

Diagnosing adults with autism

The autism diagnosis process can seem like a long and daunting experience. This information sheet is designed to give you a step-by-step guide to what you might expect to happen throughout the process. The information sheet is based on the best practice guidelines written by the National Institute for Health and Care Excellence (NICE).

“**First concern**” is a term used to describe the first time someone notices something which might be concerning. For example:

1. You might have noticed that you or the person you care for is having difficulties.
2. You may have read something about autism or seen something on television which you can relate with.
3. Your child might be undergoing the diagnostic process, and you have noticed that you have similar traits.
4. Someone working with you or the person you care for might have noticed some difficulties.
5. You or the person you care for might show more difficulties in one environment compared to another.
6. Difficulties might appear after a major life change, like a change in employment, or the loss of a family member.

Go and see your GP if you think you or the person you care for might be on the autism spectrum. Your GP will need a reason to refer you for diagnosis, so explain to your GP why you think you are on the autism spectrum, and give some examples of difficulties you have experienced in adulthood and in childhood. If you are already seeing another health or social care professional (for example a psychologist), you can also speak to them about this.

If your GP agrees to refer you, you should ideally be referred to a multi-disciplinary team which might include a psychologist, psychiatrist and speech and language therapist. However, this may not be possible in all areas, so you may be referred to an individual psychologist or psychiatrist. They should have some experience of diagnosing autism to ensure that you are accurately assessed.

The autism assessment – These are things that should happen during the autism assessment:

1. At the beginning of the assessment, staff should explain to you what will happen during the session. If you agree, someone who knows you well (parent, carer, advocate etc.) may be included to support you during the process.
2. Staff should ask you about any communication needs and sensory sensitivities so that they can make adjustments to the process where necessary.

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3. During the assessment, the professionals will want to get to know you so that they can identify your areas of strength and difficulties. They will ask you about your early life, home life, college or work, and if you have any mental or physical health problems. They will also ask you about how you cope with social situations.
4. You may be referred on for additional tests if professionals suspect you have additional problems (for example sight or hearing tests).

After the assessment – If you have been diagnosed with autism, you may be sent a written report detailing your particular strengths and difficulties. The team of professionals may also give you information on what services and support are available to you after diagnosis. However, this may not happen for everyone. If you have any questions about your diagnosis, you can call the Autism West Midlands information helpline on **03 03 03 00 111**.

What if I am not diagnosed?

If you are not diagnosed, the assessment team may send you for further assessment for another condition. If you do not agree with the outcome of your assessment, you can go back to your GP and ask for a second opinion. However, it is important to remember that the second opinion may reach the same conclusion as the first.

Can I get a private diagnosis?

You can pay to have a private diagnosis. However, some service providers may not accept private diagnoses and may ask that you get an NHS diagnosis.

What do I do if my experiences don't match up with the best practice guidelines outlined by NICE?

The NICE guidelines are set out as recommendations for best practice. It is not mandatory for people to follow them. However, if you are not satisfied with the diagnostic process, you should speak to a member of your healthcare team about your concerns.

Useful resources

You can call the Autism West Midlands information helpline if you have any questions or concerns about your diagnosis on 03 03 03 00 111.

NICE guidelines: Autism spectrum disorder in adults: diagnosis and management - <https://www.nice.org.uk/guidance/cg142>

Information for the public about the NICE guidelines <https://www.nice.org.uk/guidance/CG142/ifp/chapter/About-this-information>