



Information for Newly Diagnosed Autistic Adults in North West London

This booklet is for newly diagnosed autistic adults.

We hope it provides you information and some useful resources.

This booklet contains information on:

- What is autism?
- How you might feel about your diagnosis.
- What happens next.
- Exploring what support is available.
- What CAAS can do to support you.
- Resources and information

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.

What is autism?

Autism is classed as a lifelong developmental disability that affects how people perceive the world and others around them. It is typically referred to as autism, autistic spectrum, or an autism spectrum condition (though clinicians will often still use disorder). The word 'spectrum' was used because, while all autistic individuals share certain areas of difficulty, it will affect them in very different ways.

Autism is lifelong but is by no means a life sentence. It is not a disease that needs to be 'cured'. With the right support, autistic people can live happy and fulfilled lives.

The language we use to describe autism is really important. CAAS tend to use the term 'autistic' rather than 'has autism' following research published in the Autism journal in 2015 which looked at the language used. Although there was no single preferred term across individuals, parents/carers, and professionals, it found that autistic adults prefer identity-first terms like autistic. It is important for CAAS to reflect that preference in our practice.



The key areas of difference needed to be given a diagnosis of autism are:

- Differences in social communication and interaction.
- Restricted, repetitive patterns of behaviour, interests, or activities including sensory difficulties.

Examples of difficulties with social communication:

- Not being able to speak or being 'selectively' mute.
- Difficulty using and understanding appropriate body language/facial expressions or tone of voice.
- Echolalia or repetition of words/phrases.
- A literal understanding of language.
- Wanting to interact but struggling with initiating a conversation or small talk, preferring the conversation to focus on their interest.

Examples of difficulties with social interaction:

- Difficulty reading other people, recognising their feelings or intentions based on context.
- Social anxiety and misunderstanding of unwritten social rules.
- May find it difficult to form or maintain friendships.

Examples of restricted, repetitive patterns of behaviour, interests or activities including sensory difficulties:

- Some autistic individuals have a strong preference for routine and sameness due to the unpredictability of the world around them. Some may find new and unfamiliar experiences stressful, threatening and confusing.
- Some autistic individuals may have special interests, which can be important for their wellbeing.
- Many autistic people experience the sensory world differently which can cause both pleasure and distress.

Feelings About Diagnosis:

After you have your diagnosis it is normal to have strong feelings about the diagnosis itself, and also the process.

Your feelings, regardless of whether they are positive, negative, or neutral are valid. Allow yourself time and space to feel.



You may feel that you've found your tribe!

Finding out you are autistic might be a relief.

- You may finally be able to put a name to what is going on in your life.
- You might finally be able to understand yourself.
- You may feel a sense of relief that you are not broken, not weird, and are just you.
- You may have always known you were different and now you realise- you were right!



You may feel nothing.

Finding out you are autistic might leave you feeling unchanged.

- You may have already known you are autistic, so this information is nothing new.
- You may not know how to feel.
- You may feel neutrally.

You may feel unhappy.

Finding out you are autistic might be daunting.

- You may feel sad.
- You may feel angry.
- You may feel grief.
- You may feel confused.

These feelings may change, give yourself time.



If you need to talk to someone

The diagnostic process can be hard. If you are need to talk here are some useful numbers and websites:

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>**

SANEline.

Phone: **0300 304 7000** (4.30pm–10.30pm every day).

Campaign Against Living Miserably (CALM).

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

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

What happens next?

You may be wondering "what happens next?"

The simple answer is, that is up to you.

Remember Recovery!

The autism diagnostic process is draining. You may have been on the waiting list for year, then had to fill out multiple forms and questionnaires, and then meet with a doctor and talk for hours. That's a lot!

Reflecting on all your differences can be emotionally taxing and you deserve a break.

It is self-care, self-love, and recovery time!



When you are ready

Once you have recovered you may be thinking what do I do now?

There is no right answer to this. It is up to you.

You may need to think, process, and reflect.

