

Understanding NICE guidance

Information for people who use NHS services

Attention deficit hyperactivity disorder

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care and treatment of people with attention deficit hyperactivity disorder (ADHD for short) in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is mainly written for parents of children with ADHD but there is also information for young people and adults with ADHD. It may also be useful for anyone with an interest in the condition.

The booklet aims to help you understand the care and treatment options that should be available in the NHS. It does not describe ADHD or the treatments for it in detail. A member of your child's healthcare team, or your healthcare team, should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. Some sources of further information and support are on page 20. Medical terms printed in **bold type** are explained on pages 18–19.

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The advice in the NICE guideline covers:

- the care, treatment and support that children, young people and adults with ADHD should be offered
- how families and carers can support people with ADHD.

It does not specifically look at:

- the treatment of children younger than 3 years
- the treatment of conditions other than ADHD.

Care for all people with ADHD

Treatment and care should take into account the personal needs and preferences of all people with ADHD, and their families or carers, where appropriate. People with ADHD have the right to be fully informed and to make decisions in partnership with their healthcare team. To help with this, the person's healthcare team should give them information they can understand and that is relevant to their circumstances.

All healthcare professionals should treat people with ADHD with respect, sensitivity and understanding, and explain ADHD and its treatment simply and clearly.

The information provided by the person's healthcare team should include details of the possible benefits and risks of particular treatments. People can ask any questions they want to and can always change their mind as their treatment progresses or their condition or circumstances change.

Their own preference for a particular treatment is important and the person's healthcare team should support their choice of treatment wherever possible, but this does depend on the age of the person.

If the person is over 16, or under 16 and fully understands the treatment, they may be able to give their own agreement. If they are too young, their parents or carers may need to agree to their treatment. If more information on consent is needed the following booklets are available from the Department of Health (www.dh.gov.uk/consent):

- Consent: a guide for children and young people
- Consent – what you have the right to expect: a guide for parents.

The treatment and care of a person with ADHD, and the information they are given about it, should take account of any religious, ethnic or cultural needs the person may have. It should also take into account any additional factors, such as a physical or learning disability, sight or hearing problems, or difficulties with reading or speaking English. The person's healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

The person's family and carers should have the chance to be involved in decisions about their care, if the person agrees. Family members and carers also have the right to the information and support they need in their roles as carers, including information about self-help and support groups.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. This can be found by going to the Department of Health website (www.dh.gov.uk/consent).

The person's healthcare professional should also follow the code of practice for the Mental Capacity Act. There is more information about this at www.publicguardian.gov.uk

ADHD

ADHD is a common behavioural disorder in children and young people. It usually starts in early childhood and some people will continue to have ADHD as adults. **Severe ADHD** is sometimes known as 'hyperkinetic disorder'.

The symptoms of ADHD include being:

- inattentive – unable to concentrate for very long or finish a task, disorganised, often losing things, easily distracted and forgetful, unable to listen when people are talking
- hyperactive – fidgety and unable to sit still, restless (children may be running or climbing much of the time), talking constantly, noisy, having difficulty doing quiet activities
- impulsive – speaking without thinking about the consequences, interrupting other people, unable to wait or take their turn.

Not all people with ADHD have all these symptoms, and everyone can be inattentive, hyperactive or impulsive some of the time, particularly children. But a person with ADHD has symptoms most of the time that can seriously affect their everyday life. They may also be clumsy, unable to sleep, have temper tantrums and mood swings and find it hard to socialise and make friends.

It can sometimes be difficult to work out if a person has ADHD because there are conditions that can cause similar behaviour, such as **conduct disorder** in children or **personality disorder** in adults. The person may also have other conditions, for example, conduct disorder, **anxiety** or **learning difficulties**, as well as ADHD.

Information for parents of children with ADHD

What should happen if I think my child has ADHD?

