

# NICE guidance for ADHD: A guide for patients

NICE guideline: Attention deficit hyperactivity disorder: diagnosis and management. NG87. March 2018.



Report was developed following a workshop and subsequent discussions between Shire and the patient representative group. Phase-five healthcare consultancy facilitated this workshop, on behalf of Shire.

Patient Representative Group: Dr Tony Lloyd, ADHD Foundation; Christine Jarvis, ADHD Solutions; Niall Greene, Adult ADHD NI; Jenny Missen, ADDISS; Poppy Ellis Logan, #AttentionUK; Anne Ross, ADD-vance; Andrea Bell, ADHD Norfolk; Jenna Thompson, ADD-NI Children's Charity; Michelle Beckett, ADHD Action.



Job number: C-ANPROM/UK//1822 Date of preparation: December 2018  
Shire has initiated, funded and contributed to this report, and has reviewed this report for compliance with the ABPI Code of Practice for the Pharmaceutical Industry.

© 2018. All rights reserved. SHIRE and the Shire Logo are registered trademarks of Shire Pharmaceutical Holdings Ireland Limited or its affiliates.

## Introduction

### What is this booklet about and who is it for?

This booklet summarises the NICE guideline for ADHD (updated in March 2018) for patients and their families. It aims to help you to understand the recommendations from NICE and how you may be affected by them. It also describes what you can expect from your care.

Whilst this booklet does not cover the whole guideline, it focuses on the areas that may be of interest to you.

The full NICE guideline can be downloaded from the NICE website: [www.nice.org.uk/guidance/ng87](https://www.nice.org.uk/guidance/ng87)

The first 5 pages provide background information on what NICE is, what they do and how the guidelines are produced. On pages 6 to 29, the official NICE guidance for ADHD can be read on the left-hand side of each page, with notes from the patient representatives to explain what this means for you, the patient, on the right-hand side. Some of the words used in the NICE guideline are explained in each section but you can also find a useful glossary of words on page 30.

## Background information

### What is NICE?

The National Institute for Health and Care Excellence (NICE) provides the NHS with the current evidence base and advice to improve outcomes for people with certain health conditions. NICE Guidance sets out the 'gold standard' of care, underpinned by up to date clinical research. NICE Guidance is available for a number of health conditions, both physical and mental health conditions. It provides a structure for the NHS, local authorities, employers, voluntary groups and anybody else involved in delivering care or promoting wellbeing.

#### NICE develops its guidelines by:

- ↪ Utilising the best available evidence of what works and what it costs 
- ↪ Consulting with independent and unbiased groups of experts
- ↪ Consulting with at least 2 lay members (that means patients, service users, carers or members of the public with personal experience of using health or care services)
- ↪ Allowing organisations and individuals to comment
- ↪ Implementing regular checks and updates when needed. 

You can find more information about NICE on their website: <https://www.nice.org.uk/about>



# General recommendations

NICE says:

## Making decisions about your care

### Involved you

It is your right to be involved in making choices about your care. People often find they are happier with their care, and more likely to stick with any treatments or care plans, when they make decisions jointly with their health or care professional.

To make a decision, you need to know what your options are and what might happen if you don't want any treatment or care. Your health or care professionals should explain what might work for you – some options may not be suitable.

You need to have information about the pros and cons of the options. This must be easy for you to understand.

Your health and care professionals need to know what matters to you – no two people are the same and they should listen carefully to your views and concerns.

You and your health or care professionals need time to talk through what you want to get out of any treatments or care and any worries or questions you have.

### Before you see your health or care professional

- Write down any questions you want to ask
- Think about what you want to get out of your care. It could be things like improving symptoms, taking fewer medicines or staying independent
- Ask for an interpreter or other help to communicate if you need to
- Ask a friend or family member to come with you, if you like.

### When you see your health or care professional

- Ask if you need more information or you don't understand something
- Let them know if you need information in a different way, such as large print or easy read, or if you need someone to help you understand what is being said
- If you don't understand any words, ask for them to be written down and explained
- Write things down, or ask a friend or family member to take notes
- Check you know what should happen next, and when. Write it down
- Find out who to contact if you have any problems or questions
- Ask for copies of letters written about you – you are entitled to see these.

### Involving other people

Family and carers should also be involved in decisions about your care if you want them to be. They should be given their own information and support.

# General recommendations

The patient representatives say:

NICE says that you, the patient, have the **right to be involved in decisions** about your care. The information on this page is for all patients about their healthcare. You can read more about this by following the link below:

[www.nice.org.uk/about/nice-communities/public-involvement/your-care](http://www.nice.org.uk/about/nice-communities/public-involvement/your-care)

