

AUTISM Q&A

Are you autistic or think you might be? If so, you might have questions about what autism is and how being autistic might affect your future. From understanding what causes autism to identifying the main symptoms, we'll attempt to answer your questions here.

If there's anything else you'd like to know, please just get in touch.

www.autism-assessment-online.com

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AUTISM SYMPTOMS

DIAGNOSING AUTISM

LIVING WITH AUTISM

RESOURCES

2. WHAT IS AUTISM?

Q: What exactly is autism?

A: Autism is a condition formally known as Autism Spectrum Disorder (ASD). Autistic people face challenges with social interaction and communication. They may also engage in repetitive behaviours, have intense interests and often have sensory processing issues. People are born with autism. Whilst symptoms often become evident in early childhood, many autistic people do not discover they are autistic until adulthood.

Q: Is autism the same as Asperger's Syndrome?

A: Autism Spectrum Disorder is divided into 3 levels. Level 1 covers what would have, in the past, been categorised as Asperger's Syndrome, which was removed from the Diagnostic and Statistical Manual of Mental Disorders in 2013.

Level 1 Autism refers to people of average or above average intelligence who can lead mainly independent lives.

Q: What is Level 2 and Level 3 Autism?

A: Level 2 Autism includes people with more apparent difficulties who need support. They will struggle more with communication and may have very restricted interests or behaviours. People with Level 2 Autism may or may not have learning difficulties. People with Level 3 Autism require significant support and may include people with learning difficulties.

Q: Does that mean Level 1 Autism is mild?

A: Not at all. Although people with Level 1 Autism might find it easier to lead independent lives and have average or above average intelligence, calling their autism "mild" minimises how much impact being autistic has on them. Although they share symptoms, people across the different levels of autism face very different challenges from each other, none of which are necessarily easier or harder to deal with.

Q: What causes autism?

A: We're still learning more and more about the causes of autism. What we do know is that it is a developmental condition, which means that people are born autistic. It's not something they develop in childhood or later in life. Studies show a strong genetic link, and most autistic people will have autism somewhere further back in their family, even if those people have never been diagnosed.

Q: What is the "autism epidemic" that people go on about?

A: Increasingly more people are diagnosed with autism than they have been in the past. This includes childhood diagnosis and people who are diagnosed as adults. This has led to some people calling it an "autism epidemic". The increase in diagnoses is because of a growing awareness of autism and its presentation in people who may not have been diagnosed in the past, as opposed to an increase in the number of autistic people.

Q: My child is autistic. Does that mean I'm likely to have autism too?

A: Given that autism has a strong genetic link, you are more likely to be autistic if your child is. However, autism may have come from your child's other parent's genetic background, or autism may have missed generations. Although there is a strong genetic link, there may be other potential causes of autism, and our knowledge in this area is constantly increasing. So, having an autistic child does not necessarily mean that you are autistic too.

Q: Is there a cure for autism?

A: Autism is a developmental condition, and there is no cure for it. However, autistic people can lead happy, productive and fulfilled lives and rather than thinking about a cure, we can think of how we can lead our best autistic lives whilst learning about and managing any symptoms which cause us problems.

Q: I've read a lot about women's autism being different from men's?

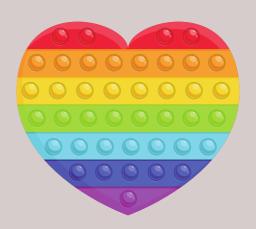
A: Girls and women often have different interests from boys and men and may make more of an effort to camouflage their autistic symptoms to hide their autism from other people. This, and the fact that girls are often more sociable than boys, means it is often easier for autism to be detected in males than females, and women are under or misdiagnosed.

Q: Do all autistic women camouflage?

A: Both autistic and neurotypical people tend to camouflage to some degree and present a version of themselves which is appropriate for the workplace, friends and other settings. Autistic women tend to camouflage more than other groups of people but not all autistic women camouflage to a high degree.

