



Tony

Tony is 40 and lives in the U.S. He has a diagnosis of ASD with co-morbid Generalized Anxiety Disorder and Complex PTSD.

He identifies strongly with PDA and has been reducing demands in his life so that he can lower his anxiety levels. His long-term goal in life is to be a moto-vlogger and plans to use this platform to discuss the PDA profile and highlight mental health issues. Here is his story ...

To give some family background, I am the oldest in a family of five boys. Though my father contributed financially, he traveled extensively for work and was therefore largely absent from the daily grind of family life. My mother, insisting that she have a large family, was consequently left with the burden of raising us more or less on her own. Though she may fall on the autism spectrum herself, she was from a family where the concept of “mental health issues” were considered a weakness, something to be kept to oneself, something to be ashamed of, so she never sought a diagnosis for herself, or her children. Two of my brothers may fall on the autism spectrum as well, but they carry the same view on mental health our mother did and so will not seek services in spite of their many struggles. Even in the most perfect of circumstances, raising 5 children is an almost unfathomable challenge. My mother herself had a very strict religious upbringing and only understood one way to deal with a non-compliant child: you used force and escalating corporal punishment to make them comply. She made it very clear to us that we were her burden, her cross to bear in life. I was referred to as her “Little Lord Fauntleroy” because I would cry too much when being hit and didn’t know how to “take a beating”. You can imagine the experience of being physically abused for someone on the spectrum with PDA.

As I got older I grew larger, and she grew frailer. The beatings caused me less physical pain, but began to take their toll on her hands and wrists. As her physical health deteriorated, she relied more on mentally/emotionally abusive techniques for coercion and manipulation such as triangulation, emotional blackmail, gas lighting, and relentless verbal berating. Being that she came from an upbringing where a child’s opinion or will was insignificant, she believed it was her parental entitlement to force her will upon her children. In other words, it was her turn to do the things to her children that were done to her throughout her own upbringing. In the world she came from, a child’s only duty was to obey absolutely and unquestioningly. This is how the vicious cycle of child abuse is so often passed down from generation to generation. In spite of the smiles we were trained to plaster across our faces in front of strangers or company, there was great familial strife and turmoil behind closed doors.

School life wasn't much better. Although the practice of corporal punishment was no longer used in the religious schools I attended, my teachers were certainly not trained to recognize the signs of autism. *If I was smart enough to do well in one subject, but was not doing well in another, then it was seen as my being lazy or deliberately insubordinate and was a reflection of bad parenting and a lack of discipline at home.* That was the report my mother was given, and her reaction was to increase the ferocity and intensity of her own disciplinary measures; clearly she must be going too easy on us. During the school day I was relentlessly bullied by the other children – this was seen as further justification by the teachers that I was a 'bad apple'. I was told I was bringing it on myself and to stop 'giving them what they wanted' by being upset at the other student's almost ritualistic daily teasing. If I got mad and exploded, that earned the dreaded phone call home, where I paid the true price for trying to stand up for myself. I would have been expelled many times, but I was the oldest in a family of 5 boys. There was a lot of potential tuition money expected from my father on behalf of my brothers, so at the time, the school would not risk my expulsion. I was regularly singled out and pulled to the front of the classroom as the prime example for the other students of "what not to be." I went on to a public high school and I saw that as a blessing. I was no longer the outcast among the same seldom-changing group of 28 children as I was from ages 6 to 12. The incoming freshman class of my high school was some 700 strong and there were plenty of others for the bullies to pursue. At seventeen I graduated high school and left home to attempt university.

My one retreat in life has been the outdoors. My few moments of peace as a child were the slow walk to the principal's office in trouble after being sent from the classroom, or the lunches where I would sneak out underneath the fence and hide in the bushes in a garden behind the church. I liked being outdoors so much that I even went through a phase where, weather permitting, I would only want to sleep outside on the deck in a sleeping bag. I couldn't stand to be at home. Not allowed to go to the mall or do the things other kids my age did, I would take long hikes into the woods out back alone. Nature would always be my one solace in the world.

