

Scottish Parliament Region: North East Scotland

Case 201004359: Grampian NHS Board

Summary of Investigation

Category

Health: Community and District Nurses and Midwives; communication, staff attitude, dignity, confidentiality; complaints handling

Overview

The complainant (Mrs C) was unhappy with the support given to her son (Master A) by a District Nursing Team (DNT), from January to June 2010. She was also unhappy with Grampian NHS Board (the Board)'s handling of her complaint. Master A, who was five years old at the time of the events complained about, was diagnosed with Type 1 diabetes in August 2006. He had a history of asthma, allergies and eczema.

Specific complaints and conclusions

The complaints which have been investigated are that the Board:

- (a) gave Master A instructions on self-administering insulin without Mrs C's consent or knowledge, or that of Master A's Paediatric Diabetes Care Team (*upheld*); and
- (b) failed to handle Mrs C's complaint properly (*upheld*).

Redress and recommendations

The Ombudsman recommends that the Board:

| | <i>Completion date</i> |
|--|------------------------|
| (i) apologise to Mrs C for the misunderstanding and confusion caused by the DNT's poor record-keeping; | 18 January 2012 |
| (ii) obtain signed consent from parents/carers where healthcare staff want a child to self-administer insulin; | 21 March 2012 |
| (iii) look into having a single named point of contact for parents/carers in relation to all of a child's diabetes care and treatment; and | 21 March 2012 |
| (iv) review how complaints are dealt with by the Moray Community Health and Social Care Partnership, to | 21 March 2012 |

ensure that the Complaints Handling Procedures are followed.

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

Main Investigation Report

Introduction

1. The complainant (Mrs C) was unhappy with the support given to her son (Master A) by a District Nursing Team (DNT), from January to June 2010. She was also unhappy with Grampian NHS Board (the Board)'s handling of her complaint. Master A, who was five years old at the time of the events complained about, was diagnosed with Type 1 diabetes in August 2006. He had a history of asthma, allergies and eczema.

2. The complaints from Mrs C which I have investigated are that the Board:
- (a) gave Master A instructions on self-administering insulin without Mrs C's consent or knowledge, or that of Master A's Paediatric Diabetes Care Team (PDCT); and
 - (b) failed to handle Mrs C's complaint properly.

Investigation

3. The investigation of Mrs C's complaint involved reviewing the documentation provided by her, and making three enquiries of the Board and reviewing the documentation provided by them. In addition, my complaints reviewer sought the view of a nursing 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 Board were given an opportunity to comment on a draft of this report.

(a) The Board gave Master A instructions on self-administering insulin without Mrs C's consent or knowledge, or that of Master A's PDCT

5. Mrs C complained that the DNT instructed Master A how to self-administer insulin injections during lunchtimes at school. She said that a Diabetes Specialist Nurse (Nurse 1) gave her advice that Master A should not self-administer insulin at his age and stage of development. In an email to Mrs C on 18 December 2009, Nurse 1 said that, in speaking to the DNT Leader (Nurse 2), Nurse 1 said:

'I also said that there is no way he could do his own injections tomorrow, next week, next month! ... After talking to [Nurse 2] I understand where he is coming from in a health aspect.'

6. Mrs C said DNT staff involvement was discussed at length between her and Nurse 2, and a care plan was put in place. DNT staff were to attend Master A's school each lunchtime to administer an insulin injection, which would be witnessed by a school auxiliary, with the aim of eventually having the school auxiliaries take over responsibility from DNT staff. Following a telephone call with Nurse 1 on 16 February 2010, Mrs C discussed Master A's care with Nurse 2. Nurse 1 emailed Mrs C on 19 February 2010 to say that Nurse 2 had confirmed that Master A was under no pressure to self-administer, but he wanted to do it, and there were days when he had done it. However, Nurse 1 said she reiterated to Nurse 2 the important aspects of supervising and assisting Master A. In May 2010, Mrs C discovered that Master A was regularly self-administering insulin injections while being supervised by a member of DNT staff and a school auxiliary. Mrs C emailed Nurse 1 about her concerns on 13 May 2010 and asked:

'Why are nurses keeping on with [Master A] doing his injection when they have been told not to.'

7. Mrs C was concerned about this because: she had not been told about it; and, in her view, Master A's technique was not correct and he had become confused about his diabetes care. Mrs C suspected a decision had been taken at 'a higher level' to train Master A to self-administer insulin injections. Mrs C told my office that Master A's care plan was a true record of informal conversations in December 2009 between her and Nurse 2, which took place while walking through Master A's school, but she did not realise they were being used to construct a care plan for Master A.