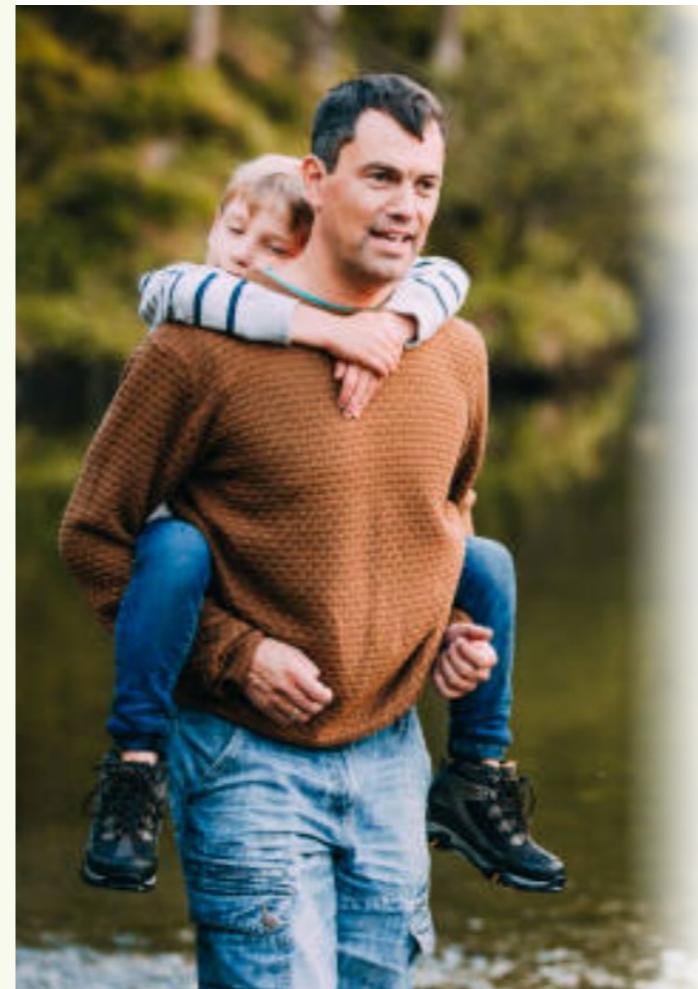
Your healthcare professional should provide **information about your treatment options**, in a way that is easy for you to understand. They should also listen to your views and any concerns so that you can **make decisions together**.

The patient representatives suggest looking at these useful tips before your appointment:

- Write things down, such as appointments and what you want to discuss at your appointments
- Take a trusted family member, parent/carer or friend with you
- If you don't understand something your healthcare professional says, ask them to explain it
- Ask them who you can contact between appointments if you need to speak to someone and the best way to contact them.



Many people find it helps to involve their **family or friends** in their care so they can support them with their ADHD, but it is your decision to include them. If you do involve a family member, carer or friend, your healthcare professional should also offer information and support to them.



# Overview of recommendations specific to ADHD

NICE says:

This guideline covers recognising, diagnosing and managing ADHD in children, young people and adults. It aims to improve recognition and diagnosis, as well as the quality of care and support for people with ADHD.

## Who is it for?

- ↳ Healthcare professionals
- ↳ Commissioners and providers
- ↳ People with ADHD, and their families and carers.

People have the right to be involved in discussions and make informed decisions about their care, as described in 'Your Care'

[www.nice.org.uk/about/nice-communities/public-involvement/your-care](http://www.nice.org.uk/about/nice-communities/public-involvement/your-care)

## ADHD: the care you should expect

NICE want this guideline to make a difference to children, young people and adults with ADHD by making sure:

- ↳ everyone is correctly diagnosed – the guideline aims to improve recognition of ADHD by highlighting which groups of people are most likely to have it
- ↳ with the right information and support, people understand their diagnosis and see it as a positive step towards getting help and understanding from others
- ↳ healthcare professionals listen to people's views about different treatment options and help them get the most from their treatment
- ↳ people have check-ups as often as they need them, whether or not they take medicines for their ADHD, and are offered support to complete their treatment
- ↳ information is shared with teachers and other healthcare professionals so that people have seamless support – especially during big changes like moving from school to college.

## Making decisions together

Decisions about care and treatment are best when they are made together. Your health professionals should talk with you about all your options and listen carefully to your views and concerns. They should also:

- ↳ give you clear information that suits your age, understanding and needs
- ↳ tell you about other ways to get help, including self-help and support groups
- ↳ support families and tell them how to get their own help and advice.

If you can't understand the information you are given, tell your health professional.

We wrote this guideline with people who have been affected by ADHD and staff who treat and support them. All the decisions are based on the best research available.

# Overview of recommendations specific to ADHD

The patient representatives say:

The NICE guideline looks at all aspects of ADHD including:

- ↳ Recognising it in people who have not been diagnosed
- ↳ Assessing people to see if they have ADHD
- ↳ Supporting people with ADHD
- ↳ Organising services to support people with ADHD and their families and carers.

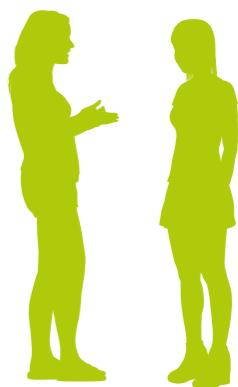
**The NICE guidance states that people with ADHD have the right to be involved in their care and how their ADHD is managed.**

The patient representatives say that being diagnosed with ADHD should be a **positive first step** towards getting help. NICE want to make a **positive difference** to the lives of people with ADHD and have set goals to achieve this. Your healthcare professional should:

- ↳ Arrange **regular check-ups, even if you aren't taking medication**
- ↳ Listen to your views and tell you about treatment options so you can make decisions about your care together
- ↳ Provide information in a way that you can understand
- ↳ Tell you where to find **help and support** such as local support groups, online sources etc.
- ↳ Provide information and advice to your family and/or carers.

You may need **extra support** at potentially difficult times in your life such as changing school or job, or between relationships – this booklet will provide more detailed advice on these situations.

**If you don't understand anything, ask your healthcare professional to explain it.**



# Diagnosis

## NICE says:

1.3.1 A diagnosis of ADHD should only be made by a specialist psychiatrist, paediatrician or other appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD, on the basis of:

- a full clinical and psychosocial assessment of the person; this should include discussion about behaviour and symptoms in the different domains and settings of the person's everyday life and
- a full developmental and psychiatric history and
- observer reports and assessment of the person's mental state.

