Case 200601724: Forth Valley NHS Board

Summary of Investigation

Category

Health: Hospital

Overview

The complainant, Mrs C, complained of a lack of local care provision for her son, Mr A, from June 2004 to March 2007. Mr A is severely autistic, has learning difficulties and also suffers from epilepsy. Specifically, Mrs C complained that Mr A was seen by his Consultant (Consultant 1) in June 2004 but that there was no direct access to care offered by Forth Valley NHS Board (the Board) following this review and the departure of Consultant 1 in May 2005. Mrs C also complained that the medication prescribed for her son by Consultant 1 was inappropriate in that, if fully implemented, it would have placed Mr A at risk.

Specific complaints and conclusions

The complaints which have been investigated are that:

(a) there was a lack of care provision for Mr A from June 2004 to March 2007; (*upheld*); and

(b) medication prescribed for Mr A by Consultant 1 in June 2004 was inappropriate in that, if fully implemented, it would have placed Mr A at risk (*not upheld*).

Redress and recommendation

The Ombudsman recommends that the Board offer Mrs C a full and sincere apology for the shortcomings identified in this report.

The Board have accepted the recommendations and will act on them accordingly.

Main Investigation Report

Introduction

1. Mrs C complained of a lack of local care provision for her son, Mr A, from June 2004 to March 2007. Mr A is severely autistic, has learning difficulties and also suffers from epilepsy. Specifically, Mrs C complained that Mr A was seen by his Consultant (Consultant 1) in June 2004 but that there was no direct access to care offered by Forth Valley NHS Board (the Board) following this review and the departure of Consultant 1 in May 2005. Mrs C also complained that the medication prescribed for her son by Consultant 1 was inappropriate in that, if fully implemented, it would have placed Mr A at risk.

2. The complaints from Mrs C which I have investigated are that:

(a) there was a lack of local care provision for Mr A from June 2004 to March 2007; and

(b) medication prescribed for Mr A by Consultant 1 in June 2004 was inappropriate in that, if fully implemented, it would have placed Mr A at risk.

Investigation

3. As part of my investigation I made enquiries of the Board on 20 June 2007 and received their response on 18 July 2007. I have had sight of all the relevant correspondence and documents and I obtained Mr A's medical records and the complaint file. I also obtained advice from one of the Ombudsman's professional medical advisers. The abbreviations used in the report are set out in Annex 1 and the medical terms used are explained in Annex 2.

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

(a) There was a lack of care provision for Mr A from June 2004 to March 2007

5. Mr A was born in August 1986 and suffers from significant autism. In April 2003 Mr A also developed epilepsy and he was referred to Consultant 1, a Consultant Neurologist at the Epilepsy Clinic, Falkirk and District Royal Infirmary. He continued to be seen by Consultant 1 and Mrs C attended a review appointment with Mr A and Consultant 1 in June 2004. The outcome of this consultation was that there was to be a further review of Mr A in

nine months time and Consultant 1 wrote to Mr A's GP in June 2004 confirming this.

6. In May 2005 Consultant 1 left the Health Board area. Mrs C told me that, at the June 2004 appointment, Consultant 1 did not mention that a further review was planned, nor was she issued with any date for such a review. Mrs C indicated that she became aware of the imminent departure of Consultant 1 following correspondence between her GP and Consultant 1 in March 2005. The clinical notes detailed that Mr A's GP was in contact with Consultant 1 in October 2004 and March 2005, regarding medication, and advice was provided on both occasions.

7. In response to my enquiries the Board have advised that Mr A was due to have a clinic appointment in March 2005 and he appeared on the clinic list for appointments due to be made at that time. I have been provided with a copy of the clinic appointment list, which includes Mr A. This is the only documented information now held by the Board and they have advised that it is not possible, due to the passage of time, to offer any further factual information.

8. Mrs C advised me that, in the meantime, Mr A's seizures continued and she remained concerned that, despite the advice provided on medication (see paragraph 6), this had not had a positive impact on Mr A's condition. By this time she was aware that Consultant 1 had left the Board and her hope was to find a professional with the expertise to address Mr A's dual diagnosis of autism and epilepsy. In an effort to have Mr A seen, his GP had considered a re-referral to a doctor at another hospital in the Board area who had seen Mr A initially, however, he learned that she too had left the area. The GP then contacted other health professionals in Scotland, without success. Mrs C stated that she also began searching for an appropriate referral and eventually felt compelled, not by choice but by clinical need, to make private arrangements for Mr A to be seen by a Consultant Neurologist (Consultant 2) in England in July 2005 following a referral by his GP.

