

Stuck Inside Me

How Autism affects me



Throughout my adolescent and adult life, I always found certain situations difficult and seemed to struggle with my mental health. I have seen a GP about this since the age of 17 where I was originally told I had OCD. A few years later this diagnosis turned in to depression and anxiety and since the age of 17 I have been on various medications to try to ease some of my difficulties and given the number for mental health support services.

Academically I always achieved and hit key milestones, but in certain social situations I struggled and have often been labelled as being awkward or stubborn.

As I got older, I worked with a lot of young people on the Autistic Spectrum and because of this could see similar traits in myself. I always felt like there was something else about me that didn't quite sit right – I didn't think I was depressed, and I wanted to know why I felt like I did and why I found some situations difficult. I struggled to manage or regulate my emotions, sometimes shut myself off from the world – even close friends, family members and partners – things just got too much and the only way I felt able to cope was to be on my own and not have anyone in my mental or physical space. I didn't always understand why some people didn't have the same views as me or respond in the way I would respond in certain situations. I struggled with busy places, lights, and noise. I often got frustrated with myself and thought 'What's wrong with me' and things like 'why aren't I normal' which is a word I try to steer clear from as much as possible now – After all, what is normal!?

At the age of 37, I decided I needed to finally get to the bottom of why I struggled with life. I kept a list, of all the times I had felt overwhelmed, of the things I found difficult, of my little routines and quirky ways, and decided I needed to speak to a GP. Because of my awareness of Autism, and that I am able to communicate articulately, I asked the GP for a referral to Adult Autism Diagnostic Services. I was met with a response of 'there aren't any in the area so I can't do that!'

Now because I'm often like a dog with a bone, and I felt so frustrated by the lack of answers I was getting, I took it upon myself to contact NHS Patient Assist with the question of 'how does an adult get an Autism diagnostic appointment'. This time, they were very helpful and told me that the service was just 4 miles from my home! I went back to the GP, saw a different Doctor and with my list and details of the service, asked again to be referred for a diagnostic appointment.

Stuck Inside Me

How Autism affects me



Twelve months later I was seen by the service and within a couple of months I had an Autism diagnosis. I feel quite lucky that I was able to get some answers finally, and I was also able to access some support services for a period of a few weeks – but unfortunately that is where the support ended for me. Don't get me wrong, the support I received was fantastic, but if I was offered that support once a week for the rest of my life then I would gladly take it.

I am able to communicate (most of the time) and able to explore my emotions and unpick what they mean – I was told I was quite self-aware. But for someone who isn't, or who doesn't have any knowledge of autism or how to get help, do they end up being missed off the radar? And how can someone who isn't as articulate or is non-verbal, get anything out of 8 sessions of post diagnostic therapy then be sent off into the big wide world with their diagnosis and very little support from anywhere else?

I have always worked, sometimes my work history was quite hit and miss, but as society teaches us from a young age, the expectation is to go to school, college and maybe University, then to get a job. Unfortunately, this expectation doesn't suit everyone – especially those with autism.

Every single day of my life is a struggle. I don't deal well with change – in my mind if something is planned and that plan doesn't happen or if it is changed it throws me off guard. I have my little routines and orders I do things in – I'm probably overly tidy, everything has a place and I find it hard when people come into my home and don't leave things the way they found them. I find public transport difficult and avoid it at all costs.

If I've had a bad experience somewhere before I will find it very difficult to go back to that place. I really struggle with busy places, certain smells, and bright lights – my senses get too overwhelmed, and it makes me feel anxious and unable to concentrate and like I have to flee the situation. If I am asked to go anywhere new I have to consider how it might make me feel, how many people will be there, will it be busy, how can I get home if I feel too overwhelmed. I sometimes find eye contact hard when I don't feel too great, which I have to try to force myself to do – it's a conscious effort. I'm also one of those people who tells it like it is – which some people find rude or not a societal norm. So, most of the time I have to think about what I want to say before I say it – which if you think about doing this on a daily basis, can be quite mentally draining.

Stuck Inside Me

How Autism affects me



Every day I worry about feeling overwhelmed – I have to plan my time and each day in advance, so I know what to expect. My mind is constantly in overdrive thinking things that I assume most neuro-typical people wouldn't even consider. I struggle to fall asleep and to stay asleep. And I think one of the biggest things I struggle with, and it happens at least every two weeks, is that I feel like I'm stuck inside myself. I'm fully aware that this might sound like a strange thing to say, and I have often had people say, 'there are people in worse positions than you' or 'you just need to snap out of it'.

Believe me, if I could snap out of feeling stuck inside myself I would do it in a heartbeat. I am fully aware that there are people in the world who are in worse positions than me – I'm not and never have disputed that. I can show emotion and empathise with people, but sometimes, when I'm stuck inside myself, everything just shuts down.

The best way to describe being Stuck as I call it is like you have been taken over by an imposter. Inside I know I am still there, my personality, my sense of humour, my interests, feelings for people I care about etc, but something stops me from being me and I feel trapped. I don't have any interest in doing things, I really struggle to even speak to people and see people, and I often shut myself off for a few days – sometimes weeks until I feel better.

I don't really want to be around anyone, and I find it hard to even do simple things like get dressed, wash, cook food for myself let alone go to work. I have to force myself to do these simple things – which again, is emotionally draining.

Now with a full-time job, this is quite hard. Just because I look OK on the outside, doesn't mean I am coping on the inside. Having a hidden condition is hard – you can't tell if someone is autistic just by looking at them, but put them in situations they find difficult, like change their routine, bombard them with too much information, force them to communicate when they don't want to, swamp their space, etc, then this is when you will see coping mechanisms come in to play. The way I cope when I feel too overwhelmed is by retreating, and eventually this ends up in me being stuck inside myself.

I often do too much, I say yes to things I really don't want to do because I know they make me feel overwhelmed – I try to fit in and try to mask how I feel sometimes so I can keep up with people and I can fit it to what society thinks I should be doing – but this is very hard and very draining. I'm slowly learning when I need to say no now.

Stuck Inside Me

How Autism affects me



In terms of my working life, luckily, I have an employer now who has put reasonable adjustments in place for me at work. I do a mix of hybrid working so some days I am office based and some days at home in my own peace and quiet. I don't have to travel to work during peak times as this is something that overwhelms me if I travel when it's very busy.

Some days I struggle to even make it to the office because I feel so stuck, so I am able to carry out tasks which don't involve a lot of communication at home – I am lucky to have an understanding manager. But not everybody is understanding. People don't always realise how hard it can be for someone just to turn up to things or even speak. I worry about what happens if I don't have this job forever and I don't have an understanding employer.

I have a lot to give – I am educated, have some really varied work experience and skills I can take to an employer. I am focussed and methodical in my approach to my work and have very good organisational skills, but sometimes, I find it hard, and I need time to recharge. I guess when I do feel stuck inside myself this is my body's way of healing my mind.

I hope that one day all employers and people in society in general, have a better understanding of autism, how it affects each and every one of us in different ways, and how easy it is sometimes just to ask us what will help to make things better.

Stuck Inside Me - How Autism affects me