**Parliament Region: Glasgow** 

Case 201000940: A Medical Practice, Greater Glasgow and Clyde NHS Board

## **Summary of Investigation**

## Category

Health: GP Practice; clinical treatment

#### Overview

The complainant (Mrs C) complained about the treatment for a nut allergy provided to her daughter (Miss C) by a GP (the GP), prior to her daughter's death from anaphylaxis. In particular, Mrs C complained that an EpiPen (an auto injector of adrenaline) had not been prescribed to Miss C. Mrs C also complained about the tone and manner of the GP when she telephoned four days after her daughter's death.

## Specific complaints and conclusions

The complaints which have been investigated are that:

- (a) the care and treatment provided to Miss C by her GP for a nut allergy prior to her death from anaphylaxis was inadequate (*upheld*); and
- (b) the tone and manner of the GP when she telephoned four days after Miss C's death were inappropriate (*not upheld*).

#### Redress and recommendations

The Ombudsman recommends that:

Completion date

(i) the GP write to Mrs C to apologise for failing to discuss the letter of 1 August 2007 with her.

30 March 2011

The Practice has accepted the recommendation to issue an apology and will act on it accordingly.

#### **Further Action**

Faced with the lack of national guidance on adrenaline auto injector prescription, there is a danger of inconsistency in approach with potentially devastating consequences. Introducing national guidance could be a safeguard against this. A national paediatric allergy network that has been set up could take this forward and build upon the work already done by Greater Glasgow and

Clyde NHS Board. The Ombudsman will draw this matter to the attention of the Scottish Government Health and Social Care Directorate.

## **Main Investigation Report**

#### Introduction

- 1. The complainant (Mrs C) complained about the treatment provided to her daughter (Miss C) by a GP (the GP), prior to her daughter's death from anaphylaxis. Miss C suffered from a nut allergy and in particular, Mrs C complained that an EpiPen (an auto injector of adrenaline) had not been prescribed to Miss C. She believed that had an EpiPen been prescribed, Miss C's death may have been prevented. Mrs C also complained about the tone and manner of the GP when she telephoned four days after her daughter's death.
- 2. The complaints from Mrs C which I have investigated are that:
- (a) the care and treatment provided to Miss C by her GP for a nut allergy prior to her death from anaphylaxis was inadequate; and
- (b) the tone and manner of the GP when she telephoned four days after Miss C's death were inappropriate.

### Investigation

- 3. Investigation of the complaint involved reviewing the GP Practice's medical records for Miss C and other documents obtained from Greater Glasgow and Clyde NHS Board (the Board). My complaints reviewer also obtained advice from a professional medical adviser (the Adviser).
- 4. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked. An explanation of the abbreviations used in this report is contained in Annex 1. A glossary of terms used in this report can be found at Annex 2. Mrs C and the GP Practice (the Practice) were given an opportunity to comment on a draft of this report.

# (a) The care and treatment provided to Miss C by her GP for a nut allergy prior to her death from anaphylaxis was inadequate

5. Miss C was born in April 2000. She was subsequently diagnosed with eczema, asthma and lactose intolerance. In February 2002, the GP referred her to a paediatric clinic for the lactose intolerance. In August 2002, she was referred to the Board's Department for Dermatology for her eczema. Miss C was subsequently reviewed by the Department for Dermatology. On 10 January 2003, they wrote to the Practice. They said that Mrs C had asked

about allergy testing, but they had told her that this would not be helpful or necessary in Miss C's case. Miss C was prescribed medication for her eczema.

