

Diagnosis of autism as an adult



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Autistic people are autistic for their whole lives. Autism is not something that you grow out of and it is not an illness that is cured. Autistic children grow up to be autistic adults.

While the recognition and diagnosis of autism in children has improved greatly in recent years (though there is still a very long way to go), there are many autistic adults who have not been formally diagnosed autistic. Some may recognise that they are likely to be autistic, others may have no idea at all.

This resource looks at the issues and process of a diagnosis of autism as an adult, as well as offering advice on supporting newly diagnosed autistic adults.

Why seek a diagnosis?

If and when to seek a diagnosis of autism as an adult is a very personal decision. Any people need time to come to terms with the idea that they may be autistic before beginning the formal diagnostic process, and others may feel that there is nothing to gain from being diagnosed and that they will be subject to prejudice and discrimination if they are.



In some cases, self-diagnosis can be sufficient, and many autistic people recognise self-diagnosis in others to be completely valid, having experienced the difficulties of getting a formal diagnosis themselves.

There are three main positive arguments for securing a formal diagnosis as an adult. They may not all apply to all individuals, and some may carry more weight than others with a particular person.

Legal protections

In the UK, autism can be a protected characteristic under the Equality Act 2010. The law says that you are disabled if “you have a physical or mental impairment, and that impairment has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities.” Autism will often meet this definition, according to its impact on the life of the person concerned.





Whether you consider autism to be a disability or not, the benefits offered by this Act in terms of protection from discrimination and entitlement to reasonable adjustments can be extremely valuable.

Access to support

It can be much easier to access support once your diagnosis is confirmed. Some formal sources of support may require this for you to access their services,

and the certainty in yourself that a diagnosis gives may make it easier for you to seek help and advice.

The autistic community is a huge source of support and while a formal diagnosis is no requirement for participation, it may help your confidence in getting started and feeling that you belong.

Understanding who you are

For many, the best part about a formal diagnosis is the explanation it often gives for difficulties that they have been struggling with for much of their lives.



An autistic person who has not been diagnosed and does not recognise that they may be autistic can very easily spend a lot of time thinking that there is something wrong with them as they are so different to others, and no understanding why they face the difficulties that they do.

A diagnosis can offer an explanation and an affirmation that they have every right to be their true selves.

How is a diagnosis made?

The diagnosis process can be hard to access and take a long time, both to get started and to complete. There is no simple test for autism based on a blood sample or something similar - autism is a behavioural and sensory difference and is diagnosed by analysing these factors.



The place to start in getting a diagnosis is always to talk to your doctor, and to be prepared to push for a diagnosis if you meet resistance. Sadly, knowledge of autism in adults and the need for a diagnosis is not as widespread as would be most helpful.

The diagnostic process will generally be carried out by a specialist and will be based on talking to the subject. They may also be observed in how they carry out tasks, and friends and family, particularly parents, may also be spoken to (with permission).



The assessor will focus on areas where autistic people are often different, such as sensory issues, social skills and focus on special interests.

Before going for the assessment, you may want to think about times when you have felt particularly different and what has made you consider that you may be autistic.

It can also be helpful to be able to quote instances of issues that arose during your childhood. It is usually acceptable to take some notes with you of things you want to be sure to mention, and the assessor may welcome this.

By the time they reach adulthood, many autistic people have become very good at masking autistic behaviours and instead copying others in order to fit in more in society.

Autistic women in particular are known to be very good at masking in this way, which is a factor in why autism is believed to be hugely under-diagnosed in females. Masking is exhausting and is often very bad for mental health, so do try to be your true self both during a diagnostic process and more generally where possible.





Dealing with a diagnosis

A diagnosis of autism in no way changes who you are, but it may well help you and others understand better why you are as you are. Autism is not an illness and does not need to be cured – it is a difference.

A diagnosis of autism is in no way saying that there is anything wrong with you.

People's reactions to a diagnosis of autism can vary widely (just as autistic people themselves vary widely!). There is no right or wrong reaction – respond to the diagnosis and move forward in the way that works best for you. Many autistic people feel huge relief at the diagnosis as it offers an explanation for many issues they have faced, but this is not the case with everybody. You should also remember that there can be many positive aspects of autism and it is not a negative condition even if it is often portrayed as such.

You will need to consider who you tell about your diagnosis and when you tell them. Again, this is an entirely personal matter and may need particular consideration in terms of telling your employer. Whatever your situation, it is worth giving this some thought in advance.



Common Misdiagnoses

Unfortunately, it is far from unknown for autistic traits to be misdiagnosed as other issues by medical professionals who do not recognise autism in adults. This is not deliberate, of course, but it is always worth considering a second opinion and getting an autism diagnosis can require a lot of persistence.

One problem is that every common autistic trait can be attributed to other conditions or personality types. For example, difficulty with social situations may be put down to being shy or introverted, and hypersensitivity in one or more areas may be assessed as a sensory processing disorder.

If you encounter these kinds of issues but are still keen to be properly assessed for autism, one idea is to make a list of the traits that you believe that have and ask for them to be considered as a whole rather than individually, which may not give a complete or accurate picture.

How to help and talk with an adult who has been diagnosed

The best thing that you can do for an adult diagnosed as autistic is to listen to them. Hear what concerns them, what they would like to find out more about and where they think they need





help and support. Always talk to them, not about them as if they were not present. Do not seek to push your views or ideas on them, but gently introduce suggestions that align with their expressed needs if that would help, such as sources of support and information. Above all, let them know that they are not alone and have your support.

An autism diagnosis is a beginning and should not be seen as a negative event. It explains a key part of who you are, and it will enable you to access support to be your true self.

It may take you a while to get used to your diagnosis and for it to sink in, and that is completely fine. Above all, the diagnosis does not change who you are and it is not about putting a label on you - all autistic people are unique and completely different from one another.

Autistic people can be and are happy, successful and valuable members of society. A diagnosis is not a barrier but a helping hand to be whatever you want to be.

