

PRETENDING A LITTLE LESS

*And so it goes, this time we hold so close at hand, slippery fast to places we can't find. Then **POP** we see, face to face, the nature of who we were and the hint of who we are, the hope of who we may become. Someday, if we are lucky, we find the wholeness of our soul and then – then we can rest assured we have done our best.*

When *Pretending to be Normal* was published in 1999, I saw society as if a big mesh fence surrounded it. I could poke my fingers through the holey mesh, and see the blurry images on the other side, and put my ear against the tight weave to hear conversations within the webbed walls, but I couldn't break down the barriers that were so real, they might as well have been made of steel chains. Read blogs and memoirs from those on the spectrum and you will quickly note most of us felt like we were on the outside looking in, always trying with all our might to prove we had potential to offer, kindness to share and skillsets to turn into productive work. We tried everything to just get a foot in the door of the NT world. We knocked and knocked and pleaded and fought and bribed and pouted and joked and offered favors and turned over every leaf to find a way in to typical society until we were exhausted and spent or until we found a way to pretend we were what

society wanted us to be. Though our pluses outweigh our negatives, we are different thinkers who can act in ways not always socially acceptable, leaving society confused. I can't bring myself to believe the NT world dislikes everyone who is different, and I don't believe there is a grand plan to keep us marginalized, but I do think society has a long history of not knowing what to make of unique individuals and not knowing what to do with us. Look back in history and you can find Aspie geniuses and savants welcomed into society's fold, but you'll also find tales and records of people likely on the spectrum, being forced to live in institutions and the crevices of relatives' homes or who knows where. Historically, there was a formal and informal unscrupulousness levied on people with differences, from the subtle sort to the blatantly obvious. Bullies and predators followed many of us. In some form or another, ridicule, ignorance, disrespect and abandonment stalked most of us at least some of the time. Sophisticated echolalia skills and all the pretending in the world didn't keep me from being an outlier. NTs always saw through my façade sooner or later. But I persevered. I learned to use humor to tone down my differences. I made fun of myself before anyone else could. I used my guileless personality as an effective cover for my insecurities and confusion. And I studied other humans like a scientist would. I studied and I learned to be Aspie on the inside and NT on the outside.

Pretending to be Normal was published just before much media attention or counseling research was shining light on the entire spectrum of autism. I was in the right place at the right time when I wrote *Pretending*. When I finished it, I felt my story was told and I hoped it would resonate with a niche group of readers. Turns out I had a bestseller on my hands. The warm reception *Pretending* was given encouraged me to continue telling stories to anyone who would listen. Three books and lots of chapters for other authors have followed

over the years. Loads have changed since I shared my memoir, some good and some not so good. I believe every word I put in *Pretending*, but of course, after all these years, I have a few more thoughts to add to my story, which as it turns out, was not a stagnant tale with a definitive ending...

Shortly after *Pretending to be Normal* was released, I received my own official diagnosis of Asperger's Syndrome. Like many adults who don't find they have AS until they've spent decades practically doing the hokey pokey with the so-called normal world, I was happy to hear a trusted psychologist tell me there was a neurobiological reason behind the heedless, anxious, confused and often sick-to-my-stomach days. The words *yes, you have Asperger's syndrome* gave me hope and immediately took away the growing fear I was going mad. Today, Professor Tony Attwood describes me personally as a woman with 'residual Asperger's Syndrome'; a way of saying I have reconfigured much of my thinking and many of my behaviors to fit within society's norms. But, cautions Dr Attwood, a residual state doesn't mean I've come to a stress-free, happily ever after zone. In fact, living with one foot in neurotypical land and one in Aspie land, is very stressful and exhausting. Truth be told, I'm usually happy when I am in Aspie land. I have decided that decades of pretending I was someone I wasn't, surely helped me experience a great deal of good and pleasant things, but it came with a price. *Pretending* also took away a lot of time I could have had exploring the things that make me feel the most comfortable. I'm not suggesting I should have ignored the social norms and slapped back every neurotypical annoyance I encountered. I like to think of myself as bicultural – a whole lot Aspie and a mid-sized chunk NT. I'm glad I can function in both worlds. However, I wish I had found complete peace with my challenges years ago. I lament the years spent worrying about what others think to

