SPSO Scottish Public Services Ombudsman

The Scottish Public Services Ombudsman Act 2002

Investigation Report

UNDER SECTION 15(1)(a)

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Scottish Parliament Region: Mid Scotland and Fife

Case ref: 201507831, Forth Valley NHS Board
Sector: Health
Subject: Hospitals / Clinical treatment / Diagnosis

Summary
Mrs C's child (Child A) had been suffering from vomiting and headaches and was referred to a paediatrician at Forth Valley Royal Hospital in January 2014. The paediatrician saw Child A on three occasions from January 2014 until July 2014. In August 2014, Child A collapsed at home and was admitted to Forth Valley Royal Hospital as an emergency. Child A was diagnosed with a brain tumour. They underwent lengthy and difficult surgery to remove the tumour, but it was impossible to remove it completely. Mrs C said that despite the evidence of Child A's deteriorating condition, the paediatrician failed to record their symptoms and carry out appropriate tests, referrals and investigations. Mrs C also said that the paediatrician failed unreasonably to consider a serious cause of Child A's symptoms. As a result, Mrs C believed that Child A's brain tumour should have been detected much earlier and that they suffered unnecessarily.

During the investigation, my complaints reviewer took independent advice from a specialist in paediatrics and a specialist in paediatric neurosurgery. The first adviser considered that Child A should have been referred for a brain scan in April 2014 (at the least) and that the paediatrician's failure to consider that Child A may have a brain tumour and arrange appropriate scans and referrals was below an acceptable standard of care. I accept that advice. I am particularly concerned about the paediatrician's failure to act in July 2014 given that they had documented their awareness of headaches in addition to ongoing vomiting. The second adviser said that it was likely an earlier diagnosis would have meant a smaller tumour and a shorter, less challenging operation. My view is that these failures led to a significant personal injustice to Child A. The unreasonable delay meant that an opportunity to completely remove the tumour was missed, and in this respect I note that Child A required additional treatment (chemotherapy) with significant risks and was left with neurological defects. In addition, Child A's collapse was very traumatic for them and their family. Given the evidence and information available to the specialist about Child A's condition (from January 2014 onwards), I am extremely concerned about their failure to properly assess and investigate Child A's symptoms, and their failures

raise questions about their competence. In view of the failings identified, I upheld the complaint about the clinical care and treatment provided and made recommendations. However, I did not make recommendations that relate directly to the paediatrician because they are no longer an employee of the health board.

Redress and recommendations

The Ombudsman recommends that the board:	*Completion date*
(i) ensure that all relevant healthcare professionals are aware of the guidelines relating to the diagnosis of brain tumours in children and young people (the HeadSmart programme); and	23 February 2017
(ii) apologise to Mrs C for the failures identified.	23 January 2017

Who we are

The Scottish Public Services Ombudsman (SPSO) investigates complaints about organisations providing public services in Scotland. We are the final stage for handling complaints about the National Health Service, councils, housing associations, prisons, the Scottish Government and its agencies and departments, the Scottish Parliamentary Corporate Body, water and sewerage providers, colleges and universities and most Scottish public authorities. We normally consider complaints only after they have been through the complaints procedure of the organisation concerned. Our service is independent, impartial and free. We aim not only to provide justice for the individual, but also to share the learning from our work in order to improve the delivery of public services in Scotland.

The role of the SPSO is set out in the Scottish Public Services Ombudsman Act 2002, and this report is published in terms of section 15(1) of the Act. The Act says that, generally, reports of investigations should not name or identify individuals, so in the report the complainant is referred to as Mrs C. The terms used to describe other people in the report are explained as they arise and in Annex 1.

Introduction

1. Mrs C complained to my office about the care and treatment her son (Child A), aged five at the time, received from a specialist (the Paediatrician) at Forth Valley Royal Hospital (the Hospital) from January 2014 until August 2014 when he collapsed and was admitted to the Hospital as an emergency. He was diagnosed with an intracranial mass (brain tumour) and had lengthy and difficult surgery to remove it, but it was impossible to remove all of the tumour.