After switching majors at college several times and struggling with depression and the new social pressures of life, I decided that I was wasting too much money on loans and indecisiveness. In retrospect, I was just jumping between circumscribed interests without a roadmap for turning them into a career, or any idea which direction I wanted to go. Having most decisions been dictated to me growing up, I had no true sense of self.

I dropped out of college and enlisted in the US Marine Corps, hoping it would turn me into something that could be loved. *The military is no place for someone with PDA and I lasted three months. The rigidity in routine was a welcome change from the aimlessness of college life, but it soon began to close in on me.* The yelling by the drill instructors was actually the least of my concerns. If I listened to what they were saying instead of how they were saying it, they were conveying very useful information. *I didn't see them so much as authority figures but simply my equals who were doing a different job than me. Again, that is not how it is supposed to work in the military, but it helped me cope.* But during a training exercise one day, I suffered a physical injury that had a serious effect on the mobility and range of motion in one of my arms. In order to even ship to boot camp, I had been granted a waiver for permanent pins in a different joint (due to an injury sustained in high school). Because during training I had now similarly injured a different limb, the decision was made to give me an entry-level/training dismissal due to physical

disability. I was not enlisted long enough for my underlying psychological issues to come to the surface.

I returned home briefly after boot camp and attempted to work, but moved right back out. Every job followed the same scenario: I was good at masking so I could get hired, the novelty of the new routine and tasks would carry me for a short while, but then it would all fall apart. I was able to get a job, but it was only a matter of months before I felt like the walls were closing in on me and I had to escape. This went on for many years. I would go from part-time job to part-time job barely able to afford a room to rent. I was entirely socially isolated. I was pretty much one financial disaster away from homelessness, and by 35 years old, I knew where this pattern of instability and isolation would lead me. While my peers were able to have a marriage, children, a house and a full time job, I could barely manage a single part time job at a time and to get enough money together to keep from falling into homelessness. How could I seem so bright in some areas, yet be utterly unable to hold even the basic pieces of my life together? Later, in seeking a diagnosis, I would have my answer.

As far as work is concerned, there is something that truly hits home about a wage being a demand. No matter how much I may truly enjoy performing the task, doing that task with a wage being held contingent on my performing that task, means it doesn't feel like it is of my own free will. If I did not do the (even enjoyable) task then my wage would be withheld, so I had no real choice but to complete said task. I completely understand the concept of a wage being a fair exchange for your efforts, and that the wage can then be exchanged for the necessities in life. At my final place of employment, it was easily arguable that the wage I was being paid was greater than the effort required in completing the tasks – the cards were actually stacked in my favor.

But this is where the pathological nature of PDA comes in. I do understand wages and I do understand consequences, but when the pressure of a demand (even a demand I have placed on myself) begins to build, I will do anything within my power to avoid that demand. When under the mounting pressure of a demand, it does not matter that I may clearly understand how beneficial completing the demand could be, or conversely how detrimental not completing the demand may be. I invariably become absolutely driven, frequently to the point of panic, in my need to avoid the demand. Although the task may require only simple effort, I will find myself exhausting all of my mental and physical resources in avoiding the demand – for as long as it takes to avoid the demand. Trying to force me to complete the demand will be very similar in nature to trying to stuff someone with claustrophobia into a closet. Once the novelty of a job has worn off and the pressure of being coerced by wage to complete a demand becomes overwhelming, it is difficult to even get me into the car to go to the place of employment, much less complete actual tasks once I have arrived at the destination.

As a coping method to give myself an illusion of choice, I have tried the technique of updating my resumé and going out on interviews at other places when I felt trapped in my current position. If the interviews went well, it would allow me to feel as though I had other options and therefore that I was choosing to do my current job instead of being coerced into doing the tasks in order to earn a wage. Usually though, if I was at the point where my resumé was ready and an interview went well, I would simply switch jobs. By that point, my work performance would have begun to deteriorate as my thoughts became consumed with how I could escape the demand instead being attentive of the tasks I was supposed to be performing. This cycle repeated itself from the time I was 17 years old and held my first job, up until I was

36 years old when I held my last. This is not a sustainable cycle. Employers are reasonably reluctant to hire and then spend the time and money to train someone who has had 17 jobs over the span of 19 years. At this point the fact that I have never technically been fired has become irrelevant.

