

My Story as a Late Diagnosed Autistic Woman - By Vanessa Hughes

Best day of my life!

In August 2016, at the grand old age of 46, I experienced the most profound, and arguably, best day of my entire life. I learned that I am autistic.

I am now 50 something. A neurodivergent woman, proud mother to two wonderful autistic/ADHD children and wife to an incredible autistic man. I'm also Mum to eight (probably autistic) adorable but rather naughty cats and friend or guardian to any animal that crosses my path. I am a British expat living in Belgium and I identify as European. I am very internationally, diversity minded.

I remember every second of my final, face-to-face assessment - as though it was yesterday. After a lifetime of feeling 'wrong', different, out of place and as if I was always missing that 'something' that seemed so obvious to others, my diagnosis finally made sense of everything up to that point. I felt like I had just discovered the real me. I felt liberated. Full of joy with a new found wonder at this *me* I had not previously been aware of.

My only regret was not knowing much sooner. Late diagnosis can mean that much damage and trauma has occurred throughout life up to that point, due to not knowing about our differences and not having them supported or understood. At best this may cause misunderstandings and loss of friendships, but the negative effects are often much worse than that. Abuse, trauma, bullying, gaslighting, exclusion, rejection, missed education and injustice are just some of the negative impacts that come from having neurodivergent brains and living without the necessary understanding, support and acceptance in society.

I have several co-morbidities and other health conditions, some of which were directly or indirectly caused, or made worse by, not being diagnosed as autistic when I was very young. Here are just a few conditions that I personally have experience with: Ehlers-Danlos Syndrome, Post Viral Syndrome, Addison's Disease, ADHD, Auditory and Verbal Processing Disorders, depression and anxiety and several auto-immune conditions. I am not only neurodivergent, but diverse in many other ways and as a physically disabled woman, I am passionate about acceptance of all difference in society.

Why I love my autistic self.

Autism has brought about many challenges for me but I would not be without it. It *is* me. I wouldn't let anyone take it away for a million pounds. An analogy to separating the *me* from *it* would be like separating the demon from the child in Philip Pullman's, His Dark Materials trilogy. It makes me who I am.

And I am a good human. Autism has made me the sensitive, empathetic, patient, hardworking, enquiring, philosophical, deep thinking, open minded, creative, fun-loving, compassionate and determined woman that I have become.

My emotions are deep and intense and I am often too empathetic, which can be painful for me. I have very strong morals and integrity. I love to please and I hate lies. I like to follow rules (although admittedly, only when they make sense to me). I am an independent thinker who often thinks outside the box. I am a free spirit, who hates to be confined by societal constraints and pointless norms. I'm extremely intuitive and very caring. I'm creative and I can hyperfocus on things that interest me to the exclusion of all else. (Not always a positive!)

Whatever I do, I attack it with 1000% and am somewhat a perfectionist. I always do things to the very best of my ability. For me, there is no such thing as a quick project or doing something by halves, even if I want to and I will often deep dive into things. I am really proud of my achievements and although they take a lot out of me, I know that it's my autistic mind that makes them possible.

I don't think I can possibly live long enough to experience everything that I would like to. I will also (try to) find ways to do things that I otherwise can't or shouldn't be able to do. As my mum always said, "Where there's a will, there's a way." My autism, I believe, has been the reason I have been able to achieve so many varied things. I've taught myself many skills, had uncountable intense interests and hobbies, written and produced my own album, found art and craft skills (that still astonish me), turned my hand to anything I've needed to for my family and had too many different jobs to list here. One of my most cherished moments was when I acted with the actress Nicole Kidman for a few seconds in the film Grace of Monaco.

As a dancer, I grew up performing on the stage and this is where I always felt most at ease. (It's much easier to perform on a stage than talk to someone in

real life!) I adore colour and nature and seem to feel connections to these things more strongly than others. I am a big kid at heart with a child-like sense of humour and since my diagnosis this side of me has been able to come through more and more. I get enormous pleasure from the simple things in life such as a flower, a bee, a drop of rain, a Disney movie or a puppet show.

