Scottish Parliament Region: North East Scotland

Case 200602439: Tayside NHS Board

Summary of Investigation

Category

Health: Communication; staff attitude; dignity; confidentiality

Overview

The complainant (Mrs C) claimed that staff within Tayside NHS Board (the Board), in particular, a Diabetic Specialist Nurse (Nurse 1), failed to provide adequate advice and support in relation to her husband (Mr C)'s condition.

Specific complaint and conclusion

The complaint which has been investigated is that there was a lack of information, and misleading information, about Type 1 diabetes provided to Mr and Mrs C at the time of, and following, Mr C's diagnosis (*partially upheld)*.

Redress and recommendations

The Ombudsman recommends that the Board:

(i) apologise in writing to Mr and Mrs C for the deficiencies in record-keeping and the lack of clarity of communication; and

(ii) consider introducing a protocol for post-discharge care of patients with diabetes to reduce the potential for confusion as illustrated by this complaint, in particular, in instances where more than one Board is involved in patient care.

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

Main Investigation Report

Introduction

1. On 6 November 2006 the Ombudsman received a complaint from a member of the public (Mrs C) against Tayside NHS Board (the Board) claiming that staff within the Board, in particular, a Diabetic Specialist Nurse (Nurse 1), failed to provide adequate advice and support in relation to her husband (Mr C)'s condition.

2. The complaint from Mrs C which I have investigated is that there was a lack of information, and misleading information, about Type 1 diabetes provided to Mr C and Mrs C at the time of, and following, Mr C's diagnosis.

Investigation

3. I was assisted in the investigation by one of the Ombudsman's medical advisers (the Adviser), an experienced senior nurse. We considered the information provided by Mrs C and the Board, which included comments on the complaint from both parties as well as correspondence between Mrs C and the Board and Mr C's clinical records. The purpose of the investigation was to use this information to establish the actions of staff within the Board in response to Mr C's diagnosis of Type 1 diabetes and to consider whether those actions fell within the range of what would be considered to be reasonable practice, in the circumstances.

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.

Complaint: There was a lack of information, and misleading information, about Type 1 diabetes provided to Mr C and Mrs C at the time of, and following, Mr C's diagnosis

5. Mr C was diagnosed with cancer of the pancreas and had surgery in August 2005 and January 2006. After this first operation he developed a form of Type 1 diabetes and began taking insulin. Mrs C had Type 2 diabetes. Mr C was subsequently diagnosed with terminal cancer.

6. Mrs C wrote to the Practice Manager at her GP Practice (the Practice) on 21 August 2006 (Mrs C forwarded the complaint to the Board on 29 August 2006) to complain about Nurse 1, who had been dealing with her

husband. Mrs C said that Nurse 1 did not provide her or her husband with information relating to the control, treatment and care of diabetes, that she had failed to do so since Mr C's surgery, and they had not seen Nurse 1 since January 2006. Mrs C said that she became aware of this apparent deficiency after attending an education meeting for diabetics. Mrs C listed eight specific points about information that was not provided. Mrs C added that Nurse 1 had advised Mr C, at a home visit within two weeks of his January 2006 surgery, that he would not be able to return to work as he was insulin dependent. However, Mrs C said that her husband was subsequently told by his employer that 'his job is being held open for his return' subject to passing a company medical examination. Mrs C also complained that a Dietician (the Dietician) assigned to advise Mr C had not been seen since February/March 2006. In summary, Mrs C said:

> '… where [Mr C's] diabetes is concerned we have, in a way, been left to our own devices. I feel that as [Mr C] and I needed ALL the relevant information/help regarding his diabetes we could receive then I am justified in making my complaint as it was not forthcoming together with lack of communication between Dietician, [Nurse 1] and ourselves.'

7. The Board acknowledged Mrs C's letter on 30 August 2006 and advised that an investigation was under way. The Board's substantive response, from the Director of Nursing, Single Delivery Unit (the Director), was sent to Mrs C on 14 September 2006. The Director responded to each of the points that Mrs C had raised in her complaint letter. In relation to an appointment for Mr C at a diabetic clinic, the Director advised that Nurse 1 contacted the Practice:

> '… in May 2006 for a referral letter to be sent to the Diabetic Consultant to arrange an appointment at the clinic. I understand that this has now been arranged.'