If you or someone else (such as a teacher) thinks that your child's behaviour could be a sign of ADHD, it is likely that you will visit your GP first. If your GP thinks that your child may have ADHD, they should ask you and your child about how your child's behaviour is affecting their everyday life.

Your GP may ask to see your child again to check if their behaviour improves, stays the same or gets worse.

A special educational needs coordinator (SENCO) at your child's school may talk to your child and help with their behaviour.

After your child sees your GP or a SENCO, you may be offered a place on a course to help parents with their child's behaviour (see box on page 8, 'About courses for parents').

If your child's behaviour doesn't improve and you and your GP think it is seriously affecting your child's home and school life and relationships with friends, you and your child should also be offered an appointment with a **specialist** in ADHD.

The specialist may be a **paediatrician**, a **child psychiatrist** or someone with specialist experience in ADHD in children and young people (such as a **learning disability specialist**, social worker or **occupational therapist**).

Your child should only be formally diagnosed with ADHD by a specialist, who should first assess your child. In the **assessment** they will want to know about your child's physical health and if they have any other conditions besides ADHD. The specialist will also ask about your child's life at home and at school, and you may be asked about your own emotional or mental health.

This assessment may include you and your child's teachers filling out a questionnaire. Where possible, your child should be asked directly about how their symptoms and behaviour affect their life, and this should be recorded in their notes.

If your child has not been seen by a specialist, but is taking medication for ADHD (see 'About medication' on pages 15–17) prescribed by your GP, your child should be offered an appointment with a specialist as a priority.

What advice and support can we expect after diagnosis of ADHD?

Your **specialist** or another healthcare professional should give you advice on having clear rules about behaviour, encouraging and rewarding your child's good behaviour, and making sure that your child's day has structure and routine.

Your specialist should offer you advice about a good diet and regular exercise for your child.

If you or a healthcare professional have noticed any food or drink that seems to affect your child's behaviour, you should be advised to keep a diary of what your child eats and drinks, and their behaviour afterwards. If there seems to be a link between certain food and drink and your child's behaviour, you should be offered an appointment with a dietitian.

There is no evidence that dietary supplements such as fatty acids (omega 3 or omega 6) or cutting out foods containing artificial colouring and other additives can help children with ADHD.

With your permission, your specialist should contact your child's nursery or school teacher about your child's ADHD and work out whether your child needs extra help in class.

During any major changes in your child's life (such as puberty, starting or changing school, or the birth of a brother or sister), your healthcare professional should make sure that there is adequate care and support for your child if needed.

Questions you might like to ask your healthcare team

- Can you tell me more about ADHD?
- Are there any support organisations in my local area?
- Can you provide any information for me and my child?
- How can I help my child?
- Are there any self-help books or videos about managing behaviour that you can recommend?

What treatment should my child be offered?

The treatment your child should be offered will depend on how old they are and their symptoms of ADHD. A specialist should give your child most of their treatment and care when they are first diagnosed with ADHD, but after this your GP may provide some care.

Treatment for very young children with ADHD

If your child is under five, they should not be offered medication for ADHD. You should be offered a place on a course to help with your child's behaviour if you have not attended one before, or if you and your specialist feel that attending one again would help (see box on page 8, 'About courses for parents').

If the treatment and care you and your child have received so far have helped your child's behaviour, your specialist may decide that they no longer need to see your child about their ADHD. Before this happens, your child should be checked for any other conditions, such as **conduct disorder** or **learning difficulties**, besides ADHD. Healthcare professionals should also see your child after they start school to check whether the ADHD symptoms are causing any difficulties with their relationships or school work.

If the treatment and care you and your child have received so far have not helped your child's behaviour, you and your child may be offered an appointment with another ADHD specialist.

Some treatments may not be suitable for your child, depending on the exact circumstances.

If you have questions about the specific treatments and options covered in this booklet, please talk to a member of the healthcare team.