If you need time, give yourself time. You don't have to do anything right away, or even do anything at all.





You may want to read, watch, and learn all you can about autism.

You may want to learn as much as you can, join forums, follow social media accounts, get hold of books, and watch videos about autism.

You may want to find other autistic people.

You might be keen to meet other autistic people, to socialise or learn through shared experience.



You may want to do nothing



After you find out you are autistic you don't have to do anything. You may have gone for a diagnosis for many reasons, but you don't have to do anything with that information. You are still you. Nothing has changed, and nothing needs to change if you don't want it to.



You may go through periods of wanting to do everything, then feel disengaged. Your feelings may change, and the amount of time you have to think about things may change.

Whatever you decide, do what is right for you, when you are ready to do it, at your pace.

Exploring what support is available.

The support and opportunities available to autistic adults vary depending on where you live.

Sometimes the best place to start is on Google!

adult autism support



Searching for "adult autism support" in your area might bring up results of local charities and organisations run by your local authority.

You could look directly on your local council website- councils will often have a directory of services.



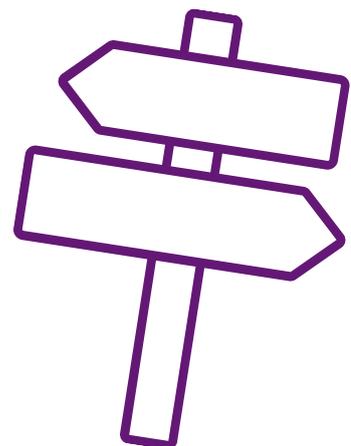
How to start

Have a think about what you want.

Are you looking for:

- advice
- information
- benefits
- mental health support

- a social group
- a support group
- a therapeutic group



- a walking club
- a running club
- sports and fitness clubs



- a hobby/ interest club
- art or crafts
- music or choir



It can be easier to refine your search if you have an idea of what you want.



Where else to look

Local Facebook groups

Online Meet-Up sites, such as www.meetup.com

Local authority online directory

Council or boroughs "local offer"

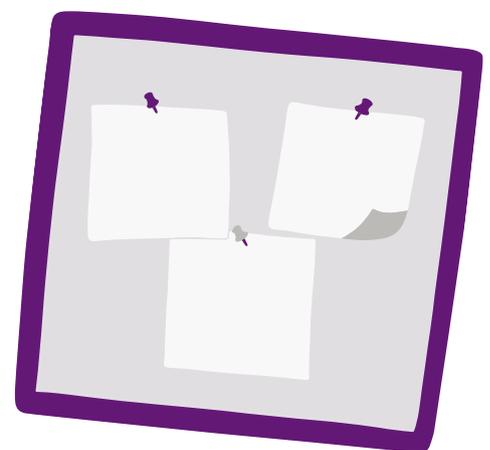
Local Community Hub or Centres

Leisure Centres

Local Charities

Local Libraries

Local notice boards in supermarkets, shops, or cafes



What CAAS can do to help?



CAAS is able to support autistic adults living in Brent, Ealing, Harrow, Hillingdon, Hammersmith & Fulham, Hounslow, Kensington & Chelsea, or Westminster.



Understanding My Autism Group

A group for autistic adults to learn more about autism, and what being autistic means to you.

The group will run simultaneously in person at our centre in Eastcote (Piccadilly and Met line) and via Zoom.



PIP Workshop

We will be running a PIP workshop to support autistic adults, and their supporters, in answering PIP forms.

We have created a series of videos breaking down the questions and how to answer them, and will also be offering question and answer workshops.

These workshops will alternate between being held at the Adult Hub (Eastcote Met/ Piccadilly line) and streamed online via Zoom, and Zoom-only sessions.

NWL Project- Individual Support

Our one-to-one service is specific to autistic adults and assists clients to manage aspects of daily life linked to their differences, that they may find challenging. i.e., difficulties with organisation skills making it challenging to complete a form or make phone calls.

