

# WHAT IT FEELS LIKE... TO LIVE WITH AUTISM

For Alis Rowe, 26, from London, being diagnosed with Asperger's syndrome explained a lifetime of never fitting in



## → WHAT YOU NEED TO KNOW

There are an estimated 700,000 children and adults with autism and Asperger's syndrome in the UK, more than one in 100 of the population. Here's the lowdown:

**WHAT IS IT?**  
According to the National Autistic Society, autism is a lifelong disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world. People with autism have difficulties in three key areas, known as the triad of impairments: social communication (difficulty with language, reading body language and facial expressions, and understanding jokes); social interaction (understanding social norms, other people's emotions and expressing their feelings); and social imagination (predicting behaviour, planning for the future and coping with change). Many also have over- or under-sensitivity to sounds, touch, taste, smells, light or colours.

Autism is a spectrum disorder, which means people are affected in different ways. Some have learning difficulties and need specialist support, others have successful careers and relationships. Asperger's syndrome is a form of autism. People with Asperger's share the triad of impairments, but are often of above-average intelligence.

Not feeling understood can lead to mental health issues. 'Eating disorders, OCD, anxiety and depression are common in those on the autism spectrum,' says consultant clinical psychologist Dr Judith Gould, spokesperson for The National Autistic Society. At present, males with autism outnumber females by an estimated four to one. 'Girls can be better at masking difficulties,' says Dr Gould. 'But we could see numbers balancing out as we become better at diagnosing females.'

**GETTING DIAGNOSED**  
The first port of call to getting a child diagnosed is seeing your GP for a referral to a specialist. Diagnosis is possible from age two, and can help children get the support they need at school. An adult diagnosis can come as a huge relief, says Dr Gould: 'It can help you understand why you've struggled all your life. It can also help partners understand a partner with autism, and may help with problems at work.' There's no cure for autism, but people can learn to manage it. **D**  
For more info, see [autism.org.uk](http://autism.org.uk); call The National Autistic Society's helpline on 0808 800 4104.

“Asperger's is often called an invisible condition. I may look normal going about my daily routine, but no one can see the massive amount of effort that goes into processing information other people take for granted. A casual conversation can be like decoding a foreign language.

I also live with constant anxiety. Every day needs to go exactly as I've planned, as I get anxious whenever my routine changes. Every time I leave the house I'm faced with challenges. A loud noise like the sound of a motorbike raises my anxiety levels, so I wear ear plugs. But what's worse is smells – some make me feel nauseous, like the smell of bananas or perfume. One of the reasons I prefer to cycle rather than use public transport is to avoid smells.

I was quirky child and a bit hyperactive, but not badly behaved. I have loving parents and a younger sister, and had a few friends at primary school – young children are accepting of eccentricities. It all changed when I went to secondary school. I never fitted in because I wasn't interested in fashion or pop music like the other girls. I became a loner and was bullied.

Just being surrounded by that level of noise and the sheer number of people inside a mainstream secondary school all day was traumatising. Looking back, I can see I was suffering from depression and anxiety. But I was doing well academically, so no one thought there was a problem.

University was better as I only had one subject to concentrate on, chemistry, which I loved. The timetable was less hectic and I went to my local university so I could live at home, and only go in for lectures. I chatted to people, but because I wasn't involved in the social scene, I didn't create long-lasting friendships. I graduated with a First, then did an MSc, then started working in computer programming. I found the work easy, but struggled with being in such close proximity to other people for hours at a time. I only lasted a few months, and left, to start up my own consultancy specialising in websites

and internet marketing for vets' clinics. I've always loved animals and have a dog and six cats.

Shortly afterwards I went to my GP and started the process of getting a diagnosis. I first began to suspect I may be on the autism spectrum around the age of 17. I'd come across information on the internet and recognised some of the characteristics. I was referred to a specialist and the relief at finally being diagnosed with Asperger's, an autism spectrum disorder, was enormous. I was 22; it was like being given permission to be me for the first time in my life.

After my diagnosis I was hungry for information, but much of it was aimed at boys and men. So I started writing about my experiences and posted them online. That became my autobiography, *The Girl With The Curly Hair: Asperger's And Me* ([amazon.co.uk](http://amazon.co.uk), £7.52). The Curly Hair Project grew from there, a social enterprise dedicated to supporting females with Asperger's and other autism spectrum disorders (ASDs). I organise workshops for parents, teachers and NHS staff on communicating with and helping girls and women with ASD. I contribute via Skype; it means I don't have to travel.

I live with my parents, can't go out to pubs or clubs and rarely go shopping, so that restricts my social life. But I've discovered Olympic weightlifting and work out every day. For me, a healthy diet, good sleep and regular exercise are essential for managing anxiety and depression.

Some people believe autism brings benefits; for me, it will always be a disabling disorder. But I've made some good friends, and also met a supportive man through match.com who's taught me a lot about relationships. I can't see myself having children, but maybe one day I'll get married.

See [thegirlwiththecurlyhair.co.uk](http://thegirlwiththecurlyhair.co.uk).



Weightlifting and sleeping well help Alis manage her anxiety

Compiled by Sally Brown. Photograph Getty