

Social Communication & Autism Spectrum and Neurodevelopmental Assessment Services Great Ormond Street

Hello and welcome to our autism spectrum assessment clinics.

You may have been referred to us for an assessment, or you may be thinking about going for an autism assessment.

We thought you might like to hear from some young people who have already been through assessment, and have received a diagnosis of autism ('autism spectrum'), about what it meant to them, and what they would have liked to have known before going for an assessment.

We would like to thank the Youth Patrons from Ambitious About Autism (a charity), for answering our questions and we hope that you find their answers interesting and useful. To protect confidentiality, we have not used any names.

If you have any concerns or questions that you would like to ask us before you come for an assessment with us, please ask your parents to contact us.

We look forward to meeting you!

What did getting a diagnosis mean to you?

"At the time I didn't really understand as I was not necessarily there for a diagnosis, it sort of just ended up that way but I was grateful that I was now given something to allow me to understand myself better"

"Seeking a diagnosis made me feel powerful and that I could finally move on with my life understanding myself and knowing that being different is good"

"I was much too young to remember my diagnosis. As long as I can remember, I've known that I'm autistic. So the questions about getting a diagnosis, I don't really have an answer to".

"At the time that I got the autism diagnosis, I didn't really understand what it meant. But as I got older, experienced bullying in secondary school then some difficult transitions into adulthood, I was really grateful that I understood why I was different and how I could help myself. Otherwise, I might have internalised the more damaging labels people gave me even more than I already did!"

"Getting a diagnosis was necessary as proof that I'm not inherently broken for being myself, and that there were other people like me".

"Getting a diagnosis meant that my parents had clearer knowledge of why I was anxious, sensitive to noises and had a lot of intense school refusal due to anxiety and stress every morning. It also meant that I was able to get some of the support I required such as a statement go get me one to one support and alert all teachers that I was vulnerable, though this was more due to a highly competent senco. I was only seven at the time

when I was diagnosed and was not informed until I was 10 and could not understand myself properly until I went to a specialist school. But it did explain as to why I was different to the mainstream majority”.

“I was too young to remember my first diagnosis. I feel like I could mention a lot though. I had ace helpers. S was one of my helpers when I was in primary to secondary school for example. They went with me to most classesuntil the end of GCSE”

What do you think young people going for an assessment need to know or would benefit from knowing?

“It's nothing to be worried about or to be ashamed of. Despite the stigma and stereotypes, autism can be an amazing thing and it has a lot of benefits that a lot of neurotypical people may not understand”.

“Going for an assessment can be daunting but its worth it and you can take someone with you if that would make the process a bit easier”

“The process often focuses on your difficulties, but remember you also have huge strengths related to your autistic traits. And that nobody can predict what a child's future will be, whether they're autistic or not!”

“Getting a diagnosis isn't the end of a journey—it's part of a much longer one to understand what works for you and what doesn't. In addition, what you need help with may change over time with life pressures and responsibilities. So much of an adult's time and energy is devoted to the essentials, regardless of autistic status!

Also, even if you're the one who searches it out, a diagnosis can really change the way you view yourself. For me, while I'd say my diagnosis was ultimately a blessing, it was also the source of a lot of pain and doubts for my future. I want to emphasise the 'blessing' part though, and I believe it would have been far worse to be blindsided by future problems as opposed to being able to prepare myself slightly in advance”.

“That the assessment does not involve anything medical, the doctors will only examine their behavioural history from birth. So I think young people going for an assessment should know that they seriously must be absolutely honest with every question the doctors ask and not to feel at all embarrassed about the answers they give as honesty is the most important to make the diagnosis accurate”.

What would you say to your younger self about the process of autism assessment and diagnosis?

“Wear it like a medal of honor, it isn't the wound people tell you it is”.

“I would say be brave and my younger self as I never wanted to acknowledge my difference but now I champion it I all that I do”

“Autism isn't a bad thing and doesn't have to be scary - there's a lot of misinformation out there, but with the right support, autistic people can thrive. And it's okay to ask for help or admit you're finding something difficult!”

“I was only seven at the time and my parents were in control but it started by a primary school teacher noticing it on me, being referred to a specialist for tests as they thought it would be useful, then a year later being formally diagnosed by a doctor in London. But overall I have little memory or knowledge of the detail”.