- 6. Between January 2003 and September 2005, Miss C continued to be seen by the Department of Dermatology for her eczema. On 12 September 2005, the Board's Associate Specialist in Dermatology (the NHS Dermatologist) wrote to the Practice. She said that her allergy testing from her last visit showed that Miss C may be allergic to peanuts. Although she had been eating nuts without any problems, the NHS Dermatologist said that she had suggested that Miss C avoid eating peanuts. She also said that she would arrange some skin prick testing and perhaps even a food challenge test to make absolutely sure that Miss C could eat nuts. She said that Miss C had a review appointment in six months' time, but Mrs C could contact her before that if there was a problem.
- 7. On 11 April 2006, the NHS Dermatologist wrote to the GP and said that Miss C was still awaiting skin prick testing for peanuts. She also said that she had arranged for her to be reviewed in one year's time, but Mrs C could contact her before that if there were any concerns.
- 8. An Allergy Sister from the Board wrote to the GP on 5 June 2006. She said that Miss C had been due to attend the medical day care unit on 26 May 2006 for a 'peanut challenge'. However, prior to the appointment, Mrs C had telephoned to say that Miss C's hay fever was bad at that time and that the family would find it difficult to withhold antihistamine (which should be avoided prior to the test). She said that Mrs C had also informed them that the family felt that Miss C's peanut challenge would definitely be positive and she would probably not need to attend, as she had suffered a reaction on two occasions in 2005 after eating nuts. The Allergy Sister said that she agreed with the family that this was probably the case and had, therefore, postponed the peanut challenge meantime. She also said that the family had subsequently telephoned to ask for information about food allergies and she had sent this to them.
- 9. Miss C saw a dermatologist privately in September 2006. He subsequently wrote to the GP and told her that Miss C had previously been allergy tested and this had revealed antibodies to peanuts, grass and house dust mite.

- 10. The NHS Dermatologist wrote to the GP on 1 August 2007 and said that Miss C had failed to respond to their efforts to arrange follow up. She said that she presumed that their input was no longer needed. She said that Miss C was still nut allergic at the last visit to the Allergy Sister and should continue to avoid nuts. She also said that Miss C should be referred onto the Allergy Service if the GP wanted the nut allergy to be reviewed. There is no evidence that the GP took any action in response to this letter.
- 11. Miss C saw the GP on a number of occasions between August 2007 and April 2009. The records show that this was mainly in relation to her asthma and other illnesses, although Mrs C did refer to her eczema in a letter to the GP in January 2008. The GP also received a number of letters from the dermatologist Miss C was seeing privately during this period.
- 12. On 9 April 2009, the GP referred Miss C to a Paediatrician. The GP said that she had had episodes of recurring abdominal pain, severe eczema, asthma and hay fever. She said that she wondered if there was a food allergy component to this. On 29 April 2009, the dermatologist Miss C was seeing privately wrote to the GP and said that her eczema had been particularly severe.
- 13. A Consultant Paediatrician wrote to the GP on 13 July 2009. She said that Miss C was thought to be allergic to peanuts. She said that she had discussed Miss C with her allergy colleagues, who were happy to see her and advise regarding any further allergy testing and also advise regarding an EpiPen. She also said that they had stated that it would be useful for Miss C to be seen by a dermatologist in case of the need for joint working and she had made a referral for this. Sadly, Miss C died after an acute anaphylactic event on 10 August 2009.
- 14. On 18 February 2010, Mr and Mrs C wrote to the GP. They said that they wanted to raise two issues in relation to her clinical care and her manner in consultation. They said that they did not cancel the food tolerance test in May 2006, but were told by the nurse that the test would be unnecessary (paragraph 8 refers). They said that they were not told about any opportunity for follow up. Mrs C said that she had asked the NHS Dermatologist if Miss C should have an EpiPen, but the NHS Dermatologist said that she thought not.

- 15. Mr and Mrs C also said that they had not been told about the letter received from the NHS Dermatologist in August 2007 (paragraph 10 refers) and there had been no discussion about whether they wanted to pursue this. They said that they had asked the GP about an EpiPen, but she felt that this was unnecessary. They said that had they been aware of the opportunity for referral to the allergy clinic, they would have accepted. They stated that had this referral occurred, their daughter would have received an EpiPen many months before she died. They also said that Miss C died on the waiting list for this service. They said that had she been seen earlier at the allergy clinic, then perhaps the trigger that caused her anaphylaxis would have been identified and she would not have been exposed to it in the first place. They asked that the GP specifically comment on why they were not informed that referral to the allergy clinic was available and why she did not make that referral.
- 16. The GP responded to this letter on 23 February 2010. She said that she had discussed the case at length within the Practice and at a Multidisciplinary Case Conference at the Royal Hospital for Sick Children (the Hospital) in an effort to determine whether the decision regarding prescribing an EpiPen should have been made clearer and sooner. She said that they had all seen opportunities to have raised the issue earlier than the referral from her in April 2009 about a possible food reaction. She said that this referral prompted the Paediatrician to re-refer Miss C to the allergy clinic and look at the issue as to whether or not to prescribe an EpiPen.
- 17. The GP said that she had noted Mrs C's remark regarding the letter received from the NHS Dermatologist in August 2007 (paragraph 10 refers). She said that her understanding was that they were attending dermatology privately. She said that the Practice were aware that Miss C's asthma and eczema were worsening, but the worsening of a food allergy was not really apparent until March/April 2009 when she referred Miss C as a possible food allergy/abdominal migraine presentation. She said that as Miss C had never had a food anaphylaxis, this was not discussed in her recollection. She said that she did not recall a conversation when Mrs C asked her if Miss C should have an EpiPen.
- 18. The Board carried out a review of Miss C's medical management after her death. My complaints reviewer obtained a copy of the report on the review. This stated that the post mortem showed that her cause of death was ascribed

