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ADHD

A compact
guide for
parents



ADHD A compact guide for parents

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ADHD is a reality not a myth

ADHD is a well defined clinical condition. All the major medical authorities recognise it, including the World Health Organisation and the American Psychiatric Organisation.

About 5% of children have it,^{1,3} so a typical primary school class will have one or two children with the condition. In the UK, many such children are still not recognised and treated.²

ADHD responds to treatment. In the UK both the National Institute for Clinical Excellence (NICE)³ and the Scottish Intercollegiate Guidelines Network (SIGN)² recommend that ADHD be treated.

Scientists are now discovering that there are important but often subtle differences between the brains of people with and without ADHD¹ – both in their development and the way that they work. It's also becoming clearer that ADHD runs in families; genes as well as environments are probably important.¹

Families are part of the treatment

ADHD is not caused by bad parenting. It's not the parents' fault if a child has ADHD, but in responding to the condition appropriately they can make a real difference to their child. If you're reading this document after seeking medical advice, you've already taken a major step towards helping your child.

There are many more things that parents and carers can do:

- Finding out as much as possible about ADHD and explaining it to other members of the family, other parents, teachers etc. ADHD is still widely misunderstood.



- Bad parenting is not a cause of ADHD, but there are skills and techniques that you can learn that will help your child behave better and concentrate for longer.
- Encourage your child to follow the treatment recommended by the doctors and other professionals. You know better than anyone that they need assistance to carry through a long-term plan.

This guide

To help improve the management of ADHD, a group of European specialists (child psychiatrists and psychologists) have produced a set of guidelines, which are being updated regularly.³ These guidelines were written for the specialists who diagnose and manage ADHD and have been adapted to provide straightforward and user-friendly advice and information for parents and carers in the UK. Similar guides are also available for general practice teams and for teachers.

First we provide some background to the condition. This is followed by a discussion of the whole process of diagnosis and treatment with a special focus on the role of the parent or carer.

We hope that you find the guide useful.

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Background to ADHD



- ADHD is a well defined clinical condition.
- ADHD is relatively common.
- ADHD tends to run in families, but probably results from a combination of factors.
- Children with ADHD often have other problems.

What is ADHD?

ADHD is a clearly defined clinical condition and not just a label for naughty or badly brought-up children.

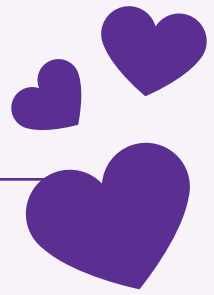
Attention Deficit Hyperactivity Disorder (ADHD) is diagnosed when a child shows abnormally high levels of:

- **Inattention**⁴ (short attention span, easily distracted, doesn't finish things, disorganised, forgetful etc).

and/or:

- **Hyperactivity and impulsiveness**⁴ (fidgets, can't sit still, always on the go, talks too much, interrupts, can't wait their turn etc).





To qualify as true ADHD, these problems:

- Must be long-term (present for at least 6 months).⁴
- Must be abnormal for the age and stage of development of the child (what's normal in a 2-year-old is not normal in a 10-year-old).⁴
- Must have been present before the age of 7⁴ (although they are often noticed from very early on in a child's life and are nearly always seen before the age of 5 years).¹ ADHD is part of the child's make-up and doesn't suddenly appear out of the blue.
- Must be genuinely disruptive to the child's everyday performance and well-being⁴ – mere naughtiness at home or not doing well at school is not enough.
- Must occur in more than one place,⁴ for example both at home and at school. Problems which are present just at home or just at school are likely to have other causes.

Some children only have problems with inattention and some (actually very few) only have problems with hyperactivity and impulsiveness, but many have a combination of both types of problem.⁴

The term “Hyperkinetic Disorder” is also sometimes used to describe those children with the most severe ADHD, where there are symptoms of inattention and hyperactivity and impulsivity which are all seriously disrupting the lives of children at home, at school and in the community.¹

How common is ADHD?

ADHD affects 5% of school-age children.^{1,3} This means that the average UK classroom will include at least one child with ADHD.