8. In responding to Mrs C's complaint, in a letter of 26 October 2010, the Board said they had no written or verbal instruction from Mrs C about Master A's self-administration of insulin. They also said that Mrs C discussed with Nurse 2 the situation of Master A becoming more involved with dialling up the dose of insulin in his insulin pen and getting him more involved in the care of his diabetes, which Mrs C agreed to. The Board said it appeared that communication between Mrs C and Nurse 2 had been misunderstood, as during the discussion the DNT understood Mrs C was giving them permission to progress slowly developing supported self-management of Master A's diabetes. The Board referred to the care plan for Master A, and said that there was no instruction from someone at 'a higher level' which influenced this.

9. Mrs C was not satisfied with the Board's response and wrote again on 28 October 2010. She was grateful for clarification that the DNT were not instructed by someone at 'a higher level'. However, she questioned the Board's view that there had been a misunderstanding, as she said Nurse 1 agreed with her that Master A should not self-administer; therefore, Nurse 2 also must have misunderstood, or even ignored, Nurse 1, and there was no mention of this in the Board's response. Mrs C also felt the Board did not address her concerns about psychological issues Master A was dealing with around being taught to self-administer. In addition, Mrs C asked for a copy of Master A's care plan.

10. In responding to Mrs C, in a letter of 10 December 2010, the Board said they understood that she had been informed from the start of the intention of involving Master A in his care, and they also understood that she made no issue of this. They said the DNT took Nurse 1's advice and that all parties, including Mrs C, were aware of how Master A's self-management programme had been progressing. In terms of psychological issues, the Board said they were not aware of any, and that Mrs C had declined the offer of support from the psychology service attached to the PDCT. The Board also said it had come to their attention that a member of their staff was feeling vulnerable and undermined because of Mrs C's behaviour, and the Board would investigate this matter and get back in touch with her.

11. In two emails of 14 December 2010 to the Board, Mrs C disputed their account of her knowledge of the way they were dealing with Master A's care, and said she did not recall being offered access to the psychology service. Mrs C said the Board's account of her knowing what was going on with Master A's care was a contradiction of their previous letter, in which they said there had been a misunderstanding between her and Nurse 2. In addition, Mrs C again asked for a copy of Master A's care plan. The Board responded in a letter dated 20 December 2010. They said they understood that, following Mrs C's communication in December 2009, Master A was not ready to self-administer. However, the DNT understood Mrs C was giving them permission to progress slowly developing supported self-management of Master A's diabetes, taking into consideration his age and stage of development. Therefore, it was not until 3 February 2010 that Master A started to handle the insulin pen. The Board enclosed a copy of Master A's 'initial' care plan. Mrs C felt this implied there were further plans.

12. In responding to my office's enquiries, the Board said the DNT did not set out to mislead Mrs C, and felt they had agreed that Master A would be supported to become slowly involved in management of his diabetes care. The DNT were not aware they did not have Mrs C's permission to progress with Master A's education in his care to self-administration. The Board also said there was no explicit conversation that Master A's gradual involvement in his care would lead to self-administration over time, and that the DNT had learnt from this experience and recognised the need to be specific in such discussion with parents or carers in future. The Board said it had been reiterated that discussions regarding care should be documented in the nursing records. The Board's view was that staff had not acted inappropriately or incorrectly regarding any aspect of Master A's diabetes care. In relation to Master A's care plan, the Board said the initial care plan was not updated as it remained relevant to Master A's care for the period the DNT were involved.

Advice received

13. The Adviser said there was evidence that showed who took the decision to train Master A to self-administer insulin, in the care plan drawn up by Nurse 2, dated 12 January 2010. This document stated: 'Allow [Master A] to become involved in his care i.e. dialling up the appropriate dosage of insulin under supervision etc'. The Adviser said she would have expected the care plan to be more explicit about the level of involvement expected of Master A and how that would be communicated to and agreed with Mrs C.

14. The Adviser said she would not have expected there to have been formal signed consent for Master A being shown by the DNT how to self-administer insulin injections. However, the Adviser said the care plan should have recorded what was agreed. This was particularly important when care was shared between a number of agencies including the school health team, the DNT, the PDCT, and Master A's GP. The Adviser said that clinical records should demonstrate the patient at the heart of the care plan and, as Master A was a young child, his next of kin should have been involved in all aspects of the decision making process. The Adviser referred to the Nursing and Midwifery Council Code: Standards of conduct, performance and ethics for nurses and midwives (the NMC Code). The NMC Code stated that nurses must keep their colleagues informed when they are sharing the care of others; and they must keep clear and accurate records of the discussions they have, the assessments they make, the treatment and medicines they give, and how effective these have been.