2. The complaint from Mrs C I have investigated is that Forth Valley NHS Board (the Board) failed to provide a reasonable standard of medical care and treatment to Child A from January 2014 until August 2014 (*upheld*).

Investigation

3. In order to investigate Mrs C's complaint, my complaints reviewer examined all the information provided by Mrs C including a copy of a diary of Child A's symptoms from May 2014. They also reviewed a copy of Child A's clinical records and Forth Valley NHS Board's complaint file. Finally, they obtained independent advice from two advisers who specialise in paediatrics and paediatric neurosurgery (Medical Adviser 1 and Medical Adviser 2). In this case, we have decided to issue a public report on Mrs C's complaint because of my considerable concerns about the standard of paediatric care provided in this case which led to a significant injustice to Child A and his family, and to raise awareness of the symptoms of brain tumours in children and young people amongst healthcare professionals.

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.

Clinical Background

5. Child A attended his GP on a number of occasions in November 2013 for reflux and vomiting and during one of these consultations (on 6 November 2013) it was also noted that one of his symptoms included headache. During this period, Child A attended the emergency department (at the Hospital) on 11 November 2013 with vomiting and headache, and the consultant discharged him to be followed up by his GP. Child A continued to see his GP, who referred him on 19 December 2013 to the paediatrics department at the Hospital to investigate his recurrent vomiting (the GP noted that he had been sick two to three times per week, particularly in the morning

after breakfast). The Paediatrician saw Child A on 22 January 2014 and considered that he may have gastro-oesophageal reflux and prescribed medication. There was no mention of headaches in the Paediatrician's handwritten notes from this clinic consultation or in the typed clinic letter. On 30 April 2014, the Paediatrician saw Child A again and decided to test for helicobacter pylori (an organism that can cause gastro-oesophageal reflux). Again, there was no mention of headache in the Paediatrician's handwritten notes from this consultation or in the typed clinic letter. Mrs C's diary of Child A's symptoms from 20 May 2014 onwards included headache and vomiting often on waking (unfortunately the electronic diary noting his symptoms before May 2014 was lost). The test for helicobacter pylori was performed on 25 June 2014 and was negative. On 15 July 2014, the Paediatrician saw Child A and noted in the clinic letter that his symptoms continued to persist and that now there was added headache[1]. On 8 August 2014, Child A awoke at 04:00 with headache and nausea, and collapsed on his way to the bathroom and lost consciousness for around two minutes. He was admitted to the Hospital by emergency ambulance and a computerised tomography scan showed a large posterior fossa mass (measuring approximately 6 x 4. centimetres) which almost certainly represented a tumour and there were indications of significantly elevated intracranial pressure. Child A was then transferred to the paediatric neurosurgery service at the Royal Hospital for Sick Children in Glasgow. On 12 August 2014, Child A underwent an operation to remove the tumour, but it was not possible to cut out the tumour completely due to its location.

Complaint: The Board failed to provide a reasonable standard of medical care and treatment to Child A from January 2014 until August 2014

6. Mrs C said Child A's GP had referred him to the Hospital (in January 2014) given the seriousness of his symptoms, but that despite the evidence of his deteriorating condition (which included a diary of his symptoms), the Paediatrician failed to record these (including headaches from January onwards) and carry out appropriate tests, referrals and investigations. Mrs C also said the Paediatrician failed unreasonably to consider a serious cause of Child A's symptoms. As a result, Mrs C believed that Child A's brain tumour should have been detected much earlier and that he suffered for longer than necessary.

[1] The Board were unable to locate the handwritten medical notes from this consultation.

The Board's response

7. The Board said Child A's case notes had been reviewed and acknowledged there was a lack of note about his symptoms (by the Paediatrician) which also failed to reflect the parents' comments or diary. The consultant paediatrician who had reviewed the notes said that had they reviewed Child A and seen the diary information about his condition, they would have acted sooner. The Board apologised that greater attention was not paid to the vital information the parents had accumulated about Child A's illness.

