

## Scottish Parliament Region: Mid Scotland and Fife

### Cases 200603874 & 200701920: A Medical Practice, Fife NHS Board and Fife NHS Board

#### Summary of Investigation

##### **Category**

Health: Communication; confidentiality and diagnosis

##### **Overview**

The complainant (Mr C) was diagnosed as having multiple sclerosis (MS) in an Edinburgh Hospital in September 1973. The consultant who made the diagnosis decided not to tell Mr C of his condition. Mr C found out that he had MS in May 2005 after referral to a neurologist but only discovered his earlier diagnosis in September 2006.

##### **Specific complaints and conclusions**

The complaints which have been investigated are that:

- (a) Mr C's GP practice failed to inform him of a longstanding diagnosis of MS (*not upheld*); and
- (b) Mr C's MS was not identified or taken into account when he was receiving treatment from Fife NHS Board (*not upheld*).

##### **Redress and recommendations**

The Ombudsman has no recommendations to make.

## **Main Investigation Report**

### **Introduction**

1. The complainant (Mr C) was seen at a neurological clinic in an Edinburgh hospital on 20 August 1973. He had been suffering from dizziness and headaches for some weeks before that and had had similar symptoms one year previously. The consultant's opinion was that there was good evidence of disseminated sclerosis and referred Mr C for further tests, including a lumbar puncture. The diagnosis was confirmed and Mr C's GP was informed in a letter to his GP practice (the Practice) on 4 October 1973. This letter also noted that Mr C had not been informed of the diagnosis, that he was currently well and that his condition would be monitored in the out-patient clinic.

2. On 21 September 2004, the Practice referred Mr C to a neurologist at the Victoria Hospital, Kirkcaldy (the Hospital) because of concerns raised by a physiotherapist about Mr C's condition. After a series of tests, the Hospital confirmed a diagnosis of multiple sclerosis (MS) in a letter to the Practice of 3 June 2005. No health professional involved in Mr C's care at that time was aware of his previous diagnosis.

3. Mr C found out about the earlier diagnosis when he approached the Practice in September 2006 to find out the exact date on which he was diagnosed as having MS for insurance purposes.

4. The complaints from Mr C which I have investigated are that:

- (a) the Practice failed to inform him of a longstanding diagnosis of MS; and
- (b) his MS was not identified or taken into account when he was receiving treatment from Fife NHS Board (the Board).

5. Mr C also complained about the original decision by a consultant in an Edinburgh hospital to withhold the diagnosis of MS from him. It was not possible to investigate a complaint against Lothian NHS Board about this matter because the records relevant to that time were destroyed in keeping with their retention schedule. In addition, it was not possible to investigate the actions of Mr C's GP at the time of the original diagnosis because paragraph 10 (2) (b) of the Scottish Public Services Ombudsman Act 2002 (the Act) prohibits the Ombudsman from investigating the actions of a family health provider if the complaint is made more than three years after that person's retirement.

6. Mr C's complaints were formally investigated by the Practice, but the Board did not have an opportunity to do this in respect of the complaints about his treatment at the Hospital. The Act requires the Ombudsman to be satisfied that the complaints procedure of the authority complained about has been exhausted before considering a complaint unless it was not reasonable to expect the complainant to do this. The Ombudsman exercised discretion to consider Mr C's complaints against the Board in this case because there was more than one authority involved and it would have considerably protracted the time needed to complete the complaints process to require that he pursue a second formal complaint to its conclusion.

### **Investigation**

7. In order to investigate Mr C's complaints, I made inquiry of the Practice and the Board, receiving their detailed responses to my questions on 5 November 2007 and 7 February 2008 respectively. I have reviewed Mr C's medical records and relevant correspondence. In addition, I arranged a meeting between senior representatives of the Practice and the Board, the Ombudsman's independent GP adviser and Mr C on 2 May 2008 to give Mr C the opportunity to ask questions about his experiences.

8. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked. Mr C and the Board were given an opportunity to comment on a draft of this report.

#### **(a) The Practice failed to inform him of a longstanding diagnosis of MS**

9. Mr C had been registered with the Practice since birth. On 4 July 1972, Mr C's GP wrote to an Edinburgh hospital asking for neurological opinion because Mr C was suffering from dizziness, loss of some sensation in his left foot and some awkwardness in walking. There is no record of the hospital's response at the time, but the same GP referred Mr C to the same consultant on 13 August 1973 because the symptoms had recurred and this time he was also suffering from headaches. After a number of tests, the consultant wrote to the GP on 4 October 1973 confirming a diagnosis of disseminated sclerosis. The consultant noted that Mr C had not been told of this, but had been informed that he had 'inflammation of the long nerves'. He also said that they would follow this up in the out-patient clinic 'from time to time'.

10. Mr C attended the neurological clinic on 19 November 1973, and it was noted that his symptoms had 'largely resolved'. However, Mr C had been

prohibited from driving by his employer. He attended the clinic again on 11 March 1974 and this time, Mr C reported that he had suffered no further problems. Therefore, Mr C was not given a further appointment but the hospital encouraged the GP to refer him again if his difficulties recurred.

11. Mr C's medical records show that, over the next few years, he received treatment for a number of conditions including some relatively minor and some more substantial injuries resulting from a number of falls, dermatological complaints, cataracts and a urological condition. In January 1996, he also received a hip replacement to his right hip, which had been damaged and treated following a fall in January 1995.

