

## An introduction for parents and carers

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 your child having difficulties.
2. Someone working with your child, for example at school, might have noticed your child having difficulties.
3. Your child might show more difficulties in one environment compared to another.
4. Difficulties might appear after a change in routine, or a change in school.

**Go and see your GP** if you think your child might be on the autism spectrum. It is your GP who will make a referral for your child to be seen for diagnosis. You will need to show your GP why you think your child needs to be referred, so document any concerns and behaviours you have before you go and see your GP. If your child is at school, speak to the school SENCO about what you’ve noticed. They may have some information about how your child is doing at school, and they may be able to offer support in helping your child get a diagnosis.

**Referral** - If your GP believes your child may have autism, they will refer you to a specialist autism team for diagnosis. Best practice guidelines state that the team should be multi-disciplinary – this means that there should be different professionals working together to assess your child’s difficulties. The team might include a paediatrician, a child and adolescent psychiatrist, a psychologist, a speech and language therapist, an occupational therapist and a paediatric neurologist.

**Receiving the referral** - When the autism assessment team receives the referral, they may recommend an autism assessment or an assessment for another condition. If they are not sure whether to assess your child, you may need to have a consultation with one member of the autism team to decide if a full assessment is needed. If they recommend an autism assessment, the assessment should start within 3 months of the referral. One member of the team will be designated as the child’s case coordinator, and they will be your main point of contact. They will explain the assessment to you and make sure you get all the information and support you need.

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

1. Each member of the autism team should speak to you and talk with and observe your child. They will need to find out about your concerns, how your child is getting on at home, at school, and in other environments, your child’s health, and your family’s health, your child’s development and your child’s behaviour.

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2. Your child should be evaluated for other conditions like visual or hearing impairments, cerebral palsy, language difficulties, mental health problems and learning difficulties.
3. Your child should receive a physical examination.
4. Once each professional has met you and your child, the team should meet and discuss their findings together. Each professional should write down their findings and gather all the information together. This information should include the child's strengths, skills, difficulties, needs and what support the child might need to learn, communicate, care for themselves and help with sensory issues and behaviours of concern.

### After the assessment

1. The autism team should share their findings with your child's GP, and if you agree, other professionals involved in your child's care like school or social services.
2. A member of the autism team should talk to you and your child about the results of the assessment soon after it is completed and give you a written report which explains all the findings.

**If your child is diagnosed with autism**, you should be offered a follow-up appointment with a member of the autism team 6 weeks after your assessment so you can ask any questions you have. You should also be given information on where you can access support in your local area.

### What if there are uncertainties, or my child is not diagnosed with autism?

If the autism team is not sure whether your child has autism, they may send them to another specialist team for further assessment. If they do not diagnose your child with autism, they may refer you to other specialists if they believe this may be helpful.

### 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

Autism West Midlands has created a post-diagnosis support pack, which you can buy on our online shop at [shop.autismwestmidlands.org.uk/products/autism-information-pack-for-parents](http://shop.autismwestmidlands.org.uk/products/autism-information-pack-for-parents).

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

NICE guidelines: Autism spectrum disorder in under 19s: recognition, referral and diagnosis - <https://www.nice.org.uk/guidance/cg128>

Information for parents and carers about the NICE guidelines <https://www.nice.org.uk/guidance/cg128/ifp/chapter/information-for-parents-and-carers>