15. The Adviser said, in the context of the health sector, there were no specific regulations or guidelines in relation to consent for insulin administration. The key issues would be ensuring that children and young people were supported via inclusive and child centred healthcare. The Royal College of Nursing in their guidance, Supporting children and young people with diabetes, stressed the importance of individualised, accessible and agreed care plans:

'... care plans should be formulated jointly by the child or young person, parents/carers, community nurse or paediatric diabetes specialist nurse, and school nurse, and agreed by a designated person – usually the head teacher or special educational needs coordinator ... within the school or early years setting ...

the care plan should be universally available to all school personnel. It should be signed off by a paediatric diabetes nurse [in conjunction with the child's school nurse and/or community children's nurse, according to local service provision], parents/carers and school/nursery staff.'

16. The NMC provided guidance on consent which stated that:

'A person in the care of a nurse ... may demonstrate consent in a number of ways. If they agree to treatment and care, they may do so verbally, in writing or by implying (by co-operating) that they agree. Equally they may withdraw or refuse consent in the same way. Verbal consent, or consent by implication, will be enough in most cases. Written consent should be obtained if the treatment or care is risky, lengthy or complex. This written consent stands as a record that discussions have taken place and of the person's choice. If a person refuses treatment, making a written record of this is just as important. A record of the discussions and decisions should be made ...

Children under the age of 16 are generally considered to lack the capacity to consent or refuse treatment. The right to do so remains with the parents, or those with parental responsibility, unless the child is considered to have significant understanding and intelligence to make up his or her own mind about it.'

17. The Medical Protection Society in their fact sheet for medical professionals practising in Scotland titled Consent – children and young people, stated that:

'Very young children, and those who are not considered to be capable of making their own decisions, cannot either give or withhold consent. Those with parental responsibility need to make the decision on their behalf.'

18. The NHS Scotland document Consent – its your decision, included a section on 'How will I be asked to give my consent?', which stated:

'A doctor or another health professional may ask you to do something to show your consent. For example, a doctor may ask to examine your foot. If you take off your shoe, it shows you agree to this ...

Usually you will be asked to say whether you agree to the examination or treatment ...

If the examination or treatment is complicated, for example an operation, you may be asked to sign a form showing you agree to it.'

19. The Adviser said Nurse 1's records were of a high standard and provided evidence that Mrs C was well informed, involved in the care of Master A, and that Nurse 1 was supportive of Mrs C's need as a mother of a child living with diabetes. Overall, the Adviser said the records she examined suggested that staff caring for Master A were mindful of his and Mrs C's needs, that Master A was treated as an individual, and that healthcare staff tried to work with Master A's family to be as flexible and attentive as possible. This was in line with the NMC Code, which stated that nurses must treat people as individuals and respect their dignity. There did appear to have been a break down in communication in relation to the care plan agreed for Master A at lunchtimes, and this may have been due to the lack of written information. It appeared the majority of communication was informal and not recorded and, for that reason, the Adviser was critical of the DNT's record-keeping. However, in the Adviser's view, all the teams involved appeared to focus on the best interests of Master A, including encouraging him to become involved in the administration of his insulin. This principle was in keeping with Diabetes UK's Children's charter for diabetes. The Adviser concluded that a child of five would not be expected to have capacity and the parent would be required to give consent for treatment. However, the consent would not have to be written. In the Adviser's view, the crux of the complaint was about the lack of communication and agreement of care. The individualised care plan should have been more comprehensive and signed off by all parties, including Mrs C.

(a) Conclusion

20. I have seen no evidence of an instruction having been given at 'a higher level' for Master A to self-administer insulin. Mrs C appeared to accept this in her letter of 28 October 2010 to the Board. Based on the care plan, the

evidence shows that Nurse 2, as part of the DNT, took the decision to allow Master A to become more involved in his care.

21. The Board said Mrs C knew what was happening and she was in agreement with it. However, the Board did not have a record of this, and Mrs C's communication with Nurse 1 in February and May 2010 appears to show that she was not aware and was not in agreement; even though Mrs C's email of 25 March 2010 said the lunchtime arrangement had been working well for her and Master A.

