

FOUNDATION The Neurodiversity Charity

Understanding and supporting your child's ADHD

Information on ADHD for Parents and Families



What is ADHD?

ADHD is a thoroughly researched condition recognised by the NHS in the UK, and across the world by the World Health Organisation, who state that ADHD occurs in 5.26% of the population. Guidelines are available on the diagnosis and treatment of ADHD from the National Institute of Health Care Excellence. In Scotland, this appears in the Scottish Intercollegiate Guidelines Network.

You can access the Patient's Guide on NHS NICE Guidelines via this link: https://www.adhdfoundation.org.uk/wp-content/uploads/2019/02/ADHD-NICE-Guidelines-Patient-Booklet.pdf

1 in 20 children have ADHD and can present in a mild, moderate or severe form. ADHD is a lifespan condition, by adulthood, many people have learned to live happy, healthy and successful lives using a range of interventions and strategies that include medication, daily exercise, healthy nutrition, stress management strategies and what are known as executive functioning skills to help them plan and organise their lives, especially in school and in the workplace.

There are three main characteristics of ADHD:

Hyperactivity

lots of energy and feeling the need to move about or fidget and sometimes resulting in poor sleep

Impulsivity

an inability to self regulate thoughts, feelings and actions

Inattention

difficulty concentrating and remembering information

These are evident in all children, but present in a more extreme form in children with ADHD.

What causes ADHD?

Most people have a combination of these three main characteristics and while hyperactivity is the most noticeable, it is the least concerning unless it is affecting sleep. Many people with ADHD also say they are very sensitive and find themselves getting frustrated easily. Everyone is different and expresses their individuality and their ADHD in a way that is unique to them.

Scientists have discovered that there are subtle differences in the brains of people with ADHD. We know for example that there is a developmental delay in children so they appear to be less mature for their age during their school years. The brain doesn't develop fully until we are in our early twenties, by which time we can learn how to self manage our ADHD effectively.



ADHD is most often caused by genetics and runs in families. Parents do not have to have ADHD to have a child with ADHD but the combination of genes from parents can result in ADHD in their children. ADHD is not caused by poor parenting or poor diet and it is not true that all children with ADHD display difficult behaviour.

Environmental factors such as positive parenting, school and adverse life events can affect how severely ADHD can impact on children. Low birth weight, premature birth and difficult labour can increase the chances of having ADHD but do not actually cause ADHD. Brain injury or epilepsy may cause ADHD. Knowledge and support from the family and school are key in ensuring that we learn to live successfully with ADHD, achieve our potential and become psychologically resilient.

Obtaining an assessment and diagnosis for ADHD

If you are concerned your child may have ADHD, firstly talk to your child's school teacher and ask them if they are having difficulty learning and remembering what they have learned in school? Remember poor behaviour is not always a sign of ADHD.

Poor behaviour in school is often the result of children learning how to behave appropriately in a school setting. and making mistakes along the way. Learning is a trial and error process. When the child appears not to be responding to what is asked of them, we have to ask ourselves what is the child's behaviour communicating to us that they are not able to put into words?

Sometimes children with learning differences become very frustrated and lack self esteem because they find the school work more difficult than their classmates. This is known as learner anxiety, and this is most often the cause of any inappropriate behaviour.

Discuss the following with your child's teacher, and request a meeting with the school's Special Educational Needs and Disabilities Co-ordinator (SENDCo). This role could alternatively be called the school Additional Learning Needs Co-ordinator (ALNCo).

Key questions to ask are:

Is my child paying attention?

Is my child showing any delay in learning?

Is my child forgetting things?

Is my child appearing tired or daydreaming in class?

Is my child unable to be still when it is required?

Is my child appearing anxious about learning and homework?

Is my child unable to organise and plan their school work properly?

Does my child frequently appear tired?

Does my child find it difficult making and keeping friends?

Have these difficulties been occurring for more than six months?

These characteristics and concerns must be evident in both the home and school.

Obtaining an assessment and diagnosis for ADHD

Remember that children with neurodevelopmental difficulties such as ADHD, can also have other neurodevelopmental conditions such as dyslexia, dyspraxia, tics and traits of autism affecting their communication skills. It is important to discuss all these issues with your child's school and your doctor.

