

Danyeale's Story

Danyeale wrote her own story.

My name is Danyeale and I was diagnosed with Asperger's Syndrome (AS or Autistic Spectrum Condition) in 2007 when I was 26 years old. Before my diagnosis I consistently experienced misunderstanding and isolation. My life has not been easy or pleasant and in many ways, even after my diagnosis which altered my life, it is a struggle.

My past has left emotional and psychological scars which unfortunately intrude upon my life, but at last I am learning who I am, discovering my own identity and forging my own destiny. There is always hope, even amidst the darkest periods of our lives. Great struggles with ourselves and our circumstances can bring us courage, and ultimately, change.

I experienced many years of misdiagnosis and being fobbed off by society and the medical/psychological communities. My diagnosis was not a process of grief, but one of realisation and profound validation. It affirmed by own personhood. Further, the identification enabled me insight, which had eluded me, and dignity as a person.

The impact of AS on my life is difficult to categorise as in many ways it is difficult to separate my own idiosyncrasies from AS traits. I am a person first and foremost, a person who has AS rather than a conveniently labelled collection of traits. The most significant AS influence on me is sensory, though for others the most significant and obvious influence relates to social interaction and communication. The sounds, sights and smells of daily existence are constant and oftentimes overwhelming. Too little attention is paid to the sensory difficulties people with AS have to cope with on a daily basis. I mean, sure, we need to know how to get along with others and form authentic friendships and safe relationships, and learn how to disclose our feelings and when, but gee ... we can't do this very well, or at all with the world constantly bombarding us. It makes it extremely difficult, if not impossible to function. This is in large part, why people with AS hide away from the world - it's just too loud, bright, and damn chaotic.

The constant sensory bombardment exacts a huge intellectual and emotional toll and is utterly exhausting. Society expects you to hold down a job, study, pay bills, do housework, and have a partner and circle of friends. The social withdrawal characteristic of AS is often nothing more than coping stratagems to avoid too much sensory stimuli. I try to avoid my AS having an impact on others, but this cannot always be achieved. It must be difficult for others to understand where I am coming from, because my disability is largely "invisible" which leads to all sorts of misunderstandings and value judgements, which benefits no one.

My aim at the moment is to complete my TAFE studies (a Certificate III in Business Administration) and then complete a Certificate III in Outdoor Recreation (Trail Riding). This is a far cry from my time at university, but steady, slow progress, is much better than taking too much on and collapsing in a heap which is what I have done in the past and seek to avoid in the future!

My goals also include getting my driver's licence, finding part time employment, and maintaining and strengthening my relationship with myself, and my relationships with those around me. I also wish to continue my volunteer work with North Queensland Riding for the Disabled and Wheelie Easy Pty Ltd. I have loved horses since I was a young girl and now I finally have the opportunity to connect with horses, develop my skills and ride in competitions. Volunteering has played such an important part in my life. The relationships I have built with these organisations have enabled me to flourish as a human being, and I am forever grateful.

I also wish to develop a writing career, get involved in leadership opportunities, and perhaps become a mentor for people on the spectrum. Additionally, I feel passionately about women with ASC who are consistently underdiagnosed and misdiagnosed. I do not want others to undergo what I had to. If I can alter others' outcomes, other people's lives, in some way, then I will feel I have achieved something worthwhile.

While most of these goals are a work in progress, some are in the maintenance phase of being achieved. Stability is one of the major factors which have allowed me to work on these goals. The love of my mother (who is undergoing treatment for metastatic breast cancer) has always been a constant in my life, and without her love, I do not know where I would have ended up.

I am currently in a healthy and loving relationship for the first time in my life with someone who truly values, cares for and loves me. It is a gift beyond value and I am thankful each day for it. Additionally, having family and friends who I can rely on for genuine friendship, advice and support is truly significant. The support of family and friends is crucial for emotional and personal growth.

I count my achievements every day, though they may be considered small and insignificant to some. It is hard enrolling in TAFE after a long period from study, coping with the demands of housework, study and being in a partnership, attempting to support my mother through her chemotherapy treatment all while trying to be a good person. No one congratulates you when you do something right but gee, they sure notice when you don't! One of the achievements I feel most passionately about is becoming a volunteer for NQ RDA.

There are ever present barriers which prevent me from achieving my goals and living my life authentically. I suppose it is like grief in a way. You make room for it in your

mind, and life. I will always have AS, and nothing, nor no one, is ever going to change that. You don't have to be "normal" to have a meaningful and happy life. You can find achievements, small or large, and happiness, in your everyday life. I realise life is for living, not for mourning, though this has been a gradual awareness. What could have been I often wonder had I been diagnosed as a child, would my life and outcomes been different? Possibly, but thinking about it is counterproductive and embittering. It is best to try and make do with what you have and who you are (which of course, is easier said than done).

My advice is to start small. Try to focus on the here and now instead of the future. Break tasks into manageable chunks, and then string them together. Use calendars, diaries and timers to help with time management and planning your life. Choose your friends and lovers carefully, and develop a circle of people around you who you can trust. When you meet potential new friends/lovers get your friends and family to vet them to make sure they have your best interests at heart. Develop your special interests, they will make your life worthwhile and may lead to employment or study. Remember to be thankful for what you have. Look after yourself, physically and mentally. Have fun and laugh, and above all LIVE!

The process of self-acceptance is a long and circuitous route, at least for me. It took diagnosis as an adult to really begin the process. It will be an interesting journey and I have taken the first step.

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