1.3.3 For a diagnosis of ADHD, symptoms of hyperactivity/impulsivity and/or inattention should:

- meet the diagnostic criteria in DSM-5 or ICD-10 (hyperkinetic disorder) and
- cause at least moderate psychological, social and/or educational or occupational impairment based on interview and/or direct observation in multiple settings and
- be pervasive, occurring in 2 or more important settings including social, familial, educational and/or occupational settings.

As part of the diagnostic process, include an assessment of the person's needs, coexisting conditions, social, familial and educational or occupational circumstances and physical health. For children and young people, there should also be an assessment of their parents' or carers' mental health.

1.3.5 In determining the clinical significance of impairment resulting from the symptoms of ADHD in children and young people, their views should be taken into account wherever possible.

# Diagnosis

## The patient representatives say:

NICE says that ADHD should only be diagnosed by a healthcare professional with **specialist knowledge** in ADHD. GPs are not able to make an ADHD diagnosis so they must refer you to be assessed by someone with specialist knowledge:

- For **children**, this specialist is usually a paediatrician or child and adolescent psychiatrist
- For **adults**, this is most often a psychiatrist.

The patient representatives say it is important to know that **ADHD is not a barrier** to being successful at school or in your career. This also means that doing well at school or in your job should not be used as a reason that you might not have ADHD.

ADHD care can vary in different parts of the country. If there is not a dedicated ADHD Care Pathway in your area, you can discuss this with your GP. A referral can be made to a different NHS Trust but it may mean that you have to travel to be seen by an ADHD specialist. This is more common for adults who need to see an ADHD specialist.

If you are not happy with the **outcome of your assessment**, you are able to ask for a 'second opinion' from another healthcare professional. You should discuss this with your healthcare professional who did your assessment. If you do not feel comfortable doing this, you should talk to your GP.

The patient representatives suggest discussing with your GP what **information** would be useful for them to include when they make the referral, such as letters from your school/employer, or any test results such as QB testing (a computer-based test used to assess the main symptoms of ADHD).

**At your appointment** with the specialist, you will be asked about the difficulties you personally experience in different areas of your life to work out if you have ADHD. This is because everyone with ADHD is different. **Before your appointment**, the patient representatives recommend thinking about all of the ways that ADHD affects you, and also those around you. For example:

- Daily life (e.g. organisation skills, time keeping)
- Social life and hobbies
- School or work
- Managing money
- Physical health
- Any other conditions you may have (co-existing conditions)
- If you are an adult, they will also ask you about your childhood and school days. It may be useful to take your school reports (if you have them) to your first appointment. It may also be useful to take a parent/carer or someone who knew you as a child as they may be able to provide information about your childhood.



There is no one test for diagnosing ADHD so specialists in ADHD have agreed "**diagnostic criteria**" to see if people have ADHD. These are called DSM-5 and ICD-10.

NICE says that your healthcare professional should **listen to your views** and understand how ADHD impacts your life. They should use this information to find the best way to help you.



# Supporting people with ADHD

NICE says:

1.4.3 Following a diagnosis of ADHD, have a structured discussion with people (and their families or carers as appropriate) about how ADHD could affect their life. This could include:

- ↳ the positive impacts of receiving a diagnosis, such as:
  - ↳ improving their understanding of symptoms
  - ↳ identifying and building on individual strengths
  - ↳ improving access to services
- ↳ the negative impacts of receiving a diagnosis, such as stigma and labelling
- ↳ a greater tendency for impulsive behaviour
- ↳ the importance of environmental modifications to reduce the impact of ADHD symptoms
- ↳ education issues (for example, reasonable adjustments at school and college)
- ↳ employment issues (for example, impact on career choices and rights to reasonable adjustments in the workplace)
- ↳ social relationship issues
- ↳ the challenges of managing ADHD when a person has coexisting neurodevelopmental or mental health conditions
- ↳ the increased risk of substance misuse and self-medication
- ↳ the possible effect on driving (for example, ADHD symptoms may impair a person's driving and ADHD medication may improve this; people with ADHD must declare their diagnosis to the DVLA if their ADHD symptoms or medication affect their ability to drive safely).

This structured discussion should inform the shared treatment plan.

1.4.4 Inform people receiving a diagnosis of ADHD (and their families or carers as appropriate) about sources of information, including:

- ↳ local and national support groups and voluntary organisations
- ↳ websites
- ↳ support for education and employment.

1.4.5 Provide information to people with ADHD (and their families and carers as appropriate) in a form that:

- ↳ takes into account their developmental level, cognitive style, emotional maturity and cognitive capacity, including any learning disabilities, sight or hearing problems, delays in language development or social communication difficulties
- ↳ takes into account any coexisting neurodevelopmental and mental health conditions
- ↳ is tailored to their individual needs and circumstances, including age, gender, educational level and life stage.

# Supporting people with ADHD

The patient representatives say:

It is important that you receive the appropriate **help and support for your ADHD**.

The patient representatives say that your healthcare professional should:

- ↳ **Discuss with you** how ADHD affects you as an individual so that you can understand it and so they can help you with any problems you have
- ↳ Use this information to find the best way to help you and make a **treatment plan** together
- ↳ Let you know **where to find help** with other areas of your life that may have been affected by your ADHD. This could be education, work, relationships and finance
- ↳ Tell you about ADHD **support groups** and other ways to find information about ADHD (you can ask about local groups and resources that are available locally and online)
- ↳ Provide information in a **format that you understand**. If you don't understand, ask for more information and explain what format would best help you to understand the information.