Ensure their needs and difficulties are understood so the school can make accommodations and put strategies in place straight away to support your child's learning and development in school. Don't wait for a formal diagnosis before putting strategies in place to support them. Information for schools can be found at www.adhdfoundation.org.uk

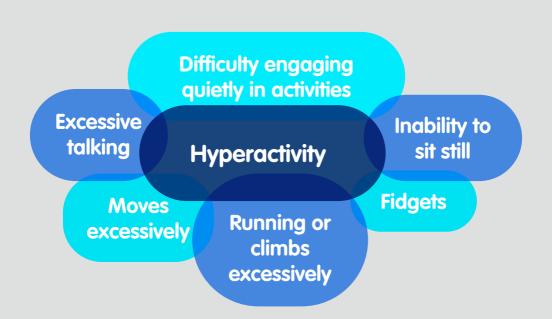
In each geographical area in the UK, there are different pathways of referral to see a specialist paediatrician who can assess and diagnose a child. Ask your local family doctor who can advise you so that together with the school, you can ensure the doctor gets all the information they need from the school before your appointment.

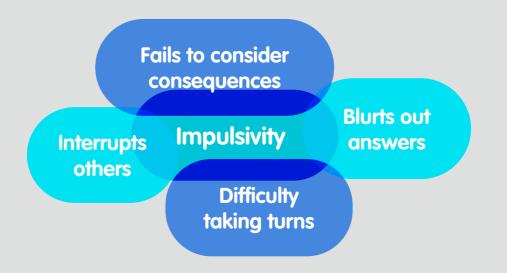
Some family GPs will make a referral in the event the school disagrees with you about whether a referral for ADHD is appropriate. Adult ADHD assessments are arranged by a family doctor who will refer to an a specialist adult ADHD clinic.

The Diagnostic Criteria for ADHD can be found in the DSM V criteria for ADHD:

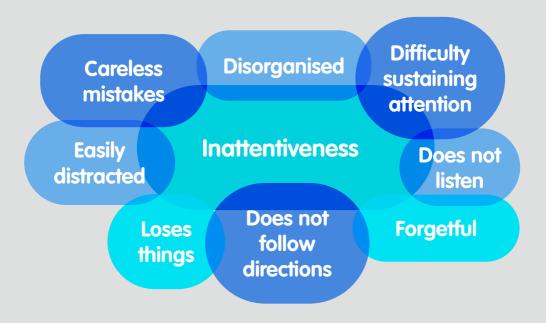
- A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development
- For children, six or more of the symptoms have persisted for at least 6 months
- For older adolescents and adults (age 17 and older), five or more symptoms are required
- Several inattentive or hyperactive-impulsive symptoms present prior to age 12 years
- Several inattentive or hyperactive-impulsive symptoms present in two or more settings (e.g. at home, school or work; with friends or relatives; in other activities)
- Clear evidence that the symptoms interfere with, or reduce the quality of, social, academic or occupational functioning

Characteristics of ADHD





Characteristics of ADHD



Executive functioning

Some ADHD specialists refer to ADHD as a disorder of self-regulation. Self-regulation requires that a person have intact executive functions. Executive function refers to brain functions that activate, organise, integrate and manage other functions. It enables individuals to account for short and long term consequences of their actions and to plan for those results.

It also allows individuals to make real-time evaluations of their actions and make necessary adjustments if those actions are not achieving the desired result. This is hard to do when your working memory, your time management and organisation skills are affected by ADHD.

Here is a list of executive functioning skills:

1. Self awareness

Simply put, this is self-directed attention.

2. Inhibition

Also known as self-restraint – the ability to not speak or act, but to stop and think before speaking or acting.

3. Non-verbal working memory

The ability to hold things in your mind. Essentially, visual imagery — how well you can picture things mentally.

4. Verbal working memory

Self-speech, or internal speech. Most people think of this as their inner monologue.

5. Emotional self regulation

The ability to take the previous four executive functions and use them to manipulate your own emotional state. This means learning to use words, images, and your own self-awareness to process and alter how we feel about things.

6. Self motivation

How well you can motivate yourself to complete a task when there is no immediate external consequence.

7. Planning and problem solving

Experts sometimes like to think of this as self-play — how we play with information in our minds to come up with new ways of doing something. By taking things apart and recombining them in different ways, we're planning solutions to our problems.

How might poor executive functioning present?