to an acute anaphylactic event and, on the basis of the specific RAST<sup>1</sup> testing, this was ascribed to peanut allergy. The report said that anaphylaxis was the most likely cause of death. Miss C's father (Mr C) has told my complaints reviewer that there remains at least some doubt about whether exposure to peanuts caused Miss C's anaphylaxis. The report on the review stated that it was agreed with the parents and the GP that such a tragic event warranted a review to identify whether lessons could be learned and improvements made. It said that two particular areas were identified.

- 19. Firstly, communication between the Board's dermatology and allergy services could be improved along with the improved handover of patients between the two services. Secondly, there is no UK guidance for the prescription of adrenaline auto injectors. The Board, therefore, produced a guideline based on best practice and a draft of this was circulated to paediatricians at the Hospital. The guideline was also to be presented to the paediatric primary healthcare interface group for discussion with general practices.
- 20. The Board also provided a copy of the guideline for adrenaline auto injector prescription. This states that adrenaline auto injector prescription is recommended if there is a history of generalised allergic reaction with nuts (or skin prick test result/RAST test result indicates a high risk of reaction and, therefore, a challenge is deemed inappropriate) and co-existing asthma requiring regular preventer therapy.
- 21. My complaints reviewer asked the Adviser for his comments on whether the GP should have arranged for an EpiPen to be prescribed to Miss C and the family given the training to use it. In his response, the Adviser said that the BNF for Children<sup>2</sup> states that 'children at considerable risk of anaphylaxis need to carry (or have available) adrenaline at all times and the child or the child's carers need to be instructed in advance how to inject it'.

<sup>&</sup>lt;sup>1</sup> Radioallergosorbent test. This is a blood test that is used to determine what a person is allergic to.

<sup>&</sup>lt;sup>2</sup> A joint publication of the British Medical Association, the Royal Pharmaceutical Society of Great Britain, the Royal College of Paediatrics and Child Health, and the Neonatal and Paediatric Pharmacists Group, *BNF for Children* ('BNFC') is published under the authority of a Paediatric Formulary Committee.

- 22. The Adviser considered whether Miss C was at considerable risk. He said that although anaphylactic deaths in children under the age of ten are very rare, nut allergies are renowned for giving anaphylactic episodes. The Adviser said that Miss C was an atopic child, but her eczema tended to be worse and more problematic than her breathing.
- 23. The Adviser's view was that until August 2007, the GP would reasonably have considered that the matter had been referred to specialists in the Board's Department for Dermatology. He said that it would be reasonable for her to have assumed that they had dealt with or were dealing with the matter.
- 24. However, on 1 August 2007, the NHS Dermatologist wrote to the GP and said that there had been no response to their efforts to arrange follow up. She said that the GP should refer Miss C onto the Allergy Service if she wanted her nut allergy to be reviewed.
- 25. My complaints reviewer specifically asked the Adviser for his comments on what action the GP should have taken after receipt of this letter. In his response, the Adviser said that in an ideal world all such letters should be actioned. However, he said that these letters are very common and most GPs only get in touch with patients who they believe to be at special risk. The Adviser said that there was nothing to suggest that Miss C was in this category in 2007. He commented that most GPs will wait for the patient or their representative to return to ask the GP to arrange another appointment.
- 26. In response to her opportunity to comment on a draft of this report, the GP said that she was unaware of any conversation between Mrs C and the NHS Dermatologist about an EpiPen and it was not mentioned in any of the Board's letters. She also said that she had referred Miss C for private dermatological care in 2006, so when the letter was received from the NHS Dermatologist in August 2007, she would have assumed that this was because the family had decided to obtain private care. She said that had it been pointed out that Miss C had never had a peanut challenge test, she believed that she would have taken further action. The GP commented that when she made the referral to a Paediatrician in April 2009, a food allergy was one possible diagnosis, with which the Paediatrician concurred.