I have a great deal of tenacity and seek to right wrongs where I find them. I am always protective of the underdog. I'm stubborn and fiercely independent too. Should this be in the 'downsides to my autism' section? Nah, I see it as positive. Mostly!

I also pride myself on trying to better myself. Always. I don't mean in terms of status or money or anything like that, but in terms of being the best person I can be. I can be very fixed in my views but I really try hard to see other viewpoints and try to work out what makes people behave in certain ways. And if I've got a bad habit or bad thought pattern I always try to change that to a more positive one. It's a work in progress!

I am also extremely proud of the fact that I am loyal and a good keeper of secrets but I do find it hard to bear when this isn't reciprocated by others. Once trust is broken with me, I find it almost impossible to get back.

My autistic challenges.

There are, of course, aspects of my autism that I find really difficult to deal with. For example, I am painfully sensitive to other people's emotions and moods and I can't bear to see animals or vulnerable people harmed in any way. I struggle to watch the news as it affects me too intensely and I simply can't cope with the emotions it causes. I am a highly sensitive person in general and take things to heart way too much. I cry at the silliest and most inappropriate things, such as the wedding of a complete stranger.

Whilst hyperfocus can be a wonderful thing, it can also be a double edged sword. In times of hyperfocus (such as writing this!) I often forget to eat, drink or perform other daily activities. I cannot switch tasks and having to do so is frustrating, exhausting and completely ruins all creativity in progress.

And let's be clear about this: I am rubbish at maths. I don't have any superpowers and I'm not a savant. I CAN make eye contact and I CAN function in society, albeit at great cost to my health and sanity. Let these and other myths about autistic people be officially busted.

Like many neurodivergent people, I need much more downtime and alone time than others. Social interaction is exhausting - not least due to having to constantly mask and monitor my own tone and responses and organise my thoughts, whilst at the same time assessing the other persons expressions and meaning and process what they are saying. This comes as naturally and easily to me as flying a plane.

I'm poor at getting my point across verbally, even when I am semi-expert in that subject. Many times I simply end up not speaking at all. I would find it easier if I could write my answers down first, in bullet point format and then reply. Oh, I do love a good bullet point list! I'm envious of people who can just string a cohesive sentence together with ease and never get lost if someone interrupts them mid speech. It's a skill that amazes me.

I am a good listener though - mainly because I am such a poor talker! If I talk I forget the main point of the story or I miss bits out, or get lost mid sentence. It's exhausting. But ask me to talk to an audience who can't talk back whilst being allowed to prepare my notes before hand - that's a doddle!

I have several difficulties with auditory and verbal processing and oftentimes, I don't process conversations immediately. Instead my brain seems to unconsciously store them for playback and processing at a later date - presumably when it has the processing power available to do so. To be honest, my brain's processor chip is slow and clunky, and several generations behind. It doesn't fire on all four cylinders - if you prefer to use a car engine analogy. Imagine your computer's fan whirring away loudly and at top speed trying desperately to cool the processor down, while the processor is struggling with all the tasks and multiple open windows it is currently having to deal with. This is my brain in its most promising state. Eventually the 'blue screen of doom' will appear and all processing capacity will be out of action. This is a shutdown or meltdown in autistic terms.

I can't bear small talk and formal dinners are an absolute no-no! I shiver at the thought. I have, reluctantly, found myself in these situations in the past and have taught myself many strategies in order to cope. These include: finding pets or young children to entertain, doing the washing up (very, very slowly), checking out the garden, spending a lot of time in the bathroom, turning the conversation more to my liking (cats), asking lots of questions as people seem to like talking about themselves, even if it bores me half to death, or the all time favourite - high quality acting.