Q: I've got a family, job, and friends and have lived my whole life. Can I really be autistic?

A: People who grew up with less awareness about autism, particularly females who are good at camouflaging their autistic symptoms, often perform well in the workplace and have close relationships with others. Leading a completely independent life, which might include a successful career and family of your own, is entirely possible whilst being autistic.



2. AUTISM SYMPTOMS

Q: I have a whole range of autistic symptoms, but I can't remember having them in childhood. Am I autistic?

A: Sometimes it's hard to remember our childhoods, but if your symptoms are having a negative impact on you as an adult, it's unlikely you would not have noticed them as a child. If you suddenly went from being happy, relaxed and outgoing to developing sensory issues and feeling socially awkward, it is very possible that your symptoms are related to other life events.

Q: Is it true that autistic people have special skills?

A: Many autistic people are exceptionally skilled in some areas, including noticing detail, developing systems and certain creative pursuits. Their heightened capacity in some areas means that some employers seek out autistic people. Most autistic people, however, are not "Savants" who might have extremely unusual skill sets.

Q: I'm a bit confused about the symptoms. I love my work and am very into the subject. Is that a restricted interest or just something I like?

A: Many people have an interest they are passionate about, which doesn't necessarily mean they are autistic. One question to ask yourself is how impactful your interest is. Does it affect your relationships or have a negative impact on your health? Would you describe yourself as so obsessed with it that it is hard for you to think about anything else? Do you only want to talk about your interest to other people and have no interest in talking about anything else? In this case, it could be an interest which points towards autism. Another issue to consider is whether you had any intense interests as a child or teenager and how intense these interests were compared to your peers.

Q: I don't like loud noises. Is that a sensory processing issue?

A: Many people, including autistic and neurotypical people, dislike loud noises. If you have a sensory processing disorder, you are likely to find other noises intolerable to the extent that you find it difficult to stay in a room with a particular noise. Sensory processing issues have little to do with simply "disliking" something. Instead, you will experience a very intense reaction to triggers, which is often felt in a physical way. Sensory issues may include sound, touch, taste, smells and visual triggers. They will have been a part of your experience since childhood.

Q: I've got a really good imagination and enjoy creative writing and painting. Can I be autistic? Many autistic people are highly creative and may have a special talent for remembering visual information or words. Whilst some autistic people struggle with imagining things, others spend a lot of time in their imaginary worlds.

Q: I've heard that autistic people lack empathy, but I think I'm very empathic. Does this mean I'm not autistic?

Some autistic people struggle with empathy or having a sense of how other people feel. Others might struggle to understand how to show empathy, although they feel very deeply for other people. Some autistic people are highly empathic and feel things at a deep level. They might sometimes struggle to know what is going on in someone's mind though. Being empathic does not mean that you are not autistic.

Q: I love stroking certain fabrics and feel that some colours massage me. Why is this considered a disorder?

A: The word disorder is often used with regard to sensory processing experiences. Whilst they can be problematic at times, sometimes these differences provide a wonderful alternative experience of the world.

Q: I have a history of trauma and I'm not sure whether my symptoms are due to autism or past trauma?

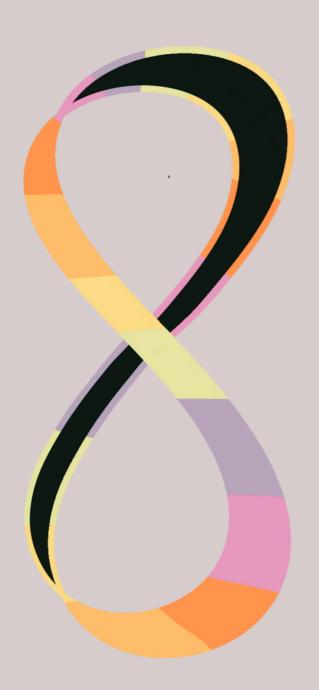
A: There can be an overlap of symptoms, which is why accessing an official diagnosis is important if possible. One question to ask yourself is when your symptoms appeared. If they weren't there as a child, they are more likely to be the result of past trauma or another condition.