Shutting down due to feeling overwhelmed by the amount of information

Forgetting the steps needed to complete a task

Requiring somebody else to initiate and/or organise their tasks

Not knowing how to start

Being unable to filter what's important and what's unimportant to focus on

Being unable to motivate themselves



Getting distracted by other things

Being unable to do things well consistently Expressing an emotion every single time it is felt

An inability to imagine how to get from start to end

Not knowing where to start

ADHD and emotional maturation

Children with ADHD appear to be developing more slowly than their peers. Some scientists estimate that this can be as much as one third of their chronological age.

Children with ADHD can be seen as poorly behaved because their brains are developing at a slower pace than those of other children their age, so they appear immature.



Children with ADHD can appear very sensitive and easily upset. They will often seek comfort and reassurance by seeking affection and closeness to parents. Some children with ADHD may seek friendships with slightly younger peers with whom they identify more than children their own age.

Children with ADHD often struggle making and maintaining friendships. They experience difficulty with taking turns and can be impatient and easily frustrated. Managing conflict or indeed understanding social cues and the rules and regulations of social groups may also be difficult for your child.

We recommend that children with ADHD are encouraged to participate in sporting groups and activity groups such as scouts, cadets and outdoor activity clubs. Such structured groups and activities will help your child learn how to develop friendship skills.

Frequently co-occurring difficulties associated with ADHD

ADHD can also be associated with other neurodevelopmental conditions as detailed below. This does not however, mean that if your child has a diagnosis of ADHD, they will also have all the other conditions, but conditions can coexist.

29% of children with a primary diagnosis of ADHD also have ASD (Autistic Spectrum Disorder) and over 40% will also have dyslexia. Dysgraphia, dyscalculia, tics and Tourette's syndrome can also co-occur—or indeed you child may display traits of more than one other neurodevelopmental condition.



There are a range of treatments and interventions for ADHD that include:

Psycho educative training for parents/carers and children/young people (Information, Advice and Guidance)

Parent/carer training programmes that is specific to ADHD

Cognitive Behavioural Therapy

Systemic Family Therapy

Stress reduction strategies, such as progressive muscle relaxation, yoga and deep breathing

Medication

The NHS NICE Guidelines recommend a multi modal approach that may at times require the use of a combination of treatment which you can discuss with your ADHD specialist doctor.

Nutrition and Diet

A healthy balanced diet is essential for everyone and can also play a key role in the successful management of ADHD.

Hyperactivity can result in the body using up the energy obtained from food too quickly, resulting in the body craving carbohydrates to restore its energy. Over reliance on carbohydrates can affect mood, motivation and concentration and result in frequent bouts of tiredness. It can also be a cause of weight gain through over eating.

Regular meals, - and depending on your level of activity, regular snacks are needed to maintain energy levels. Children will struggle to learn in school if they are tired and need energy from food.

Ensure your child always has a good breakfast that includes some protein. Protein enables the body to utilise energy over longer periods, whereas a child with ADHD can quickly burn up the energy from a bowl of cereal that consists mainly of carbohydrates.

Food supplements such as Omega 3 fatty acids commonly found in fish oil have been proven to be effective in helping brain growth and are often used in conjunction with ADHD medications.



Exercise

Regular daily physical exercise is proven to help regulate ADHD, reducing anxiety and elevating mood.

All ADHD specialists recommend that exercise is part of a healthy lifestyle. Regular exercise also improves neurotransmission in the brain.

Sleep

Poor sleep is a frequent difficulty for those with ADHD. Poor sleep and the resulting tiredness can further impair ADHD. Regular bed and waking times for children, ideally with some exercise and stress reduction strategies before bedtime all help. Parents should explore this with their child and discover what works best for their family life.

The natural body clock in our brain can be affected by ADHD so the mind and the body will benefit from a routine with set times for going to bed and waking in the morning. Some children are supplemented with melatonin - a natural hormone to help with poor sleep.

Planning and Organising

Executive functioning skills training often forms part of parent support programmes and psycho education programmes. People with ADHD often experience difficulties planning and organising themselves and can be very forgetful.

Employing time management and organisation and planning skills to help your child learn how to put structure and routine in to daily life, is proven to reduce the anxiety experienced by many people with ADHD.

Diaries, posters around the home, timetables and smart phones, can help your child remember important tasks and appointments - and yes, remind them when they have to tidy their bedroom or share in family tasks and responsibilities.