About courses for parents

The aim of the course is to equip parents with the necessary skills so that they can help to improve their child's behaviour.

A course is about 8–12 sessions and usually takes place in a group with other parents. The course will help parents to understand their own and their child's feelings and behaviour. It is a chance to meet other people in a similar situation, help one another and share experiences. There will be activities and 'homework' so that anything new can be practised at home.

One-to-one sessions with parents may also be offered if people find it difficult to attend the group sessions or if their healthcare professional thinks that a one-to-one session would be more appropriate. Some of the one-to-one sessions should also include the child if they are of pre-school age.

If you agree, the professional running the course may give your child's teacher written information about what was covered in the sessions.

The professionals running the programme should make sure help is available if parents find it difficult to attend these sessions.

Treatment for school-age children with ADHD

If your child is old enough to go to school, they should not usually be offered medication first.

Your child's teachers should be informed about how to support children with ADHD. If they have also had training about ADHD, they should be able to use a number of methods to help your child in class.

You should be offered a place on a course to help parents with their child's behaviour (see box on page 8, 'About courses for parents'). Sometimes it is helpful if your child also attends a course of group treatment, which may be a **psychological therapy** called **cognitive behavioural therapy (CBT)** or **social skills training**.

This should cover:

- solving problems
- developing their ability to control themselves
- listening when other people are talking to them
- coping with and expressing their feelings
- improving relationships with their friends and other children.

If your child is a teenager, one-to-one psychological therapy for them may be an option instead of a course for both of you.

If your child has a learning disability as well as ADHD, you should be given the choice of group or one-to-one sessions for you and your child.

If the treatment so far has helped, your child should be assessed for any other conditions, such as **anxiety**, aggression and **learning difficulties**, so that these can be addressed.

If the treatment so far has not helped, your child should be offered medication (see pages 15–17, 'About medication'). This should be alongside other support and treatment including courses for parents and children. Medication may also be offered if you and your child would prefer not to attend a course for parents or have psychological treatment.

Treatment for school-age children with severe ADHD

If your child has **severe ADHD**, they should be offered medication as this is the best treatment for them. Medication should only be started by a **specialist** in ADHD after a full **assessment** of your child's symptoms, and after discussion with you and your child (see pages 15–17, 'About medication').

If a treatment described in this booklet appears suitable for your child, but it is not available, you should talk to your local Patient Advice and Liaison Service (PALS) in the first instance. If they are not able to help you, they should refer you to your local Independent Complaints Advocacy Service.

After this, your GP can continue to prescribe your child's medication and check how your child is doing. As well as your child being offered medication, you should also be offered a place on a course to help parents with their child's behaviour (see box on page 8, 'About courses for parents').

If you do not want your child to take medication, or if your child does not want to take it, your specialist should talk to you about this. You should still be offered a place on the course to help parents with their child's behaviour. If the course helps, your child should be assessed to see whether they have any other conditions such as **anxiety**, aggression or **learning difficulties**, besides ADHD. The specialist should develop a long-term plan for your child's care after discussion with you and your child.

If the course does not help, then your specialist should talk to you again about medication or extra psychological help for your child.

If you want to know more about the treatments for ADHD there are some examples of questions you could ask your child's doctor on page 14.

What happens when my child becomes an adult?

At school-leaving age, young people with ADHD should be assessed to see if they need treatment as adults. If they still need treatment, the responsibility for their care should be transferred to adult services, and this should be arranged by the time your child is 18. Your child should be given information about adult services and offered a full **assessment** of their symptoms when they transfer.

Questions about support for children, parents and carers

- Where can I find local activities (such as sports, summer camps and holiday schemes) for children with ADHD?
- Are there any other ways of helping my child, using books, websites and toys?
- Is there any additional support that carers might benefit from or are entitled to?