the point I forgot I had a right to my own opinion. I'm sad I poured apologies about my 'odd' behaviors over people who frankly did nothing to deserve my apologies, people who I've come to believe actually owe me an apology for the way they treated me. Maybe it's because my age is encouraging my body to creak more and my mind to drift more, but I just miss missing me. You understand? If I had it to do over again, I would have put more spunk behind my affirmation I was proud to be Aspie, but I also would have sought help for my anxiety, my obsessive compulsive thinking and my sensory dysfunction all along my journey instead of now, nearing the end. Everything's a balancing act. Find a balance. That's a key lesson I use as my fifty-something mantra.

I feel most balanced when both my feet are planted in Aspie land and one arm is touching NT life. That's my balanced personal equation. I tried playing the 'be just like everyone else' balancing game and I stumbled and fell way too often. I can't speak for others on the spectrum, but I can suggest that everyone honor their intuition, challenges and strengths so they can make the best personal decision concerning how much of their neurological system and how many of their behaviors they are willing and able to alter.

I've learned to look at AS support ideas with subjectivity, knowing that no two people on the spectrum are alike. We all have different personalities, strengths, weaknesses, learning styles, backgrounds and expectations. For me, I like the Aspie bits that send my brain to seek logical and pragmatic solutions to problems and situations, yes, even social situations like boring birthday party banter. I love the sensory integration quirks when they are responsible for those over-the-top sensory information moments we with an ASD seek for comfort. I'm not embarrassed I love finding dark, absolutely quiet hidey-holes to curl up in. On the contrary, I feel sorry for the NTs who have no idea how sweetly soothing such

experiences are. And while I understand honesty isn't for everyone, I personally think it's more important to lean toward full disclosure rather than secrecy, white lies or the head in the sand disease, because in my mind that's the foundation upon which is built a transparent and authentic society. On the other hand, I admit to feeling awkward and sad when it's pointed out to me I've missed a joke or a main point or asked to go get an animal that is really just the figment of a film maker's imagination, but I'm beginning to give myself a break on this one. I tell myself it's okay this fifty-four-year-old mind sometimes thinks like a little girl. At least I can say part of me still acts young!

To keep this discourse fair and two-sided, I should probably list some of my neurotypical behaviors (now that I'm a residual Aspie), but honestly, those behaviors are learned and rather forced. They are not suddenly innate and they never will be. For instance, eye contact still makes me nervous, yet the fact I can do it doesn't make me enjoy it. Small talk is also doable, but it bores me to pieces and worse, it makes me very anxious. I can deal with change pretty well these days, but I don't prefer it. I have managed to unearth a bunch of keys to many of the NT's hidden nooks. If only I found those nooks more enticing. There are tons of times I want to fly head on into Aspie, but to do so I need to make sure I'm in a safe place surrounded by people who understand my native language and people who share the same goals I do. Lucky for me, I found that place and those people thanks to my favorite Aspie trait, the perseverating interest.

A special interest has magical powers. It can compel an unruly child to behave when it is used as a reward. It can help an Aspie find friends among others who enjoy the same interest. It can simultaneously satisfy the need for inquiry and calm. And as Temple Grandin often reminds us, a

perseverating interest can be the ticket to happy employment. Indeed, this turned out to be the case for me.

