



THE TRUTH ABOUT WOMEN AND AUTISM

Alis Rowe is an entrepreneur and has a first-class degree in chemistry. She also has high-functioning autism. Here, she talks about why it's different for women and how she navigates her days. Interview by *Marina Gask*

'AUTISM ISN'T JUST MANIFESTED

in symptoms such as severe shyness. Shy people can be pulled out of their shell, but for me, autism is like being permanently trapped in a glass jar. The jar represents the barrier between you and the world, meaning that you're an observer, never a participant in life. But I believe there are holes in the jar, and someone you feel comfortable with – like a family member – can shine a torch to light them up, so you can come out occasionally.

There's a lovely woman in Kent who has a daughter on the autism spectrum. They use my glass jar theory to communicate with each other, with the daughter being able to tell her mum when she's feeling particularly anxious and doesn't want her to force her to come out. They're now able to understand each other better.

Helping other "aspies" communicate is one of my proudest achievements since setting up my social enterprise, The Curly Hair Project in 2013. The initiative is dedicated to supporting women and girls with autism and Asperger's syndrome, providing training for teachers and NHS staff. My role involves writing books, and giving seminars at schools and exhibitions around the UK. Women experience autism differently from men and, through The Curly Hair Project, aspies can find support, books, information and people they can identify with, often for the first time.

Today, at 26, my life appears pretty good. As well as the project, I run a successful business, working remotely as a web developer for vet surgeries. Some aspies can achieve a great deal: Ladyhawke (musician Pip Brown) and actress Daryl Hannah are both on the autism spectrum. For myself, while I'm close to my mum, dad and sister, Dulcie, my happiness is fragile and my movements restricted. Life needs to be predictable. I've lived in the same semi-detached home in south west London all my life. It's my security and having a routine makes me feel safe.

RULED BY ROUTINE

Running The Curly Hair Project is so rewarding, but it also takes its toll. Using public transport brings on anxiety (I wear earplugs as the noise is painful) and I'm also hypersensitive to smells (a whiff of ►

rubbish can make me want to throw up). I struggle with all the attention when public speaking, so I make sure others play an active role. And the fact that I also have obsessive-compulsive disorder means that I have to wash my hands immediately after hand-shaking.

I'm doing valued work, but in spite of the great people I've met, I don't have any close friends. Fellow aspies have opened up, but I don't feel close enough to share my feelings. I'm scared of people saying the wrong thing when I'm unhappy because it can make me feel even worse. Most of my friendships are conducted online.

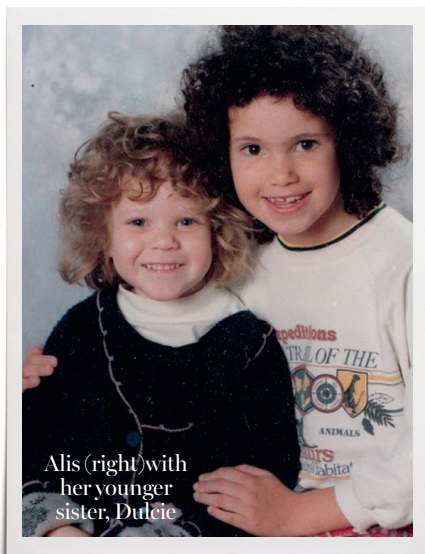
As a result of my symptoms, there's this layer of depression that's always pressing me down – and the only way I can guard against this, apart from sessions of cognitive behavioural therapy and taking anti-depressants, is by sticking to my strict routine. This means a 5am paper round, walking my dog Bear, looking after my seven cats and lifting weights in my home gym each day.

I'd say I'm very typically autistic, but there are variations, like the aspie I met who's extrovert. She struggles to recognise social boundaries, which means she can seem overwhelming. A common giveaway sign of autism is body language. I'm aware that most of the time I come across as "awkward", most likely because I feel it. I work so hard to say the right things and be a good listener – I don't consider my body language or facial expressions.

I met my partner, a student, five years ago on Match.com. When we met, I told him I was autistic and, realising it was the only way our relationship would work, he moved into the house opposite. We've learnt a lot about the condition together, but I'd never live with him unless he moved into my home, where I'll be living for the foreseeable future. I'm definitely not having children. I've no idea what will happen when my parents are elderly, but I imagine that I'll care for them.

GROWING UP DIFFERENT

I was a hyperactive child – at primary school I was just considered "quirky". But that all changed when I was 11 and got to secondary school. My world fell apart: I realised I couldn't join in with conversations and withdrew into a ball of social anxiety. I shunned attention, and just stopped speaking. I literally didn't say



Alis (right) with her younger sister, Dulcie

I've lived in the same family home all my life. Having a set routine makes me feel safe'

a word. I got bullied mercilessly, tripped up and tormented for being weird.

By 14, my anxiety was off the scale, and I was also very uncomfortable in myself. I didn't like boys, clothes or make-up, so I was convinced I was the wrong sex. Excruciatingly shy, I told no one. This was when the suicidal thoughts started. With intense, negative emotions, aspies often have meltdowns, typically involving screaming, crying and even becoming aggressive. For me though, it's shutdowns. As a teen, I just withdrew into myself, retreating, emotionally exhausted, to the safety of my room for hours.

At college, with 11 grade-A GCSEs, I tried so hard to fit in, but the strain was enormous. How do you tell your friends

they make you anxious? Socialising revolved around pubs, where the noise would be too much (and I've never had alcohol because I don't like trying new things). I did join friends for a couple of meals, but I was overwhelmed and couldn't speak. As they all drank and relaxed, a gulf opened up. By the time I'd got three A-levels, a first-class chemistry degree and a Masters, I was mentally exhausted from trying to be like everyone else. I knew from browsing symptoms online at 17 that I had autism, and my diagnosis at 21 meant that I could get psychiatric support, which has helped immensely. But it never goes away.

WHAT THE FUTURE HOLDS

My ambition? To make a reasonable salary, help others and grow my business. I'm jealous of today's autistic girls, now that awareness of the condition is improving. My lonely teens would have been vastly improved if I'd read a novel like *M Is For Autism* when I was feeling suicidal. It's co-written by the pupils of Limpsfield Grange, a school for autistic girls where I sometimes do seminars, and it really helps you get inside the head of a girl on the spectrum. There are still a lot of young women who suffer from overwhelming anxiety and don't know why, who might recognise their symptoms.

I've worked hard to get here and I'm proud to be using my experiences to help others. Thanks to the love of my family and partner, I don't have to spend every moment inside the glass jar.' ■

M Is For Autism by the students from Limpsfield Grange School And Vicky Martin (£8.99, Jessica Kingsley Publishers); Thegirlwiththecurlyhair.co.uk

FEMALE AUTISM: THE FACTS

- Often considered a 'male' condition, girls and women may wait longer for a diagnosis of Asperger's syndrome (high-functioning autism), says the National Autistic Society. Its 2012 survey showed that one fifth of girls with Asperger's were diagnosed by the age of 11, compared to half of males.

- Girls can be more adaptive than boys and may be better at hiding their 'difference'. Female symptoms may also be less severe, including struggling with social cognition.
- No statistics exist on the number of women on the spectrum, but many experts believe that large numbers of

girls go into adulthood without a diagnosis, often unconsciously mimicking friends or masking the signs of autism. This can lead to secondary problems such as anxiety, eating disorders, OCD, Tourette's syndrome, self-harm or depression.

- The National Autistic Society helpline is on 0808 800 4104