



Waiting for an Autism Diagnosis Appointment

This leaflet is for people who are waiting for an appointment to determine whether or not they may be autistic.

We understand the waiting list can be long, so this leaflet will hopefully answer questions you have about:

- What you can do whilst you wait for your appointment.
- What to expect before the appointment.
- What to expect during the appointment.
- What happens after the appointment.



About this booklet

This booklet was written in January 2022. We try to ensure the information we provide is accurate at the time of research.

We understand that language and the views of the autistic community evolve, and we are aware that this booklet may not be in keeping with these changes.

This booklet was written by the Adult Team at CAAS, with input from multiple members of staff who are all either neurodivergent or have neurodivergent family members. Our hope is to try and produce a well-rounded document that is applicable to as many people as possible.



About CAAS

From working in the field for 25 years, personal experience of staff, and through talking and listening to ADHD/autistic people we have an in-depth understanding of the needs of our clients and how to support them.

We provide information, training, support groups, and practical help to residents of NorthWest London. Our support services encompass education, benefits, parenting, and care advice with signposting to other agencies if appropriate. We also offer specialised parenting courses, workshops, and training.

We aim to support, educate and empower individuals diagnosed with ADHD or who are autistic, their families, and the community.

Through raising awareness we change perceptions and break down barriers.

Whilst waiting for a diagnostic appointment

The waiting list for a diagnostic appointment can be years. This can feel like a long time, so what can you do whilst you are waiting?



Learn

You can:

- Learn about autism from books, watching content from autistic social media creators, or websites and blogs.
- Reflect and think about what the symptoms that led you to seek a diagnosis mean to you.
- Look into how other autistic people do things you find difficult- and look into what coping strategies are suggested for autistic people to help you with things you find hard.

It might be helpful to make notes on anything that resonates with you or you feel represents you, for your appointment. It could help you answer questions about the things you find difficult or your differences.



Join a support group

Many support groups, social groups, or online forums will accept people who are "on the pathway" to diagnosis, or waiting for an appointment. Sometimes spending time with other autistic people can help you through the diagnostic process, and also help you learn about coping strategies.

If you need to talk to someone

If you need to talk to someone, return to your GP. Just because you are waiting for an appointment doesn't mean that you can't ask for more support. It might be that your GP can offer you more support or services- such as counseling, mindfulness, or talking therapies (IAPT).

If you need to talk urgently here are some organisations who can listen:

Samaritans

116 123 (24 hours a day, 365 days)

Email: jo@samaritans.org

Webchat: <https://www.samaritans.org/how-we-can-help/contact-samaritan/chat-online>

Campaign Against Living Miserably (CALM).

Phone: **0800 58 58 58** (5pm–midnight every day)

Webchat: <https://www.thecalmzone.net/help/webchat>



What to expect before your appointment

Before your appointment, you will be asked to fill out some questionnaires. These will ask you about what you find difficult, and how you experience the world. They can seem long and repetitive at times, but fill them out as best you can. They are to get a rough idea of what your differences are, but are not a conclusive diagnosis by themselves.

If you have someone in your life who knew you as a child, they might be asked to give their account of your differences. They may be sent a questionnaire and be given a separate appointment to you.

What to expect at your appointment

At your appointment, you will be asked questions about your childhood. You will also be asked questions about what you find difficult in your life. The questions may feel similar to the ones you already answered on the questionnaire.

You may be asked to share documents from other clinicians and services if you have any.

You can request to be by yourself at your appointment if you would feel more comfortable talking with the clinician privately.

You can also request to have someone present to support you.



When will I find if I am autistic?

You may be told at your appointment, or find out when your report arrives by post or email.

Whether you are told at your appointment or have to wait for the result, you will receive a report from the clinician you spoke to at your appointment.

It will detail what was spoken about at the appointment, as well as information from the questionnaires you (and possibly other people) filled out. This will create a full picture of what your differences are, and why the clinician has come to their conclusion based on the information given.

What to expect after your appointment

If you received a diagnosis of autism read the report carefully and make sure it represents you. If you feel that there is information missing, incorrect information included, or you feel you have been misunderstood let the diagnostic service know.

The report may contain recommendations, resources, and information. If you have been given recommendations you may need to follow up with your GP. For example, if the clinician has recommended counseling or talking therapy.

If you did not receive a diagnosis of autism, and you disagree with this conclusion you can get a second opinion. You will need to go back to your GP and ask for a referral to another clinician or team.

If you aren't sure what to do next go back to your GP who may be able to signpost you to other services.

You can also email CAAS at: adults@adhdandautism.org

We will happily send you a copy of our Post Diagnosis booklet for newly diagnosed autistic adults which has information on what you can do once you receive your diagnosis.