We can support adults who:

- Are over 18 years old.
- Are either diagnosed or on the pathway for an autism assessment.
- Do not have a co-occurring learning disability



Parents, Carers, Supporters of Autistic Adults Drop-In

Once monthly Zoom meeting for parents, carers, and supporters of autistic adults.

The drop-in offers the opportunity to meet other parents and supporters in a similar situation.



Contact us

If you are interested in Individual Support, the PIP Workshop, Understanding My Autism Group, the Parents and Supporters Drop-In, or if you have any questions please email us, visit our website, or go to our socials:



@caasadulthub



adults@adhdandautism.org



@caasadulthub



www.adhdandautism.org

Sharing Diagnosis

As a newly diagnosed autistic person, you may wonder if and when to tell other people you are autistic.

It is up to you. You don't have to tell anyone at all, or you can tell everyone you meet. What is important is that you are happy, but also understand that not everyone understands what autism is, and they may have wrong or outdated ideas about autism.

It might be that as well as telling people you may also have to educate them or answer questions they have.

Just remember; once you have told someone you can't "untell" them- so maybe have a think and weigh it up.



Potential benefits of telling people in your life

- They can learn how to support you.
- You can be open with them- it can create an open discussion and honesty can lead to stronger relationships.
- They may be more understanding if you struggle.

Potential difficulties of telling people in your life

- They might react negatively.
- They might not understand.
- They might not believe you.
- They might tell other people without your permission.

Only you can know who the trusted people in your life are, and whether or not you would like to share.

Potential benefits of telling people your employer

- They can learn how to support you.
- You may be able to work more efficiently with support or adjustments.
- They have a legal obligation to support you under the Equalities Act 2010- with things like reasonable adjustments. Reasonable adjustments are changes that are made to ensure workers with a disability are not substantially disadvantaged when doing their jobs.
- They might be able to work with you to create a more neurodivergent-friendly workplace, not only for you but for others.
- Legally your employer must keep your diagnosis confidential.
- You may be eligible for financial support from the government Access To Work scheme.

Potential difficulties of telling people your employer

- Even though there is legal protection in place to protect autistic people, some companies may leave you out of a promotion or opportunities. If you feel this happens to you, you can challenge it as it is classed as discrimination and is illegal.
- You may be treated in a way you don't like- this could be due to a misunderstanding of what autism is and what you need. This could be rectified through education and communication.

More information: www.gov.uk/browse/disabilities/work

Autistic Adults NW London Trello Board

www.trello.com/b/qVjC7adv/autism-resources-nw-london



Here is a link, and QR code, to our Trello board. It is a collection of resources, links, and information for autistic adults in NW London.

We have chosen to include the Trello as it is updated frequently and we can ensure the information on it is relevant and up to date.

Some of the topics found on the Trello:

Daily Living Information:

Housing ,Benefits, Legal advice, Advocacy

Learning:

Books, Websites, Blogs, Podcasts

Autistic or Autism Friendly Social Media channels:

YouTube, Instagram, TikTok, Facebook

Mental Health support information

Apps and technology

NW London borough specific information

Other NW London Organisations

Haringey Autism- Support for parents of autistic children
<https://www.haringeyautism.port5.com/>

ALAG- Asperger London Area Group- Social group.
<https://alag.org.uk/>

#Actually Haringey- Support, information, and groups.
autismhub@haringey.gov.uk

HACS- Hillingdon Autism Care and Support
<https://www.hacs.org.uk/>

NAS ASSIST Ealing and Hammersmith and Fulham-
Support, information, and groups.
Telephone: [020 8962 3015](tel:02089623015)
E-mail: assistlondon@nas.org.uk

Resources for Autism.
www.resourcesforautism.org.uk/

National Organisations

National Autistic Society- Information and groups.
www.autism.co.uk

Autism Links- Directory of information.
www.autismlinks.co.uk

Autism UK- Information and groups
<https://autisticuk.org/>