

Colouring Outside The Lines

Ask The Experts...

This is the third in a series of Ask The Experts publications designed to connect parents of autistic girls with autistic women.

As parents of autistic girls, members of Colouring Outside The Lines were asked what questions they would like to ask autistic women in order to help them support their daughters as effectively as possible. As a group, we strongly believe that by connecting our daughters with the autistic community, especially autistic females, we can ensure that their future is bright and their minds inspired.

Our first group of experts have kindly agreed to respond to various questions about school, support, diagnosis, relationships & careers.

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Rose Hughes

This is Rose Hughes. She is 24 and was diagnosed at 23 with Female Asperger's Syndrome.

Alongside this, Rose is diagnosed with Bipolar/BPD and anxiety/depression. She also has Addisons Disease, EDS and Hypo-Thyroidism!

However, this list is merely a summary of the adversity Rose has faced to become a well known mental health and Autism advocate.

She is also a qualified personal trainer who has a vast social media following and a blog. Her family reside in Belgium and she hopes to one day complete her Masters in Speech and Language Therapy.

What are the best bits about being autistic?

Having been diagnosed in January and still going through the acceptance phase I struggle with this question. Having said that, I know that there ARE times I feel more positive towards it.

I think the best bits about being Autistic for me are related to how open-minded it has made me. I don't seem to be phased by anything and therefore, I don't judge people. I have a heightened sense of understanding, despite the silly assumption that we cannot empathise.

Alongside this, the fact that I can see outside the box is likely what has set me apart from others. I have never struggled to do a good job and I am very thoughtful. I note that I am much more giving in relationships and very sweet and sentimental. Despite my own issues, I tend to really take care of my partner.

I think my Autism is also why I have always strived in the workplace. I tend to be an 'over-worker' and have always felt so valued in each job I've done because I don't do anything less than 100%.

Did you have an early 'diagnosis'? Did that help? If not, do you think an early 'diagnosis' would have helped?

I wish I had known earlier but unlike my parents who were diagnosed at 46 and 50, I actually tend to argue that I am glad I didn't know. (Roses's mum has added the following: "Had we known, I would have got you more help, support and understanding at whatever school you were at. And my reasoning for an early diagnosis was that other people would have understood your differences, or at least tried, and not constantly battered your already poor self-esteem by constantly telling you to "try harder", "stop being so naughty", "concentrate". Without the diagnosis we and everyone else expected you to behave "normally" and constantly told you off when you didn't. You were also seen as a "strange" child because your behaviour was not as expected. An early diagnosis would also have meant that we understood you better and could treat you accordingly. As well as not constantly feeling like failing parents.")

However, I don't want to change that. I think I suffered and I struggled but it has made me who I am today. I am strong and I think everything comes at the time it needs to. To be honest, I am still unsure. I know knowing has improved my life, helped me to have an 'excuse' for needing different things and helped me because I was struggling in sales driven workplaces.

How can parents can help their daughters to understand/accept their 'diagnosis'?

When it comes to your daughter understanding and accepting their diagnosis, I think the NUMBER ONE thing is to not set a time limit. It doesn't always take 6 weeks and it might not even take less than a year. Acceptance can take the person as long as they feel necessary. I know that for me, I accepted it before I was officially diagnosed but even now my Mum has to try and respect that sometimes I don't want to read into it and I don't want to talk about it or relate EVERYTHING back to my Aspergers.

It's good to ask them, what they think would be most helpful. Some girls probably won't even want someone alongside them, they may want to deal with it privately. Pressure is awful.

My 15 year old has previously spoken very positively about her autism, but now she seems to be hating being autistic - how can I help?

Although I am 24, I have similar moments! This, I think, is all part of the acceptance of who you are becoming and the stigma attached to any label. I know that I aaaalways wanted to just be 'normal'. My Mum and I fall out about this because for her, being told she is Aspie (as she calls it) at 46 years old, was incredibly cathartic for her. (In fact- we just had another over this question). I know that for her, she 100 percent is pleased to be Aspie. She is PROUD. She does however dislike that her family are because she knows in a way it means we suffer more. (Rose's mum adds: "I'm not 100% happy and often feel sad and frustrated with my Aspiness. But on the whole it makes me happy to know that there are reasons for my problems and that things I couldn't understand about myself for 46 years were finally explained. That alone is incredibly liberating.")

For me, finding out meant another label, but one that is in a very stigmatised, misunderstood box. I don't see many people, like myself, as representatives of Autism. Instead you see the extremes plastered across magazines and Hollywood etc and this makes you feel uncomfortable. I struggle to wear the label and accept it as my skin because I see myself as the same as my neurotypical friends. I am not willing to enjoy being 'weird' or 'quirky'. HOWEVER, there have been many times where I have felt quite the opposite and I have happily stood up and broadcasted it. I have embraced being Autistic and the assumptions people make of me because of it. I think for any young woman it isn't easy to accept and there will be more moments of denial as opposed to acceptance. I don't know why, but for me I never felt shame or discomfort saying I have depression or anxiety or BPD or Bipolar syndrome but to admit I am Autistic has not yet become something I find easy. I only 'came out' whilst working at the National Autistic Society because of a Channel 4 programme I am on. This and many videos, social media blogs etc helped me to feel more comfortable and maybe being back in Belgium, where Autism is not really 'a thing', has made me retreat into myself again.

How can I let my daughter know I empathize and support her, without stressing her further? She won't let me hug her...

It must be so tough to not be able to hug because we all feel this is the first thing to do when someone is upset. But if you've asked permission to hug and someone very quickly says NO and seems ready to blow, the best thing you can do is to just put your own emotions aside and try to sit there. If, for example, you can maybe touch their hand, and see if that creates more or less conflict you can access from there.

A simple presence can be enough at times. Other times people may want complete space. If a girl hates any company whilst she processes you have to learn to respect that. Maybe during a time the girl ISN'T upset, you can discuss the best way for you both to deal with these things. Ask her if she maybe wants to have 5 minutes alone, knowing you will come and check on her every 5 minutes. Ask her if you can stroke her hair, touch her hand, maybe there can be a blanket she hugs or a stress item she can use and you can see these things as a sign not to approach. I know that when someone makes it clear that MY FOUL MOOD is making THEM upset, I then get worse, angry and upset when I JUST WANT silence and to be left to brood over what I am feeling.

Were you in a mainstream school? Did you receive any support? Would a school especially for autistic girls have been better for you?

I went to 2 primary schools in Kent. I went to Secondary School in Paddock Wood. At 11 I moved to Switzerland. I went to a Swiss International School and an American High School. I was asked to leave. At 15 I was moved to Belgium to a British International School. Shortly into that, I was expelled. After a year out, I went to boarding school in Sussex.

Until I went to the Boarding school I went through hell. Teachers hated me. Schools didn't want me. I was not naughty but I was SEEN as naughty. I was misunderstood. I was weird. Someone at boarding school just had the ability to treat me in a way that worked and I managed to pull myself together and get some A Levels. What I remember the most about school is how disliked I was and how poorly teachers treated me. I wasn't diagnosed with anything except depression. I did odd things and I hated rules that didn't make sense to me. I used to wander off and I did lie and do things I shouldn't at a young age.

I have considered what an Autistic specific school would have been like for me and most of the time, I don't think I would have liked it and I don't think looking back that is what I would like to have done. I don't know though. This for me is really tough because I think being higher functioning and being obsessed with being like the girls I know, I struggle to believe I would have had the same opportunities and become such an inspirational presence on social media had I not have attended mainstream schools. I think I wouldn't have been so ill or lost or expelled so often had I had the label and been better understood.

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