Information for young people with ADHD

If your parents, carers or teachers think that your behaviour is causing problems for you and you are not able to concentrate at school, they may talk to you and arrange for you to see a doctor about these problems. The doctor will talk to you about whether your behaviour is causing you serious problems at home and at school. If it is, then you will be offered an appointment with an expert or '**specialist**', who will ask you some questions about how it feels when you can't keep still, or can't concentrate.

If the specialist thinks that you have a condition called ADHD (which stands for attention deficit hyperactivity disorder), they will work out what treatments can best help you. If you agree, you and your parents should be involved in all the decisions about your care (see page 3). You can find more information about ADHD on page 4 of this booklet.

The treatments for ADHD include medication and '**psychological therapy**' to help you cope with your feelings and behaviour. If your ADHD is not causing you serious problems, you should not usually be offered medication first.

If you and your parents agree, your doctors may let your teachers know about your ADHD so that they can help and support you at school. Your parents or carers should be offered a place on a course that will help them to give you extra support when you need it (see box on page 8, 'About courses for parents'). You may also be offered psychological therapy with other young people with ADHD, which can help you to:

- solve problems by yourself
- control your feelings and behaviour
- listen to other people when they are talking
- have better relationships with your friends and other people.

If you are a teenager, your doctor may offer you a psychological therapy for you on your own.

If these treatments do not help your ADHD, you may be offered medication (there is more information in the 'About medication' section on pages 15–17).

If your ADHD symptoms are severe and are seriously affecting you, your doctor should offer you a package of care that includes medication and psychological therapy. Medication, which should be the first treatment offered, should only be started by a specialist in ADHD and not by your GP.

If you decide not to have medication and the course for your parents or your psychological therapy does not help, then your doctor may talk to you again about the possibility of taking medication or having another type of psychological therapy.

If you want to know more about the treatments for ADHD there are some examples of questions you could ask your doctor on page 14. When you reach school-leaving age, you should be offered another **assessment** to see if you need to carry on with your treatment. You should be given full information about the care and treatment available for adults.

Information for adults with ADHD

If you find it difficult to concentrate, your behaviour is hyperactive and impulsive, and this is causing you difficulties in your everyday life, you should see your GP. Your GP should offer you an **assessment** with a **specialist** in ADHD if you were not diagnosed with ADHD as a child. If you were diagnosed with ADHD as a child, you should be referred to general mental health services.

The specialist should thoroughly assess you to see whether you have ADHD. Only a specialist can make a formal diagnosis of ADHD.

You should be fully involved in all discussions about your healthcare. Professionals should always treat you with respect and give you the information you need in a form that is suitable for you, including details about support groups and voluntary organisations. There are some examples of questions you might like to ask your healthcare team on page 14.

Medication should usually be offered to you first, unless you would prefer to try a **psychological therapy** (such as **cognitive behavioural therapy [CBT]**). Medication should only be prescribed under the guidance of a specialist.

More information about medication is given on pages 15–17. Medication should always be part of a package of care, which should address other needs you may have because of your diagnosis. These may include psychological help and support in finding or continuing in a job.

If you are taking medication but still have symptoms of ADHD, you should also be offered a course of CBT. CBT may also be offered if medication has not helped you at all, if you have side effects from the drugs, or if your symptoms are getting better but you still need some additional support.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team.

Questions about treatment for all people with ADHD

- Why have you decided to offer this particular type of treatment?
- What are the pros and cons of having this treatment?
- What will the treatment involve?
- How will the treatment help? What effect will it have on symptoms and everyday life? What sort of improvements might be expected?
- Is there some other written material (like a leaflet) about the treatment?
- How long will the medication take to work? What should I do if I don't think it is working?
- How long will the medication need to be taken for?
- Might there be problems when the medication is stopped?
- Are there any serious or long-term side effects with medication for ADHD? How common are they?
- What should I do if there are any side effects? Should the GP or specialist be called, or should I go to the emergency department at a hospital?
- Are there different treatments that could be tried?
- What will happen if the treatment is not followed?

