Dear Scottish Parliament Inquiry on ADHD Treatment Pathways,

Summary: A compassionate, transferable, efficient approach from the Netherlands

This letter is written with a few concepts in mind:

- That 50% of ADHDers will also have Autism. This means that autistic needs also need to be taken into consideration, simultaneously, as we are caring for the whole individual. Autistic experience will impact how ADHD presents.
- I was treated in the Netherlands, where they have 11 dedicated clinics nationwide, run with the input of staff and volunteers who have lived ADHD experience. This helps enable a strong feedback loop, influencing the Dutch treatment pathway.
- Most of this letter is about improving the overall experience, at no cost, but there are
 areas mentioned that should result in cost and time savings, including at the very end
 of the treatment pathway.

Here is an alternative diagnostic experience:

1. Referral Received By CMHT

This helps ADHDers mentally prepare and manages expectations.

Letter sent directly to the patient as soon as they join the waiting list to explain:

- The current waiting time for an assessment.
- What to do if someone doesn't receive an appointment in the expected time period (i.e. to encourage them to call if they do not receive the letter within a few weeks of when it is expected).
- What will happen during the assessment and how long the assessment will take
- What information the patient should bring with them for the assessment to achieve the best possible outcome. This also gives the patient time to prepare.
- What titration is, how long it takes, and when it is likely to start after an assessment.
- Interim recommendations for managing ADHD (e.g. local and national support groups, exercise, mindfulness and private options).
- That if the patient moves address they should update their details with the CMHT because GP systems don't always support the automatic passing on of this information.

2. Waiting List Placement

Currently, patients are sent to the back of the queue if they change regions (CHMT areas). This is unrealistic and unfair, given that waiting lists are years-long and people have life events (e.g. going to university, meeting partners, changing jobs, supporting loved ones) meaning they might need to move address, causing personal and professional conflicts.

Suggestion would be to agree a policy between CHMTs, where the percentage position that the patient is on for one CMHT's assessment (or pre-assessment) waiting list is carried over to the new CHMT. This is both respectful of CMHT resources, stops unnecessary re-evaluations, and unfair penalisation when someone has already waited a long time for an appointment.

e.g. If the patient is positioned at 300 of 600 people in the waiting list, they are then positioned at the 50% mark in the new CMHT's waiting list once they move, regardless of how long it is.

This should also be explained to people in the initial expectation-management letter, as it is a reasonably frequent occurrence.

3. Shortly Prior to Appointment

This ensures that the appointment is productive as possible.

- Send the appointment details one month in advance as patients still have holidays, are carers and workers, and have other demands on their time. This helps patients manage other appointments too, as ADHDers are more likely to have other medical conditions than the general population.
- The appointment details should include a reminder of the appointment process which
 does not presume any prior knowledge, and also explains how long the appointment
 is likely to take. ADHDers are more likely to be disorganised and forgetful than
 average due to processing issues, so reminders do no harm.
- Give examples of the questions to be asked in advance, so the ADHDer has time to
 prepare and think of examples. Due to the way we process information, we often
 can't answer such questions on the spot, and need time to reflect. This includes
 asking for childhood examples, giving the ADHDer time to find and speak to
 childhood friends, and to see if they can gather school reports.
- Send a reminder one week beforehand, and text message reminder the day before. We are dealing with ADHDers and time blindness is a thing.
- Recommend that the patient brings someone to support them, ideally someone from childhood, and explain why. This is because ADHD sometimes robs us of perspective and/or reduces our ability to respond in the moment. We might claim that we are fine and have no problems, when we are actually in people-pleasing mode and playing down our issues and the impact they have despite having requested the appointment! Someone from childhood can crucially confirm that the experiences are life-long and in multiple domains (a useful ADHD diagnostic).
- The supporter also knows the ADHDer and is more likely to be able to interrupt and help with focus in a manner likely not to cause additional stress.

4. Combine Assessment and Titration

Too many assumptions made, leading to poor outcomes. Patients have no experience of what this is - it will be their first and last time going through this process.