In relation to foot care, the Director advised that 'staff recall discussing the basic information required' and supplemented this with written advice in an information pack, and that the pack also included contact details for diabetic nursing staff. The Director said that the information pack would also have provided information dealing with driving, and related matters, for diabetics. In relation to eye screening, chiropody and liver and kidney function, the Director advised:

> '… Patients are referred to the Eye Screening Service though the GP service when registered as Diabetic … Patients are not automatically referred to the Chiropody service unless this is indicated … Any follow up

for liver and kidney function is carried out at the discretion of the GP if the results of tests indicate this is required.'

In terms of Nurse 1's alleged comments to Mr C at the home visit about not returning to work, the Director said:

> '… [Nurse 1] would wish to apologise that she has caused such upset, as this would never have been her intention.'

The Director went on to say that Nurse 1 would not normally have mentioned employment matters at such an early stage after surgery and diagnosis, but as Mr and Mrs C had raised the issue she felt she had to deal with it as it was:

> '… important that you and your husband's thoughts on this were realistic, and that you were both in possession of the full facts. She recommended discussions with [Mr C's] employers in relation to this. She regrets that this has caused such distress for you both.'

The Director also said that she was sorry that Mr and Mrs C felt unsupported by the Dietician, but that her understanding was that at their last contact, a telephone conversation in April 2006:

> '… progress was very satisfactory and additional supplementary nutrition was no longer required. It was agreed at this time that you would contact the service again when [Mr C's] chemotherapy was completed or earlier if required.'

The Director concluded by saying:

> 'Clearly you both feel you have been let down by the service and this is regrettable. The Diabetic Specialist Nurses try, wherever possible, to support patients and their families in managing their Diabetes and I am sorry you feel this has not been your experience. I understand that you have contact details for the staff involved in your care and would encourage you to use them whenever you require assistance.'

8. Mrs C was not satisfied with the Director's response on behalf of the Board and wrote to the Ombudsman on 6 November 2006. As well as rehearsing the points made in her complaint letter to the Board, Mrs C also said that Nurse 1 did not contact the Practice for a referral for a diabetic clinic appointment until May 2006 and the appointment did not take place until 16 October 2006. Mrs C was adamant that neither she nor Mr C received an information pack from Nurse 1 or other staff, that Mrs C made an eye screening appointment for Mr C

in July 2006, and that the Practice Nurse made appointments for Mr C to attend the Chiropodist and for liver and kidney tests after being told they had not yet been done. Mrs C said that she wanted Nurse 1 to be retrained or to have a more professional attitude and to take into consideration individual patient's needs.

9. In response to my enquiries, the Board provided Mr C's medical records, a copy of the information pack normally provided to patients diagnosed with diabetes, and answers to specific questions. SCI-DC (diabetes database) shows that there was contact between Diabetic Specialist Nurses, including Nurse 1 and another Diabetic Specialist Nurse (Nurse 2), and Mr and Mrs C between August 2005 and April 2007, with fifteen entries from August 2005 to February 2006, no entries from March 2006 to September 2006, and seven entries from October 2006 to April 2007. The records also included a sheet outlining the education given to Mr C by Diabetic Specialist Nurses. There are three entries, two for Nurse 1 regarding insulin adjustment on 9 September 2005 and 26 September 2005, and one for Nurse 2 regarding a range of topics, on an unknown date.

10. The records also show that Mr C was referred by the Diabetic Specialist Nursing Unit to his local Nutrition and Dietetic Service on 29 August 2005, and that he was given dietary education by the service on four occasions: 29 August 2005, 18 January 2006, 16 October 2006 and 23 April 2007. There was also contact from the Dietician with Mr or Mrs C on 30 January 2006, 14 February 2006, 15 March 2006, and 25 April 2006. On this last occasion, the Dietician spoke to Mrs C by telephone and recorded in her notes:

> '[Mrs C] positive re progress with food intake … awaiting diabetic clinic appointment – patient to discuss with GP.'

On 16 October 2006 at the dietary education session, the Dietician noted that she issued Mr C with written information and that:

> '[Mr C] reports that he is happy with his weight at present – almost his 'normal' weight … asked him if he had any further questions. Did not wish further appointment at present.'

On 23 April 2007 at the dietary education session, the Dietician noted that she issued further written information to Mr C and that his:

> 'Motivation low. He did not agree with any changes he could make … no follow-up at present.'