The more serious cases that qualify as Hyperkinetic Disorder affect about 1.5% of primary school children.¹ In the UK, not all of these children will have been investigated and diagnosed.

ADHD is more common in boys than in girls, with a ratio of approximately 4 boys to 1 girl.³

Is ADHD my child's only problem?

While in some cases a child's problems can be solely to do with ADHD symptoms, it is very common for children with ADHD to have other problems as well.

These may include:¹

- **Conduct disorder** (persistent lying, stealing, truancy, vandalism etc) and oppositional defiant disorder (persistent and abnormally uncooperative and defiant behaviour).
 - **Anxiety and depression.** Children with ADHD often have low self-esteem or feel insecure because of failures at school or in making friends.
 - **Language** problems, **reading** and **writing** problems.
 - **Clumsiness.**
 - **Tic disorders.**
-

There is also a link between ADHD in children and delinquency and academic underachievement in adolescents and young adults.

What causes ADHD?

We don't know exactly, but we are starting to understand better. What we do know supports the idea that ADHD is a real condition.

There is not just one single cause – ADHD is almost certainly the result of a combination of factors, and this combination will vary from child to child.

The role of genes

- Studies of twins suggest that 65%-90% of the risk of having ADHD is associated with a person's genes.¹ This means that ADHD is often inherited and tends to run in families.
- Specific genes have been linked to ADHD. People with these genes don't all have ADHD but they are more likely to have it than people without these genes. Many of these genes have to do with action of dopamine and norepinephrine, substances which enable nerve cells in the brain to network with each other. The main medical treatments for ADHD boost the function of dopamine and norepinephrine.¹



The role of other factors

Some factors in the child's development may increase the chances of having ADHD, but are not the whole cause of the problem.

These include:¹

- Difficult or complicated labour.
- Low birth weight.
- Mother using benzodiazepines (tranquillizers like diazepam or temazepam), smoking or drinking excessive alcohol during pregnancy.
- Brain diseases and injuries.

Brain scan studies and psychological studies have found subtle but distinct differences between the brains of people with and without ADHD, in their structure, the way in which they develop and the ways that they work.¹

Whilst all of these scientific techniques are proving helpful in understanding the causes of ADHD they are unfortunately not helpful in diagnosing whether someone is suffering from ADHD or not. There is no "test" for ADHD and there is unlikely to be one in the near future.



Diagnosis



- Who does what and when?
- What can you expect?

Your family doctor

ADHD is diagnosed by specialists. The job of your family doctor (GP) is to recognise children who might have ADHD and send them to a specialist for assessment.

The GP might ask about:

- Your child's behaviour (is (s)he easily distracted, does he finish things he started, does he fidget a lot, can he wait his turn etc).
- When the problems started and how long they have lasted.
- How your child's behaviour is affecting life at home and school – do the problems occur just at school, just at home, or everywhere?

Practical point

Sometimes children behave unusually well at the appointment. If this happens, tell the doctor that this is not typical behaviour and explain carefully how it differs from your child's normal behaviour.

To make sure that there is not another cause for your child's problems, the doctor will probably do a physical examination. (S)he may ask about other aspects of your child's life. For example you may be asked about whether your child has hearing or sleep problems as these can cause some behavioural difficulties in children.

The doctor may also ask you and/or your child to fill in a short questionnaire to give a clearer picture of your child's problems.



Diagnosis

The specialist team

The medical specialists who work in ADHD are child psychiatrists and paediatricians. They often work in a team with other health professionals such as specialist nurses and clinical psychologists.

At the first appointment, the specialist may not start a full assessment. (S)he may judge that in your case some advice and support may be enough to improve things. If this doesn't work, then a full assessment may be required.

A full assessment will probably be spread over more than one appointment and involve more than one member of the specialist team. Whilst the specialists will be watching the behaviour of your child all the time, they will realise that behaviour on any one day may not be typical.

As part of the assessment, parents, teachers and your child may be asked to complete questionnaires to get a fuller picture of the symptoms.

Brain scans and EEGs (a painless test to assess brain activity) are not routinely done for ADHD itself, but may be requested if other problems may crop up which need this sort of investigation, for example if your child has had fits in the past.



