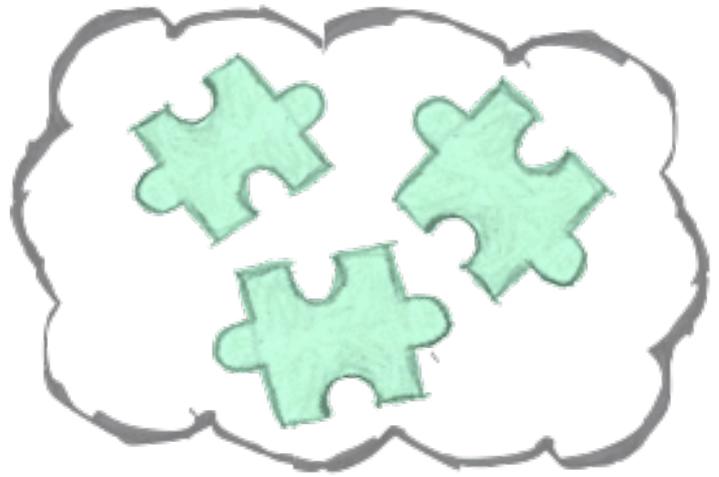


My Invisible Disability

A book
about Autism

By Caitlin
Hire



Introduction

Hi, my name is Caitlin. I am 15 years old. I was diagnosed with Autism Spectrum Disorder (ASD) when I was 13. I have now also been diagnosed with ADHD, major depressive disorder and a processing delay. I take medication for depression, ADHD & insomnia.

What is Autism?

Autism is a lifelong developmental disability that affects the way people experience life and interact with others. We see, hear and feel the world differently to other people.

Autism is not an illness or disease but a social disability. All autistic people share some difficulties, but being autistic will affect people in different ways. Autism is specific to an individual. If you learn anything from this book let it be that every autistic person is different.

Autism is diagnosed by difficulties in behaviour, social interaction, communication and sensory sensitivities. Some of these characteristics are common with people on the spectrum; others are part of the disability but not a problem for all people on the spectrum.

People with ASD often have other conditions, such as:

- A learning disability
- ADHD

- Epilepsy
- OCD
- Generalised Anxiety Disorder
- Depression
- Bipolar Disorder
- Sleep problems

Extra Facts & Statistics

Autism affects 1 in 68 children and boys are nearly five times more likely to have autism than girls.

1 in 42 boys are diagnosed with autism, while only 1 in 189 girls are diagnosed.

Autism is the fastest growing developmental disorder, yet most underfunded.

At least one in three autistic adults are experiencing severe mental health difficulties due to a lack of support.

34% of children on the autism spectrum say that the worst thing about being at school is being bullied.

17% of autistic children have been suspended from school; 48% of these had been suspended three or more times; 4% had been expelled from one or more schools.

60% of teachers in England do not feel they have had adequate training to teach children with autism

My Story

The Start

I have always found school very difficult. I have always been left out or picked on for being weird or annoying. The teachers had always treated me as a 'naughty' student.

I was told off for things that nobody else struggled with. For as long as I remember, I was the 'naughty' girl everyone was told to avoid. I was often sent out of lessons for being disruptive or for 'making a scene'. I was punished for 'not concentrating' because I didn't make eye contact. I was told off for things I had always done and thought were normal, such as needing to know the specifics of everything, and I mean everything. I've always needed to understand exactly why I am being told to do something, or I can't do it. Teachers always assumed I was making an excuse. I took up a lot of teaching time.

My school reports and parents evenings were always the same. "Caitlin is not concentrating". "Caitlin doesn't try". "Caitlin is disruptive". "Caitlin is rude". You get the point.

I was trying so desperately to remember all the things I shouldn't do and I was confused as to why I had these problems and no one else did. I didn't know how to explain them. So I tried to suppress my "weird" behaviours.

"Normal"

By the time I was in secondary school, I had developed this idea of what "normal" was. I was so desperate to fit into this category I had created, I would plan out social situations in my head. I'd only do or say things I had seen other kids do or say. I was constantly asking myself if everyone else was finding it this hard to fit in, or if there was something wrong with me.

I was so desperate to be "normal" I had developed a mask. I wanted to believe that if I wore it long enough I would lose me and I would become the mask I believed would fix me. I believe this was when my depression started.

The New School

In Year 8, I started a new school. A fancy grammar school. I had always found change difficult, more difficult than other kids. It took me around 10 months to adjust to the school. The rules I had spent years learning had changed. Now there were also trains and iPads to deal with.

