

Down's syndrome and Complex Needs

Attention Deficit (Hyperactivity) Disorder or ADHD

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What is ADHD?

Attention deficit (hyperactivity) disorder (ADHD) is a condition that affects people's behaviour. People with ADHD can seem restless, may have trouble concentrating and may act on impulse.

Symptoms of ADHD tend to be noticed at an early age and may become more noticeable when a child's circumstances change, such as when they start school.

Most cases are diagnosed when children are under 12 years old, but sometimes it's diagnosed later in childhood.

All children, including children with Down's syndrome, display these traits from time to time, but children with ADHD demonstrate them to a much higher degree than their peers and do so across environments—at home, in school, and during play.

Sometimes ADHD was not recognised when someone was a child, and they are diagnosed later as an adult.

The symptoms of ADHD usually improve with age, but many adults who were diagnosed with the condition at a young age continue to experience symptoms. People with ADHD may also have additional conditions, such as sleep and anxiety disorders.

ADHD can co-occur with other diagnoses, like Down's syndrome or Autism.

There are three recognised subtypes:

- hyperactive-impulse type
- inattentive type
- combined type

If you are concerned about your child's attention, impulsive behaviour, and excessive fidgeting then you should talk to your child's Paediatrician, or Gp to rule out other reasons or to look further at whether there may be ADHD (see below).

ADHD and Down's syndrome

Attention Deficit disorder with or without hyperactivity occurs in people who have Down's syndrome as it does in the general population and there will be the same issues of distractibility, impulse control and attention difficulties. These should all be looked at within the context of the child's developmental stage.

According to the American organisation National Down Syndrome Society (NDSS) the frequency of ADHD in children with Down syndrome is not known with certainty. However, ADHD-like symptoms are more common in young children with Down's syndrome than they are in typically developing children.

They recommend that before an official diagnosis of ADHD is made, other possible medical conditions, changes to education and communication needs should be ruled out first.

The following (adapted from the NDSS website) is a list of conditions that could present ADHD-like symptoms and should be considered:

- **Hearing and Vision issues:** children with Down syndrome are prone to hearing loss and vision issues. Both vision and hearing should be assessed regularly to rule out things like ear infections, the need for glasses, and other vision and auditory diagnoses that may contribute to attention difficulties.
- **Gastrointestinal Issues:** people with Down syndrome are at increased risk for coeliac disease and constipation. Both diagnoses can cause changes in energy, behaviour, and restlessness.
- **Thyroid Issues:** about 30% of people with Down syndrome have thyroid disease at some point in life. Most have hypothyroidism or an underactive thyroid gland; a few have a disease that results in an overactive thyroid gland (Graves' disease). An underactive thyroid gland can, among other things, make a child very tired and apathetic. Too much thyroid activity can cause agitation and restlessness. Therefore, both conditions can look like poor attention and behaviour.
- **Sleep Disorders:** people with Down syndrome are frequently diagnosed with various sleep disorders. These disorders are a group of conditions with many different causes, but all result in insufficient sleep. Lack of sleep can result in restlessness, poor attention, mood swings, inability to focus, and challenging behaviours.
- **Communication:** people with Down syndrome have many barriers to effective communication. The receptive language skills of children with Down syndrome are often much stronger than their expressive language skills. A child may express his or her frustration by acting out or by inattention.
- **Education:** children with Down's syndrome have a wide range of learning styles. A child's educational team may need to try more than one method of presenting material before finding the one that works best for the child. If material is presented in a way that is not compatible with a child's learning style, that child may appear bored, hyperactive, fidgety, or inattentive.

Incidence of ADHD in Down syndrome

Research

According to 'Down Syndrome – Current Perspectives' approximately 1 in 20 children with Down's syndrome in the USA is diagnosed with ADHD (Coe et al. 1999). Ekstein et al. (2011) have rated the presence of ADHD in individuals with Down's syndrome to be as high as 44%. Rates have also been reported as increased in the UK, compared with other children with similar levels of intellectual disability (Turk 1998).

Rates of hyperactivity have been reported to diminish as individuals enter adolescence (Stores et al. 1998).

ADHD and ASD

Margaret Froehle & Robin Zaborek in their book 'When Down Syndrome and Autism Intersect' talk about how individuals with DS-ASD may also be diagnosed with ADHD. They highlight the problem that sometimes only the diagnosis of ADHD is given when, in fact, an autism spectrum disorder is present.

They recommend that, despite the presence of ADHD symptoms or behaviours, that a more thorough assessment be made, particularly in terms of social skills and relationship issues, if there are suspicions of possible autism spectrum issues.

ADHD assessment (taken from NHS website)

The referral for assessment will be sent to the appropriate service in the area you live in. It will also depend on the age of the person to be assessed.

A child may be referred to one of the following types of specialists for a formal assessment:

- a specialist child or adult psychiatrist
- a paediatrician – a specialist in children's health
- an appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD
- A Camhs service

There's no simple test to determine whether you or your child has ADHD, but a specialist can make an accurate diagnosis after a detailed assessment. The assessment may include:

- a physical examination, which can help rule out other possible causes for the symptoms
- a series of interviews with you or your child
- interviews or reports from other significant people, such as partners, parents and teachers

Diagnosing ADHD in children depends on a set of strict criteria. To be diagnosed with ADHD, a child must have a number of symptoms of inattentiveness, or symptoms of hyperactivity and impulsiveness.

Read more about the symptoms of ADHD at the link below:

[nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/symptoms/](https://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/symptoms/)

To be diagnosed with ADHD, a child must also have:

- been displaying symptoms continuously for at least 6 months.
- started to show symptoms before the age of 12.
- been showing symptoms in at least 2 different settings – for example, at home and at school, to rule out the possibility that the behaviour is just a reaction to certain teachers or to parental control.
- symptoms that make their lives considerably more difficult on a social, academic or occupational level.
- symptoms that are not just part of a developmental disorder or difficult phase, and are not better accounted for by another condition.

After diagnosis

Using strategies can be very helpful and you will find a few suggestions in the box below. Some people take medication to help with symptoms and this is something that should be discussed with a health professional. In some areas parents are offered courses to attend to help them understand their child's condition.

Receiving an additional diagnosis can be difficult for the person and for parents. It is important that you are offered the opportunity to talk about the diagnosis and its impact and have the chance to ask any questions.

Helpful strategies

- Plan the day
- Set clear boundaries
- Notice the positive
- Give clear instructions
- Incentive scheme (involve your child in it)
- Intervene early
- Manage social situations
- Exercise
- Eating
- Bedtime routine
- Help at school

There are ADHD specific organisations whose websites may have useful information (see resource list below), some led by people who have ADHD.

You are also welcome to call our helpline if you would like to talk to someone.

Resources

NHS website: [nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/](https://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/)

NICE guidelines: [nice.org.uk/guidance/ng87/informationforpublic](https://www.nice.org.uk/guidance/ng87/informationforpublic)

Young Minds website: [youngminds.org.uk/](https://www.youngminds.org.uk/)

ADHD Foundation: [adhdfoundation.org.uk/](https://www.adhdfoundation.org.uk/)

ADHD UK website (created by people with ADHD): [adhduk.co.uk/](https://www.adhduk.co.uk/)

NDSS website: [ndss.org/](https://www.ndss.org/)

Mental Wellness in Adults with Down's syndrome Dennis McGuire and Brian Chicoine

When Down Syndrome and Autism intersect Margaret Froehlke and Robin Zaborek

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