12. On 23 June 2004, Mr C's GP referred him for physiotherapy because of 'general weakness and reduced mobility in his legs'. In a letter dated 31 August 2004, the physiotherapist suggested that Mr C may benefit from a neurology opinion as she was concerned that Mr C's symptoms 'were not mechanical'.

13. The GP referred Mr C to a neurologist at the Hospital on 12 September 2004 and a diagnosis of a 'progressive form of Multiple Sclerosis' was confirmed in a letter to the GP on 3 June 2005.

14. In September 2006, Mr C contacted the Practice to find out the exact date of his diagnosis of MS. He needed this information for insurance purposes. A receptionist informed him of his diagnosis in Edinburgh in 1973. Mr C complained to the Practice that he had not been informed of the original diagnosis and the GP arranged to meet with him on 13 September 2006. The GP explained that he had not been aware of this earlier diagnosis because his medical notes had not yet been summarised on the Practice's computer system. Such summarisation would have allowed the 1973 diagnosis to be clearly visible whenever the file was opened.

15. The Practice held a Significant Event Analysis meeting on 29 September 2006 to consider this matter and concluded that it was important for patient records to be summarised. For patients whose records had not yet been summarised, the Practice concluded that GPs should undertake a full examination of the records when making a referral. In a letter dated 7 June 2007, they also apologised for the way in which Mr C was informed of his original diagnosis.

*(a) Conclusion*

16. In their submission to the Ombudsman, the Practice said that they regretted the distress caused to Mr C by the revelation of his earlier diagnosis of MS. They also noted that they had apologised to him sincerely that this fact was not known to his GPs because his records had not been summarised. However, they considered that, even if the GPs had been aware of the 1973 diagnosis, they would not necessarily have known that Mr C did not know that he had MS. They also considered that it would not be reasonable for the Practice to contact patients when summarising records to check if they were fully aware of their own medical history. However, the letter from the Edinburgh consultant from 4 October 1973 emphasised clearly that Mr C had not been informed.

17. At the meeting held with Mr C and representatives of the Practice and the Board on 2 May 2008, it was acknowledged by all the medical professionals present that the culture surrounding disclosure of information to patients has changed considerably since Mr C's original diagnosis. It would no longer be acceptable to withhold a diagnosis in this way and it is assumed that patients have a right to know important information about their health.

18. It is clear that the GPs currently involved in Mr C's care did not intend to withhold information about his condition and were not aware of his previous diagnosis of MS. However, it is also likely that, if Mr C's records had been summarised as part of the process of transferring records to electronic storage, Mr C's GP would have been aware of his MS before the new diagnosis in May 2005. As the process of summarising patient records only began in January 2004, this would not have made a significant difference. Before this time, a GP would have had to review Mr C's file fully to be aware of the 1973 diagnosis, and it would not be normal practice to do this during routine consultations. As a result of their Significant Event Analysis, the Practice have undertaken to ensure that yet-to-be-summarised records are reviewed in this way for significant clinical decisions.

19. The circumstances in which Mr C remained unaware of his condition were unusual and the shock and anger he felt when he discovered his earlier diagnosis were entirely understandable. The Practice did have access to information about that diagnosis, but it was not immediately visible to anyone accessing Mr C's file and it would not be reasonable to expect a GP to read a

patient's entire file before every consultation. The Practice accept that, with hindsight, it would have been desirable for this to have happened when there were concerns about Mr C's symptoms. The Practice have apologised to Mr C and have taken steps to prevent a situation like this from recurring. Taking all the circumstances into account, I do not uphold this complaint.

**(b) Mr C's MS was not identified or taken into account when he was receiving treatment from the Board**

20. Mr C received treatment at the Hospital for a number of conditions between 1994 and 2005, when his MS was rediagnosed. There are no records for his treatment before 1994, as his records were destroyed in keeping with government guidance. Although it is possible that the Hospital may once have had copies of the letters from the Edinburgh hospital where Mr C was diagnosed in 1973, those letters were addressed to his GP and may not have been copied to the Hospital. Mr C attended the orthopaedic department in 1994/95, the urology department in 1999 and 2004, the ophthalmology department in 2004 and the neurology department in 2005.

21. Without access to any written record of Mr C's earlier diagnosis of MS, and because he was not in a position to share this part of his medical history, clinicians at the Hospital were not aware that he had MS. However, I asked the Board whether they considered that the conditions for which Mr C was treated may have indicated the likelihood of MS as an underlying condition, and if so, whether this knowledge would have led to a different approach to his treatment on any of the above occasions.

22. Following my inquiry to the Board on 2 November 2007, they asked specialists in each of the departments where Mr C was treated whether knowledge of his previous diagnosis would have led to a different approach to his treatment. In each case, the specialists considered that such knowledge would not have necessitated an adjustment to the treatment offered.

*(b) Conclusion*

23. It is clear that the clinicians involved in Mr C's care between 1994 and 2005 could not have known about his earlier diagnosis of MS. Until a physiotherapist expressed concern about Mr C's symptoms in August 2004, Mr C did not present with symptoms that may reasonably have raised suspicions about an underlying condition such as MS. Staff at the Hospital were not, therefore, in a position to inform Mr C of his earlier diagnosis or to

make any adjustments to his treatment in the light of that information. However, it seems likely that, even if the earlier diagnosis had been known, this would not have led to any significant changes to Mr C's treatment. For these reasons, I do not uphold this complaint.

**Explanation of abbreviations used**

Mr C	The complainant
The Practice	Mr C's GP Practice
MS	Multiple sclerosis
The Hospital	Victoria Hospital, Kirkcaldy
The Board	Fife NHS Board