Statement from Mrs C

8. Mrs C told my complaints reviewer that when the GP referred Child A to the Paediatrician (in December 2013), they had told her to keep a diary of Child A's symptoms and so she had maintained a detailed diary from then. Initially, this had been in electronic form, but unfortunately this was lost and she started a paper diary from May 2014. Mrs C remembered clearly reading out her diary extracts to the Paediatrician and recalled specifically telling them that Child A had had headaches (one entry said that he had woken up screaming with a headache) but that the Paediatrician appeared uninterested. However, initially, while she had noted that generally Child A woke up with a sore head the family were focused on his sickness. Having said that, Mrs C was clear that Child A's vomiting followed by a headache was a pattern he had consistently exhibited and that was the very first entry in her electronic diary that had been read out to the Paediatrician. She recalled that the Paediatrician responded that an individual would have a headache if they were sick a lot. (Mrs C also said that she had known for a while something was very wrong because Child A's pupils went very small before he was going to be sick.) Mrs C was clear that she mentioned Child A's headaches to the Paediatrician at the appointment in January 2014 and thereafter. As the months passed, she was increasingly concerned about the headaches and had asked the Paediatrician to carry out more tests. She had become extremely frustrated at not being listened to, as well as extremely worried.

Relevant guidelines

9. The HeadSmart programme and The Royal College of Paediatrics and Child Health aim to reduce the length of time it takes to diagnose brain tumours in children and young people by educating healthcare professionals and, in the case of HeadSmart, the public, including when to refer children and young people for a brain scan. The HeadSmart programme state that symptoms of brain tumours in children from aged five to 11 included (amongst others):

persistent or recurrent vomiting; persistent or recurrent headaches; abnormal eye movements; and blurred or double vision. The Royal College of Paediatrics and Child Health (2008) issued a guideline called 'the brain pathways guideline: a guideline to assist health care professionals in the assessment of children who may have a brain tumour'. The guidelines state, amongst other things, that:

> 'if nausea and/or vomiting were continuous or recurrent for more than two weeks then the likelihood of an underlying brain tumour is increased and this should be considered in the differential diagnosis. Delayed diagnosis has been associated with attributing persistent nausea and vomiting to an infective cause (in the absence of corroborative findings e.g. contact with similar illness, pyrexia, diarrhoea) … CNS [central nervous system] imaging (within a maximum of four weeks) is required for persistent vomiting on awakening (either in the morning or from a daytime sleep) … Vomiting due to raised intracranial pressure is characteristically worse after prolonged period of lying down and thus vomiting that persistently occurs on waking is more likely to be associated with an intracranial lesion than vomiting occurring at other times … CNS imaging (within a maximum of four weeks) is also required for persistent headache that wake a child from sleep or that occur on waking.'

Medical advice

10. My complaints reviewer asked Medical Adviser 1 if appropriate tests, referrals and investigation had been undertaken within a reasonable time in light of Child A's symptoms. Medical Adviser 1 responded that at the first consultation on 20 January 2014, the Paediatrician's clinical impression was one of possible gastro-oesophageal reflux. Medical Adviser 1 said that with hindsight, Child A's morning vomiting could be interpreted as a red flag. However, there was no mention of headache as a complaint and no evidence that the Paediatrician enquired about this as a symptom. A physical systemic examination was recorded with no notable findings and no neurological or ophthalmological examination was recorded. On balance, Medical Adviser 1's view was that the care and treatment provided at this consultation was appropriate, but if it could be established that the Paediatrician was made aware of the concerns about headaches, then the clinical care at this consultation was below an acceptable standard. There was also no reference to the family's diary in the medical notes.