When I wrote *Pretending*, I was actively teaching at university level as an adjunct professor. This was a great job for me but, much to my dismay, I never found a tenure track open in my position. I'm a psycholinguist, a member of a field that has far more supply than demand. I enjoyed every year of my teaching, but eventually I had to accept my dream to teach full time was just a dream. I trolled around a few years, squished between the unpredictable world of freelance writing and the part-time position of autism consulting. I focused most of my attention on my kiddos but then they got their driver's license and didn't need Mom so very much. Depression hit pretty hard. Desperate to get me up and out of the house, my husband encouraged me to return to my most favorite activity in the whole wide world – horseback riding. Ah. Horses. I sat on my first pony when I was a toddler and I had my first horse when I was eleven. I've been caught in their spell for as long as I can remember. If you're a horse person, you'll know what I mean when I say – if you love horses you LOVE horses and that's that. No matter if you have one horse, a hundred and one, or none, horses will always be part of who you are. You'll probably read horse books, collect horse art, follow horse stories in the media, have horse jewelry, and use calendars and notecards with horses printed on them. I am a lifelong horse girl so it was easy to take my husband's advice to return to horseback riding. Within no time I had bought a horse, started competing in local shows and working at the barn my horse was boarded in. Soon, that wasn't enough. I knew I had to buy my own boarding facility and immerse myself in the horse world full time. I am now the proud owner of Kirkshire Farm, a stable that boards twenty-eight horses, provides training and clinics for riders. Kirkshire is my safe haven that stemmed from my

perseverating interest until it became the place that erases my stress and eases my depression while providing me a place to earn money and socialize with like-minded folks. I go to the barn to work, of course, but I also go there when I need an escape.

One month before I hit the half a century mark, my business partner went bankrupt on the debt she owed to us on the horse farm, my daughters all went off to college, I had tests to rule out colon cancer and the biggest hurricane of all swooped me up. My father, who was my mentor and best friend, had a fateful fall that took his life and altered mine forever. I knew I would lose him someday, but I couldn't imagine how bad that day would be. When it came, I came undone. I slept on a mattress on my living room floor for months. For a long time I was torn to pieces. Now I am only frayed. My horse's unconditional love and kindness slowly stitched most parts of me back together.

If you had asked me just following my diagnosis if I thought AS would ever be my saving grace, I'd have said no. While I never shunned my Aspieness, I tried to be clever about how and when to let my AS out and about. I kept my sense of self strong and happy on the inside, but I was less open about really proclaiming the good parts of AS when I gave presentations or wrote other books. I never put AS in the cornfield to disappear and wither on the vine, but I can't say I was entirely happy with who I was when I wrote *Pretending*. It was hard to be A-okay with AS when society was still pretty darn unaccepting. *Pretending to be Normal* was my first step toward proclaiming autistic equality was a right not a privilege. I wrote it hoping to nudge open the door for personal freedom and community acceptance, no matter who you are or what you're dealing with. Much progress has been made in the world of autism since 1999. Yet struggles between our community and from beyond our core group,

are continuing and in some instances, life for people with AS is even more complicated than it was when the diagnosis was first recognized as an official neurobiological challenge. Point of fact – Asperger's Syndrome is no longer part of the American Psychological Association's DSM-5. That's a shame – a real step backward in our collective progress toward a better understanding of autism as a whole. Debate is raging more intensely than ever on whether or not a cure to autism should be or must be or shouldn't be or won't be an issue. Females are still under-diagnosed and under-supported, not to mention about as misunderstood as ever. Minority populations and people with low socio-economic status are still much underrepresented and largely continuing on without support. The elderly autistic population remains second fiddle to the young. People in many parts of the world face a life with no supports or promise for a brighter future with autism.

The AS community can't seem to find a fortified home. Our progress is wobbling, but it will not fall. No matter what label or lack of label we may or may not have, our community has come together, and together we will continue toward finding a safe and enriching life. We have so much to be grateful for. The nifty insights and abilities that have come as a result of having Asperger's Syndrome, are the very ingredients that help to make Aspies fabulous and notable. When I get depressed thinking about the women, elderly, minorities and others in the world who are still without solid supports and still unable to be all they can be, I quickly realize our work is far from being done. Thankfully, tenacious commitment is part of the Aspie character. I can't see a future without Aspies' contributions and wisdom. And for that, I am thankful.