About medication

What medication is used for ADHD?

The medications recommended to treat ADHD in children and young people are **methylphenidate**, **atomoxetine** and **dexamfetamine**.

People with ADHD should not be offered drugs called '**antipsychotic drugs**' to treat their symptoms.

What should happen before medication starts?

The **specialist** should offer to give the person:

- a full physical and mental health **assessment**, including discussion with the person about their views and preferences for treatment
- clear instructions about taking the medication.

Which medication should be offered?

For children and young people, this will depend on a number of things, such as:

- whether they have other conditions such as **Tourette's syndrome**, **tics** or epilepsy
- the side effects associated with each medication
- whether the child or young person will need to take the medication while they are at school
- their preferences.

In children and young people, methylphenidate should normally be offered if they do not have any other serious mental health problems or if they also have **conduct disorder**. Methylphenidate or atomoxetine should normally be used if the person also has tics, Tourette's syndrome or **anxiety**, or if they are misusing **stimulants**. If methylphenidate has been tried and does not help, atomoxetine should be offered.

The type of methylphenidate that should be offered to children and young people is usually long lasting (sometimes called 'modified release') so that they do not have to take another dose during school hours. Tablets that work straight away (sometimes called 'immediate release') may be considered if children and young people need to take their medication at different times of the day.

Methylphenidate is usually the first treatment offered to adults with ADHD.

Are regular checks needed?

Adults with ADHD, partners, parents or carers and teachers should be asked to keep a record of changes in symptoms and behaviour when medication is started or the dose is changed. A specialist should contact them regularly to check on how things are going.

Healthcare professionals should also check for side effects regularly. These could include:

- weight loss or not reaching an expected height in children and young people
- an increase in heart rate or blood pressure
- **anxiety**
- serious changes in mental state (such as seeing or hearing things that are not there)
- seizures
- the appearance of **tics**.

If there are side effects, the dose of medication may need to be reduced, stopped or changed.

For all people taking medication for ADHD, their weight should be measured 3 months and 6 months into the treatment, and every 6 months after that. In children and young people, their height should be measured every 6 months. A healthcare professional may suggest stopping the medication over the school holidays to allow the child's growth to 'catch up'.

If any person on medication for ADHD loses weight, then healthcare professionals should advise that the drug is taken with or after food rather than before meals. Additional meals or snacks in the early morning or late evening may help. The healthcare professional may seek dietary advice and suggest high-calorie foods of good nutritional value. If weight loss continues, a different drug may need to be considered.

All people taking medication for ADHD should have their heart rate and blood pressure checked every 3 months and before and after any change in dose.

Atomoxetine

Healthcare professionals should warn that some people (especially young adults) taking **atomoxetine** may feel more agitated or irritable than usual, have thoughts about suicide, self-harm, and experience unusual changes in behaviour, especially during the first few months of treatment or after a change in dose. Parents or carers should be asked to report these effects to their healthcare professional. Healthcare professionals should warn people (of any age) taking atomoxetine, and their parents and carers if applicable, about the rare possibility of liver damage (the signs of this are stomach pain, nausea, dark urine or **jaundice**).

Healthcare professionals should ask older boys and men about any sexual problems as a result of taking atomoxetine. They should also ask girls and women whether the medication has had any effect on their periods.

Parents and teachers should be advised that **stimulant** medication can be misused. The risk may increase as the child or young person gets older or if their circumstances change.

How can a person be supported when taking their medication?

Visual reminders to take medication regularly (such as clocks, pill boxes and notes on calendars or fridges) can be helpful. Taking medication should be part of a daily routine (for example, before meals or after brushing teeth). Having a positive attitude about taking medication, and giving appropriate praise to a child, may also help. If taking medication regularly is difficult, the healthcare professional may suggest attending a support group.

What if medication does not help?