A full assessment should usually include:

An interview with you, covering:

- Your child's behavioural problems.
- Your family – do relatives have similar problems?
- Details of the pregnancy and birth.
- Details of the child's development – when did he start to walk, talk, etc?
- Any other previous medical problems and medications.
- Relationships within the family.

An interview with your child, covering:

- How he gets on in the family, at school and with friends.
 - Whether he seems depressed or anxious.
 - What he thinks about his problems and how he copes.
 - Contact with the school or pre-school.
 - The team will also want to get information from their teachers about how your child currently behaves and performs. They will also be interested in the teacher-child relationship, how the teacher copes with your child's behaviour and how any problems have developed over the child's time at school.
 - A physical examination, vision and hearing check.
-

Treatment: What you should expect



Advice, information and support for you and your child's teachers is a very important part of ADHD treatment.

Advice and support

As a minimum, you should expect the specialist team to develop an understanding of your child's problems and to assist you to understand them more clearly by offering you explanations, advice, support and lots of information about ADHD.

Treatment options

The exact treatments offered depend on the individual case. However treatment is likely to include:^{2,3}

- **A structured advice, support and behavioural programme** for parents and/or the child and/or teachers. This includes specific training on how to most effectively manage your child's behaviour and promote ways of bringing out the best in them.
- **Medication.**

Medication should only be prescribed following assessment by a specialist in ADHD. If symptoms are mild or temporary, medication may not be needed at all. In many cases it is recommended that a combination of both medication and a structured advice, support and behavioural programme is the best way to manage the full range of problems experienced by those with ADHD.^{2,3} However, the extent to which this is possible will vary from region to region based on local resources and expertise.

All these approaches work in many cases. None of them work in every case. If one approach doesn't work, the specialist is likely to try another.

Some children may also be able to work one-to-one with a therapist, to develop techniques for monitoring their own behaviour and controlling it better.

Practical point

Structured advice, support and behavioural programmes

ADHD isn't caused by bad parents or bad teachers, but research has shown that structured programmes of advice and support for parents and teachers can improve the child's behaviour and concentration and reduce the risk of their behaviour getting worse. Therapists work with parents and teachers individually or in groups. They help them to:

- Focus on particular problem times or situations (e.g. mealtimes, getting ready for school, start of the lesson) and track the child's behaviour over time.
- Work out in advance what to do when your child behaves well or badly – then do it consistently.
- Develop techniques for getting your child to listen (e.g. eye contact, one thing at a time, what to do rather than what not to do).
- Use token systems and contracts.
- Use 'time out' as a sanction.

Our "15 tips for parents" on a perforated tear-off card, at the end of this booklet, give a taste of this approach.

Treatment: What you should expect

Help with other problems

ADHD seldom occurs without other problems, and specific help may be offered for these:

- **Training in social skills** to help children make and keep relationships and avoid aggressive behaviour.
- **Counselling** to improve self-esteem.
- **Remedial teaching.**



Medication



- What specialists prescribe.
- Guidance on the question of drug abuse.

Main agents

The medicines licensed in the UK for ADHD are:³

- Methylphenidate.
- Dexamfetamine.
- Atomoxetine.

Methylphenidate and **dexamfetamine** belong to the same class of medicines, called stimulants.¹

Atomoxetine acts in a slightly different way and is not classed as a stimulant.⁵



Practical point

The development of long acting medicines

The effect of methylphenidate lasts only for a few hours, so three daily doses are recommended.¹ Three longer acting once-daily preparations of stimulants lasting between 8 and 12 hours^{6,7} (equivalent to methylphenidate two or three times daily) are currently available in the UK. Atomoxetine is also taken either once or twice daily.⁷

For the child, long-acting medicines can avoid embarrassment and increase privacy at school making it more likely that they will take the medicine as prescribed. For the school, not having to dispense a medication is a great advantage.¹ However, once daily dosing may reduce dose flexibility and tailoring at different times of the day.