My poor memory for things that others remember easily is a huge frustration. I am ashamed to admit that I don't even remember important milestone dates

and times for my children, stories I've learned about my relatives, details of important historical events or political facts. I do, however, recall random facts or details that are, more often than not, useless. Although, to be fair, they have proved useful in quiz and game nights! If ever I was a witness to a crime scene, however I'd be useless at describing the perpetrators faces, hair, clothes or anything else, but would probably remember the fluffy little dog that made an appearance or the music that was playing in the cafe nearby. Despite my good IQ, my working memory and executive functions are really very poor, and yet I can 'pass as normal' in this respect. Often though, others see me as far less intelligent than I actually am. If only I could have a euro for the number of times people have expressed surprise as they suddenly become aware of my intelligence or knowledge. Sigh.

I struggle with recognising faces. I could sit with someone for three hours, each week for a year in a language class, yet not recognise that same person in town at the weekend - especially if their usual hairstyle had changed. This is really embarrassing. Watching films is always interesting as I won't remember who the characters are. If there are several male roles introduced for example I will confuse them all and spend the entire film asking my husband if that man is the protagonist, the father, the boyfriend or the brother of the villain. Bless his patience, especially when I ask the inevitable question, "Have I seen this film before?"

I am a real home loving person. My home is my sanctuary. I need eight therapy cats because one isn't enough, right? When I'm not home I find ways to comfort myself and lower my anxieties. My wheelchair and adapted car both have names and I talk to them as if they were friends when I need to. My cars have always had names and become my best friends in times of stress. Such as, being stuck in my little Fiat 500 in the middle of a muddy field in the rain! (She was called Edith by the way!) Oh that was a story!

We have a healthy collection of soft toys peering down on us from around the house, all named and part of this crazy family and I will never be able to give up my childhood dolls. They were my best friends growing up and all these things give me comfort and joy. Wherever I go now I keep my sensory and comfort 'kit' with me at all times - noise cancelling headphones, miniature soft toy, scented tissues, meds, lip salve, water, phone charger, hand gel, sun glasses, moist toilet tissues, (yes, these ARE essential), list of important phone numbers, soft scarf, and a few other personal items, in case I need them.

I get very anxious and stressed when plans change. I plan to the nth degree including anything and everything that could possibly go wrong. I need to be in control of myself and things around me. If a bus or a train unexpectedly

changes the route or breaks down, I find this really distressing and difficult to deal with and I will no longer be able to think clearly and rationally.

Whilst on the subject of driving, I need to know exactly where I will be able to park before I go anywhere and I will always use a satellite navigation device when driving or even when in my wheelchair, to prevent anxiousness and disorientation. In fact I usually have two systems! One is a back up should the first one fail. Belgium is renowned for its diversions. The signs are bright orange and always fill me with dread as even Mrs SatNav can't help me out with these. Often there will be more than one of the dreaded Orange Disorientation Devices, with one diversion pointing to another; all involving a long, convoluted route which is bound to get me lost or driving round in circles. This is when talking to my car really helps to calm me.

Public transport and crowded public places are difficult as I find them overwhelming, disorientating and very tiring. They are also full of smells and horrid lighting that steal all my necessary brain functions. I prefer to drive but will only use car parks that are easy to navigate and that I know well. If I can't park easily close to the place I need to go, I simply won't go!

This reminds me of a term I coined whilst trying to navigate one particular car park. It was pre diagnosis and I was well known for my poor skills in noticing signs, even important ones. I can never see the sign I need to - be it the exit sign or the floor level sign; toilet sign or lift. The more signs there are, the more I just can't see any single one. It's as if all the signs are shouting at me at the same time, telling me to notice them, "Look at me! Look at me!". As a result I notice none of them. I called this 'sign-blindness'. It was meant to be a tongue in cheek term, but I truly think it should be a real thing!