ADHD Medication

There are a number of different medicines for ADHD. Medicines for ADHD that are licensed in the UK are:

- Methylphenidate (stimulant medication)
- Lisdexamphetamine (stimulant medication)
- Dexamphetamine (stimulant medication)
- Atomoxetine (non stimulant medication)
- Guanfacine (non stimulant medication)

Non stimulant medications can take up to several weeks before there is a noticeable benefit. Stimulant medications become active within an hour of ingestion. There are some types of stimulant medication which last for only a short time – four hours or so; others are longer lasting and can continue to be active for 8 to 12 hours.

There is no standard dose and doctors usually start with a small dose, gradually increasing it until everyone is agreed that the medication is working effectively. This process is called **titration**. It may take some time to get this exactly right and every individual is different. It is important that parents and teachers as well as the young person agree that the medication is working effectively.

Treatment with medication can improve symptoms of ADHD quite dramatically. Medication is not a cure for ADHD. Medication is only one strategy you can use to live successfully with ADHD. Remember that daily exercise, good sleep, healthy nutrition, social skills training and cognitive behavioural therapy, are all important tools in living successfully with ADHD.

Side affects of medications vary from individual to individual. Many report an upset stomach for the first few weeks of taking ADHD medications. For most people, these side effects disappear after a short time. It is important that you as a family make an informed and educated choice of treatment for your child. If you have any concerns about medication or side effects, please discuss these concerns with your doctor.



Many parents express concerns about medications for children. You should discuss your concerns with your child's doctor so you can make an informed choice about whether medication should be used as one way of supporting your child.

Different types of medication are available and some children respond better to certain types of medication than others. Your child's clinician will advise you how to approach this and they may trial different types of medication and dosage until your child is responding to medication in the best way. Always follow your doctor's advice and guidance on all matters relating to medication.

Information for Parents and Carers

Parenting a child with additional needs requires additional knowledge and skills. Parents of children newly diagnosed with ADHD, should be offered a training programme to understand and support their child's ADHD.

ADHD is not caused by poor parenting, but parents do need to understand how to parent a child with ADHD. Learn how to make your home ADHD friendly, and ensure your child's school has been trained to meet the educational needs of your child to ensure their emotional well being. It is a legal requirement that school staff are trained to meet the needs of every learner.

Parents can obtain a wealth of information from the following web sites:

www.adhdfoundation.org.uk

www.childmind.org

www.additude.com

www.specialneedsjungle.org

www.wholeschoolsend.com

www.sendgateway.org.uk/whole-school-send

1. Be informed

Learn as much as you can about ADHD and those other neurodevelopmental differences that frequently co-exist with ADHD (such as dyslexia, dyspraxia, dysgraphia and dyscalculia).

The more you know, the better you will be able to understand your child and support them both at home and at school. Look at the links on our website for the NHS NICE Guidelines (SIGN in Scotland) on what to expect from the NHS (https://www.adhdfoundation.org.uk/wp-content/uploads/2019/02/ADHD-NICE-Guidelines-Patient-Booklet.pdf).

And the OFSTED document on 'Supporting Neurodiverse Pupils (https://www.adhdfoundation.org.uk/wp-content/uploads/2020/04/OFSTED-GUIDELINES-Nick-Whittaker-Neurodiversity-Conference-January-2020.pdf)







2. Keep a record of every meeting and appointment at the school and the doctors

Always take your note book with you (or record them on your smart phone) and date and time them. Things discussed and agreed can often be forgotten or overlooked so be the best advocate your child can have by making sure you have copies of all notes, reports and documents relating to your child's health and education.

3. Take a strength based approach

Focus on the positives with your child; encourage them to recognise the things they are good at rather than just those issues they struggle with.

4. Boost your child's confidence and self esteem

Remind the constantly how much they are loved unconditionally, praise the effort they make, help them learn to manage their ADHD, - don't be the parent who just says "Do as I say" – 'show them how' and be patient with them as they make mistakes. ADHD is not an excuse – its an explanation. Children have to learn to be accountable for their actions – and remember that if you follow all the instructions in this booklet, you will make your child's life much less stressful as they learn how to deal with ADHD.

5. ADHD does not define your child

Please ensure that your child and everyone in the family knows that ADHD is one part of who they are; it does not define them and nor we should we interpret everything about them through the lens of ADHD. Every human being is unique and experiences the world in their own way.

6. Find support accessible to you

Join a support group and participate in parents skills programmes, on line training, podcasts and webinars. Your family need to support one another and seek support from other groups, charities and agencies.