In my early twenties I was extremely depressed and had no self-esteem. My friends had girlfriends but a romantic life was something it seemed everyone else was entitled to, but not me. In retrospect, I now understand that my difficulties in picking up on certain social nuances and my tendencies to choose practicality over style in clothing, combined with my negative outlook on the world, would simply raise too many "red-flags" in the eyes of the girls my age who were trying to figure the world out for themselves. I had no clue who I was or what I wanted in life outside of wanting to find someone who thought I was worth loving.

Throughout most of my life, it had been suggested that I should speak to a psychiatrist but there had always several things had stopped me. A big one was that with so much bouncing around in life, I only had very intermittent health insurance coverage. Also, the first time my parents took me to see a psychiatrist, by order of my school, was in the second grade. At the time it was for lying and telling my parents I had no homework, coupled with my lack of remorse in lying to my parents and the teacher. In retrospect, that was demand avoidance: "Do you have homework?" to which I had replied "no" so that the demand would go away. I would hide the homework in my desk at school, which inevitably led to the assignments being discovered when my teacher investigated why my desk could barely shut due to all the papers crammed inside. The psychiatrist asked me why I lied and at that age all I knew was that I didn't want to get in trouble. When the psychiatrist asked me why, I made her promise not to tell my parents. She promised and I explained about the beatings at home. The psychiatrist promptly had my mother come into the office and told her exactly what I had said. They had to pull me, kicking and screaming, from between the psychiatrist's desk and the wall where I had wedged myself. After that, I knew that psychiatrists were not to be trusted and, though I was sent to one by the school many times after that, I knew that the goal was to lie to them enough for the psychiatrist to shift the blame onto someone else (usually my father not being around) and say absolutely nothing more or I would get into serious trouble for embarrassing my mother when I got home. By the time I was in my mid twenties, I had another consideration. I still had younger brothers living with my mother, who were under the age of eighteen, but they were not being abused as I was when I was their age. This meant that if I reported that I had been abused, my younger brothers would have been pulled out of the house by Child Protective Services and very likely sent to foster homes. So even if I went to a psychiatrist, I would have still had to lie about my history and so I didn't see the point in wasting my time.

The third reason is that even if I did have health insurance, to just walk into a random office for a fee and explain my life over and over until I met someone I trusted, was a pretty awful sounding and potentially expensive proposition. Having spent a week under psychiatric care in my early twenties for an attempted suicide, I had learned that often the pathway to a mental health diagnosis can involve trying different medications, and if one reduced your symptoms, then depending on what medication it was and what it was used for, that was the diagnosis you were given. Not only did the side effects of the medications I was given almost always outweighed any benefit seen by me, I was also of the curious mindset that one's diagnosis should be determined first, and an appropriate medication assigned after the fact. But at that time, at the hospital my health insurance could afford, it was simply not how things were done. I was absolutely unwilling to take what appeared

(to a young me) to be arbitrary medications in the hope that one of them may give a hint as to what I should be diagnosed with. But by 34 years old I had realized that regardless of my poor past experiences with mental health professionals, some sort of action needed to take place because I was setting myself up for a potentially homeless future.

I was thirty-five when I was finally able to get my health insurance situation sorted. It began with someone at the Department of Veteran's Affairs recognizing the glaring signs of PTSD in me, and resulted in my ultimately seeking mental health services at the VA's local clinic. It was around this time that I had started reading about Asperger's Syndrome. I first heard about Asperger's Syndrome through one of those truly cringe-worthy: "Do you have these symptoms? Then you might have..." style of article. Though as a general rule I have only disparaging things to say about such articles, ironically it prompted me to seek out some more reputable information on the subject. This eventually led to my buying and reading Dr. Temple Grandin's book "Thinking In Pictures" and joining a number of Autism and Asperger's groups online. While I struggle with social difficulties online just as I do in real life, the wealth of information and similar life experiences of others my age on the spectrum just could not be denied. I printed out everything that the Autistic Self Advocacy Network had on the subject, and after about a year of researching the terminology, I was then able to better articulate my experience of the world to my psychiatrist. Finally, after grueling assessment process, I was ultimately diagnosed with an Autism Spectrum Disorder (Asperger's), alongside General Anxiety Disorder and Complex PTSD.