- (a) Conclusion
- 27. The death of a child is a deeply distressing and traumatic experience for a parent and Mr and Mrs C have my deepest sympathy. Although Mr C has told my complaints reviewer that there remains at least some doubt about whether exposure to peanuts caused Miss C's anaphylaxis, this is in some ways irrelevant in relation to the complaint that Mrs C has referred to me. The complaint made by Mrs C is about the care and treatment provided to Miss C by the GP and about the fact that she did not prescribe an EpiPen for the nut allergy before Miss C's tragic death.
- 28. Peanut allergy affects up to one in 200 people in economically developed countries. Unlike many other types of food allergy, it is often lifelong. However, the Board's paper on their review states that in one ten year period in the UK, only three anaphylactic deaths were recorded in children under the age of ten. The paper also states that another study suggested that the risk of anaphylaxis death in a child with a known food allergy approaches one in 800,000. That said, protocols are still important for these rare incidents. Health care professionals are often aware of what action to take when more common illnesses/diseases occur, but are less likely to be aware of the action to take when faced with such a rare one.
- 29. There is a lack of clear guidance for health professionals in Scotland about when to prescribe an EpiPen. Greater Glasgow and Clyde NHS Board have now produced guidance and it is likely that Miss C would have received an adrenaline auto injector if this guidance had been in place before her death.
- 30. I agree with the Adviser's comments that prior to August 2007, the GP would reasonably have considered that the matter was being dealt with by the Board's specialists. However, the Board's Department for Dermatology wrote to the GP on 1 August 2007 and said that there had been no response to their efforts to arrange follow up. They said that Miss C was still nut allergic at the last visit to the Allergy Sister and should continue to avoid nuts, but that the GP should refer her onto the Allergy Service if she wanted her nut allergy to be reviewed.
- 31. I have considered the Adviser's comments on this aspect of the complaint. Although he has stated that the GP's actions were reasonable, my view is that there was an onus on the GP to follow up the letter received from the NHS Dermatologist in August 2007. Notwithstanding the responsibilities carried by

parents for making appropriate decisions about the welfare of their children, health care professionals should ensure that parents are aware and fully informed of the options available to them for obtaining treatment for them. At the very least, the GP should have informed the parents of the letter and discussed it with them when they next attended the Practice. I have not seen any evidence that the GP discussed the letter dated 1 August 2007 with Mr C or Mrs C. While I note the GP's comments at paragraph 26 that she believes she would have taken further action had she been aware that Miss C had never had a peanut challenge test, it remains the case that the GP had been advised in June 2006 that Miss C's peanut challenge test had been postponed and in August 2007 the GP was advised that Miss C had failed to respond to efforts to arrange follow up.

- 32. In the circumstances, I uphold this complaint.
- (a) Recommendation
- 33. I recommend that: Completion date
- (i) the GP write to Mrs C to apologise for failing to discuss the letter of 1 August 2007 with her.

  30 March 2011

# (b) The tone and manner of the GP when she telephoned four days after Miss C's death were inappropriate

- 34. In their letter of complaint to the GP Practice of 18 February 2010, Mr and Mrs C referred to a telephone conversation that they had with the GP on 14 August 2009, four days after Miss C's death. The family had listened to the call on loudspeaker. Mrs C said that she was firstly struck by the manner of the GP, which lacked any understanding or sympathy. They said that she offered no words of condolence and her tone was cold, matter of fact and accusatory.
- 35. Mrs C said that the GP had stated that she had cancelled a food challenge test and that training on using an EpiPen would normally follow that. She said that the GP had highlighted a breakdown in Miss C's care and suggested that it was Mrs C's actions that had caused this. She said that she believed that the GP was defending her own position and in doing so, was blaming her (Mrs C) for the fact that Miss C did not have an EpiPen. She said that this was a horrendous time for them and the GP's comments at the time led her to believe that she was responsible for Miss C's death. Mrs C also said that she believed that the GP's comments and manner showed a lack of judgement.