9. On 2 September 2005 Mr A's GP wrote to the Board. He explained that Mr A had previously been seen by Consultant 1 in the Epilepsy Clinic but had not been reviewed for some time. The GP advised he was aware that Consultant 1 had left, therefore, leaving a void in epilepsy care in the area. He detailed Mr A's drug regime and explained that Consultant 1 had not been able to review Mr A prior to her departure. He confirmed that Mrs C had, therefore,

sought out an expert in dealing with both epilepsy and autism in England, whom Mr A was currently seeing (Consultant 2). He advised that Consultant 2 had suggested that Mr A have a prolonged EEG, or an EEG while sleeping, to try and 'type' his epilepsy (as Consultant 2 had indicated Mr A could have either generalised or localisation related epilepsy). Mr A's GP went on to ask if this was something that could be arranged locally, ie, by the Board. On the same day, the GP also wrote to the Deputy Director of Public Health at the Board to enquire whether on-going care of Mr A by Consultant 2 could be funded by the Board. He replied on 15 September 2005 that, in order to arrange funding for Mr A to attend Consultant 2, he would need to be in receipt of a supportive letter from an appropriate Board consultant.

10. An appointment for a prolonged EEG was subsequently arranged by the Board at a hospital in Glasgow on 14 November 2005 and the results were sent to Mr A's GP as well as a Consultant Neurologist at the Glasgow hospital. On 18 November 2005 Mr A's GP wrote to a Consultant Neurologist at the Board, requesting that he consider whether it was appropriate that Mr A be seen elsewhere, funded from the local budget and if so whether he could write to the Deputy Director of Public Health in support of this.

11. In December 2005 a Consultant Neurologist (Consultant 3) took up post with the Board and, in January 2006, he wrote to Mr A's GP. He advised that he had no objection to the GP making a referral to Consultant 2 but that he (the GP) would need to establish with the Board whether this was reasonable, given the 'availability of neurological services more locally'. Following this, on 28 March 2006, Consultant 3 wrote to the Deputy Director for Public Health at the Board to advise that, in his opinion, services were available locally appropriate to Mr A's need. In his view, the request for the referral was based on parental choice and he, therefore, did not consider such a referral to be 'necessary', which he understood was the test that would apply in these circumstances. This was communicated to Mr A's GP in a letter dated 29 March 2006.

12. Mr A continued to see Consultant 2 on a self funding basis and, on 11 May 2006, Mr A's GP wrote to Consultant 3 asking him to meet with Mrs C to discuss the situation locally. In the meantime Mrs C had written to her MSP, on 22 April 2006. In this letter she acknowledged that there was now a local neurology service but that in early 2005 there had been no one available to see Mr A and that was why the private referral to Consultant 2 was made. She

advised that Consultant 3 had spoken to Mr A's GP on 20 April 2006 and offered to meet, however, she doubted now whether such a meeting would resolve the situation while there remained a lack of expertise in dealing with epilepsy in patients with autism. Her MSP subsequently contacted the Board on her behalf.

13. In the meantime, an appointment was made for Mr A to see Consultant 3 in July 2006. However, following discussion with Mr A's GP, Mrs C decided not to take up this appointment. In her correspondence with me, she advised that this was because she was awaiting the outcome of her approach to her MSP and she also felt it inappropriate for Mr A to sit through her discussions with Consultant 3 regarding the issue of local provision, given Mr A's lack of understanding of his condition and the wider issues.

14. On 10 July 2006 the Board responded to Mrs C's MSP. They reiterated the decision that it was parental choice for Mr A to attend Consultant 2. It was accepted that there had been problems with the neurology service since Consultant 1 left, which had now been resolved with recruitment and assistance externally. The response referred to the statements made by Consultant 2 in earlier correspondence that more local services, such as those available for instance in Glasgow or Dundee, would be appropriate for Mr A's needs. Following Mr A's initial referral to Consultant 2 she had written to Mr A's GP in July 2005 with the request for an EEG (see paragraph 8). In this letter she had indicated that there could be health professionals more locally, either in Glasgow or Dundee, who could see Mr A. This letter was copied to the Board by Mr A's GP in September 2005. In further correspondence with Mrs C's MSP, dated 6 September 2006, the Board reiterated that the position was as detailed above and apologised for the delay in reaching an achievable outcome for Mr A within the Board area.

