Charlotte's Story: My Experience Receiving an Autism Diagnosis on the NHS

Centre for ADHD & Autism Support

Before Diagnosis

I always knew I was different. It might sound extreme, but most of my childhood felt like surviving a war zone of sensory and social missiles. From the stress of morning assemblies to the chaos of the canteen and the fear of judgement about my eating habits, school was a daily endurance test.

Being asked even a simple question in class could put my nervous system into overdrive. And yet, if you'd asked me if I liked school, I would've rattled off a rehearsed list of reasons why I did. I thought everyone else struggled too, so I leant to mask. So expertly, in fact, that even now people find it hard to believe the reality of my inner experience.

I was frequently told I'd make a good actress. It makes sense now: when you spend a lifetime analysing people to survive, you develop a natural ability to mirror. I've always needed recovery time after socialising, always been labelled sensitive or an "old soul," and even my childhood nickname included the word chameleon.
I remember feeling so offended when a classmate once said, "you don't have a personality, because you act differently with everyone". They weren't wrong, even if I of course had a true personality, but I could only use it when the world felt safe enough for me.

Masking let me survive, but it cost me my health. At 38, after an unfair dismissal at work triggered intense emotional collapse, I reached burnout: not just from stress, but **autistic burnout**.

Getting Diagnosed

To me, the line between mental and physical health is artificial. Neurodivergence, trauma, and stress are physical. They have an impact on our energy levels, digestion, neurology, etc. After 1.5 years of barely existing, I received a formal diagnosis by 40. What a special 40th birthday gift! And they say autistics don't get sarcasm.

Once my GP referred me, I waited about a year. The assessment included the ADOS (observational) and the ADI-R (a structured developmental interview). For the latter, a parent or close person is usually interviewed. While the process was transparent and professionally handled, I noticed the limitations of diagnostic tools, especially for adults and women.

Late diagnosis brings its own layer of grief, confusion, and adaptation. None of which are considered in standard assessments. A later diagnosed patient's behaviours often differ entirely from younger individuals, but this isn't adequately accounted for. Still, I was relieved and grateful to finally receive my diagnosis. It brought validation, but also an emotional reckoning no one warns you about.

After Diagnosis

The relief was real. So was the grief. Thankfully, I had already been reading extensively and following lived-experience voices, which helped. But ongoing support is minimal. Beyond a few leaflets and general signposting, I was left to navigate things alone. Resources are geared towards parents or children, which can feel infantilising, especially for "high-functioning", late-diagnosed adults. It felt like a dead end. What has helped is the voices of other late diagnosed autistics: in forums, blogs, and social media, who told their truth, filled the gaps, and reminded me I wasn't alone.