22. At the time, there was no standing requirement for formal written consent. There appears to have been good communication between the DNT and the PDCT. However, the DNT's record-keeping, including the care plan and about their communication with Mrs C, was poor. This led to misunderstanding and confusion over Mrs C's apparent agreement to Master A self-administering, and over Mrs C's knowledge of how his care was progressing. The Board have acknowledged this by reminding staff of the need to be specific in discussion with parents or carers in future, and that such discussions should be documented in the nursing records. This was important given, as Master A's mother, Mrs C's significant role as a key partner with healthcare staff in Master A's care. The NMC publication Record keeping: Guidance for nurses and midwives, makes clear that good record-keeping is an integral part of nursing practice, and is essential to the provision of safe and effective care. It is not an optional extra to be fitted in if circumstances allow.

23. In my view, allowing a five-year-old child to self-administer insulin should require a record of detailed discussion with the parents/carers regarding the specifics of what will happen with their child, so that the parents/carers can make an informed decision on whether to give consent, and what they are consenting to. In this case, there were insufficient grounds for Mrs C to make a decision to allow Master A to self-administer insulin. Based on the available evidence and relevant guidance, the Board failed to have the care plan signed off by Mrs C, Nurse 1 and school staff. I am also of the view that, taking into account relevant guidance and the fact that Master A was only five years old at the time, Mrs C should have been asked specifically to give consent for him to self-administer insulin, which was a risky and lengthy treatment, and this should have been clearly recorded. There is also a lack of clarity on which individual in the Board had ownership of Master A's treatment, and I am of the view that much of this complaint, and the situation that led to it, could have been avoided

by having a single named point of contact for Mrs C in relation to all of Master A's diabetes care and treatment. Given the failings identified, I uphold this complaint.

(a) *Recommendations*

| | <i>Completion date</i> |
|--|------------------------|
| 24. I recommend that the Board: | |
| (i) apologise to Mrs C for the misunderstanding and confusion caused by the DNT's poor record-keeping; | 18 January 2012 |
| (ii) obtain signed consent from parents/carers where healthcare staff want a child to self-administer insulin; and | 21 March 2012 |
| (iii) look into having a single named point of contact for parents/carers in relation to all of a child's diabetes care and treatment. | 21 March 2012 |

(b) The Board failed to handle Mrs C's complaint properly

25. Mrs C found the Board's responses to her complaint to be inadequate and contradictory, and felt they attempted to intimidate her by suggesting they were to investigate her behaviour towards a member of Board staff. Mrs C said the Board did not admit they had been wrong or offer an apology, and they failed to adhere to their own timescales for dealing with her complaint. Mrs C complained that the Board avoided sending her a copy of Master A's care plan for over three months, even after numerous requests to do so, and there may have been other care plans which were not shared with her.

26. Mrs C first sent a formal complaint to the Board on 16 September 2010, but did not receive a response. She telephoned the Board on 24 September 2010 and was told that her complaint had been received. Mrs C emailed the Board on 28 September 2010 asking for a written acknowledgement and an explanation of why this had not happened. The Board responded by email the same day, confirming that a written acknowledgement was being sent to her, and that her complaint was being investigated. A formal acknowledgement dated 28 September 2010 was sent to Mrs C. As she had not received a response, Mrs C telephoned the Board and was told a letter had been sent to her. Mrs C said this was longer than the 20 working days set out in the complaints procedure, however, the Board said their start date was the receipt of her complaint on 28 September 2010. Mrs C received the Board's response in a letter dated 26 October 2010.

27. Mrs C was not satisfied with the response and wrote again on 28 October 2010, sending it by email. She emailed the Board on 1 November 2010 asking for confirmation of receipt, which she received by return email. However, as Mrs C did not receive a written acknowledgement, she telephoned the Board on 17 November 2010. Mrs C was told that her complaint had been received and was being dealt with. As she had not received a response, Mrs C telephoned the Board on 6 December 2010. Mrs C was telephoned by the Board on 8 December 2010, and they suggested holding a meeting to discuss Master A's care. However, Mrs C declined the offer as she had already met with Board staff in August 2010. Mrs C emailed the Board the same day to request an immediate response to her complaint. In an email reply, the Board apologised that her complaint had not been dealt with in line with their usual standards. The Board also wrote to Mrs C on the same day to apologise for the delay in responding. The Board responded to Mrs C's complaint on 10 December 2010. Mrs C was not happy with the Board's response and so emailed them twice on 14 December 2010. The Board responded in a letter dated 20 December 2010, which included a reference to contacting my office.

28. In responding to my office's enquiries, the Board said they were unable to ascertain why Master A's care plan was not sent to Mrs C until December 2010, but it would not have been intentional. In relation to the allegation made against Mrs C, the Board said that one staff member involved in Master A's care had raised how they felt during the initial investigation of the complaint. However, they subsequently refused to make any formal complaint and the matter was not taken further at that time. The Board also said they believed their Complaints Handling Procedures had been followed in this case. The Board's Complaints Handling Procedures stated that all written complaints were to be acknowledged within three working days. Formal responses were to be sent within 20 working days of the complaint being received by the Feedback Service, and that escalation measures were to be initiated when responses were not received within 20 working days.