15. On 11 September 2006 Mrs C complained to this office. Specifically, she complained that there was no Consultant Neurologist available locally to see Mr A and this was the reason he was referred privately to Consultant 2. Although the Board had subsequently stated that there were services available in Glasgow or Dundee, at no time were they offered even when her GP had asked for consideration to be given to an alternative pathway of care (see paragraph 8).

16. In response to my enquiries, the Board advised that local services (in Scotland) were available via Dundee and Glasgow regional centres and referrals could have been made. They also offered to assess Mr A, should he be referred to them, and Mrs C subsequently took up this offer with an initial consultation between Mr A and Consultant 3 held in March 2007. Mrs C subsequently advised me that it was likely that Mr A will revert to local care provision under the care of Consultant 3 with input from a specialist outwith the Board area. Subsequently, Mrs C advised me that Consultant 3 has offered to make an initial referral to this specialist which Mrs C will take up once Mr A's condition is more stable, given his level of autism.

(a) Conclusion

17. I can well understand Mrs C's concern when, following Mr A's review by Consultant 1 in June 2004, she received no further review appointment. Mr A's seizures continued and, while advice on medication had been provided by Consultant 1 prior to her departure, it is understandable that Mrs C felt she had to consider the available options for Mr A's continued care. She advised that both she and Mr A's GP explored possible alternative health professionals in Scotland. When this was unsuccessful, this led to Mr A seeing Consultant 2 from July 2005, on a self funding basis.

18. Given the passage of time, I have been unable to establish why a review follow-up appointment was not made by the Board after Mr A's last consultation with Consultant 1 prior to her departure although, clearly, they accept that one should have been made. The Board also accept that there were problems with the neurology service following the departure of Consultant 1, until the appointment of Consultant 3. However, I have not seen any evidence that the Board were contacted directly to chase up the review appointment or to find out what arrangements, if any, were being made for Mr A's care until the GP's letters of 2 September and 18 November 2005, asking whether there were any alternative pathways of care that could be funded by the Board (see paragraph 8). Nevertheless, no follow-up review or appointment was offered either locally or elsewhere in Scotland although, by this time, the Board were aware from Consultant 2's correspondence that there may be services available in either Glasgow or Dundee which could be appropriate to Mr A's needs.

19. In the meantime, although an appointment with Consultant 3 was offered by the Board in July 2006 this was refused by Mrs C, while she awaited clarification of the Board's position, and I can understand her reasons for this,

given the difficulties she had experienced. The Board have advised me that a further appointment was offered at that time, however, this is disputed by Mrs C and I have seen no evidence that such an appointment was offered. While I am pleased to note that Mr A has now been seen locally, in all the circumstances, looking at the provision of service previously offered to Mr A, I uphold this complaint.

(a) Recommendation

20. The Ombudsman recommends that the Board offer Mrs C a full and sincere apology for the shortcomings identified in this report.

(b) Medication prescribed for Mr A by Consultant 1 in June 2004 was inappropriate in that, if fully implemented, it would have placed Mr A at risk

21. When Mr A developed epilepsy in April 2003 he had been started on Lamotrigine (also known as Lamictal) for his seizures. Following his last review by Consultant 1 in June 2004, she had written to his GP advising that Mr A should continue to increase his Lamictal in 25 mg stages each time he had a seizure. She explained that, only if they could get this medication up to a reasonably high dose, could they get a clear idea whether or not the drug was having any effect.

22. Mr A's GP wrote to Consultant 1 on 20 October 2004 advising that Mr A had now reached a dosage of 200 mg twice daily with the Lamotrigine, following recurrent episodes of seizure. The GP advised that Mrs C was concerned that Mr A was getting increased facial twitching as the dose increased and, therefore, was reluctant to continue increasing it without further advice. Consultant 1 replied on 23 November 2004. She advised that, if Mr A's seizures seemed to be controlled by his current dose of Lamitrogine, she would have been inclined to leave it as it was and not increase the dose further. She advised that there were some situations in which Lamotrigine can precipitate myoclonic jerks and it may be that Mr A's facial twitching was due to that. If, however, his seizures were not well controlled then the medication could be increased further to see whether control could be improved but she would probably not exceed a dosage of 250 mg.b.d.