I, like many autistic folk, am sensitive to various materials and textures. I'm most comfortable wearing pyjamas all day. I detest corduroy (with a vengeance) as well as some velvet textures. All my clothes, towels and bedding have to be of a particular texture and I'm even fussy over different types of fleece material. I can't bear tight or restrictive clothes, wrinkles in socks or clothes labels. Socks also get kicked off at the end of the day to free my toes. Don't get me started on underwear!

Artificial lighting tires me out very quickly. I need lots of natural light to see and paradoxically, I am also sensitive to sunlight. I am also sensory seeking and I do love bright, glittery, colourful lights such as fireworks and laser shows. When I win the lottery I will be creating a blackout room filled with such treasures!

Another extreme sensitivity for me is noise. Motorbikes, dishes, pots and pans, lorries, dogs barking, helicopters and screaming children *hurt* me and make me want to run away and hide. Those awful hand dryers in public toilets are p.a.i.n.f.u.l. and should be banned (in my humble opinion). I'm tempted to take 'Out Of Order' tape with me everywhere I go and stick it all over them so nobody can use them. Unwanted noise drains my batteries quickly. I use noise cancelling headphones over my hearing aids (needed as I can't hear speech in noise) and that really does help a lot.

Smells. Oh boy, do these bother me. My husband says I have the nose of an elephant. Smells irritate my brain and compete for my attention, just like all my sensory sensitivities do. I wouldn't dare wheel through the perfume section of a store - heaven forbid! And if someone wears a perfume or aftershave that I don't like or is simply too strong (i.e. more than one molecule), I will not be able to concentrate and may experience headaches or nausea. Smells in public places are a big deterrent and why - oh- why did some bright spark think that installing stinky air fresheners that spray when you go into a public toilet were a good idea? Really? (Another good use for that tape perhaps.) My husband is under strict Household Regulations relating to his aftershave brand and quantity and it's really rather limited for the poor chap. As for travelling together in the car - best not use any at all if you would like a peaceful and complaint-free journey.

To the outsider, my organisational skills are fabulous! Want a themed party that goes completely over-the-top in every way and is as imaginative as the best fantasy film? I'm ya girl! Want to go on a trip and need everything organised down to the minutest of details? That's a job for SuperNessy. Need someone to keep on top of four household members' medical appointments, medication lists, weekly tablet dispensers, symptom tracking, prescription ordering, supplies and stock levels? Piece of cake.

Yet, it isn't really a piece of cake. In order to do these things, my brain has to work overtime. I will need lists of lists of lists. Lists everywhere - by my bed, in the shower, in the loo, in the kitchen, the bathroom, the garden shed, the local supermarket and everywhere in between. Files of lists, coloured pens, coloured paper and sticky notes galore. This is how I do all these things so well. It doesn't really come easily and naturally, but I'm good at it because I've had to be.

One word of warning about sticky notes and cats - we have one or two cats who are particularly partial to the tantalising taste of sticky notes. These little kitty delicacies will disappear overnight in our house. There goes my super-important-not-to-be-forgotten-never-to-be-seen-again sticky note.

Beware all ye cat-loving-sticky-note-users!

My biggest frustration of all is the brain fog accompanied often by severe headaches and constant fatigue due to a combination of my autism and other physical conditions. It's so frustrating not to be able to remember the facts and information I spend so much time learning. By rights, I should be a walking encyclopaedia, ready for a spot on Mastermind. I should be able to quote all the tomes of research I have read and with all the devoted study I've put into learning languages I should be fluent in French, German and Dutch by now. I should have a degree in biochemistry and cats. Definitely cats. And I should have an Oscar for my acting skills.

This should all serve as an example of how dangerous the very much outdated term 'high functioning autism' is. To the outsider I appear perfectly OK. Functioning, able, capable, at ease and so on. But I am not. I camouflage and mask and hide things extremely well. Like a duck, my feet are paddling madly under the water whilst on the surface all is calm. But to what cost? The personal cost of this is invisible to all other than close family and other neurodivergent people with similar problems.