If **methylphenidate** or **atomoxetine** (together with courses for parents and **psychological therapy** for the child or young person) do not help children and young people with ADHD, healthcare professionals should review the treatment so far. The dose of the medication may then be increased or **dexamfetamine** or another drug may be offered. Other psychological treatments may also be offered.

In adults, if methylphenidate does not help, either atomoxetine or dexamfetamine may be tried instead. Psychological help may also be offered.

For how long should medication be taken?

Medication should be continued for as long as it is helpful. This should be reviewed every year after a full **assessment**, and at least every year in children and young people. Healthcare professionals should work with the person to find a pattern of treatment that works best. This may include periods when medication is not taken.

Explanation of medical words and terms

Antipsychotic drugs: a type of medicine that is sometimes used to treat serious changes in mental state (such as seeing or hearing things that are not real).

Anxiety: feelings of worry or fear that can be difficult to control.

Assessment: a meeting with a healthcare professional, when they will ask questions about a person's physical and mental health, to establish what the illness is, how severe it is and what treatments would suit the person best. An assessment may involve a physical examination and tests.

Atomoxetine: a type of drug called a 'selective noradrenaline re-uptake inhibitor' used to treat ADHD.

Child psychiatrist: a doctor specialising in the treatment of children's mental health.

Cognitive behavioural therapy (CBT): a psychological treatment where people work with a therapist to look at how their problems, thoughts, feelings and behaviour fit together. CBT can help people to challenge negative thoughts and change any behaviour that causes problems.

Conduct disorder: a disorder affecting children who show antisocial, aggressive or defiant behaviour. It is more serious than childish mischief or teenage rebelliousness.

Dexamfetamine: a type of drug called a stimulant; it can improve concentration and reduce restless or hyperactive behaviour in people with ADHD.

Jaundice: a condition that causes yellowing of the skin or the whites of the eyes.

Learning difficulty: a condition in which children experience problems with specific aspects of learning such as reading, writing or concentrating. It is often used to describe children and young people with special educational needs.

Learning disability specialist: a person with expertise in working with people who have learning disabilities or learning difficulties.

Methylphenidate: a type of drug called a stimulant; it can improve concentration and reduce restless or hyperactive behaviour in people with ADHD.

Occupational therapist: a person with expertise in treating psychiatric and physical conditions using activity.

Paediatrician: a doctor specialising in the treatment of children.

Personality disorder: a condition that leads to a person having unstable moods, thoughts, behaviour and self-image.

Psychological therapy/treatment: a general term used to describe meeting with a therapist to talk about feelings, moods and behaviour.

Severe ADHD: also called hyperkinetic disorder. A person with severe ADHD has all the symptoms of ADHD (inattention, impulsivity and hyperactivity) in more than one situation (such as school or workplace, home, or with friends). The symptoms affect a person's life to a great degree.

Social skills training: teaching people to be more socially aware in their relationships with other people.

Specialist: a psychiatrist, paediatrician, learning disability specialist, social worker or occupational therapist with expertise in ADHD.

Stimulant: a drug that increases activity in the brain, and has a calming influence on hyperactivity and improves concentration.

Tics: movements of the muscles over which a person has no control.

Tourette's syndrome: a disorder in which a person has tics and speaks involuntarily (sometimes in obscenities).

More information

The organisations below can provide more information and support for people with ADHD. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- adders.org, 0871 590 3693, www.adders.org
- ADDISS, 020 8952 2800, www.addiss.co.uk
- Adults with Attention Deficit Disorder UK (AADDUK), 01934 863 556
www.aadd.org.uk
- MIND, 0845 766 0163, www.mind.org.uk

NHS Direct online (www.nhsdirect.nhs.uk) may also be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further information and support.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the best available evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals working in the field. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of this guideline aimed at healthcare professionals are available at www.nice.org.uk/ICG072

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1685).

We encourage NHS and voluntary sector organisations to use text from this booklet in their own information about ADHD.