11. Medical Adviser 1 outlined that the next consultation occurred three months later (on 30 April 2014), and a month later than intended. Again, there was no mention of headache as a complaint in the handwritten notes or the typed letter from the consultation, and the Paediatrician had documented that they had asked the family to maintain a diary of Child A's vomiting (again there was no reference to the family's diary). No neurological or ophthalmologic examination was recorded. Medical Adviser 1 said that the documentation in relation to the vomiting, in particular its frequency and timing, was poor. Given Child A's ongoing symptoms and failure to respond to the medication (prescribed to address the possibility of gastro-oesophageal reflux), alternative diagnosis should have been considered and Medical Adviser 1 said that, therefore, this consultation fell below an acceptable clinical standard. Medical Adviser 1 explained that an intracranial mass needed to be excluded in children with persistent regular early morning vomiting.

12. In relation to the consultation on 15 July 2014, Medical Adviser 1 said that the care and treatment provided was significantly below an acceptable standard. The Paediatrician was aware of the ongoing vomiting and had now documented their awareness of added headache. There was no reference to the family's diary (that the Paediatrician had requested) and their clinic letter gave the impression that the headache was a new symptom as reported to the Paediatrician. Moreover, it did not appear that the Paediatrician had considered an intracranial mass in their differential diagnosis but had instead diagnosed constipation and prescribed a laxative. There was no indication the Paediatrician offered any explanation for the headaches, and no evidence that any detailed questioning about the nature of the headaches was undertaken (no description of the nature, severity or timing of the headaches). Furthermore, there was no evidence that a neurological or ophthalmologic examination was performed. Medical Adviser 1 said that urgent cranial imaging was indicated and should have been undertaken. Medical Adviser 1 added it was of note that when Child A presented to the Hospital on 8 August 2014, the doctor who reviewed him was in their fourth year of paediatric training and yet made the correct diagnosis in their differential diagnosis based on the same clinical information that was available to the Paediatrician three weeks earlier. Medical Adviser 1 said that brain tumours in children were not uncommon and the Board should undertake in-house training to ensure all clinical staff were aware of the HeadSmart programme, so that their clinicians were aware of the symptoms of brain tumours in children and young people.

13. Turning now to the injustice the failings led to, my complaints reviewer asked Medical Adviser 2 what difference it would have made to Child A in terms of surgical options and/or treatment and prognosis had he been referred for a neurosurgical opinion in either April or July 2014. Medical Adviser 2 explained that the operation Child A underwent (on 12 August 2014) consisted of two parts, both performed under the same general anaesthetic. First, a tube into the fluid cavity of the brain was inserted to relieve the pressure. The second part of the operation was lengthy (around 11 hours) due to the fact that the tumour was stuck to the brainstem and intimately related to important arteries near the base of the brain. Because of these relationships to critical structures, a complete resection was not possible and a piece of tumour was left. Medical Adviser 2 said that Child A was admitted to intensive care post-operatively and made a gradual recovery from surgery. He was noted to have a sixth nerve palsy (squint) and dysarthria (unclear speech) post-operatively. In subsequent out-patient letters, it was also noted that he had a weakness on one side of the body. In the following months, scans showed growth of the residual tumour and so he underwent treatment with chemotherapy.

14. Medical Adviser 2 went on to say that they agreed (with Medical Adviser 1) that the possibility Child A had a brain tumour should have been considered earlier and that at the least the Paediatrician should have documented the presence or absence of headache or other neurological symptoms and a neurological examination and assessment, particularly in April 2014 when it was clear that the treatment for the initial diagnosis (of gastro-oesophageal reflux) had not stopped the vomiting. Medical Adviser 2 said it was certain that, if imaging studies had been arranged earlier in Child A's clinical course (as they should have been), the tumour would have been detected and the psychological trauma for Child A and his family relating to his very frightening collapse on 8 August would have been avoided. Moreover, it was very likely that an earlier diagnosis (at least prior to the onset of recorded headache in July) would have meant a smaller tumour and a shorter and less challenging operation. Medical Adviser 2 went on to say that it was possible (but could not be proven in the absence of contemporaneous imaging) that an earlier diagnosis would have permitted surgery which would have completely removed the tumour and/or left Child A with no neurological deficit, both of which have made very significant differences to his long-term prognosis. Instead, Child A had gone on from the operation needing treatment with chemotherapy, treatment which was arduous for both patients and their family and not without side effects and risks. In

addition, Child A was left with neurological defects following the surgery including a squint and hand weakness.

