

## **A Life With Asperger's Syndrome.**

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***(HINT: Click the "+" sign on the pdf toolbar to increase print size)***

I am Stan Hood, 64 years old. This is my first year at the university of Canterbury and I am aiming at a BA, psychology major.

My working life has been in electronics hardware and electro-mechanical goods in commercial and industrial environments, being involved in design, construction, installation, adjustment, maintenance, and repair of this kind of equipment.

I also had electronics as a hobby interest. Years before the terms geek, or nerd had been invented, I was a very good example of one. Not much else interested me as work or hobby other than radio and electronics, apart from an ongoing curiosity about why I was different to other people. This difference was both my perception as well as the perception of my peers and my school teachers, as evidenced by their slightly different way of inter-acting with me.

My mother used to say I was "highly strung". It is true that I was a nervous child even though I did not want to be. I suppose this was the nearest assessment one could make of my demeanour in those decades before the work of Hans Asperger was introduced to the English-speaking world in the 1980s with the translation of his works from German.

My own diagnosis of Asperger's syndrome occurred a little over a year ago. It was made by one of the professional people I chose from a small list of names given me by a counsellor at Autism New Zealand. Mostly, Asperger's syndrome is said to be on the autism spectrum. Asperger's syndrome is also sometimes known as high-functioning autism.

What a relief it was to at last discover what I was. All my life I had the sense of being born on the wrong planet. I never could understand much of the meaningless banter of ordinary social intercourse. I just assumed when I was young that everybody was having just as tough a job as me to figure out what the purpose of this meaningless social babble was. Too often I would take the words literally, and then I would wonder why, further down the track, a former friend might become hostile, or, I might not be invited to be in certain playground groups.

As a child I thought I was a normal human, but recognized that other kids had some amazing power to help them cope with the perceived almost insurmountable difficulties of common social situations.

Aspies may not understand the social niceties, but neither are we dimwitted. The typical Aspie is said to be of above average intelligence.

Some Aspies have difficulties with speech. Possibly dyslexia, stuttering I understand is not uncommon. I stuttered very badly for much of my childhood. The corollary of speech is hearing: in my childhood I also had difficulties with hearing while at the same time I was able to pass simple though formal medical tests for hearing ability.

And so it was, in Primer 2 at school, about six years old, I began to be taught the alphabet and to learn some simple words. I cannot tell you what sounds I truly made, but I swear that I repeated exactly what I heard the teacher say to me when she wanted my individual response right afterwards. But whenever I repeated the sound, my classmates would laugh, and the teacher would hit me hard across the knuckles with a wooden ruler. This painful exercise would be repeated several times.

I felt crushed. I was being punished for trying as hard as I could, and I still remember it really hurt. Eventually, without telling mum, I would hide under the bed instead of going to school.

When the headmaster came around looking for me, mum used her magical powers of motherhood to find my hiding place immediately.

The headmaster heard my tearful explanation that I didn't want to go to school because I was always getting hit with a ruler because I couldn't say some letters of the alphabet. He threatened to take me to school by force and give me the biggest thrashing of my life. For a second there I remember being in absolute terror, absolutely cornered, unable to run because of my mother's grip on my arm, and facing a hiding at school with a leather strap, to be followed by an impossible situation with the wooden ruler in the classroom.

Thank God for an understanding mother. Nobody threatened her nervous little boy and got away with it. I can still remember my great sense of relief when she took my side, and I stood there and watched her go to work on the headmaster on my behalf. By the time she had finished with him, he was a nervous wreck. I did go back to school with him, in his car. All the way there he was extremely kindly. I was put in a different classroom with a kindhearted teacher. Then they got rid of that crabby teacher.

Some time later, I was enrolled in a speech clinic, one-on-one coaching, half hour a week for three years. By the time I was 12 years old I was the best speaker in class, even though I did not like speaking in front of people.