The symptoms of ADHD may affect your ability to **drive safely** but appropriate management of ADHD symptoms may improve this. Some medicines used to treat ADHD may also affect your ability to drive safely. You should avoid driving until you know how your symptoms or medication affect you and you must tell the DVLA if you are affected.

If your healthcare professional has concerns about your ability to drive safely, they should discuss this with you directly, as well as telling the DVLA. If your healthcare professional asks you to declare your diagnosis of ADHD and your medication to the DVLA, you must do so. You could be fined up to £1,000 if you do not tell DVLA about a condition that might affect your ability to drive safely. You must also inform your insurance provider once the DVLA confirm the status of your licence.

Please do not worry if you are requested to report your diagnosis and medication to the DVLA; they will write to your healthcare professional who will then provide a report on your behalf to the DVLA.

**Talk to your healthcare professional if you are not sure about driving and driving regulations.**

You can find more information by following this link: [www.gov.uk/adhd-and-driving](http://www.gov.uk/adhd-and-driving).

You may be entitled to free or discounted travel if your ADHD means you can't have a driving licence.



## Supporting families and carers

### NICE says:

1.4.6 Ask families or carers of people with ADHD how the ADHD affects themselves and other family members and discuss any concerns they have.

1.4.7 Encourage family members or carers of people with ADHD to seek an assessment of their personal, social and mental health needs, and to join self-help and support groups if appropriate.

1.4.8 Think about the needs of a parent with ADHD who also has a child with ADHD, including whether they need extra support with organisational strategies.

1.4.9 Offer advice to parents and carers of children and young people with ADHD about the importance of:

- ↳ positive parent- and carer-child contact
- ↳ clear and appropriate rules about behaviour and consistent management
- ↳ structure in the child or young person's day.

1.4.10 Offer advice to families and carers of adults with ADHD about:

- ↳ how ADHD may affect relationships
- ↳ how ADHD may affect the person's functioning
- ↳ the importance of structure in daily activities.

1.4.11 Explain to parents and carers that any recommendation of parent-training/education does not imply bad parenting, and that the aim is to optimise parenting skills to meet the above-average parenting needs of children and young people with ADHD.

## Supporting families and carers

### The patient representatives say:

**Families and/or carers** are important in helping to support you on your journey with ADHD. Caring for someone with a long-term health condition can be hard so the people who care for you should also be supported. The patient representatives suggest bringing someone with you when visiting your healthcare professional – this could be a parent/carer, partner or a trusted family member or friend.

If you care for someone with ADHD, have a think before attending appointments about the impact that your role in caring for them has on you – it is important to **seek support** if needed and this appointment provides an opportunity to ask about this. There are dedicated **support groups for carers** that may be useful and the healthcare professional should be able to let you know where to find this support. Your carer may also be entitled to Carer's Allowance – see here for more information: [www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance)

Families and carers of children with ADHD should be **involved in treatment decisions** about their child and given information about how to help them. As children get older, they become more independent and should be encouraged to take **increasing responsibility** for their own health. Young people and adults with ADHD should give their consent for their families/carers or partners to be involved in their healthcare.

Research has shown that ADHD may run in families. If you think someone else in your family may have ADHD, the patient representatives suggest that this person talks to their GP about being referred to a specialist for assessment.

Parents/carers of children with ADHD may be offered **parent-training and education** to help support their child. It is important to know that this does not mean they are “bad parents”. The goal of parent training is to learn new skills to meet the above-average needs of children and young people with ADHD.



## Planning treatment

NICE says:

1.5.1 Healthcare providers should ensure continuity of care for people with ADHD.

1.5.2 Ensure that people with ADHD have a comprehensive, holistic shared treatment plan that addresses psychological, behavioural and occupational or educational needs. Take into account:

- ↪ the severity of ADHD symptoms and impairment, and how these affect or may affect everyday life (including sleep)
- ↪ their goals
- ↪ their resilience and protective factors
- ↪ the relative impact of other neurodevelopmental or mental health conditions.

1.5.3 Regularly discuss with people with ADHD, and their family members or carers, how they want to be involved in treatment planning and decisions; such discussions should take place at intervals to take account of changes in circumstances (for example, the transition from children's to adult services) and developmental level, and should not happen only once.

## Planning treatment

The patient representatives say:

**Continuity of care** means that a patient sees the same healthcare professional at each appointment, or a healthcare professional whom has access to all information relating to your case, so they can get to know you and have a better understanding of your needs. This may be your doctor, nurse or other healthcare professional such as a therapist. Of course, sometimes it is necessary for this to change, perhaps because the person has moved or changed jobs.

NICE says everyone should have a “**comprehensive, holistic shared treatment plan**” but what does this mean? The patient representatives describe this as follows:

- ↪ **Comprehensive** means to deal with all (or nearly all) aspects of how your diagnosis of ADHD impacts you and how any co-existing conditions impact you and your ADHD
- ↪ **Holistic** means treating the whole person, taking into account other factors, not just the symptoms of ADHD e.g. your strengths, family values, your likes/dislikes
- ↪ **Shared** means that you are involved with any decision about your treatment so that there is a collaborative approach to your care. It is important to share your treatment plan in other settings, as they may be able to make some changes to suit your needs e.g. your school, college or your place of work may be requested to make some environmental modifications to ensure you are reaching your full potential. This also includes other healthcare professionals who should take into account your ADHD when treating you for other conditions.



