safer to conceal my disabilities. But then, if we all did that, how would the world ever change.

