



The Scottish Parliament
Pàrlamaid na h-Alba

Alex Cole-Hamilton
Member of the Scottish Parliament, Edinburgh Western

Caroline Hiscox
Chief Executive of NHS Lothian
Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG

10th September 2024

Dear Caroline,

We are writing to you regarding a broad range of interconnected issues as a result of NHS Lothian's plan for ADHD diagnosis and care. These include medication shortages, length of waiting times, shared care arrangements after private assessment, and self-management before a care plan is in place.

We believe urgent steps need to be taken to address these concerns which have been raised by our constituents. We have provided a summary below which outlines the issues in broader terms. We'd be grateful if you would respond to each point, so that we are able to keep our constituents updated.

1) Medication Shortages

Since October 2023, Scotland, along with the rest of the UK has been impacted by the global supply chain disruption of ADHD medicine and in the Lothian Health Board specifically, both guanfacine and lisdexamfetamine medications. We have great concern about the side-effects of a complete cessation of medication for some patients as a result of the shortages, specifically severe mental fatigue which can cause and impact wider issues and in severe cases, cause injury and death.

- a) To what extent is the supply chain still disrupted and what impact is this having throughout NHS Lothian?
- b) How long does NHS Lothian expect to see the effects of this disruption?
- c) What support is in place for those who require regular medication and have had to reduce their dosage or in some cases, completely stop taking their prescribed medication?

2) Length of waiting-times

A number of constituents have contacted us to raise concerns over the waiting time for both receiving a diagnosis and initiation of medication. We understand that there is an increased number of people seeking neurodevelopmental assessment, however I would appreciate if you could outline:

- a) What is the current expected waiting time for adults to receive a diagnosis?
- b) What is the current expected waiting time for children to receive a diagnosis?

- c) What is the current expected waiting time for adults, having received a diagnosis, to be prescribed medication?
- d) What is the current expected waiting time for children, having received a diagnosis, to be prescribed medication?

3) Shared care arrangements after private assessment

Constituents have also contacted us regarding a lack of clarity about the shared care pathway in NHS Lothian. We understand that shared care agreements are in place to support primary and secondary care working together to safely prescribe across the age range and that NHS Lothian do accept suitable private opinions and diagnoses into the queue for the initiation of medication where these are suitably robust but this is only after a specialist review.

- a) What is the current expected waiting time for patients to receive an NHS specialist review of their private diagnosis?
- b) If approved, do patients then join the end of the waiting list for the initiation of medication? If so, how long is this waiting period expected to be?
- c) What is also being done to communicate this clearly to patients who are planning to use the shared care pathway?

4) Self-management before a care plan is in place

We understand that there is an online platform which is used to provide information to patients on important aspects of their care. This includes information on exercise and sleep hygiene, as well as further information on other constructive actions that can be taken.

- a) We were made aware that this platform was not available to patients diagnosed with ADHD. Can you confirm if this still is the case and are there plans to extend its availability?

Research has found that ADHD medication can be lifesaving - particularly when the window between diagnosis and the initiation of medication is shortened¹. ADHD is a neurological disorder that must be taken very seriously, and you will understand that an update on NHS Lothian's approach to the issues raised in this summary will be useful for ensuring our constituents have access to the latest information.

We look forward to your response.

Kind regards,



Alex Cole-Hamilton MSP



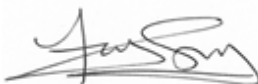
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Jeremy Balfour MSP



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