As we get older, our **needs change** and this is the same for people with ADHD so your healthcare professional should regularly **review** your treatment to account for these changes. If you feel that you need additional support from your healthcare team outside of your scheduled appointments, you should contact them for advice.



## Planning treatment – continued

### NICE says:

1.5.4 Before starting any treatment for ADHD, discuss the following with the person, and their family or carers as appropriate, encouraging children and young people to give their own account of how they feel:

- the benefits and harms of non-pharmacological and pharmacological treatments (for example, the efficacy of medication compared with no treatment or non-pharmacological treatments, potential adverse effects and non-response rates)
- the benefits of a healthy lifestyle, including exercise
- their preferences and concerns
- how other mental health or neurodevelopmental conditions might affect treatment choices
- the importance of adherence to treatment and any factors that may affect this.

1.5.5 Ask young people and adults with ADHD if they wish a parent, partner, close friend or carer to join discussions on treatment and adherence.

1.5.6 Reassure people with ADHD, and their families or carers as appropriate, that they can revisit decisions about treatments.

## Planning treatment – continued

### The patient representatives say:

When discussing treatment for your ADHD, your healthcare professional should explain the benefits and potential harms of your treatment options, including side-effects and the possible consequences of not having treatment. This will help you to decide what is right for you. All medicines have potential side-effects, and although not everyone gets them, you should be aware of what they are. The patient representatives suggest that you talk to your healthcare professional about any questions or concerns you may have and ask them about any rumours or information you may have heard from others.

Once you have agreed your **treatment plan** with your healthcare professional, it is important that you try to **stick to it**. There are things you can do to help yourself and the patient representatives suggest trying some of these ideas:

- Set an alarm to remind you to take your medication or go to an appointment 
- Make it part of your routine – maybe keep your medication with your toothbrush so you remember to take it at the same time every morning 
- Use a pill box – this is a box with compartments labelled with the days of the week so you can easily see if you have taken your medication each day
- Use technology if available, for example, calendar reminders on your phone
- Ask your family, carer, school or employer to help you.

When you are a child, your parents/carers are responsible for caring for you, taking you to appointments and helping you manage your symptoms. As you get older, you can take more **responsibility for your own health**. You may wish for your parents/carers to stay involved but may decide to include other people in discussions too, such as a partner or a trusted close friend. Even if you aren't able to bring someone with you, it may be helpful to have a discussion with them ahead of your appointment.

When **reviewing your treatment plan**, it is important to gather the view of other people who know you well. This way your healthcare professional can better determine how your treatment plan is working. Your healthcare professional may request feedback from your school, college or parents/carers.

It is important to know that you can talk to your healthcare professional about **changing your treatment plan** if you feel that it isn't working out for you, either during your next appointment, or by phoning your local clinic. You should be involved with any decisions about changes to your treatment and understand why changes are being made. If you feel unsure at any stage, ask your healthcare professional.



## Children under 5 years

NICE says:

1.5.7 Offer an ADHD-focused group parent-training programme to parents or carers of children under 5 years with ADHD as first-line treatment.

## Children aged 5 years and over and young people

NICE says:

1.5.10 Give information about ADHD and offer additional support to parents and carers of all children aged 5 years and over and young people with ADHD. The support should be ADHD focused, can be group based and as few as 1 or 2 sessions. It should include:

- ↪ education and information on the causes and impact of ADHD
- ↪ advice on parenting strategies
- ↪ with consent, liaison with school, college or university
- ↪ both parents and carers if feasible.

1.5.13 Offer medication for children aged 5 years and over and young people only if:

- ↪ their ADHD symptoms are still causing a persistent significant impairment in at least one domain after environmental modifications have been implemented and reviewed
- ↪ they and their parents and carers have discussed information about ADHD
- ↪ a baseline assessment has been carried out.

## Children under 5 years

The patient representatives say:



ADHD is most often diagnosed in school-age children but the symptoms may be present before this, especially hyperactivity. It can be difficult to diagnose ADHD in pre-school children as they are likely to have a short attention span and bursts of activity, even if they don't have ADHD.

For children under 5 years old who are diagnosed with ADHD, the first line treatment is a **parent-training programme** to help parents/carers support their child and manage the symptoms of ADHD. This does not mean they are "bad parents" or that they are in some way responsible for their child's ADHD. Having a child with ADHD may

mean that they have **above-average needs** so the aim is to help parents/carers learn techniques to support and help their child.

As children grow older their condition may change so the patient representatives recommend parents/carers keep in touch with their local services and groups for ongoing support.

Not all areas have a specified ADHD Parenting Programme. If this is the case, please discuss this with your healthcare professional who will be able to direct you to online resources or other parenting programmes that may be suitable.

## Children aged 5 years and over and young people

NICE says:

1.5.10 Give information about ADHD and offer additional support to parents and carers of all children aged 5 years and over and young people with ADHD. The support should be ADHD focused, can be group based and as few as 1 or 2 sessions. It should include:

- ↪ education and information on the causes and impact of ADHD
- ↪ advice on parenting strategies
- ↪ with consent, liaison with school, college or university
- ↪ both parents and carers if feasible.

1.5.13 Offer medication for children aged 5 years and over and young people only if:

- ↪ their ADHD symptoms are still causing a persistent significant impairment in at least one domain after environmental modifications have been implemented and reviewed
- ↪ they and their parents and carers have discussed information about ADHD
- ↪ a baseline assessment has been carried out.