I was getting in trouble even more than I was before. I was being punished daily for things I didn't understand. I felt isolated. There were a few groups I could 'hang out' with but I was always the odd one out. I felt like an alien. I felt like the entire world was against me.

Towards the end of Year 8, I had my first proper best friend, a shy girl called Jasmine. I liked being around her because she

didn't talk much and I talked a lot. She has social anxiety like me. We were opposites, yet very similar.

"Autism?"

At the start of Year 9 I started seeing an 'early help hub' key worker. I was also seeing 3 or 4 councillors for depression as I was self-harming and suicidal.

The lady from the early help hub had been observing me in lessons and we had been having appointments with her at home. In one session, she asked me if anyone had ever spoken to me about a condition called Autism.

Other than the kids at school using it as an insult, picking on other "weird" kids, I had not heard much about it. I knew it was something to do with the brain but I didn't think much of it.

She had advised my mum to go to a drop-in clinic and speak to a psychologist, which she did. She explained everything and her concerns and the psychologist advised her to get me an initial assessment. The wait was two years plus to get this done through the 'Umbrella Pathway' (NHS), so my parents decided to go privately. After the initial assessment it was decided I'd benefit from a "multidisciplinary assessment". Over a 6 week period I saw key specialists to get a full understanding of my challenges.

Meanwhile, at school, I was spending all my time in the Behaviour Management Unit and detention. School seemed to be punishing me even more now. I was suspended twice, and I

was told that I would have to leave unless I started to fit in and behave like the other students. The school was asked for information as part of the assessment process but they were reluctant to help. The school volunteered a total of four words "Overreactive, Attention Seeking & Resentful" and refused to expand further. I was so embarrassed and humiliated that I kept what was happening to me a secret. I didn't even tell Jasmine.

Diagnosed.

At the end of the assessment period I was diagnosed. Autism Spectrum Disorder! Yes, I wasn't an alien, I wasn't stupid. I was just different. Everything made sense! - or that's how I wish I'd felt. Any sense of relief I should've felt was stripped away from me by the school. I wanted to be relieved. I mean, I had just found out I wasn't an idiot. I wasn't stupid. I did belong in this world. But I wasn't relieved, I wasn't happy. I felt broken. I was so angry, and I was angry at myself.

School didn't make a single change to help me, they didn't bother to give any of the support I deserved. They told me if I wasn't able to conform I was going to have to leave. So I had just found out that I was going to have to leave my school because I'm me.

I had a diagnosis that I was taught to be ashamed of. I was taught that I didn't belong. They carried on punishing me for things I couldn't change. I continued to attend every day and I went to all my classes. I didn't want to leave. I couldn't stand having to change everything again.

For the first time in my whole life, I had friends. I was settled. I was comfortable. But because I am me, I had to leave it all. It was completely out of my control. I felt as though I was less of a person because of this diagnosis. I wasn't good enough for the school, for anyone. I was self-harming daily, and I really wanted to end my life.

Mum had to agree to withdraw me at the end of the year so that they wouldn't expel me. Yeah, if my mum hadn't agreed, I would have been expelled. I would have been expelled for being autistic, or that's how it felt. I was being asked to leave because of something I couldn't change, and that absolutely destroyed me.

Now I had to start the change process again. The part of life I found most terrifying. A local school offered me a place as I had nowhere else to go and they said they could support me with my diagnosis. I was an emotional wreck. I didn't want to go somewhere new. I had never been to a mainstream school before. I didn't want to go.

Change again.

The first day at my new school marked my first suicide attempt & hospital admission. I missed the first month of school. Not a great start. When I went back to school, I spent all my lessons in the Inclusion Suite. I didn't make any friends. I felt even more isolated. I didn't feel supported. I didn't even know what support I needed.

I was so anxious all the time and I had no one to talk to. I hated it, I was throwing up every day due to stress. I started pretending to be ill. I would refuse to get up. I would shout and scream. I was attending for a maximum of two days a week but most weeks I didn't attend at all. I was a mess, I couldn't communicate my feelings and I couldn't cope.

After another hospital admission, Mum began to realise the stress school gave me was making things worse. My depression had gone through the roof. It was causing even more problems. Mum stopped trying to force me into school, so I stopped attending completely.

My mum had to leave her job to support me. Since then, she has spent her time taking courses to help her to understand me. She gets me the support I need and is my absolute hero. My dad makes me laugh more than anyone can. I love spending time with him. He is my best friend.

