

A guide to

Getting an ADHD Assessment as an adult in Scotland

This is a guide for adults living in Scotland who think they may have ADHD and have not been diagnosed before.

It explains:

- Things you may want to think about before seeking an ADHD assessment
- How you can request an assessment on the NHS in Scotland and what to do if your request for one is turned down
- Things to consider if you are wondering about using a private healthcare provider.

Why would an adult need an ADHD diagnosis? Isn't ADHD just about children?

ADHD is a condition which becomes apparent in childhood (before the age of 12) and usually lasts into adulthood. However, because ADHD was not as well understood in the past as it is now, there are many adults with ADHD who never received a diagnosis when they were children. It is thought that around 2.5 – 4% of the adult population would benefit from treatment for ADHD¹, but less than 1 in 1000 adults (0.1%) in Scotland were taking medication for ADHD in 2017².

Many adults with undiagnosed ADHD will be managing their condition very successfully themselves and their lives may be going well without the need for a diagnosis or treatment. But, for others, ADHD has a significant impact on them day to day, significantly affecting their ability to achieve what they want to, hold down a job, manage relationships and negotiate family life. If not addressed, ADHD can also lead on to mental health problems like anxiety and depression. For people whose lives are being significantly affected by ADHD symptoms, finding out for sure whether they have ADHD and getting the right treatment can be very helpful – even life changing.

How would I know if I had ADHD?

ADHD can only be diagnosed by a specialist health professional, usually a psychiatrist. To do this, they will take a detailed history from you, look at evidence from your earlier life (possibly hearing from other people who knew you well in childhood), and find out how much your symptoms affect you now.

ADHD is not something which you can diagnose in yourself based on what you read on the internet or by taking online tests. Similarly, there is no simple test, like a blood test or brain scan, which can detect ADHD. However, there are clues you can use to help you decide whether to seek an assessment for ADHD.

ADHD is a neurodevelopmental condition affecting brain structure and neurotransmission: the way in which messages are communicated around the brain and different areas of the brain are activated. ADHD is caused by a complex mix of environmental and genetic factors, but it is a strongly hereditary condition.

ADHD has three core symptoms which affect people with it to different degrees.

Inattention Difficulties with concentration, short term and working memory

Difficulties with planning and getting started (activation)

Being disorganised and losing things

Being easily distracted by small things which others wouldn't

notice

Impulsiveness Acting or speaking on the spur of the moment without thinking

through the consequences.

Difficulty controlling emotions

Hyperactivity Whilst adults with ADHD are usually much less active than children

with ADHD, they may still have symptoms such as restlessness and the need to tap or fidget. Some people are diagnosed with attention deficit disorder (ADD) without hyperactivity: this is

particularly often the case for girls and women.

Whilst they are not core symptoms, many people with ADHD have problems with sleep and with regulating their emotions.

ADHD can be diagnosed on its own, but often comes alongside other associated conditions. These include sensory difficulties (being over- or under- sensitive to sights, sounds and other sensations), dyslexia, dyspraxia (coordination difficulties), tics, and autistic spectrum disorder.

You can use a self-rating scale to give you some indication of whether ADHD-type symptoms are impacting your life. There are many of these tests around. For example:

- The World Health Organisation ADHD Self Report Scale ASRS v 1.1 (on pages 45-46 of these Royal College of Psychiatrists' Guidelines) can be printed out and completed and is useful to take along to appointments.
- If you prefer a quick online test, try: https://www.psychologytoday.com/us/tests/health/adhdattention-deficitdisorder-test

What are the pros and cons of getting a formal diagnosis of ADHD?

Having an ADHD assessment is a big decision which is worth thinking through carefully. Talking to people who have been diagnosed in adulthood, some of the things which they have said about getting a diagnosis are:

What's good about having a diagnosis

- "I now understand myself better and have an explanation for many of the things I've experienced throughout my life."
- "Knowing that I have ADHD enables me to find out more about how to manage my life and symptoms more effectively."
- "I now know that I'm not stupid, or lazy, but that there is a real difference in how my brain works which has been holding me back."
- "I can now access ADHD treatment, like medication, coaching and counselling, which is helping me with ADHD symptoms."
- "With the ADHD diagnosis, I can ask for 'reasonable adjustments' to help me at work or study."