Growing up as an undiagnosed autistic woman

Growing up, my mum used to say that I could never be bored - and she was right. This hasn't changed. I have always been very happy in my own company. As a child I would invent games and clubs - mainly for my dolls as I couldn't seem to keep friends interested. Looking back, I think I probably came across as rather bossy and controlling. I had little in common with other kids of my age and 'hanging out' or talking about things I wasn't interested in was really very boring.

I remember feeling homesick as a child, on the rare occasion I had to leave the safety of home. I still feel that now actually. I don't like staying in other people's homes. I guess it is the familiarity I miss, and yet I would rather stay in a hotel on my own than in someone's home. Neither do I really like having other people stay in my own home. Even if I love them or they are close friends, I just don't like it. I don't really have the words to explain why this is. It's just how I am.

As I approached my early teens, like many spectrum girls, I began to find life increasingly difficult. I could no longer hide in my sheltered world of dolls, books and fantasy. School became more difficult. I always had to work harder

to remember the stuff I had learned - and there was so much to learn. Social rules became a problem.

To me, girls were scary, bitchy, two-faced, gossipy things with unspoken rules and strange obsessions about stuff I didn't understand. This was a new club that I was forced to be a member of, yet I never understood the rules of membership. Life as an emerging adult brought with it so much pressure and uncertainty. I found more solace with the other "oddballs" at school. My best friend at secondary school was a boy. There was no need to be something I wasn't and I didn't have to try to follow unspoken rules when I was with him.

After leaving home at quite a young age, I was somewhat vulnerable and as an autistic girl developing into a woman this didn't go unnoticed in the male population that I came into contact with. Looking back, I am amazed that I didn't get into even more dangerous situations because I was so incredibly naive and just didn't pick up the signs that I should have done. I landed myself in some very tricky situations over the years and was taken advantage of on several occasions. This, I believe, is one of the most important reasons girls need to be diagnosed at an early age and prepared better for the world we live in.

My post diagnosis journey.

After my diagnosis, I took a ride on a rollercoaster of emotions. I would have preferred to have had some post diagnostic support to help me work through these feelings, but it simply either wasn't available, or was ridiculously priced. There were bouts of feeling extremely sad, grieving for what could have been different had I known earlier and much reframing of my entire life up to that point. I felt anger at the people who should have diagnosed me sooner and at the people who took advantage of me and hurt me. I felt regret at things I did or didn't do or could have done better at. I felt embarrassment for the times I'd had meltdowns and embarrassed myself. And then there was the sadness at all those missed opportunities.

It was akin to bereavement in a way. I was losing something I had grown used to for 46 years. What if things had been different? Would I have avoided so many mistakes? How much easier would life have been? Would I have got so ill, so young? Would I have been a better mother and wife? Would my children have been diagnosed sooner and been spared all that trauma and damage? How could life have been easier for us all if my dad had been diagnosed when he was young? The questions poured in to the processing centre for a long time and of course, many are useless 'what ifs' because even if we had all been

diagnosed earlier, the understanding and support would simply not have been there in those days.

There have also been times when I have questioned my actual diagnosis. Am I really autistic? Do I really deserve this diagnosis? Am I really any different to anyone else in the world? But these thoughts don't last for long as I soon come back to reality and realise how utterly autistic I actually am. And then I smile to myself. It is a happy feeling for me. In the words of a great song from a great musical (The Greatest Showman)...This Is Me.

The downside to telling friends and family of course was the inevitable, "But you don't look autistic? ... it must only be mild... but only boys get that, don't they? ...aren't we all a little bit autistic?" Here it was, the invalidation. The insults really, but of course, I do understand completely where these words were coming from. They come from a lack of education and awareness about autism, that I once experienced myself. A misconception and a Rain Man perspective. They are meant to be words of comfort and acceptance. At times like this I try very hard to remain calm and understand that these words are usually well-meaning though misplaced and I will gently and consistently educate the people in my life who are willing, about autism in women.