It was about a year and a half later that I first learned about PDA in a comment on a forum for Autism and Asperger's, and after reading the information on the PDA Society's website, I definitively had the light bulb moment. I printed out literally everything posted in the resources section on the PDA Society website and went through the reference booklet with a highlighter. I have since provided my psychiatrist and therapists with a copy of the Clinician's Reference Manual, and my psychiatrist even put in writing for me that he believes I have PDA.

I tend to see a description of Asperger's to be a great starting point in explaining how being on the Autism Spectrum impacts me personally. I have found that there is reasonably good understanding about this profile of autism, so I often just tell people I have Asperger's, because it is easier than beginning to describe PDA to someone with limited understanding of Autism Spectrum profiles. Should the conversation develop further, I can start to discuss the subtle differences one may notice between the Asperger's and PDA (those differences are enormous, diagnostically speaking, especially when it comes to which management strategies are effective).

There are many things about the PDA profile that truly speak to me. For example: the importance of developing a relationship with someone who has PDA if you are going to place demands upon someone with PDA. This strongly transfers to the workplace. "Splitting" is one of the ASD symptoms I struggle with; if someone is nice then they are good, yet if someone is mean or rude, then I see them as bad. If I like the person (or boss in the workplace scenario) because they have built a relationship with me, then I am infinitely more likely to acquiesce a demand made by that person - as a favor I am choosing to do my "friend." If someone has not built a relationship with me or is rude in their placing a demand upon me, then they are not someone for whom I am choosing to do a favor; they are an enemy attempting to force a demand upon me. Under the circumstances where my boss had a positive relationship with me, I was infinitely more productive. Ultimately, this would not stop the flow of daily demands, which are the nature of having a job, from becoming overwhelming. I may

have felt guilty for underperforming and letting my friendly boss down, but that did not make the mounting demands feel any less smothering and I would inevitably leave the position.

I like to describe the experience of being under a demand as similar to having claustrophobia. The anxiety keeps rising steadily until it becomes a non-negotiable, panic-driven need to flee from the source of the demand. A demand can come in many shapes and forms. The worst for me is when I feel I am being coerced or bent against my will to do a task - having to do something because a reward is being dangled over my head contingent on my completing the task. If someone requests I do something for them, then I can choose to do the activity out of my own free will sometimes without a problem. But if a reward is withheld, contingent on my completing the task, then nearly every time I will forgo the reward and chose free-will over coercion. If I put too much pressure on myself to follow a self-imposed task, I can feel the anxiety radiating from the task; approaching the task feels like trying to slowly reach out and touch a lit burner on a stove.

When it comes to the workplace, initially I may be able to focus on the novelty of the situation. Once that wears off then I may be able to complete tasks because I tell myself that I am choosing to do a favor for the person requesting the demand. Once I have exhausted my ability to “trick” myself into feeling anything other than forced to be there, I can for a short while force myself to go through the motions out of sheer willpower - but those instances I am enduring extraordinary levels of anxiety that begin to have serious physical repercussions. Borrowing heavily from tomorrow's ‘spoons’ I can sometimes get by for a short while, but by then I need a clear and concise exit strategy. By this point, if I have not found an exit strategy, I will just leave - no matter what the consequences. Under this much pressure from demands a shutdown in the near future (that can leave me without the will to even get out of bed to carry out basic hygiene) is usually imminent if I do not find a way to escape the demand, or in this case, job. I have tried to just force myself past this point and continue working - the world would love to tell me the problem is a lack of self discipline. This has resulted in complete mental breakdowns in the past – I turn into the human equivalent of a coyote with its paw caught in a bear trap. The coyote wants all 4 paws, and may even need all four paws to survive in the wilderness... but when faced with being caught in the bear trap the coyote will, in an anxiety driven panic, likely sever its own paw to be free in spite of the potentially deadly consequences. I do not enjoy the graphic nature of the analogy, but it paints a very accurate picture of the degree of self-detriment I may be willing to inflict upon myself to get out from beneath the severe pressure of demand.