If you are worried about your childs emotional well being, speak with an expert in ADHD – remember that not all doctors, nurses, teachers or school counsellors have been trained to understand how to support a child with ADHD.

They need your knowledge and expertise as a parent who has learned what ADHD is and how it can impact on an individual.

7. Become a good listener, communicator and collaborator

You will need to the support and co-operation of many people to ensure your child's needs are understood and that they are able to access good health care, a good inclusive education and access all those things that children enjoy so they can achieve their potential and mature into a successful young adult.

8. Teach your child 'The Friendship Factor'

Loneliness can affect our health and happiness. One of the most important parts of childhood is making friends. Human beings are a social species – we thrive in relationships.

We learn how to belong and feel safe in our family home, in our school and in our community as well as groups our child joins such as Scouts, Brownies, Girl Guides, sports clubs, etc. We need our friends to share good times with and be there for us when things are difficult.

Good friendships help to build resilient children who are able to make their own way in the world. Make one to one time with your child and help them learn what a good friend is – patient, kind, sharing, forgiving, helpful and how to communicate with others in a calm, sensitive and respectful way.

Be a role model for them – be the type of friend that you needed when you were a child.

9. ADHD is a family affair

ADHD is largely genetic but influenced by environmental factors such as home life, school and any really positive or difficult events in our early childhood – ADHD is not just about genetics; the world around us affects how ADHD presents in your child.

Have you as a parent got ADHD or dyslexia, dyscalculia, sensory integration difficulties, tics or autism? Have any of your relatives?

Again be informed – as a family. Ensure that siblings understand their brother or sister experience the world in a different way. Equally any family friends or relatives. ADHD is characterised by a developmental delay of about to 3 years – sometimes more.

This means your child may seem and behave in ways that are less mature than that of other children their age. This may affect their ability to make friends and feel that 'they belong'.

10. Celebrate your child's achievements and progress

Always look for opportunities to pay your child a compliment; every day. Children learn from modelling the behaviour of those around them. Be a role model they can learn from – be the parent you needed when you were a child. Be the teacher you needed when you were a child. Be there at those special moments and always be ready with words of encouragement, kindness and support.





The ADHD Foundation Neurodiversity Charity is an integrated health and education service supporting families with unique lifespan service.

The Foundation is the National UK ADHD Charity and the leading user led ADHD charity in Europe, supporting over 6000 parents annually in the UK and training over 15000 education and health professionals annually.

The Foundation takes a strength based approach to neurodiversity and maintains that if 1 in 5 human beings are neurodiverse – have either dyslexia, ADHD, dyspraxia, dyscalculia or autism that they are not 'disordered' or errors of genetics, but that this differences are part of the natural and diverse nature of human neurology, The Foundation showcases how many successful neurodiverse individuals lead happy, healthy and successful lives and can be found in every career and profession. These differences can be very varied and affect different individuals in different ways. There are some who experience severe and distressing lifelong impairment to their lives and health and this is why and when the term 'disorder' is appropriate and access to lifespan expert care is needed.

We live in a neurotypical world which means that for the 20% of human beings who are neurodiverse, the world can be more challenging at times and that awareness, understanding, and appropriate accommodations and support are needed by many neurodiverse individuals – especially in childhood so they can achieve their potential, thrive and succeed in education where they are often excluded because of our outdated educational paradigm and concept of intelligence. Fortunately this traditional misconception of intelligence, ability and employability is changing as many 21st century organisations actively recruit neurodiverse employees, recognising their unique way of thinking. Schools are also recognising that such learning differences do not indicate a lack of ability or intelligence. Schools and Universities are now exploring how we can more accurately measure learning and academic progress instead of relying on standardised exams for the 1 in 5 learners who do not have 'standardised' neurotypical brains.

The Foundation working in partnership with NHS, Department for Education, health, education and social care providers and the business sector, work to create better life chances for the 1 in 5 of the population who are neurodiverse. You can access further information from www.adhdfoundation.org.uk contacts us via email: info@adhdfoundation.org.uk and follow information, articles and news daily via Facebook 'ADHD Foundation' and on Twitter @ADHDFoundation.

Thank you to Ethypharm for their support with the costs of printing this booklet. Ethypharm had no editorial control over the content.



Disclaimer

This patient information booklet has been sponsored by Ethypharm, and produced by Dr Tony Lloyd and Tracy Dickens of the ADHD Foundation. This is a brief guide, with the content of this booklet solely derived from the ADHD Foundation, and not Ethypharm.