## Children aged 5 years and over and young people

The patient representatives say:



For children who are aged 5 years or over when they are diagnosed with ADHD, parents/carers should be given information about ADHD and offered **parent-training programmes**. As above, it is important to know that if the healthcare professional recommends parenting programmes, this does not mean that there has been "bad parenting" in the past. Training and education should be **specific to ADHD** and should ideally involve both parents/carers where possible.

With your permission, the healthcare professionals should also contact the child's **school** so that appropriate help can be provided in the classroom.

If your symptoms are still causing you problems after seeking the support mentioned above, the patient representatives recommend talking to your healthcare professional about getting further help and support.



## Baseline assessment

NICE says:

1.7.4 Before starting medication for ADHD, people with ADHD should have a full assessment, which should include:

- ↪ a review to confirm they continue to meet the criteria for ADHD and need treatment
- ↪ a review of mental health and social circumstances, including:
  - ↪ presence of coexisting mental health and neurodevelopmental conditions
  - ↪ current educational or employment circumstances
  - ↪ risk assessment for substance misuse and drug diversion
  - ↪ care needs
- ↪ a review of physical health, including:
  - ↪ a medical history, taking into account conditions that may be contraindications for specific medicines
  - ↪ current medication
  - ↪ height and weight (measured and recorded against the normal range for age, height and sex)
  - ↪ baseline pulse and blood pressure (measured with an appropriately sized cuff and compared with the normal range for age)
  - ↪ a cardiovascular assessment
  - ↪ an electrocardiogram (ECG) if the treatment may affect the QT interval.

## Baseline assessment

The patient representatives say:

Your healthcare professional should do a thorough **assessment** before you start medication for ADHD. This is not only about medication but making sure you get the help you need in other areas of your life affected by your ADHD such as school or work. The patient representatives say this should involve:

- ↪ Checking your current symptoms. Rating scales (such as QB Tests) can be used to give a baseline assessment, at the start of your treatment, and to measure how your symptoms may reduce or change, over time. Your healthcare professional will discuss this with you
- ↪ Checking for other mental health conditions
- ↪ Asking about your current situation – are you in college or work? Do you need help with housing? Your healthcare professional should be able to signpost where to find help with these things
- ↪ Talking to you about recreational drugs and other substances or addictions
- ↪ Asking you what sort of help you need.

As with many medications, it is good practice to check your **physical health** before starting a new medicine. This may include:

- ↪ Asking about other conditions you may have
- ↪ Asking about any other medicines you take
- ↪ Checking your height and weight so it can be monitored during treatment
- ↪ Checking your pulse and blood pressure
- ↪ Asking about your heart health and arranging any tests that may be needed.



# Review of medication and discontinuation

NICE says:

1.10.1 A healthcare professional with training and expertise in managing ADHD should review ADHD medication at least once a year and discuss with the person with ADHD (and their families and carers as appropriate) whether medication should be continued. The review should include a comprehensive assessment of the:

- preference of the child, young person or adult with ADHD (and their family or carers as appropriate)
- benefits, including how well the current treatment is working throughout the day
- adverse effects
- clinical need and whether medication has been optimised
- impact on education and employment
- effects of missed doses, planned dose reductions and periods of no treatment
- effect of medication on existing or new mental health, physical health or neurodevelopmental conditions
- need for support and type of support (for example, psychological, educational, social) if medication has been optimised but ADHD symptoms continue to cause a significant impairment.

1.10.2 Encourage people with ADHD to discuss any preferences to stop or change medication and to be involved in any decisions about stopping treatments.

# Review of medication and discontinuation

The patient representatives say:

A healthcare professional with training and expertise in managing ADHD would usually be a doctor (paediatrician, child & adolescent psychiatrist, or adult psychiatrist) or ADHD nurse. Sometimes, your GP may carry out other assessments to check on your general wellbeing, such as checking your blood pressure or weight.

Once you have started taking medicine for ADHD, your healthcare professional should **follow up** with you **regularly**, until you are stable and your treatment goals have been achieved, and thereafter you should **see your healthcare professional at least once a year**. This is to see that the medicine is helping you and that you are taking it correctly.

They will also ask about **side-effects**. Sometimes side-effects get better once you have settled on the medicine or you may learn to manage them. If side-effects are bothering you, your healthcare professional may adjust the dose of the medicine or it may be necessary to change to a different medicine.

**You should not stop taking your medicine without first talking to your doctor.** The patient representatives recommend talking to your healthcare professional about questions or concerns you have about your treatment – they will be able to help you.

Your healthcare professional should also ask about changes in your situation or any new health problems to see if any additional help is needed. If you are having problems in life that medication can't help with but that are due to your ADHD, they must support you to find other ways to help this e.g. environmental modifications and support with social care needs.



## Involving schools, colleges and universities

NICE says:

1.4.12 When ADHD is diagnosed, when symptoms change, and when there is transition between schools or from school to college or college to university, obtain consent and then contact the school, college or university to explain:

- ↪ the validity of a diagnosis of ADHD and how symptoms are likely to affect school, college or university life
- ↪ other coexisting conditions (for example, learning disabilities) are distinct from ADHD and may need different adjustments
- ↪ the treatment plan and identified special educational needs, including advice for reasonable adjustments and environmental modifications within the educational placement
- ↪ the value of feedback from schools, colleges and universities to people with ADHD and their healthcare professionals.

## Involving schools, colleges and universities

The patient representatives say:

Most people with ADHD are diagnosed as children although some are not diagnosed until later in life as adults. As we get older, our **needs change**, so how we manage ADHD may also need to change over time.

Although the symptoms of ADHD can make it difficult to concentrate at school, the patient representatives say it is important to know that ADHD does not affect how intelligent you are and should not be a barrier to education.