What may be difficult about having a diagnosis

- "ADHD is a lifelong 'label'. Although attitudes towards ADHD are improving and becoming more enlightened, there are still some people out there who see ADHD in a negative light. Some people think that I'm using 'ADHD' as an excuse."
- "I now have to make decisions about whether and how to tell friends, relatives, my employer and my family."
- "I now realise that I have missed out on years of understanding about myself and feel angry that I didn't have this knowledge earlier in life."
- "I'd like to think that knowing I have ADHD is 'the answer' and that my life will get much easier from now on, but things are not always that simple. Medication isn't a 'magic bullet' and it affects everyone differently."

It's worth giving some thought to how you will handle an ADHD diagnosis before seeking the assessment.

You can read some personal stories of people who have been diagnosed with ADHD (and share your own story) at http://adhdaction.org/our-stories

So I've decided to seek an ADHD assessment... how should I go about it?

Within Scotland, ADHD can be diagnosed and treated on the NHS. The Scottish Intercollegiate Guidelines Network (SIGN) guideline on ADHD³ and the 2018 NICE guideline on ADHD⁴, which guide the NHS, make it clear that ADHD is a serious condition which should be diagnosed and treated if it is causing significant difficulties.

An expert working group from the Royal College of Psychiatrists of Scotland published guidelines in 2017 about how psychiatrists should diagnose and manage ADHD. These guidelines recognise that there are not enough consultant psychiatrists in Scotland with a specialist interest in ADHD running dedicated ADHD clinics, and therefore the guidelines aim to help all psychiatrists to assess and treat ADHD consistently. General psychiatrists can contact members of the expert group if they have questions or difficulties about the best way to proceed.

- **Step 1:** Make an appointment with your GP. Take along the completed ASRS Self Report Scale mentioned on page 3 above. If your GP thinks that you are showing sufficient symptoms and that these are affecting your day to day life, they will refer you to your local psychiatric (mental health) team for assessment.
- **Step 2:** Look out for your appointment letter. There may be a wait of a number of weeks or months to see the mental health team, and this can be frustrating. Being impatient is a symptom of ADHD, but you may need to be patient! If you haven't heard within a 2-3 weeks of seeing your GP that your referral has been received by the mental health team, it's worth contacting your GP to check what's happening.
- **Step 3:** See the mental health team. When you go for your appointment with the mental health team, they may send or email you questionnaires to complete beforehand. It's advisable to take along any evidence you have about how you were as a child, such as school reports, or letters from family and friends who remember you.

You may want to take a long a trusted friend or family member with you to appointments with your GP and the mental health team about ADHD diagnosis. This will help to ensure that the clinicians you see take you seriously, and may also help you to remember exactly what was said during appointments and the next steps to be taken.

You can also take notes or even ask to record the consultation on your phone, so you will be have a record of what was said.

What problems might I encounter in seeking an NHS diagnosis, and how should I deal with these?

Hopefully the assessment process should go smoothly, but the following are some problems which adults have encountered, and suggestions on how to deal with them.

Problem		Suggestion
•	My GP refuses to refer me to the mental health team because he/she thinks my symptoms are not severe enough	Make an appointment to see a different GP within the practice, and take along a list of your symptoms and a description of how these are affecting your life.
•	My GP tells me that adults can't be diagnosed with ADHD, or that I can't have ADHD because I have a degree, a job, a happy marriage or a relatively stable life	Show your GP the Royal College of Psychiatrists' guidelines and politely ask him/her to read them.
•	The wait to see the mental health team is going on too long and I can't wait	There is currently no target for referral-to-treatment in Scottish adult mental health services, and waits can be long. You may need to be patient, but if you feel that your mental health is deteriorating and you need to be seen sooner, go back to your GP and ask him/her to make contact with the mental health team again. In extreme cases you could write to your Health Board or your local MSP to complain.

- The appointment I've been sent with the mental health team is with someone who cannot diagnose ADHD (such as a clinical psychologist or CBT counselor)
- Contact the service before the appointment and ask to see a psychiatrist instead. If necessary, point out the <u>Royal College of Psychiatrists'</u> guidelines.

