ADHD: the diagnostic process & how to wait well

From the length of wait times to the professionals you'll see and the structure of the assessment process, the diagnostic process for ADHD varies widely across the country. So how can you know what you can and should expect? I spoke to Dr Cassie Coleman, a Consultant Paediatrician with extensive experience in completing assessments and leading multi-disciplinary assessment teams both within the NHS and privately, to answer some key questions.

What are the national guidelines around ADHD diagnosis?

- The NHS page is quite generic but highlights the need to have an initial conversation with your GP as ADHD is a medical diagnosis: **https://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/diagnosis/**

- There are more specific NICE guidelines available which clinics don't have to follow but it is considered best practice: **https://www.nice.org.uk/guidance/ng87**

[Note: the language around diagnosis is often reflective of a medical model of disability. This means that your child's needs may be expressed as deficits or as deviating from a perceived 'norm'. A neuro-affirming approach recognises that the way someone who is ADHD experiences the world may be different to someone who is neurotypical but that this experience is equally valid. At the same time it acknowledges that there are associated challenges and that support and accommodations can be required.]

What does the assessment entail?

- There is huge variation from 1 hour online tick box assessments to 3 hour Multidisciplinary assessments.
- Assessments should include consideration of:
    - a full neurodevelopmental history
    - information from school
    - Conners questionnaires (standardised ADHD questionnaires) completed by teacher, parent and, if the child is over 11 years old, the child themselves.
- This may vary depending on where your child's assessment is being conducted but Dr Cassie collects all questionnaires in advance (be prepared - there can be a lot to fill in) and then on the day, goes through the history with

both child and parent/carer to find out what they're finding difficult at home and school. Her team then do a full cognitive assessment with a psychologist to check, for example, IQ, processing speed and working memory and finally a computer test called the QB check which is an objective ADHD test.

Who can conduct an assessment?

- Assessments should be done by a medical professional
- Some assessments are done by Educational Psychologists but this is a grey area. Parents/carers are often recommended to go to an educational psychologist at first and at times a diagnosis is suggested or even given. However in order for medication to be offered a paediatrician may then need to go through some of the diagnostic process again to ensure they comply with the NICE guidelines. This can be really confusing for parents and result in frustration if they have just paid for an educational psychology assessment believing this will confirm or rule out a diagnosis. Dr Cassie highlights that an educational psychologist shouldn't be providing a diagnosis but rather a recommendation for an assessment.

What to expect following an assessment?

- Reports can also vary hugely – Dr Cassie's are lengthy with lots of recommendations included for both home and school.
- Other parents report receiving a short report with leaflets to read.
- Whatever the outcome of your child's assessment, the person they are, and their needs, will not have changed.

What can I do whilst I'm waiting?

1. **It's OK to Ask**

   Some parents report feeling as if they should already know the answers or as if they don't want to 'bother' the professionals but you haven't done this before so there's no way you could know. There's also so much different information available that the only way to ensure your understanding is accurate is to ask. When you ask it also enables you to advocate meaningfully for your child. (Read more about this here: https://medium.com/@hello_34819/what-are-they-talking-about-four-reasons-why-asking-can-enhance-advocacy-51b7c0748745)

In order for you to support and advocate for your child effectively it can be helpful to:

- Get clear on the process for the organisation to which your child has been referred, ensure you get accurate information by asking them directly.
- You may want to ask about the waiting times, the process, language which you don't understand. Please find attached a table of example questions.
- Identify what you need to know, collate your questions then email or speak to the organisation directly.

2. Seek out neurodivergent voices

The assessment process will either confirm or rule out a diagnosis of ADHD. However, I've yet to meet a parent waiting for that assessment who hasn't wanted to understand more about ADHD in the meantime. It's both natural and helpful to do so, as Neurowild beautifully (& literally!) illustrates:



See full illustration here: https://www.instagram.com/p/CnQS1Lav2Kg/?utm_source=ig_web_copy_link

It's worth considering which perspectives you're seeking out though and how helpful they are for you and for your child. When you research ADHD a lot of the information which is readily available is based on a model which focuses on deficits. Parents have described how absorbing endless information filtered through this lens can feel exhausting, overwhelming and scary.

There is another perspective though and you can choose to seek out information available from ADHD adults to help you understand ADHD as a

different but no less valid or less valuable type of brain. If you would like suggestions for resources please do message me and equally if you have suggestions I'd love to hear from you.

Consider not only which of these perspectives is going to help you understand and effectively support your child but also which of these messages is likely to be the most helpful for your child to absorb as they move through the process.

3. **Adopt a 'needs-lead approach'**
    - Whether or not your child receives a diagnosis the needs with which they are presenting are already evident and as such can be supported whilst the assessment is pending.
    - If you are noticing particular behaviours which are, for example, unsafe or confusing, recognise that these are indicative of need and try to understand the 'why' that is driving the behaviour. When you understand this you can put strategies in place that effectively meet those needs.
    - Implementing strategies can also help you gather information and understand what is or isn't supportive to your child so you can start to create a 'toolkit' of ideas that help your child as well as starting to understand what doesn't (equally useful to know!).
    - Advocate for a needs-lead approach to support to be adopted in school too.

If you need support to implement any of the ideas discussed here I help parents and carers of children with additional needs to navigate the SEND system calmly, confidently and effectively. Message me on hello@jodiewarren.com if you'd like to find out more about how I could help you.

Thank you to Dr. Cassie Coleman for her help in creating this handout. Dr Cassie is a Consultant Paediatrician based near Oxford who is passionate about supporting families on their journey from initial assessment to diagnosis and then follow up.

For more resources which explain neurodivergence and neuro-affirming practices I highly recommend exploring Neurowild's work - www.instagram.com/neurowild_ or download visuals here: https://www.teacherspayteachers.com/Store/Emily-Hammond-neurowild

Example Questions

1. **The wait:**

- How long are current waiting time?
- If it's longer than 18 weeks do you meet the criteria for Right to Choose?
- What happens after the appointment?
- What support is available locally whilst waiting?

2. **The assessment:**

- Does the provider have resources which can help explain the process to your child e.g. a photo book/social story/video?
- How can you effectively prepare? For example, if there's a long waiting time continuing to take notes & update records
- Will you find out whether a diagnosis has been confirmed on the day?
- What will happen at the appointment?
  - *how long will it be?*
  - *how will it be structured?*
  - *who will you see?*
  - *is there an area you child can play in whilst waiting/a quiet area they can access if needed?*
  - *will you be in with your child or separate?*
- Consider which bits of the process you child might find difficult & ask questions so you can proactively plan to support them ahead of time. For example:
  - *not knowing what to expect*
  - *communicating with unfamiliar people*
  - *different sensory experience*
  - *change to routine/having to wait to go in*
  - *understanding the purpose of the assessment e.g. feeling they're being judged/worrying about getting things 'wrong'*
- Consider what you need to know in order to prepare them but also what do you need to know in order to prepare yourself?

The language:

- Is there a term you're unfamiliar with or a term you're unsure of in this particular context? Remember, it's OK to ask.