Advice received

29. The Adviser said that, in her view, the Board made a reasonable attempt to resolve the issues. The Adviser noted the Board offered to meet with Mrs C at her home to discuss the issues. However, Mrs C responded stating that another meeting would not serve any purpose. In the Adviser's view, it was

unfortunate that a meeting did not take place as key elements of the complaint related to miscommunication, and further face-to-face communication could have been helpful in reaching a solution for Mrs C.

(b) Conclusion

30. Mrs C's initial complaint was unaccounted for, for about a week after she sent it to the Board, and it took the Board more than 20 working days to respond to Mrs C's second complaint.

31. In relation to the care plan, Mrs C first requested a copy on 28 October 2010, and made a second request on 14 December 2010. A copy was sent to Mrs C on 20 December 2010, seven weeks after her first request. The evidence does not support Mrs C's view that it took over three months for her to receive the care plan, or that she made numerous requests for it. Nevertheless, Mrs C's request for a copy of the care plan in her letter of 28 October 2010 was clear, and the Board should have sent a copy in response to that request. It is also clear from the clinical records that there was only one version of the care plan.

32. Although a member of Board staff was unhappy with Mrs C's alleged behaviour, I am of the view that it was not appropriate to have included a reference to this in their response to Mrs C's complaint. This matter should have been raised in a separate letter. It would also have been good practice for the Board to notify Mrs C formally that the matter was not being pursued.

33. I am also of the view that, although the Board did try to make a reasonable attempt to resolve the situation, taking into account the findings under complaint (a) in this report, their written responses were unclear. When read in succession, they appeared contradictory regarding Mrs C's apparent consent for, and awareness of, Master A's self-management programme. Taking all of these issues into account, on balance, I uphold this complaint.

(b) Recommendation

34. I recommend that the Board:

Completion date

- (i) review how complaints are dealt with by the Moray Community Health and Social Care Partnership, to ensure that the Complaints Handling Procedures are followed.

21 March 2012

35. The Board have accepted the recommendations and will act on them accordingly. The Ombudsman asks that the Board notify him when the recommendations have been implemented.

Explanation of abbreviations used

| | |
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| Mrs C | The complainant |
| Master A | The complainant's son |
| DNT | District Nursing Team |
| The Board | Grampian NHS Board |
| PDCT | Paediatric Diabetes Care Team |
| The Adviser | A nursing adviser to the Ombudsman |
| Nurse 1 | A Diabetes Specialist Nurse |
| Nurse 2 | The DNT Leader |
| The NMC Code | The Nursing and Midwifery Council Code: Standards of conduct, performance and ethics for nurses and midwives |

Glossary of terms

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|-------------|--|
| Asthma | Asthma is a long-term condition that can cause a cough, wheezing and breathlessness, caused by inflammation of the airways. The severity of the symptoms varies from person to person |
| Diabetes | Diabetes is a long-term condition caused by too much glucose, a type of sugar, in the blood. Type 1 diabetes occurs when the body produces no insulin. Without insulin, the body is unable to break down glucose in food into energy |
| Dialling up | Selecting the dose of insulin to be injected |
| Eczema | A group of inflammatory skin conditions that can affect people of all ages. Symptoms include itching, redness and rash, and dry and thickened or flaky or scaly skin |
| Insulin | A hormone produced by the pancreas |
| Insulin pen | An device, which looks like a large pen, and is made up of an insulin cartridge, a dial to measure the dose of insulin, and a needle to deliver the dose |

List of legislation and policies considered

Children's charter for diabetes (Diabetes UK; May 2010)

The code: Standards of conduct, performance and ethics for nurses and midwives (Nursing and Midwifery Council; approved December 2007; implemented May 2008; redesigned April 2010)

Complaints Handling Procedure (Grampian NHS Board; 2nd edition February 2010)

Consent (Nursing and Midwifery Council; April 2008)

Consent – children and young people (Medical Protection Society; September 2009)

Consent – it's your decision; How you should be involved in decisions about your health care and treatment (NHS Scotland; August 2010)

Record keeping: Guidance for nurses and midwives (Nursing and Midwifery Council; published July 2009, implemented August 2009, redesigned April 2010)

Supporting children and young people with diabetes; Guidance for nurses in schools and early years settings (Royal College of Nursing; August 2009)