Decision

15. Mrs C complained that the Board's assessment and treatment of Child A was unreasonable. In reaching my decision, I have carefully considered Mrs C's account of what happened and Child A's clinical records. The advice I have accepted is that Child A should have been referred for cranial imaging in April 2014 (at the least) and that the Paediatrician's failure to consider a brain tumour as a differential diagnosis and arrange appropriate scans and referrals was below an acceptable standard of care. I am particularly concerned about the Paediatrician's failure to act on 15 July 2014. These failures led to a significant personal injustice to Child A in that it was likely an earlier diagnosis would have meant a smaller tumour and a shorter less challenging operation. The unreasonable delay also meant that an opportunity to completely remove the tumour was missed, and in this respect I note that Child A required additional treatment (chemotherapy) with significant risks and was left with neurological defects. In addition, Child A and his family endured what Medical Adviser 2 described as a psychological trauma when he collapsed on 8 August 2014. I agree.

16. I have also considered the evidence from Mrs C that she reported to the Paediatrician during the consultation in January 2014 (and in April 2014) that Child A had been suffering headaches given Medical Adviser 1's advice that had the Paediatrician been made aware of this, then the clinical care at this consultation was also unreasonable. In this respect, I note the clinical records indicated that Child A suffered from headache on two instances in the period leading up to his referral in December 2013 (on 6 and 11 November 2013) and so Mrs C's account that Child A's symptoms (at times) included headache is supported. Moreover, Mrs C's diaries from May 2014 are detailed and comprehensive, and I am satisfied that given Mrs C's increasing concern she had documented detailed information about Child A's condition in a similar way from the referral until May. It is also significant that the Paediatrician's record-keeping was poor, and that they had failed to refer to the presence or otherwise of headaches. I have, therefore, determined that on balance it is likely Mrs C did tell the Paediatrician from January 2014 onwards that Child A's symptoms included headache.

17. The standard by which I judge a clinician's actions is whether they were reasonable in the circumstances. In making my decision on this case, I considered whether the Paediatrician's decisions and actions taken were within a range of what would be considered acceptable professional practice at the time in question. Given the evidence and information available to the Paediatrician about Child A's condition (from January 2014 onwards), I am extremely concerned about their failure to properly assess and investigate his symptoms. Their failings in this case raises questions about the Paediatrician's competence. I uphold the complaint. I make several recommendations to address the failures identified. I note that the Paediatrician is no longer an employee of the Board and so I have made no recommendations that relate directly to the Paediatrician.

Recommendations

18. I recommend that the Board:	*Completion date*
(i) ensure that all relevant healthcare professionals are aware of the guidelines relating to the diagnosis of brain tumours in children and young people (the HeadSmart programme); and	23 February 2017
(ii) apologise to Mrs C for the failures identified.	23 January 2017

19. The Board have accepted the recommendations and will act on them accordingly. We will follow up on these recommendations. The Board are asked to inform us of the steps that have been taken to implement these recommendations by the date specified. We will expect evidence (including supporting documentation) that appropriate action has been taken before we can confirm that the recommendations have been implemented.

Annex 1

Explanation of abbreviations used

Mrs C	the complainant
Child A	the complainant's son
the Paediatrician	a specialist in paediatrics at Forth Valley Royal Hospital
the Hospital	Forth Valley Royal Hospital
the Board	NHS Forth Valley Board
Medical Adviser 1	an adviser to the Ombudsman who specialises in paediatrics
Medical Adviser 2	an adviser to the Ombudsman who specialises in paediatric surgery
GP	general practitioner

Annex 2

Glossary of terms

differential diagnosis	the process of differentiating between two or more conditions which share similar signs or symptoms
dysarthria	unclear speech
helicobacter pylori	an organism that can cause gastro-oesophageal reflux
intracranial mass	brain tumour
posterior fossa mass	a small space in the skull found near the brainstem and cerebellum
sixth nerve palsy	squint