I remain to this day intrigued, that my child brain heard the sounds I made, the same as sounds I heard others make, but everybody else heard them as different sounds.

A few years went by from my six-year-old moment of terror. I would say I wasn't doing too badly, socially. I had one or two budding geek friends who found out that I was reading all of the science books in the children's library. Aside from C.S.Lewis' new books, "The Chronicles of Narnia", it was science books all the way for me. I also didn't like sports, couldn't see any sense in it.

I had noticed that I was not good at negotiating playground deals for myself, such as a little bartering with toys, marbles, trinkets or sweets. That sort of stuff went on all the time at my school. I had learned that I could not handle the perceived extremely high stress levels of the normal social inter-actions of such a negotiation.

At the age of about 10 or 11, I found myself engaged in one of these negotiations, and I remember realizing that a), I had not been so good at this sort of thing in the past, and b), this time I would, by rote, say all the usual words of the negotiating process which I had by then learned and see if I could successfully haggle over a deal "just like the other boys did all the time". So we did our banter, and my levels of panic were getting higher and higher all the time, and just when I knew I would have to stop and physically run from this terrifying experience of haggling, the other boy suddenly smiled, said "OK" in a perfectly relaxed friendly tone, and walked away apparently satisfied. And I just stood there for a minute, quietly wondering how other children, all the time, did this sort of thing and could stay so calm. I thought then that I would find the answer in maybe a year, maybe two or three, certainly before I grew up. Kids are aware that there are some things they don't understand yet, but they will when they get big. That never happened with me. You don't cure Asperger's syndrome, whether it is identified as such or not: You have to manage it, even if you don't know that "it" was to be given a name only several decades hence. Managing Asperger's syndrome is a job for life.

Asperger's syndrome doesn't go away, no matter the nights you silently weep alone in your bed as you slowly grow through adolescence, into young adulthood, and you still can't make any sense of the social rituals, and more importantly for the young, there is the major matter of wooing, and winning a partner for life.

I can only relate the male side of this. I learned some words and appropriate actions from some of my friends for attracting a female. Do you know that by intellectually following that advice, that one may obtain a whole raft of ratings from doing the same ritual, repeated for different women? - Too fast, too slow, too boring, too creepy... However, any possible offensive or inappropriate words were not deliberate, it was simply the social blindness of this Aspie.

Then there was the time, I was about 16, I punched a boy during morning assembly at school because he would not stop his whispered insulting remarks, every morning without fail. Every morning I would try to ignore him, because I did not know how else to resolve the matter. Then I would ask him very politely if he would stop doing that, please. Of course he ignored my polite requests. Six months went by, before I allowed my increasing frustration to boil over. Then I knew that no matter what, this was the day he was going to stop annoying me. I really meant to hurt him. At the time I hoped I had.

Please beware the shy introverted Aspie will build up pressure until it can explode into a perceived over-reaction, which the Aspie at least will find devastating to have been forced into (in his perception).

I found out when I was 19 years old and in my first job, that an adult male social group still had some similar expectations of how males should be made to react with each other. Introversions and shyness are apparently not allowed. I still can't figure out why. Male aggression distresses me. In a civilized human group, I have never understood why this apparently insatiable need to select a "top dog" by male aggressive behaviour. And, to change metaphors, I likewise did not care nor understand any need for placing members of a human social group at different heights on the totem pole of hierarchy.

I have learned a couple of little snippets of information in my first year psychology courses: psychologists assess mental states by observing behaviour patterns, and people on the autism spectrum lack a desire for social intercourse.

If you want to take anything from my words today, please take this. I believe you will find that people on the autism spectrum, especially adolescents and young adults, very strongly desire social acceptance, and social inter-action. Never mind what the peer-reviewed academic word says. Behavioural evidence based on our all too common wooden lack of physical responses, coupled with our hesitant or stuttering way of verbal communication, may incorrectly be assessed by psychologists as a lack of desire, when the truth as I know it from long experience is, the lack is in the ability to perform the positive-looking neurotypical behaviour in the social context.