- 36. The GP responded to this letter on 23 February 2010. She said that she recalled the conversation on 14 August 2009. She said that she had spoken to the pathologist earlier that day, who had telephoned her to clarify if there was a history of nut allergy and, if so, if Miss C had been provided with an EpiPen. She said that this was the first indication she had that Miss C's death was due to anaphylaxis rather than an asthma attack. She said that she had informed the pathologist that Miss C was nut allergic, but she had not been provided with an EpiPen. She said that she then proceeded to look through Miss C's records to clarify the reason for this.
- 37. The GP said that whilst speaking to Mr C, she came across a letter that said that an appointment had been missed. She said that she could only apologise if stating this sounded in any way accusatory. She said that this was certainly not her intention. She stated that she and all of the Practice were deeply upset and shocked by the news and being cold and unsympathetic was the furthest thing from her mind.
- 38. The GP said that she was saddened that it had been Mrs C's experience that she had been inconsistent or off hand, as she had believed that she had a good relationship with her and Mrs C's children. She said that she was sorry that this was her perception and that she and the other partners in the Practice would be willing to meet Mrs C to discuss any of the issues.
- 39. Mr C wrote to my complaints reviewer on 29 June 2010 to clarify this complaint. He said that the GP had stated in the telephone conversation that the family had cancelled an appointment for a food challenge test and EpiPen training normally followed that. Mr C said that there are two possibilities in terms of why the comments were made. He said that it may be that the GP was being unknowingly, at least somewhat insensitive in making these comments to recently bereaved parents by telephone, four days after the death of their nine year old daughter. He said that the alternative explanation is that the GP knowingly sought to replace responsibility for their daughter's death onto the parents.
- 40. My Adviser has said that it was difficult to comment on the telephone consultation. He said that the parents were inevitably upset, but many doctors also feel various emotions when a patient, especially a child, dies suddenly and unexpectedly. He said that these emotions may include a degree of guilt, which may help to explain this difficult telephone call.

- (b) Conclusion
- 41. The telephone call from the GP to the family on 14 August 2009 must have been extremely difficult for both parties, as it had just come to light that Miss C had died from anaphylaxis rather than from an asthma attack. Everyone involved would clearly have been upset by this news. The family and the GP would most likely have been deliberating over the matter and questioning whether there was anything that they could have done differently to prevent Miss C's death.
- 42. With this background, it is not surprising that the GP's and family's perspectives of the conversation differ. I was not party to the conversation and am unable to comment on what was said during the call or on how it was said to the family.
- 43. I have no doubt that the conversation with the GP would have added to Mr and Mrs C's distress. However, having considered the GP's response to the complaint about this matter, I am satisfied that it was not her intention to sound accusatory or to attach any blame to the parents. The GP also said that she was sorry that this was Mrs C's perception and offered to meet her to discuss the matter.
- 44. In the absence of any clear and objective evidence in relation to the GP's tone and manner during the call, I am unable to uphold this complaint.
- 45. The Practice has accepted the recommendation and will act on it accordingly. The Ombudsman asks that the Practice notify him when the recommendation has been implemented.

#### **Further Action**

46. Faced with the lack of national guidance on adrenaline auto injector prescription, there is a danger of inconsistency in approach with potentially devastating consequences. Introducing national guidance could be a safeguard against this. A national paediatric allergy network that has been set up could take this forward and build upon the work already done by Greater Glasgow and Clyde NHS Board. The Ombudsman will draw this matter to the attention of the Scottish Government Health and Social Care Directorate.

#### Annex 1

## **Explanation of abbreviations used**

Mrs C The complainant

Miss C Mr and Mrs C's daughter

The GP Miss C's GP

The Board Greater Glasgow and Clyde NHS

**Board** 

The Adviser The Ombudsman's GP Adviser

The Practice Miss C's GP Practice

The NHS Dermatologist The Board's Associate Specialist in

Dermatology

The Hospital The Royal Hospital for Sick Children

Mr C Miss C's father

## **Glossary of terms**

Adrenaline auto injectors A medical device designed to deliver a single

dose of adrenaline

Anaphylaxis A severe form of allergic reaction to triggers

such as peanuts, foods, drugs, insect bites or

stings

Antihistamine A type of medicine that is often used to treat

allergic health conditions

Atopic A state of sensitivity to common antigens such

as pollen, food, and insect bites

EpiPen An auto injector of adrenaline

Lactose intolerance The inability to metabolize lactose, a sugar

found in milk and other dairy products

Radioallergosorbent (RAST)

Test

This is a blood test used to determine what a

person is allergic to