## My experience of being diagnosed with Autism Spectrum Disorder as an adult…

In August 2017, still suffering from severe anorexia, I decided that this was my last straw, I needed answers. I dived deep into research, hoping to find a solution to my endless suffering. From an early teenager I was diagnosed with depression, anxiety and OCD. Nothing seemed to help though, not medication or therapy; I just thought that I had failed in life, and that there was no hope for me. Then I developed anorexia and I felt like an even bigger failure. I research Personality Disorders, something that I could kind of relate to. Unknowing that this has a lot of the same traits of Autism.

I visited my doctors, he knew me very well as I used to go at least 3 times a month, basically every time I had a massive meltdown, I would see him. Although I just felt a burden, he always reassured me that I wasn't wasting his time. He was the one that suggested I am Autistic, I had never considered this, I had the misconception that if you had High Functioning Autism you also had to be really clever, something that I didn't think of myself. I did a hell of a lot of research, told my therapist, her reply was "I thought you might be". So, why didn't she tell me? This made me wonder how many people knew I am Autistic, when I didn't have a clue.

My therapist decided to refer me to the ASD diagnosis team at the CWP (Cheshire and Wirral Partnership). I was sent a 17 page questionnaire; basically I had to tell them my life story and what struggles I have in life, so they had a better understanding for when they interviewed me. I managed to get seen within 4 months; because of my severe anorexia I was considered at high risk so was priority.

The day came, 22nd December 2017, the day of my diagnosis interview. The team is based at Bowmere Hospital in Chester, about an hour from where I lived. I was really anxious, then my thoughts turned to 'What if I am not Autistic, and that I am just a freak?'. Okay, so maybe a bit harsh choice of words, but that's how I truly thought. I had already researched every aspect of what the interview involved. I would be seen by an Occupational Therapist for 45 minutes, then a Psychiatrist for another 45 minutes. My dad would be in a different room with the other therapist and then we would switch. Not having my dad in the room with me terrified me, what if I said something wrong, what if I didn't give them all of the information they needed.

During the interview things started to click, the things that I had always considered to be normal, like being able to hear certain frequencies, such as electricity coming from a phone charger . I never realised I had Sensory Processing Disorder either, but then again I didn't really know what it was. I had always been this way, I didn't know any different. This is what makes it so much harder to explain to a neurotypical what Autism is, I have lived with it all my life, I don't know what is 'normal' and what isn't. It has taken a hell of a lot of research for me to be able to talk about it.

Once we had both been interviewed (at this point I was knackered from all the questioned asked), it was time to be reunited with my dad. I was so overwhelmed already, and they hadn't even given me an answer, another thing I was dreading. I had convinced myself that I was just different from everyone else, but when the words hit me from the OT and Psychiatrist "We both think you are on the Autistic Spectrum", I just froze. I had so many questions, but I had no time to ask them. It was up to me to find answers. The diagnosis service informed me that they would write a report, with a conclusion of diagnosis. Something that I would receive within 10 weeks. I wanted to know there and then, I had waited long enough. I needed to know the answer, but in all honesty I knew the answer. I am Autistic, always have been, always will be.

That day I was devastated, I had a massive meltdown, and thought my life was over. It took me a while to get used to the diagnosis, it overwhelmed me so much, I had no idea what to do. I had a lot of emotions running through my mind. I felt grief for my life, the feeling of not being diagnosed earlier really upset me, to this day I still get really frustrated about not being diagnosed earlier. I had to grieve for my younger years, the years that I found so hard because I did not know why I was so different to every other person. The thought that I could have had so much support throughout school and university, I thought I was just really dumb. I now realise that I can only learn in certain ways, and the way that I was taught at school did not suit my learning style.

I revisited the ASD diagnosis service in April 2018 to receive my official diagnosis, by this time I had a lot more understanding of Autism, but still unknowing where I could get help. Then I came to the realisation, finding help as an Autistic adult is near impossible in England. Cue more anger at not being diagnosed as a child. I had my diagnosis; it was up to me to choose how to plan my future. Being Autistic makes it very hard for me to make decisions, I normally try to get reassurance from my dad, sometimes I am too scared in case I make a wrong decision in life. And, I have made plenty of them already.

I decided to give therapy one last chance. This time Psychotherapy, something that I had never had. I thought it might work, because I knew my diagnosis. I had about 3 sessions, realised it wasn't going to work, but my therapist willed me to give it a chance. Most sessions were wasted making a map of my relations, which we never actually used. It just felt like counselling. I turned up, told her my issues, she couldn't fix them, I left more confused and upset. Looking back on it I know why therapy never really worked for me, it was because none of the therapist I saw had any (or little) understanding of Autism. A lot of the time I just confused them with my Autistic traits. I realised that the only good feeling that I took from therapy was that I was able to tell my problems to someone, but I found that they were rarely listening properly. This is something that really annoyed me, I have always felt like my voice or opinion never really mattered.

*I have now given up on therapy and am feeling considerably better writing a blog when my mood is low instead of chatting to someone about the way I am feeling.*

*In September 2019, Cheshire and Wirral Partnership ASD team created a monthly Adult Hub. Until this point, I had never considered talking to fellow Autistic people about my experiences. I was very happy when I turned up to the first session to realise the lady that diagnosed me was leading the meetings. It did take me a couple of sessions to find my voice, but once I did, I realised that the group has helped me in a way that therapy didn't. The people there understand and relate to what you are going through, we help each other out. We listen to one another; we have empathy for each other. Empathy is a thing we struggle to get off a neurotypical, mainly because most of them will never understand what we go through in life. This group has given me confidence to talk openly about my experiences living with autism. Seeing how much other Autistic adults struggle in the world makes me very upset and frustrated, why should they have to suffer. I took it upon myself to offer my experiences to the NHS, as they said that I can be of help to their services. I don't see myself as anyone special or inspiring, I can see how I am brave in a way, but that's the only way I can be alive. This is what I have to go through to have a life. I struggle, but it could be a lot worse.*

*Being diagnosed helped me so much. Yes, it would have made my life a hell of a lot easier if I would have been diagnosed in childhood. Although, I will not let my years of suffering go to waste. I will use my experiences to help others (something that brings me a lot of happiness).*

*It is all about how I can help myself, how I can change my life for the better. I am Autistic and hate change, but I want to be productive with my life, I want to do things. The thing that I don't want is to be stuck in the same routine every day for my entire life. Yes, that would be a safe option, I would have less meltdowns, but that is no life for me. I need an adventure, something that will stimulate my mind.*

*I've got a few exciting projects lined up, so watch this space!*

*Love*

***Amanda***