Q: I play with my hair and pick my nails. Is this a sign of autism?

A: One symptom of autism is repetitive behaviours, which may include "stimming" type behaviours. Unless behaviours are unusual and very strongly indicative of autism, including rocking, swaying and head-banging, it's difficult to establish whether they suggest autism or whether they are simply anxiety or soothing related behaviours which many people might display.

Q: What are the main social or communication symptoms that point towards autism?

A: Autistic people experience problems including misunderstanding what people mean, processing verbal information slower than most people, not knowing when to enter a conversation, having problems when interrupted, and finding it hard to talk about anything than their specialist interest. Some autistic people become very quiet and others provide excessive levels of detail and find it hard to read communication cues which prevent a comfortable "toand-fro" of conversation. Autistic people often struggle greatly with small talk and find it hard to be in social situations, which can feel exhausting and upsetting. Sensory issues and a need for routine can exacerbate social problems for autistic people who, despite their best efforts to fit in, often feel as if they are singled out as "weird" or socially inept.



Q: I can't tell whether I'm just very shy or autistic. A: Shyness and social anxiety present very similarly to autism in many people (although some autistic people don't have any social anxiety). Firstly, if you are shy or socially anxious, you are not autistic unless you display some of the other diagnostic criteria (including repetitive behaviour, restricted interests or sensory processing differences). Secondly, it is useful to consider your childhood. Were you shy in all situations? Or did you only become shy when you started school? Have you always felt socially awkward or did it start after an event in teenage years or early adulthood? Autistic people live with social and communication problems every day and, although they may be completely comfortable with some friends and family members, there will be tell-tale signs earlier in life. Friends and family might have noticed conversation patterns including coming across as rude, repetition, interruption or talking for long periods of time on subjects of interest to the autistic person which all indicate potential autism.

3. DIAGNOSING AUTISM

Q: I don't have a diagnosis. Can I call myself autistic?

A: If it's possible, seeking out a diagnosis is advisable. Autism may share symptoms in common with other conditions. Without the assistance of a healthcare professional trained in autism assessments, it is possible to mistakenly identify your symptoms as autism when they may suggest a different condition. However, given the expense and waitlists for autism assessments, some people have no choice but to research autism and identify as autistic, often while waiting for an official evaluation.

Q: How long will I have to wait for a diagnosis?

A: For a full psychiatric diagnosis on the NHS or other free healthcare system, you can expect to wait several months or years. If you have a private assessment, wait times are likely to be far shorter.

Q: Who can diagnose autism?

A: For a full clinical diagnosis, which not only diagnoses autism but diagnoses alternative mental health conditions or neurological disorders, a psychiatric assessment is required. A psychiatric diagnosis of autism will go on your medical records and is an official diagnosis. Clinical Psychologists can also make clinical diagnoses. Therapists who are trained in autism assessment methods, such as ADOS-2 make be able to offer their opinion on whether you are autistic or not. This is not a clinical diagnosis and will not appear on your medical records. A trained counsellor. speech therapist or other type of therapist may work as part of an inter-disciplinary team, in which case their assessment will contribute to a psychiatric evaluation, or they may work independently in which case they can offer a non-clinical assessment.

Q: I've scored quite low on the screening tests. Does that mean I'm not autistic?

A: Anything below a "borderline" score is suggesting quite strongly that you are not autistic. However, the tests are difficult to complete and people often find the questions confusing. Some questions are outdated and do not match the experience of women, in addition to lagging behind in terms of our knowledge of autism. For these reasons, a borderline score does not rule out autism.

Q: Does a high score mean I'm autistic?