I have never directly discussed my diagnosis with members of my extended family and certain other acquaintances, but I don't hide it either. It's not that I'm ashamed at all (as I think my story has made clear) but I can predict how some people would respond and it just wouldn't be healthy for me. I know that the comments and ensuing discussions would be painfully invalidating, upsetting and bad for my blood pressure! A bit like trying to defend myself in court.

I have become an overnight passionate advocate for autism acceptance and understanding and in particular about the need for girls to be diagnosed at an early age. So many girls and women are misunderstood, mis-diagnosed, demonised, traumatised, abused, excluded, and badly damaged. This must stop and will only do so by awareness and education.

Families may try to encourage 'normal' behaviours and rules and, if the children are neurodivergent, despite their best efforts to conform, further assaults to self-esteem, confidence and mental health will begin to pile up and compound each other. When a girl isn't accepted as the person she is, by her teachers, friends and peers, at home, at her after school clubs and in society in general, the only way forward is mental ill-health and a lifetime of difficulties at university, college, work and life in general, and of course, ultimately, adult relationships.

If a girl reaches adulthood 'broken' by these negative life experiences, she may already be well on her way on a downward spiral of poor health. As life goes on it gets harder and harder to navigate. Depression and anxiety are common by this stage, as is PTSD. What often follows is a long list of psychiatric misdiagnoses and mistreatment.

Once in the hands of psychiatrists, many of whom are still tragically far behind in understanding and diagnosing autism in females, many women begin to accumulate mental illness diagnoses of bi-polar, borderline, or psychosis. Or all of the above. These are common co-morbidities of autism but should never be flippantly or lightly diagnosed, simply due to a lack of awareness of the similarities between them and autism in women. And when they are co-existent, autistic women often need adjusted treatment or care, not necessarily the same as non-autistic women. One treatment that is a prime example of this is cognitive behavioural therapy (CBT). The dangers of using this therapy for autistic people is well researched, but not well known amongst professionals.

Most often however, autism isn't considered, raised or suspected. Even when the woman brings up the subject themselves, their questions are often dismissed because they can 'make eye contact' or are 'too intelligent' and the myth that autism only exists in boys is still infuriatingly pervasive amongst medical professionals.

The good news however - and it is wonderfully good news - is that with diagnosis, support, education of families and teachers and of society in general, girls and women can lead the lives they deserve. They can be genuinely happy and healthy. They can be accepted and celebrated as normal in their own neurodivergent way; loved for their quirks and differences, their talents and pure wonderfulness. Allowed to blossom and to find work or contribute to society in a way that suits them and ultimately, to participate in fulfilling, loving relationships if they choose to do so.

Hopes for the future.

As for the future, I feel mixed emotions. It's a good time for the neurodiversity movement right now, but still I worry for my future and that of my children. I worry about not having people to advocate for us should we need it. I worry about losing control of everything that keeps me comfortable and regulated. I worry about where the general mindset of autism is going - in

the wrong direction, just as it did for Down Syndrome. I worry about talk of ‘fixing’ and ‘curing’ autistic people.

Autism is not a disorder. It’s a difference and it has its challenges. It may produce ‘disordered’ neurotypical behaviour on Planet Typical, but on Planet Neurodivergence, it’s perfectly normal behaviour. It is disabling in a neurotypically defined and favoured world. It may be accompanied by intellectual difficulties, learning difficulties, behavioural challenges, mental or physical health problems or anything else that all humans experience. But I am not disordered and I am not wrong or broken. I am simply neurodivergent. Just as neurotypical humans are neurodiverse in *their* own way. I am happy with my autism. I consider it a gift. It makes me who I am and would not want to be without it. To end, here are two of my favourite quotes:

[So-called] Mild autism doesn't mean one experiences autism mildly... It means YOU experience their autism mildly. You may not know how hard they've had to work to get to the level they are," Adam Walton

"If you've met one person with autism, you've met one person with autism," Dr Stephen Shore.