The MET

Mum and my CAMHS key worker talked through alternative options, and my key worker asked school to make a referral to a local unit for children who are too ill to access mainstream schools.

I was accepted and I started straight away. Since then my life has completely changed. I am currently doing my GCSE's at the Medical Education Team (MET) unit in our town. I have also

been diagnosed with ADHD, for which I am now on medication.

The MET has helped me more than I ever thought was possible. I have now fully accepted my diagnosis, as they have taught me that I'm not broken. I am now comfortable talking about my diagnosis and explaining myself to others.

I have been doing DBT, and I am always learning things about how my ASD affects me. I have learnt lots of communication skills, crisis management and how to co-operate with others.

I have come to grips with who I am and although I sometimes wish I was neurotypical, I have learnt that I'm never going to be, and that's not a bad thing.

I still see CAMHS and I still suffer from depression. I have lots and lots of bad days. But I enjoy school and I'm finally getting the support I need. Accepting myself and my diagnosis was the first step to recovery.

How autism affects me

Autism affects everyone differently. Here's how it affects me (or some of the bits at least).

I find making friends difficult because:

I don't like to be touched or hugged, so I don't display my love in the ways that other people do. People therefore think that I don't like them. Most people like hugs, which I think is a bit

odd. How does grabbing someone and holding them mean "I love you"?

I find it difficult to "put myself in other people's shoes". Mum says this doesn't mean wearing their trainers, it means seeing things from their point of view. This is silly because things that upset me don't upset other people, so how will I know their point of view? This means I can only really focus on me, which people see as being selfish.

I can't read non-verbal communication, basically facial expressions and body language. I use to practice with drawings like these, 

People's faces are way more complicated than this! People don't really look like these pictures. When was the last time you saw someone with a mouth like this ? So, people get angry with me for missing the things like how they feel.

I also find sarcasm very difficult. I can't notice changes in voice tone, and why say something you don't mean, to say what you mean?

Most people don't like being corrected or told their opinion is wrong and I have a tendency to correct people if they get something wrong or I tell them exactly how I feel about their opinion. This upsets people. I say stuff as it is.

I often ask questions which are seen as rude or personal. I once asked my science teacher if she had ever had cancer because she was telling us about it. I didn't understand that this was rude and I got a detention for it.

I find day-to-day life difficult because:

I find queuing and crowds difficult because lots of people touch and bump into you, you get pushed and shoved and there is too much noise and smells to take in, so my brain shuts down and goes into sensory overload. I can't block out small things, like flickering lights or classroom clatter.

I'm not good at looking after myself because I hate showers. I can't stand the feeling of the water, so I try to stay out of the way of it, not ideal for washing! I hate brushing my teeth. The feeling of the foam around my mouth really, really frustrates me. I can't cut my nails because it feels so uncomfortable. I don't like having things on my face, so washing my face is challenging.

I struggle with using words to explain myself and I tend to get myself very worked up if someone doesn't understand me. I often use sounds like 'ugh' and 'meh' to describe my feelings.

I don't like unpredictability. I plan everything and everything has to follow the plan. I can't deal with any changes in routine. Plans often change, which is scary because I don't know what will happen next.

I am extremely literal, so I have a problem with sayings and people often use metaphors to explain themselves. Why would it be raining "cats and dogs"? Why can't people just say, "Oh look, it's raining?"

What my mask stops you from seeing:

When I am 'masking' you would hardly notice I have a disability. I hide as much of my atypical behaviour as possible. I do it out of habit because I don't want to have to explain myself. But when I am stressed, I find it difficult to mask, so my condition becomes very visible. For example, I look directly at the ground, I flap, rock and tap, my talking becomes much faster and random. I act as you would expect a younger child to act. I flick between topics. I repeat myself and other people. These are all signs I'm close to a sensory overload or 'meltdown'.

My Sensory Overloads / Meltdowns

When I am feeling so stressed that a meltdown is likely, I sit in a ball and rock backwards and forwards really fast, while counting repeatedly, in attempt to calm myself down. This is called Stimming.

People with autism react to anxiety or stress by Stimming. Stimming is short for 'self-stimulatory behaviour.' Stimming is a repeated movement used to give sensory input. Common examples are movements like hand flapping, clicking, flicking, feeling fabrics, and tapping. Anything that engages senses.