A: Not necessarily. People can score higher on tests because they misunderstand questions or they have another condition which leads to some autism-like symptoms. Some people receive high scores based on current experience and did not have symptoms in childhood, which suggests they are less likely to be autistic.

Q: What do the screening tests mean?

A: Screening tests have been developed over many years by psychologists, psychiatrists and academics. They are designed to show whether you might have autism, based on your answers to questions about autism symptoms. Because they have been tested against the experience of non-autistic and autistic people, your answers can be compared to people with autism and those without. Different screening tests are designed to explore different autistic symptoms. Based on comparison with many other people, your score will suggest whether you are likely to have autism or not.

Q: How do I get a NHS (or similar) assessment?

A: Visit your GP in the first instance. They will ask you to complete a screening test called the AQ-10. A score of 6 or above is required to suggest possible autism. Provide your GP with as much additional information as possible as to why you think you are autistic and ask for a psychiatric referral.

Q: How many people are involved in the assessment?

A: The diagnostic process will vary depending on who you see. A NHS assessment may include being assessed by a team of healthcare professionals, including a psychiatrist. There may be one or more people present during your assessment. Private assessments will more often be conducted by one person.

Q: How long will my assessment be?

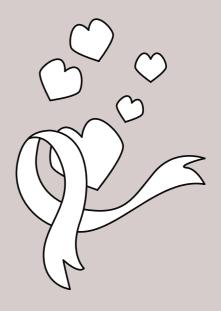
A: You will have at least one interview, which will probably be between two to three hours. During this interview, you will discuss your autistic experience. The interviewer will also draw on your parent/s' testimonial, if available. The interviewer will also be assessing how you act and communicate during the interview. Assessment methods such as the ADOS-2 rely on what is observable during your time together.

Q: Do my parents have to be involved?

A: You will be given the opportunity to include a written testimonial from your parents and their contribution is extremely valuable. Some people do not have access to their parents for this information, however. You will fill in a form which details some of the reasons you believe you are autistic.

Q: How long will I have to wait for an assessment?

A: If you are accessing an assessment through the NHS or similar "free" healthcare provider, you may have to wait several months or years for an assessment. Privately, the wait times are far shorter and will depend on your service provider.



Q: I've read that autism is often missed in girls and women?

A: Until recently, there has been little awareness of the different presentation of female autistics, leading to under and misdiagnosis. There is more awareness but some healthcare professionals remain less familiar with female presentation. If possible, you should try and find someone with experience of assessing autism in females.

Q: I've read that the ADOS-2 doesn't always pick up autism because people are good at masking?

A: The ADOS-2 is only ever used as part of an overall assessment. Particularly with adults, who may be skilled at camouflaging their symptoms, the ADOS-2 will be used in conjunction with the information you can provide about your experience in everyday life and with your parental testimonial if you have one.

Q: I'm worried that I'll have an autism assessment which reveals I'm not autistic.

A: People often think that an autism assessment will provide them with the answers they're looking for as to why they struggle with aspects of life. For autistic people, a diagnosis is very helpful. However, if you have been struggling, wrongly thinking that you are autistic will prevent you from receiving the right support and implementing the right self-care measures. Discovering that you have a trauma history, are socially anxious, have a mood disorder or generalised anxiety (amongst other conditions) will help you access the right help and support. All of these conditions are every bit as impactful as autism, and all require self-awareness and compassion in moving forwards.

4. LIVING WITH AUTISM

Q: I'm autistic. Will I need medication?

A: Autism is not a condition which is medicated. However, if you are autistic, you may experience anxiety, depression or other mental health conditions. In conjunction with your GP, you should explore whether medication is appropriate.

Q: I'm scared my life as I know it is over.

A: If you've just recently been diagnosed, you may feel worried about your future. Remember, you're exactly the same person you were before your diagnosis. You just have more knowledge than you had before. This is empowering. You can have the same life as before, but you'll be able to meet your needs and navigate it far more effectively. Or you might find that your previous life wasn't working for you and you need to make some significant changes. Most people notice a significant improvement in their life post-diagnosis.