Changing schools, going to college or on to further education can be stressful life experiences. The patient representatives say that people with ADHD should be provided with **extra support** during these times and a **plan** in place to manage the change. Your education provider should appreciate that this should be in addition to the general support available and should be specific to ADHD. Your healthcare professional should be able to help with this, for example:

- ↪ by explaining what ADHD is
- ↪ how it may affect you (e.g. difficulty with short deadlines or managing long-term projects)
- ↪ what they can do to help you.

Your healthcare professional will ask you to agree (consent) to them contacting your school or college about your ADHD. It is important to **involve your school, college or university** as they are able to give you feedback on how you are doing with your treatment plan.

The next page looks at some tips to help you cope at school, college or at work.



## School or work

NICE says:

**Reasonable adjustments:** refers to the legal obligations of employers and higher education providers to make sure that workers or students with disabilities, or physical or mental health conditions are not substantially disadvantaged when doing their jobs or during their education.

**Environmental modifications:** changes that are made to the physical environment in order to minimise the impact of a person's ADHD on their day-to-day life. Appropriate environmental modifications will be specific to the circumstances of each person with ADHD and should be determined from an assessment of their needs. Examples may include changes to seating arrangements, changes to lighting and noise, reducing distractions (for example, using headphones), optimising work or education to have shorter periods of focus with movement breaks (including the use of 'I need a break' cards), reinforcing verbal requests with written instructions and, for children, the appropriate use of teaching assistants at school.

## School or work

The patient representatives say:

The government says that employers and education providers must make changes to make sure that you are supported to reach your full potential in an education setting or work environment. The list below provides examples of **environmental modifications** that commonly support people with ADHD.

**Environmental modifications** are changes to the area where you work or study to help you manage your ADHD. Examples may include:

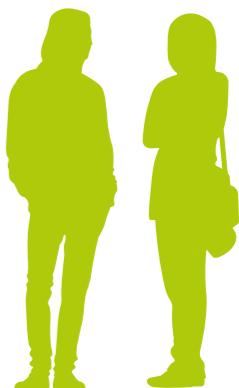
- ↳ Quieter working space or position in classroom or office
- ↳ Flexi-time arrangements
- ↳ Buddy system
- ↳ Structured working day and breaks in long classes or meetings
- ↳ Provide beepers/alarms as reminders
- ↳ Regular supervision with frequent feedback
- ↳ Mentoring
- ↳ Incentive/reward systems
- ↳ Breaking down targets and goals into shorter more manageable chunks
- ↳ Supplement verbal information with written material
- ↳ Using headphones to muffle sounds.

You can get advice on **reasonable adjustments** from the Disability Employment Adviser (DEA) at your local Jobcentre Plus office, or the Disability Employment Service if you're in Northern Ireland. You can apply for **Access to Work** if you need extra help but you should talk to your employer about reasonable adjustments before you apply for Access to Work. If the help you need at work is not covered by your employer making reasonable adjustments, you may be able to get help from Access to Work, which may include a grant to help cover the costs of practical support in the workplace. An Access to Work grant can pay for:

- ↳ Special equipment, adaptations or support worker services to help you do things like answer the phone or go to meetings
- ↳ Help getting to and from work.

It will not affect your other benefits although you might not get a grant if you already get certain benefits. There's a different system in Northern Ireland. Please see this website for more details: [www.gov.uk/access-to-work](http://www.gov.uk/access-to-work)

You can also request a referral to occupational health if you are in employment. The responsibility to make reasonable adjustments for you sits with your employer or education provider. A failure to make reasonable adjustments is a breach of the **Equality Act 2010**.



## Transition

### NICE says:

1.1.4 A young person with ADHD receiving treatment and care from CAMHS or paediatric services should be reassessed at school-leaving age to establish the need for continuing treatment into adulthood. If treatment is necessary, arrangements should be made for a smooth transition to adult services with details of the anticipated treatment and services that the young person will require. Precise timing of arrangements may vary locally but should usually be completed by the time the young person is 18 years.

1.1.5 During the transition to adult services, a formal meeting involving CAMHS and/or paediatrics and adult psychiatric services should be considered, and full information provided to the young person about adult services. For young people aged 16 years and older, the care programme approach (CPA) should be used as an aid to transfer between services. The young person, and when appropriate the parent or carer, should be involved in the planning.

1.1.6 After transition to adult services, adult healthcare professionals should carry out a comprehensive assessment of the person with ADHD that includes personal, educational, occupational and social functioning, and assessment of any coexisting conditions, especially drug misuse, personality disorders, emotional problems and learning difficulties.

## Transition

### The patient representatives say:

ADHD was once thought to be a childhood condition but is now known that **ADHD can continue into adulthood for some people**. As you get older, the type of symptoms you experience may change. For example, you may feel less physically hyperactive or you may have learned to cope with some of your symptoms.

**Transition** is the process of moving from the care of children's services to adults' services. It covers the period before, during and after a young person moves between the two services. It means that the healthcare professionals who help you manage your ADHD will change and that where you go for appointments will change too. The aim is to make sure you have a smooth transition between services with a structure in place to support you during this time of change.

In some parts of the country, there may not be an adult service set up for patients with ADHD. You should discuss this with your current healthcare professionals and they will advise you on what to do. You may be referred to a general adult mental health service or to an adult ADHD service in a different area or to your GP.

Before starting the process of transition, your healthcare professional will **re-assess** your current symptoms and needs to see what, if any, ongoing support and treatment you need.