Note - There is no standard dose of these medicines – the best dose varies from child to child. Normally the specialist will start with a low dose and gradually increase it, looking for the best balance between effectiveness and side effects. At this stage, parents and teachers may be asked to monitor the child's behaviour quite intensively using standard questionnaires.



While these drugs frequently provide effective treatment, they also have side effects. As always, if you have any concerns about your child's health or medication you should consult a specialist or general practitioner.

Treatment expectations

It is important to understand the potential benefits and limitations of medical treatment for ADHD.

- Treatment can greatly improve the symptoms of the child's ADHD, but cannot cure it completely.
- The child's doctor will be able to discuss the best treatment based on their individual needs.

While treatment is effective, it can also cause side effects. Side effects that may occur with medication for ADHD include disturbed sleep, less appetite, stomach upset, and headache, but there may be others too.

For a full list of possible side effects please speak to a health professional.

It may take some time to find the best dose of drug treatment to use for the child. The specialist may prescribe a low dose to begin with, then increase it, aiming to achieve symptom relief while minimising the risk of side effects.

During the early stages of treatment, you may be asked to help monitor the child's symptoms using forms provided to you, and to look out for side effects.



Length of treatment

How long will the child need medication for ADHD?

This is not fixed in advance. It may need to continue for years, and some adults are helped by medication¹ (although these medications are not licensed for use in adults). Medication should be stopped periodically (for example, once a year) to see how the child gets on without it.

Stimulants and drug abuse

Does the use of methylphenidate and dexamfetamine in childhood increase the chances that the child will become addicted to similar drugs, or other drugs, in later life? This question naturally worries many parents, teachers and health professionals. More research needs to be done here before we can answer with certainty. However we know that having ADHD increases the risk of substance abuse (drugs and alcohol) in later life.¹ Overall, the studies that have been done suggest that stimulants do more good than harm in this area. In young people with ADHD treated with stimulants, the risk of substance abuse is almost halved compared with those not treated with stimulants.¹

Practical point

In the UK methylphenidate and dexamfetamine are controlled drugs. Taken by mouth, methylphenidate is no good as a recreational drug, but there are some cases of it being diverted for illicit use by intravenous injection.¹ Once-daily formulations mean that children do not have to bring medications to school. The once-daily preparations are much more difficult to grind up or snort.⁹

Dietary approaches



Parents often feel that diet plays a role in their child's ADHD.

The possible role of foods or additives (such as sugar, artificial colourings and preservatives) in causing behavioural disorders in children, particularly ADHD, has been a controversial subject.²

Published evidence suggests that while particular foods or additives don't cause ADHD in most cases, in some cases ADHD patients have specific reactions to particular foods that can play a role for them. Furthermore a recent carefully designed trial showed that a combination of artificial colourings and preservatives significantly increased levels of ADHD symptoms in the general population.¹⁰

The role of omega-3 fatty acids (important for brain development and function) in improving the symptoms of ADHD has been investigated in recent years. Dietary supplementation with fish oils (providing EPA and DHA) appears to alleviate ADHD-related symptoms at least in some children.¹¹

A food diary is one way of trying to find out whether there is any link between behaviour and food in an individual child.¹

Elimination diets (i.e. avoiding specific foods) are sometimes recommended by specialists, although these may turn out to be effective for a minority of children only.¹



Other useful information

Support group

This group provides advice, information and support to individuals and families, and also promotes better awareness of ADHD.

ADDISS – ADHD Information Services

2nd Floor, Premier House

112 Station Road

Edgware

HA8 7BJ

Phone: 020 8952 2800

www.addiss.co.uk

info@addiss.co.uk

www.chadd.org

www.adders.org

Other resources

www.livingwithadhd.co.uk



15 tips for parents...

1. Find out as much as you can about ADHD. Good ways to do this include:

- Talking to people involved in the care of your child – doctors, nurses, psychologists, teachers.
- Using the internet. There's a vast amount of information of variable quality. The web sites we list on page 26 are good places to start.

2. Get attention. When giving instructions, make sure that you have the child's full attention.

- Turn off the TV/ radio/ music.
- Use the child's name.
- With young children, gently hold their hands and point their face towards yours.
- Approach older children from the front.
- Look them in the eye.
- Speak clearly, without shouting.