- Clearly explain the process and give this in written format too. The biggest issue that ADHDers have at this stage is that doctors are aware of what titration is, but for patients this is often the first time that they have even heard of the word. Some examples include explaining:
 - That not every drug suits every individual and that initially people are given the drug most likely to work but it is not guaranteed.
 - Report any issues this will help the prescriber navigate the course to finding the right drug(s), for instance there are slow and fast release drugs.
 - Sometimes a combination of drugs will be necessary, and include the example of an afternoon dip.
 - That once titration is completed regular medication will be handled by the GP, with perhaps occasional reviews by the CMHT.
- Advise patients to keep a diary and explain what to document. Offer patients the right
 to be seen online or in person, explaining the pros and cons. This gives flexibility
 both for the members of NHS staff, as well as the patients, especially if they have
 other health issues or transport complications.
- Ideally combine assessment and titration into a single day's appointment (e.g. assessment in the morning, and a titration appointment later the same day). Given that 90% of people seeking assessment have ADHD there is very little wastage, and this increases likelihood of the ADHDer completing both, as you reduce the individual appointments they need to remember and organise to show for.
- Combine ADHD and Autism assessment. Given that 50% of ADHDers have Autism, but adding an autism assessment to an ADHD assessment doesn't add too much time to an assessment, overall this will save time for the CMHT and provide support for the ADHDers, especially in terms of improving their self-awareness. If doing this, it should be mentioned in the earlier letters. This also helps avoid any blame game/buck passing between the Autism and ADHD assessment teams, which also ends up being inconclusive for the ADHDer and sends them to the back of the queue each time.
- Consider whether a psychiatrist is needed for every assessment. In the Netherlands
 qualified nurses carry out assessments, but have a psychiatrist on hand to
 immediately refer more complex cases. Often a number of assessments are going on
 simultaneously by a number of nurses, so that the (single) psychiatrist is available to
 all of them and it tends to be a more efficient system.

5. Titration Follow Up Appointments

Value the patient's time.

Again, offer patients the right to be seen online or in person. Here I suspect it will be
even more beneficial, especially for shorter follow up appointments. This gives
flexibility both for the members of NHS staff, as well as the patients - potentially
potentially providing flexibility for staff, which can improve staff retention in the long
run. Any vital checks (blood pressure etc), can be taken by the GP surgery and
passed along.

• The first follow up appointment should be after two weeks, not one month. ADHD drugs tend to be fast acting. Currently follow ups are a month apart - at best. This delay can cause anxiety and does not provide any medical benefits, especially if a drug is having counterproduce reactions, nor does it reduce the overall waiting list. Later appointments, if all is going well, can be at a reduced cadence.

6. After Titration

- Rather than the CMHT reviewing the ADHDer every six months, pass the case to the GP to look after, with the option to escalate to the CMHT if necessary. Basically the CMHT doesn't add anything to the process for most ADHDers once they are settled on the right drug. This also frees up significant resources to prioritise for the existing waiting list.
- If a patient moves, currently they need to be referred to a new CMHT, but again, this
 doesn't add any practical value and the GP should be supplied with enough
 information for routine management of prescriptions unless or until there are
 problems.
- Medication is only part of the solution. Trying to integrate into society for an ADHDer
 is often a struggle, so give ADHDers the choice of more support and resources. This
 will hopefully help and provide an economic benefit to Scotland in terms of more
 ADHDers being able to pursue employment given that we are more likely to be
 unemployed. The following can also be offered as a stop-gap whilst ADHDers are
 waiting for their formal assessment.
 - Pointers to local support groups, ideally including funding to start up new groups as necessary, as this will reduce the number of crisis referrals.
 - DBT (dialectical behavioural therapy, the newer form of CBT, with better proven outcomes).
 - Mindfulness courses.
 - Reminders to ADHDers that exercise helps in body regulation. Perhaps give a free local council gym/swimming pool pass for 3 months to encourage this habit?
 - ADHD Coaching. This author is an ADHD Coach, so I will readily admit to potential bias with this last point but ADHD Coaching can provide tailored support in overcoming specific practical ADHD-related challenges that medication doesn't address.

Reference

The Dutch national ADHD clinic, which has informed the vast majority of the above suggestions, can be found at https://adhdcentraal.nl/en/. It explains the Dutch treatment pathway, in English as well as Dutch, in even more detail, in a patient-accessible fashion.

I'm more than happy to be contacted via https://naturallypaul.com/contact/ if anyone has any questions or wants a Dutch/ADHD Centraal contact.

Yours faithfully,
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ADHD Aware & Scottish ADHD Coalition volunteer