At 40 years old, and with knowledge of the PDA profile on the Autism Spectrum, I can take a proactive approach in reducing the daily demands I face. Too many times in life I had forced myself into mental, financial, and physical ruin (stepped into a bear trap) just because the world tells me that I “should be able to do it because everybody else can.”

Coming to understanding more about myself, and no longer trying to pass myself off as neuro-typical, I have finally been able to enter into a romantic relationship with more honesty and authenticity. I have met an incredible woman and we have been together for nearly five years now. For perspective, the few and far between relationships I have had in the past had lasted up to 6 months. Instead of trying my hardest to convince someone I was normal while there was clearly something different about me, this time I was able to go into the relationship saying “this is why I am different.” With the help of a therapist and many hours of pre-scripting, I was

able to develop a roadmap for my current girlfriend to help navigate the areas of life that being on the Autism Spectrum has made more challenging for me. Without a diagnosis I was just flailing through life, but having a diagnosis has helped me understand the parameters under which I will better be able to function, and therefore allow me to contribute more substantially in a relationship.

My girlfriend and I live almost the reverse of a 'traditional' relationship when it comes to work and housework. In jest, I say that I try to be the best 1950s housewife that I can be for my girlfriend. She works at a grocery store whilst I do the cooking and housework. I do not see it as a demand because if I don't get the dishes done one day, I am not in trouble about it, she would be happy to do them. I cook in large batches and portion it out so that on days where I can not face the demand of cooking, there is food for her to take for lunch or for me to put in the microwave. I shudder to think where I would be right now had I not met her, so I try to do any household chores I can before she has to ask. She is going out there to work every day and interacting with people. I don't do the housework as a demand, I do it out of gratefulness. When it seemed that the entire world looked at me and saw only dysfunction, she saw someone worth believing in. Doing the housework is not a demand to me, it is an act of love. I would rather overcompensate on my good days by doing all the housework than live with the guilt of feeling like I was taking advantage of this loving and generous person who has been so good to me. Having our relationship structured like this affords me another priceless benefit: it allows me to pursue my interests without there being a wage held over my head to coerce me into doing them.

Discovering that I am on the Autism spectrum has been enormously illuminating regarding my past the "whys" behind so many of the difficulties I have experienced in life. However, learning about the specifics of PDA has shown the first glimmer of light from the end of the tunnel with regard to managing the more debilitating aspects of my disability. This has given me, for the first time, the potential for me to live a more fulfilling life. Being able to work at what I want, whenever I want, without being under any demand (other than those I put upon myself,) has allowed me to flourish in some of my interest areas, such as motorcycles. Lately, I have been teaching myself to work on and restore my motorcycle. There are often months that pass when I cannot touch the bike. In these cases it may be because I have put too much demand upon myself to complete a certain project, or perhaps during that time the demands of simple daily living take all the mental resources I can muster. The key difference now though, is that I do not have to worry about losing a job and thus starving or losing my home because I could not touch the motorcycle (in this example) during those months. The intensity with which I pursue my chosen interests is consuming, often to the exclusion of everything else around me. In the past I have never been able to pursue such a complicated interest. Before I could even begin such an interesting or absorbing task to the degree necessary for me to show any progress, I would have to drop everything to be forced into situations I only had the panicked desire to escape from. Hobbies would seldom get off the ground. I really have no idea how I would have succeeded thus far without my girlfriend, but there is more to it than just being grateful. She is an intelligent, amazing, understanding and infinitely compassionate - I am lucky to have her. I truly love her with all of my heart.