- My Health Board tells me that there is no ADHD assessment service for me to access in my area
- We are aware that a few Health Boards have decided to stop diagnosing ADHD usually due to a shortage of consultant psychiatrists. You could write to your local MSP to ask them to take this up with your Health Board and to ask whether you can be assessed in another Board. You could point out that ADHD has long been recognised by the World Health Organisation, the Scottish Intercollegiate Guidelines Network and the Royal College of Psychiatrists as a condition which needs to be diagnosed and treated. Stating that there is no service in a particular area is discriminatory and unfair.
- I went for my assessment appointment, but I felt unhappy with the outcome and that the I wasn't assessed properly, or that the person doing the assessment didn't know enough about ADHD.
- You have a right to request a second opinion from another specialist. Read <u>The Charter of</u> <u>Patients' Rights and Responsibilities</u> (page 11) for more details.

The Scottish ADHD Coalition is keen to gather case studies of adults who have found it hard to get a proper assessment for ADHD on the NHS, and to help people navigate the system. Please contact us if we can help.

I'm thinking of going private for an assessment. What should I consider?

Some people go to see a private clinician for an ADHD assessment. There are a number of private specialists in Scotland and England who can offer ADHD assessment services. If this is something you are considering, it may be worth thinking through the following.

Possible benefits of getting a private assessment

- Shorter waiting time to be seen
- (Possibly) longer consultation in which to talk to the specialist
- Ability to choose a clinician who has a particular interest and specialism in ADHD, as opposed to a 'general' psychiatrist

Questions to ask before getting a private assessment

- How much will the assessment cost? Does this include any follow up review appointments? Costs for a private ADHD assessment vary but can range from £500 - £1500.
- Will my GP accept this clinician's diagnosis and be willing to prescribe any ADHD medication I need on the NHS? Often this is the case, but ADHD medicines can cost between £500 -£2000 per person each year, so this is worth considering.
- What is the cost for follow up reviews? Even if your GP agrees to prescribe ongoing ADHD medication for you on the NHS, you will need to see a specialist at least once a year to monitor your condition whilst on ADHD medicines.
- Does this clinician have recognised expertise in ADHD and the competence to diagnose ADHD and to identify and treat any other mental health disorders I may have? It is worth noting that the NICE guideline⁴ and the SIGN guideline³ on ADHD both state that ADHD should only be diagnosed by a suitably qualified clinician working as part of a multidisciplinary team.

Some private psychiatry services offer online consultations over secure video link. This has the advantage that you can be seen from the comfort and privacy of your own home and may be a good option if you live far from a specialist centre. However, if you are seen online then, before medication can be prescribed, you would need to get an up to date blood pressure, pulse, weight and height check, and possibly a check for any heart murmurs. These can be done via a GP or pharmacist.

If you have satisfied yourself that going private is the best option for you, you will still need to see your GP to get a referral. The Scottish ADHD Coalition cannot recommend any particular private clinician, but we do have details of some that other people have used, so if you would like a list, please contact us.

Finally...

Having an ADHD assessment is an important event, one which can potentially change your life. Don't rush into it. Do your research, prepare well, and this will give you the best chance of an outcome which is useful for you going forward.

If you meet obstacles along the way, **don't give up**. Follow the advice in this booklet or, if needed, <u>contact us</u> for further advice.

Where to go for more information

- Royal College of Psychiatrists of Scotland <u>Guidelines on Adult ADHD</u> for health professionals, 2017
- Royal College of Psychiatrists (UK) <u>ADHD in Adults</u> (under review 2018)
- Professor Thomas Brown half hour video introduction to ADHD
- NHS Lothian <u>Self Help Resource for Adults with ADHD</u>

References

- 1. Faraone SV, Biederman J. What is the prevalence of adult ADHD? Results of a population screen of 966 adults. Journal of attention disorders. 2005;9(2):384-91.
- 2. Medicines used in Mental Health 2004/5 2016/17. NHS Scotland Information Services Division (ISD), 2017 October 2017.
- 3. Management of Attention Deficit and Hyperkinetic Disorders in Children and Young People (Clinical Guideline 112). Scottish Intercollegiate Guidelines Network (SIGN), 2009.
- 4. Attention deficit hyperactivity disorder: diagnosis and management (Clinical Guideline NG87). National Institute for Health and Care Excellence (NICE), 2018.

With thanks to the Psychiatrists and people with ADHD who provided input to this guide. To give us comments or feedback for the next edition please email info@scottishadhdcoalition.org

Visit <u>www.scottishadhdcoalition.org</u> to find out more about us and access a range of other useful information and links about adult ADHD.

Scottish ADHD Coalition, Scottish Charitable Incorporated Organisation no. SC047630 Updated July 2019