Q: How should I tell people?

A: You are under no pressure to tell people or to tell everyone. Stay in control of the process and be prepared for comments such as, "But vou don't look autistic". Develop some confidence about what autism means for you before sharing and don't feel pressured to share with people who you know will dismiss your experience (at least, not until you feel confident enough to deal with them!). This is your diagnosis and you need to take ownership of it in a way that is right for you.

Q: Will I still be able to work?

A: If you were able to work before your diagnosis, you will be able to continue working. You may find work easier because of your understanding of autism and you may choose to share your assessment with your employer. Some people find that they consider a change in career after discovering they are autistic, which should be considered in a sensible and financially viable manner.

Q: Can therapy help with autism?

A: As an autistic person, it is likely that you have experienced some issues in life which are related to being autistic. Therapy can help you work through relationship, career, communication and other issues. When you visit a therapist skilled in working with autistic people, they will be able to explore the role autism plays in your life whilst they help you in specific areas.

Q: Do I need to tell my employer if I am autistic?

A: You do not have to disclose to your employer that you are autistic. If you choose to do so, your employer must keep any medical information you might share with them private. Many people do decide to share that they are autistic at some stage, in which case your employer is legally obliged to make any recommendations which might help you cope as an autistic person in the workplace.

Q: Can I claim benefits as an autistic person?

A: This is something to discuss with the benefits agency in your country. Depending on how autism impacts you, you may be able to claim benefits.

Q: My friends/ family/
partner don't believe l'm
autistic, which is upsetting.

A: People often find it hard to acknowledge that their friend, child or partner is autistic when they have received a diagnosis in adulthood. This is usually due to a lack of knowledge about how autism can present in adults. Friends and family can also feel anxious if their loved one has received a diagnosis. They may worry that you will change in some way or have concerns about your future relationship. Encouraging them to learn about autism and talk to you about your experience is important. Nobody has the right to disregard your experience but equally, you may be far further along the road in terms of your knowledge and you might have to be patient whilst other people catch up.

Q: Now that I know I'm autistic, I think I have been misdiagnosed with Bipolar Disorder/ BPD/ Depression (or similar). Should I stop taking my medication?

A: You should never stop taking medication without the full support of your GP or psychiatrist. Autistic people often have other mental health conditions at the same time, and medication may be required to manage these conditions. Stopping medication can be dangerous and should be done in a controlled manner, with medical support. If you have recently received an autism diagnosis, speak to your healthcare provider for further advice.



5. RESOURCES

There are various charities and organisations which provide support and advice for autism (details are offered of UK and USA organisations and other countries may have similar resources). Some provide online meet-ups and some provide face-to-face groups. In addition to larger organisations, there are various online support groups which are not officially monitored. As with any group, a lack of official monitoring can have adverse effects.

In addition to groups, self-help books can be a great starting point for understanding more about autism and providing guidance on how to proceed. Online magazines and blogs can also provide useful information. As with all unregulated and unmonitored sources of information, it is important to remember that not all information on the internet is accurate.

UK: National Autistic Society https://www.autism.org.uk

USA
Autism Society
https://autismsociety.org

Asperger/ Autism Network https://www.aane.org

BOOKS & PUBLICATIONS

Books

Jack, C. (2021) Women with Autism: Accepting and embracing Autism Spectrum Disorder as you move toward an authentic life. Glasgow: Casacat Press Ltd.

<u>Nerenberg, J. (2021) Divergent Mind: Thriving in a world that wasn't designed for you. Harper One</u>

<u>Grandin, T. & Panek, R. (2014) The Autistic Brain: Exploring the strength of a different kind of mind. Rider</u>

Online magazine

Regular magazine: Autism Spectrum News

Blog by Claire Jack

https://www.psychologytoday.com/gb/contributors/claire-jack-

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