

## SPSO decision report

**Case:** 201700043, Lothian NHS Board - Acute Division

**Sector:** health

**Subject:** clinical treatment / diagnosis

**Decision:** some upheld, recommendations

### Summary

Mr C was diagnosed with motor neurone disease (MND - a rare condition that progressively damages parts of the nervous system) a number of years ago, and his health has been regularly monitored since then. When his condition did not progress in the way that would be expected of MND he was sent to another consultant neurologist for a further opinion as to the likely cause of his symptoms. This consultant told Mr C that they did not think he had MND. Following that consultation he was seen a few months later by his regular consultant, although the notes from the previous consultation were not available at that time. Once Mr C's regular consultant had obtained the notes, they followed up with a letter to Mr C's GP. In this letter the consultant advised that Mr C was thought to have distal hereditary motor neuropathy (a progressive disorder that affects nerve cells in the spinal cord which results in muscle weakness and affects movement). The letter, a copy of which the GP provided to Mr C, contained a lot of medical terminology. Mr C contacted the consultant's secretary, saying he did not understand the new diagnosis and wanted more information. He hoped to have another appointment at which he could ask some questions, but was given a routine appointment for a year ahead. He was unhappy about the refusal of an earlier appointment, as the matter was causing some anxiety. He also wondered why it had taken so long to reach the new diagnosis.

We took independent advice from a consultant neurologist, who considered the consultant's communications to have been clear and detailed. The adviser noted that a covering letter was sent out after Mr C expressed some confusion about the letter with a lot of medical terminology in it. The adviser considered that this covering letter could have been sent out with the initial letter. Although the adviser was not critical of the clinical care, they considered that it would have been better practice for the consultant to have agreed to seeing Mr C earlier, given that he had been diagnosed with a life-threatening condition and was expressing a lack of understanding about the implications of his new diagnosis. We noted that if this had been arranged it would likely have given Mr C some assurance and may have avoided the need for him to pursue his complaint. We also found that the board did not provide the consultant with clear detail of the complaint to us, and therefore an opportunity was missed to resolve Mr C's complaint at an earlier stage. We upheld this aspect of the complaint.

With regards to the new diagnosis, the adviser explained that there is no single exclusive diagnostic test for MND and that it remains a clinical diagnosis based on examination over a period of time. It was only as time passed, and Mr C's condition did not progress in the way that would be expected of MND, that other rarer conditions were considered. The doctors treating him were alert to this and our adviser had no criticism of his clinical care or the timescale of the diagnosis. We did not uphold this complaint.

### Recommendations

What we asked the organisation to do in this case:

- Apologise to Mr C for not providing an appointment sooner than his scheduled one to explain his diagnosis in more detail.
- Provide an appointment sooner than the one currently scheduled. This appointment should be with a

different consultant.

What we said should change to put things right in future:

- The consultant should reflect on their refusal of an earlier appointment, taking all of the circumstances into account and in particular the significant change in diagnosis and uncertainty about its implications.

In relation to complaints handling, we recommended:

- The board should reflect on their internal complaints handling, with particular focus on communication, to ensure that clinical staff involved in a complaint are fully aware of the exact nature of the complaint when they are responding to it.

We have asked the organisation to provide us with evidence that they have implemented the recommendations we have made on this case by the deadline we set.