

TOURETTE SYNDROME AND AUTISM

AUTISM AND TOURETTE SYNDROME (TS) ARE NEURODEVELOPMENTAL CONDITIONS THAT CAN OCCUR TOGETHER. UNDERSTANDING THE SYMPTOMS OF EACH CONDITION CAN HELP YOU TO COPE WITH THE CONDITION AND ALSO HELP OTHER PEOPLE SUPPORT YOU.

People with TS and their families often seek help because movements or sounds they see in their child or family member do not quite fit the pattern of tics or because a teacher or healthcare professional has suggested an assessment for autism. This factsheet explains what autism is, how it can occur alongside TS, how tics differ from autistic repetitive movements and where you can access help and support.

DISCLAIMER

A note about words. Our earlier factsheet used 'Autistic Spectrum Disorder'. Diagnostic manuals still use 'autism spectrum disorder', but most autistic people and UK charities now prefer 'autism', 'autistic person' or 'on the autism spectrum'. Asperger syndrome is no longer a separate diagnosis and sits within autism, though many people diagnosed before the change still use it about themselves. We follow each person's own preference.

WHAT IS AUTISM?

Autism is a lifelong neurodivergence. Being neurodivergent means having a brain that works differently from what is considered typical. It shapes how a person communicates, experiences the world and relates to other people. Autism is also legally recognised as a disability, meaning autistic people have the right to support that helps them thrive.

An autism diagnosis is usually based on these areas:

- **Communication:** Communicating and understanding information in different ways, including spoken language, tone of voice, gestures and facial expressions. Some autistic people speak very little or not at all, and communicate in other ways, such as writing, sign language or communication aids.
- **Behaviours and interests:** Focused and persistent interests, repeated movements or actions called stereotypies (often called stimming) and a preference for order, predictability, sameness or routine.
- **Sensory processing:** Being much more or much less, sensitive to sound, light, touch (e.g. texture), taste, smell, balance, movement and internal signals such as hunger or temperature.

Autism is a spectrum condition, which means that each autistic person has their own combination of characteristics, strengths and support needs.

HOW COMMON IS AUTISM?

Autism is common. At least 700,000 adults and children in the UK are autistic – that's more than 1 in 100 people. However, the real figure is likely higher as many people never receive a diagnosis.

HOW OFTEN DO AUTISM AND TS OCCUR TOGETHER?

Having more than one condition is common for people with TS. In the largest study of its kind, involving more than 1,000 people with TS, around 86% had at least one other condition. This was most often attention deficit hyperactivity disorder (ADHD) or obsessive-compulsive disorder (OCD).

Around 5–20% of people with TS are autistic and around 9–12% of autistic people have TS – more than would be expected by chance.

DO TS AND AUTISM HAVE SIMILAR SYMPTOMS?

- **Physical features:** Repetitive movements and complex body movements (e.g. head-banging, spinning)
- **Speech abnormalities:** Involuntary repetition of words, phrases or sentences
- **Sensory sensitivities:** Over or under sensitive senses (e.g. hearing, touch)

TICS OR STIMS?

Tics and autistic repetitive movements (stims) can look similar, but they come from different processes and a person can have both.

Tics tend to:

- come with a building sensation (premonitory urge) that the tic relieves
- result in pain and discomfort
- be sudden or irregular rather than rhythmic

Examples: Kicking, nose twitching, coprolalia

Stims tend to:

- feel calming or enjoyable
- be rhythmic and repeated in a similar way each time

Examples: Rhythmically rocking the body, hand-flapping, repeated tapping of an object

Telling tics and stims apart can be difficult, so it is reasonable to ask your healthcare providers to consider both.

SUPPORT AND MANAGEMENT FOR AUTISM AND TS

There are different forms of support which can help people with autism and TS. These may be communication-based, behavioural, educational or medical. It can be difficult to decide which type of support will be best, and so it's a good idea to discuss this with your health care team.

GETTING AN ASSESSMENT FOR AUTISM

Getting a formal assessment for autism can be useful as it can help you understand yourself better, access further support and explain your needs to other people. It isn't the right path for everyone, though – waiting lists, costs of access to private care and concerns about stigma may stop people. Remember that a formal diagnosis isn't required to access many forms of support, but it can sometimes help.

If you feel an assessment could be right for you:

- Start with your GP, who can refer an adult or child for an autism assessment.
- For children, parents can speak to teachers at school. They may be able to support a referral, as staff often notice characteristics across the school day.

- Expect a wait. UK guidelines recommend a first appointment within 13 weeks of referral, but you may have to wait longer – sometimes up to several months or years. As an NHS patient, you have the right to choose the healthcare provider you would like to be referred to.
- If you do not want to wait, you can consider a private assessment. This is funded by you and not the NHS, but may mean a shorter wait time. The provider you choose should follow national guidelines and be registered with an appropriate professional body such as the Health Care Professional Council (HCPC).

DISCLAIMER

While you are waiting. Under the Equality Act 2010, schools, colleges and employers must make reasonable adjustments for a disabled person. A formal diagnosis is not required for support. Reasonable adjustments must be made for anyone with a disability, which may include things like sensory adjustments or putting in place predictable routines and clear communication. If you are employed, the Access to Work scheme may help you work out the kind of support you need – see the 'Where To Get More Help' section below.

SUMMARY

It's possible to have both TS and autism. Some symptoms can look similar, but they come from different processes; tics tend to come with an urge that builds and can sometimes be uncomfortable or distressing, while autistic movements (stims) are usually calming or enjoyable. If autism seems to fit you or someone you care about, it may be worth asking your GP and, for a child, the school about an assessment. Waiting lists are long, so remember that you do not have to wait for a diagnosis to ask for understanding, adjustments and support.



WHERE TO GET MORE HELP

For more information and support you can contact the following organisations:

Tourettes Action Helpdesk: www.tourettesaction.org.uk

National Autistic Society: 0808 800 4104 – www.autism.org.uk

NHS: www.nhs.uk/conditions/autism – Information on autism

NHS: www.nhs.uk/conditions/tourette-syndrome – Information on Tourette syndrome

NICE: www.nice.org.uk – Health and social care guidance that GPs follow

ACAS: www.acas.org.uk/reasonable-adjustments/adjustments-for-neurodiversity

– Information on reasonable adjustments for neurodiversity at work

Access to Work: www.gov.uk/access-to-work

– Government grant to support you at work if you have a physical or mental health condition



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