Transition to adult services should be a **proactive** process, led by your healthcare team. Ideally, the process of transition will be started early so that everything can be in place in plenty of time. Like other areas of healthcare, adult services in your local area may have a waiting list (sometimes up to two years) so it is important that this is planned in advance.

A **formal meeting** should take place to plan transition, involving both your current healthcare professional and future one, and you should be fully informed about adult services. The **Care Programme Approach** (CPA) is a package of care for people with mental health problems. You can involve someone else in your care, such as a parent/carer or partner, but it is your decision.

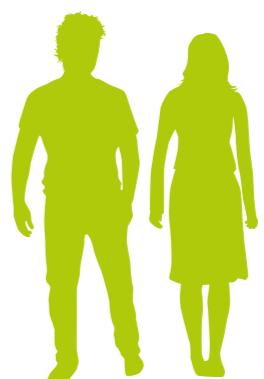
Following transition, you should have a **comprehensive assessment** with your new healthcare professional/team so they can understand more about you to provide you with optimal care and treatment that meets your needs. As we go into adulthood our needs change and new situations arise e.g. moving out of your family home and taking on more responsibility, so the management of your ADHD needs to adapt to your changing life and needs.

The patient representatives say that this should look at:

- your specific needs and symptoms
- your current situation such as college or work
- any co-existing conditions you may have, and how they affect your ADHD.

To make sure that you provide all the important information to your healthcare team, the patient representatives recommend thinking about all of the ways that ADHD affects you in each area of your life, and also those around you, before your appointment. It may be useful to attend with a parent/carer, trusted family member or friend.

Bear in mind that "addictions" could refer to drugs or alcohol, as well as other areas of addiction such as gaming, gambling, hoarding or other behaviours.



## Glossary

**ADHD:** Attention Deficit Hyperactivity Disorder.

**CAMHS:** Child and Adolescent Mental Health Service

**Care Programme Approach (CPA):** a package of care for people with mental health problems involving a care-coordinator (usually a nurse, social worker or occupational therapist) and a care plan. It sets out what support you'll get day to day and who'll provide it.

**Comprehensive:** including or dealing with all, or nearly all, elements or aspects of something.

**Environmental modifications:** changes that are made to the physical environment in order to minimise the impact of a person's ADHD on their day-to-day life.

**Formal:** a formal meeting is usually one that has been planned in advance with a structured agenda, clear goals and invited attendees. At the meeting, notes should be taken and actions recorded.

**Healthcare professional:** in ADHD, this would usually be your doctor (paediatrician, child & adolescent psychiatrist, or adult psychiatrist) or ADHD nurse. It could also be a psychologist or therapist such as an occupational therapist.

**Holistic:** characterised by the treatment of the whole person, taking into account mental and social factors, rather than just the symptoms of a disease.

**Lay person:** a person who does not have professional qualifications or expert knowledge, especially in law or medicine.

**NHS:** National Health Service.

**NICE:** National Institute for Health and Care Excellence – an organisation that provides national guidance and advice to improve health and social care.

**QT interval:** The QT interval is the approximate time taken for the heart ventricles to contract and is measured by an electrocardiogram (ECG).

**Reasonable adjustments:** refers to the legal obligations of employers and higher education providers to make sure that workers or students with disabilities, or physical or mental health conditions are not substantially disadvantaged when doing their jobs or during their education.

**Settings:** physical location, for example, home, school or the workplace.

**Shared treatment plan:** a written treatment plan shared between the healthcare professional and the person with ADHD; this may be shared more widely (for example, with families, schools or social care, if relevant and agreed).

**Specialist:** a person highly trained in a particular branch of medicine. In ADHD, this would usually be your doctor (paediatrician, child & adolescent psychiatrist, or adult psychiatrist) or ADHD nurse.

**Substantial:** means more than minor or trivial.

**Transition:** the process of moving from the care of children's services to adults' services.

## Where can I find out more?

You can read the full NICE guidance on ADHD and the supporting documents on the NICE website:  
[www.nice.org.uk/guidance/ng87](http://www.nice.org.uk/guidance/ng87)

The specific information for the public on ADHD and the care you should expect can be found here:  
[www.nice.org.uk/guidance/ng87/informationforpublic](http://www.nice.org.uk/guidance/ng87/informationforpublic)

Information on 'Your Care' and 'Making decisions together' can be found here:  
[www.nice.org.uk/about/nice-communities/public-involvement/your-care](http://www.nice.org.uk/about/nice-communities/public-involvement/your-care)

The NHS Choices website has more information about ADHD:  
[www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd](http://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd)

The organisations below can give you more advice, support and insight into living with ADHD:

→ ADD-NI: [www.addni.net](http://www.addni.net)

→ ADD-vance: [www.add-vance.org](http://www.add-vance.org)

→ ADHD Action: [www.adhdaction.org](http://www.adhdaction.org)

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

→ ADHD Norfolk: [www.adhdnorfolk.org.uk](http://www.adhdnorfolk.org.uk)

→ ADHD Solutions: [cmsms.adhdsolutions.org](http://cmsms.adhdsolutions.org)

→ Adult ADHD NI: [www.adultadhdni.org](http://www.adultadhdni.org)

→ Attention Deficit Disorder Information and Support Service (ADDISS): [www.addiss.co.uk](http://www.addiss.co.uk)

→ #AttentionUK: [www.attentionuk.org](http://www.attentionuk.org)

Shire is not responsible for the content of these websites.





 Shire

Job number: C-ANPROM/UK//1822  
Date of preparation: December 2018