I do a lot of stimming. For example, I flap my hands, tap my legs, rub my clothes, knock my chest (because I find the sound comforting). I am often told to "stop rocking" or "not flap" this is annoying because these make me calm. It annoys people, but

people use metaphors and do lots of other things that annoy me. So, if I can't Stim, they should stop doing things I find annoying.

Sometimes these things are publicly frowned upon. I think this is silly because they aren't hurting anyone. Stimming is used to calm me down, but I also do it because it is a soothing activity. However, my stimming doesn't always prevent a meltdown.

A meltdown is an intense reaction to an overwhelming experience. It's a complete loss of behavioural control.

Meltdowns can be caused by too much sensory input, changes in routine, anxiety, communication difficulties and many more things. It is specific to the individual.

For me, a meltdown feels like an extremely painful tension all the way through my chest, building up and up until you feel like you are going to explode. Head thumping, spinning out of control. I kick, scream, cry, shout and lash out at things. I break things, hurt myself or other people. This only stops when I'm too tired to carry on, so I start to calm down.

Meltdowns are NOT the same as tantrums.

A tantrum is an act for attention or control. A tantrumming child has control over what they do. They may decide where to have it for maximum effect, making sure there are people watching. They are aware of their surroundings and they still have some idea of where the limits are.

A meltdown has no plan and the person in meltdown can't tell

what other people around them are thinking, let alone trying to manipulate them. With a meltdown, there is absolutely no control, they're so overwhelmed that there's nothing they can do about it. In a meltdown, the brakes are off completely. They have no sense of what might or might not be dangerous.

The rules no one teaches

There are lots of rules in society. Rules that no one teaches. Neurotypical people pick up these rules without being taught.

Having autism is like playing a game where everyone else knows the rules, everyone apart from you. If you get the rules wrong, people don't want to play with you.

For example, I don't always know when to say thank you or sorry. How do I know what is acceptable and what's not? Sometimes saying the logical thing is actually rude. That is very confusing for me.

I don't know most of the rules that are hard wired into neurotypical children through practice and intuition. So I get shouted at and told off. That makes me not want to try.

Frustrating things people say to me when I tell them I have autism.

"You seem normal."

How is this a compliment? You are literally implying that my condition is not normal. If I seem 'normal' that's how I want you

to see me and I am trying very hard to come across that way. It comes across like you think I am lying.

"I know someone whose autism is really severe. Yours isn't that bad."

This is the most demeaning thing someone can say. If I have told you that I am autistic, I don't want to know that there are people worse off than me, I know. But my problems are just as valid. Every Autistic person is different. I have huge difficulties to face.

"You don't look autistic"

Please tell me what an autistic person is 'supposed' to look like.

"People with autism don't want friends."

I struggle with social skills, which can make it difficult for me to make friends. I might seem shy or unfriendly, that's because I am unable to communicate with people the same way you do.

"So you can't feel emotions?"

Autism doesn't make me unable to feel emotions, it just means I often show them in a different way.

"Yeah but everyone is a bit autistic."

You're either on the spectrum, or you're not. You can have autistic traits, but not everyone is autistic. So just because you struggle with something an autistic person struggles with, doesn't make you autistic.

Next Steps

I finish Year 11 this year, so I am going to have to go to college. Change again. I need to make huge choices about what I do next. Most colleges only give special educational needs support to children who have an EHCP (Educational Health Care Plan), which I don't have.

My current school won't put an application in because they don't think I need enough support to qualify. It makes me frustrated that my school won't try. In college I can't access support without one.

My mum is putting in a referral, because she wants me to get the support I need. She says I might not get one because I'm great at masking.

Masking helps me cope with the day's unpredictability, but it helps to "hide" my disability from my teachers. I feel like I can't win. I don't want to have to leave the MET, so I even mask there (even though it's the best unit I've ever been taught in), just in case seeing the full-on, real me all day is too much for them to handle, and they send me back to my actual school.

Masking is exhausting, but it's what I need to do in this neurotypical world to survive. It makes home life lots harder, but I have to relieve the tension somewhere. I spend lots of time, avoiding family time to stay calm, listening to music, looking through my Harry Potter stuff, avoiding people and melt-downs.

College is going to happen whether I want it to or not. It

frightens me because I hate new situations, new routines, new people, new anything really. I know myself much better than I ever have, but I'm going to lose all of my current support and that caused me to take another overdose over the Christmas holiday. Life with ASD is a constant struggle, and I'm only 15 - a long way off having this sorted yet!

Written By Caitlin Hire