I know that at least some young Aspie males yearn for that ability for easy social inter-action. Please be prepared to assess lack of observable behaviour in this regard as an inability, not a lack of will to engage. The desire is there, the means to display it is malfunctioning.

If you see passion in me today, it is because I was absolutely determined to find some ways of understanding my world, after the breakup of my first marriage. I meant those marriage vows, until death do us part. And it hurt, very badly, when it ended.

I felt shattered, inadequate, worthless. I had to do something to prove to myself that I was as good as anybody else. So I went out and did the most terrifying things in the world. I wasn't going to stop trying until I had succeeded in public speaking, and I did, in time. I wasn't going to stop trying until I had gone on stage, the spotlight on me as a leading actor, and singing solo. This took me a little more time, but I did it.

And so I discovered, in a public forum, even an Aspie can learn to hide behind a public persona.

But that is by way of explanation of how I am managing today. It is not entirely relevant to the young people, and adults in their 20s (the folks whom everybody here today will mostly be dealing with), who may go to bed, alone in the world, and shed silent tears of frustration in their utter misery of a cruel world which they don't understand, and which does not understand them.

When I went out into the world as a young man, gentle and passive, intelligent, caring, loving but socially inept, I would easily have my feelings hurt. I misunderstood innocent social banter as literal conversation. I still have that problem, but I make better guesses at it now.

So please, no banter with Aspies, be literal. You will then be understood, and quietly appreciated.

Aspies can appear blunt with their conversations, even terse or aggressive-sounding. This is almost certainly due to the Aspie's nervousness at speaking to a being whose social rituals he does not understand. Perhaps, like me, some Aspies may have some inability to assess how they sound like and thus cannot modulate their voice appropriately. I think my inability for this is erratic, but am not sure.

Please try not to respond to a terse-sounding Aspie in kind. The next one you speak to in kind could be me, and I would not have meant any offensive tone beforehand.

My opinion is however that you do not have to handle the Aspie with kid gloves. Just be literal, you don't have to talk in the deliberately over-the-top joyous tones one may use for a small child in order to prevent fear. Remember the Aspie is typically of above average intelligence so being obviously spoken down to, won't be appreciated.

If you come across a young Aspie who appears to be gay because of a perceived passive or subservient body language, perhaps combined with a soft, hesitant or higher-pitched voice, don't be too hasty in your assumption. I displayed all of those characteristics for decades and I have always been straight. It just so happens, I really am a gentle person who takes people as they come, I live and let live. The higher pitch of the voice is probably due to excessive nervousness.

An Aspie may appear shifty or untrustworthy, because he does not like to make eye contact with you. He may also turn away from you because he is shy or has developed an inferiority complex. Be gentle with the poor innocent guy.

Eccentricity: if you find an Aspie, especially a young Aspie, who indulges in eccentric behaviour or dress code, it probably isn't an attention-getting technique. Indeed, the opposite: a young Aspie like I was will be diverting attention from himself, to a physical prop. This immediately puts the Aspie in control of what, about himself, the neurotypical tormenter would otherwise be drawn to. Thanks to the deliberate eccentricity, the Aspie's social inabilities are no longer noticed and they do not become sources of torment. Eccentricity is a tool I enthusiastically embraced in my youth. It helped.

Eccentricity is probably not an indicator of Asperger's syndrome. It is a tool I accidentally stumbled across.

Finally, is Asperger syndrome simply a personality type? I have heard that suggestion made. And I say, call it what you will, it has been in my life forever, it won't go away, it has taken me through the utmost despair, the embarrassments of mistaken assumptions and I have had to manage it without external help, indeed I had never heard of a name for it, for almost all of my life. I don't care what anybody calls it or where anybody places it in the whole human spectrum of conditions. Some of us have it. You have no idea how fantastic it is to get a little help now and again.