23. In March 2005 Mr A's GP wrote again to Consultant 1. By this time the dosage had reached 250 mg twice daily but, unfortunately, this was not controlling the seizures. Having reached this level of dosage, he was now

seeking a further opinion regarding possible further additions to the medication or alternative treatment. Consultant 1 replied on 30 March 2005. She advised that if Mr A were able to push his dosage further she recommended this, aiming for an upper limit of 700 mg a day. If, on reaching this, Mr A's seizures did not improve then the dosage of Lamotrigine should be reduced down to about 200 mg and a small dose of epilim (which contains the active ingredient sodium valproate) should be added, very cautiously. She suggested about 100 mg a day. She advised Mr A might then benefit from the synergistic effect of Lamotrigine and epilim used together. She suggested that an alternative approach would be to treat Mr A with clobazam (frisium) on occasions when he was undergoing a stressful change in his life.

24. Mrs C complained that epilim should not be introduced until the Lamictal had reached a much lower level of about 125 mg daily, otherwise Mr A would be at risk of becoming toxic with too much Lamictal in his blood, as the epilim would increase the time the Lamictal remained in his body.

25. The advice I have received from the Ombudsman's adviser is that there is a well known interaction between sodium valproate and Lamotrigine. When used together, the effect of sodium valproate is to increase the active form of Lamotrigine in the blood to a level higher than would normally occur when Lamotrigine is used alone. This risks causing increased side effects or toxicity of Lamotrigine. It is clear from the clinical correspondence that Consultant 1 was aware of this interaction but her opinion on how low the dose of Lamotrigine should be before adding valproate differed from that of Consultant 2. This is a matter of clinical judgement relating to the relative risks of increased frequency or severity of seizures while achieving the lower dose and those of increased side effects at the upper dose.

26. The adviser added that the use of any anti-epilepsy drug is associated with a risk of side effects or toxic effects. There is, therefore, a need to balance the risks and benefits. There is no specific correct dose of any anti-epilepsy drug or combination of drugs. The appropriate dose is the smallest dose that gives good control of the seizures with the minimum of side effects and no toxicity. Thus the doses required vary very considerably from patient to patient. The adviser's view was that this is a matter of clinical judgement relating to the relative risks of increased frequency or severity of seizures while achieving the lower dose and those of increased side effects of the upper dose. He considered that the opinion of Consultant 1 was reasonable.

(b) Conclusion

27. Mrs C complained that the medication prescribed by Consultant 1 was inappropriate and, if fully implemented, would have placed Mr A at risk. However, the advice I have received from the Ombudsman's adviser is that it is clear from the clinical correspondence that Consultant 1 was aware of the risks from the interaction of the medication she had prescribed and that her opinion on the dosage was reasonable. I have to be led by the advice I have received on this point and, accordingly, I do not uphold this complaint.

28. The Board have accepted the recommendations and will act on them accordingly. The Ombudsman asks that the Board notify her when the recommendations have been accepted.

Annex 1

Explanation of abbreviations used

Mrs C	The complainant
Mr A	Mrs C's son
The Board	Forth Valley NHS Board
Consultant 1	Consultant Neurologist (formerly Forth Valley NHS Board)
Consultant 2	Consultant Neurologist (England)
Consultant 3	Consultant Neurologist (Forth Valley NHS Board)
EEG	Electroencephalogram

Annex 2

Glossary of terms

Autism	A developmental disorder characterised by deficits in social interaction and communication
Electroencephalogram	A technique for studying the electrical current within the brain
Epilepsy	A disorder characterised by recurrent seizures
Lamotrigine	An oral drug that is used for treating seizures. Lamotrigine is the generic name and Lamictal a common brand name version
Neurologist	A doctor who specializes in the diagnosis and treatment of disorders of the nervous system
Sodium valproate	A medication used to treat seizures and available in tablet, syrup and injection form. Sodium valproate is the generic name and epilim a common brand name version