3. Be positive. Tell them what to do, rather than what not to do. "Darren, please eat your chips" is better than "Stop playing with your chips".

4. Make clear rules, and write them down, so that there's no argument about what the rules are. Focus on areas of behaviour that are really important to you and others in the family, and don't waste effort on less important ones.

5. Set up routines. Children with ADHD tend to respond better to routines, because they have a better idea of what they are supposed to do. Changes to routine create distraction and uncertainty. So getting ready for school in the morning, or getting for a bed at night, should proceed according to a fixed routine.

6. Praise. Try and catch your child being good. When they have completed a task or behaved well, say how pleased you are, and what exactly you are pleased about. The praise should be immediate, not hours or days later. It's easy for children with ADHD to get into a vicious circle of criticism, which makes them feel bad about themselves, which make them behave badly. The aim is to set up a virtuous circle of praise, which makes them feel good about themselves, which helps them to behave better.

7. Reward. Set up a reward scheme. Your child earns points for good behaviour, and a certain number of points mean they can get something they want, that has been agreed in advance. You can use anything you like to keep track of the points: gold stars stuck on a card, plastic tokens put in a jar, etc. A reward scheme can work over the short term, e.g. 1 point for each 10 minutes good behaviour on a long car journey, and over the long term, e.g. 10 points for a week at school with all homework completed on time. To help you with this 'deal cards' are available. You can use these to make deals with your child and then stick them on the fridge or on a kitchen cupboard so that you can both remember the deals that you have made.

For example: The child does something that you want, such as:

- Keep their room tidy for a week.
- Get dressed in 10 minutes for 5 days in a row.
- Not interrupting Mum when she's on the phone, for a week.

In return, the child gets something that they want, such as:

- 15 minutes extra on the internet.
- Hiring a DVD.
- 30 minutes extra playing outside.

8. Plan for peace. Organise things at home to cut out stress and confrontation. For example if doing a big shop with your child is a nightmare, try and find another time to go shopping on your own in peace. If you're dreading a long car journey, think about breaking it up into two or three shorter journeys with stops between to do something else. Yes, they should be able to do these things at their age, but is it worth making a big issue out of it?

9. Focus on strengths. Boost your child's confidence by praising them and encouraging them in the things that they are good at.

10. Can't and won't. The tricky thing about dealing with children with ADHD is knowing the difference between "Can't" and "Won't". Talking out of turn, forgetting instructions, being disorganised, being easily distracted – these are part of ADHD. They can be worked on and improved, but they can't be helped, and are not wilful naughtiness. But any child, including those with ADHD, can also sometimes deliberately misbehave. As a parent, you are the person best placed to become an expert on telling the difference between "Can't" and "Won't".

11. Say how you feel about bad behaviour. Rather than criticising the child directly e.g. "You're behaving badly", talk about the way their behaviour affects you, e.g. "It really upsets me when you...."

12. Avoid arguments. There are clear rules. You know them, the child knows them. End of story.

13. Count to three. For example if the child has taken someone else's toy, say "Darren, please give the dinosaur back to James. I'm going to count to three. One... (wait 5 seconds)... two (more forcefully)... three."

14. Use time out. This is like the "sin-bin" in ice hockey where players who have committed fouls spend a fixed period of time during a game. You can establish a special place – a chair, a step, a corner – where the child goes to cool off (and let you cool off) for a fixed period (e.g. 5 or 10 minutes). You can use a kitchen timer. During the time out, don't talk to the child and don't answer them. When the time is up, don't talk about the problem. They have served their time, and now the slate is clean. If the child refuses to take time out, then threaten to withdraw a privilege, such as playing on the computer or going out to play football. If necessary carry out the threat. A 'Do not disturb' sign is available. Encourage your child to colour this in and decorate it, they can use this sign whenever they need some time alone.

15. Look after yourself. Being the parent of a child with ADHD is exhausting and can be depressing. Try to organise an occasional break for a few hours or even a few days. It's difficult to be a good parent when you're at the end of your tether.

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