11. The Practice wrote a referral letter to the Diabetic Clinic on 28 August 2006. The letter said:

> 'I have discussed referral to yourself regarding his diabetic care a few times over the past year, as has [Nurse 1] but until now [Mr C] did not want to be referred for hospital follow up. I think now that his [cancer] treatment is all behind him he has changed his mind and would now like to be seen by yourselves … he has not had any HGB A1C done, because he was not keen on this monitoring during his treatment phase. He has an appointment with our Practice Nurse this week to have his routine diabetic bloods done …'

The medical records also confirm that Mr C had an appointment with a Diabetic Consultant (the Consultant) on 16 October 2006, and in a follow-up letter from the Consultant to the Practice on 30 October 2006, the Consultant said:

> '[Mr C's] diabetic control is extremely good which is a credit to himself. I thought that it might be prudent to link him up with [Nurse 2], one of our diabetes specialist nurses so that he has access to advice if it is necessary.'

12. In responding to the complaint in September 2006, Nurse 1 advised the Board's complaints staff that Mr C was:

> '… able and encouraged to contact the [Diabetic Specialist Nursing Unit] if he had problems or required advice.'

Nurse 1 provided the information that went into the Director's letter to Mrs C of 14 September 2006, that matters relating to foot care, driving, eye screening, liver and kidney function had all been dealt with, as had the issue of the potential for Mr C to return to work (see paragraph 7). Nurse 1 went on to say that Mr C had received diabetes education when he started taking insulin after his surgery, and concluded her remarks on the complaint by saying that:

> 'On reflection, and taking into account … other medical issues in [Mr C]'s life on commencing insulin, it may have been beneficial for [Mr C] to receive an update session covering the points raised in this complaint. There is a lot of information given at the time of commencing insulin … He was invited to education sessions but refused …'

Dietician 1, in her response to the complaint, outlined for the Board's complaints staff the dates on which she had contact with Mr and Mrs C, beginning with her

first home visit on 29 August 2005 at which time she said that 'dietary education was commenced and written literature given'. She listed other instances of contact through to 25 April 2006, saying:

> 'Progress very satisfactory and no longer requiring nutritional support. It was agreed that [Mr C] would telephone on completion of his treatment … scheduled for mid/end June [2006], or earlier if required. There has been no contact made by [Mr or Mrs C].'

In their internal complaint response summary on 14 September 2006, the Board said that Mrs C's complaint was 'partly upheld' as there was 'some perceived lack of communication'. The summary noted that an apology and explanation had been given to Mrs C, along with an assurance that action would be taken. The action taken was noted as 'Discussed with staff concerned'.

13. In her response to my enquiries, Mrs C reiterated that neither she nor Mr C received a written information pack. I asked Mrs C about Nurse 1's comment that Mr C was invited to education sessions but refused. Mrs C said that:

> 'No such invitation was made to my husband. If it had been he would have taken the invitation up.'

Mrs C went on to contrast her experience with that of her husband:

> 'When I was diagnosed as Type 2 Diabetic I was informed of education sessions … and I requested that my husband be allowed to attend, this was granted and he attended with me, one year after his original diagnosis.'

14. In their response to my enquiries, the Board said:

> 'Strictly speaking, [Mr C] does not have classical type 1 diabetes … However, from a practical standpoint his condition means that [Mr C] is prone to the same complications as patients who have type 1 diabetes … therefore his education has been in keeping with that which is given to patients who have type 1 diabetes.'

The Board also said that they do not have a formal written protocol for care following discharge, and outlined their usual practice for diabetes patient follow-up. They pointed out that:

> '… in [Mr C's] case, his initial diagnosis did not take place within Tayside therefore his initial care did not follow our usual pattern.'

In terms of the Diabetic Specialist Nurse and Dietician records, in relation to contact with Mr and Mrs C, the Board said that it was not usual for such records to be jointly agreed between the patient and the clinician. The Board explained that the information pack referred to in their response to Mrs C was the 'Insulin Start Pack' and they enclosed a copy for my information. They said that the pack was colour-coded to be given to patients over a period of time:

> 'The white pages are discussed in the first instance and when the patient is confident and ready to move on to the next stage the yellow pages are covered then the green pages. The stages when the patient moves through this programme are determined by the patient and are different for all patients. I can find no formal record that this pack was given to [Mr C].'

The Board confirmed that Mr C was registered on SCI-DC on 24 August 2005 after the first contact with a Diabetes Specialist Nurse within the Board area was recorded. The Board also explained that Mr C's foot care was dealt with in line with the Scottish Intercollegiate Guidelines Network (SIGN) 55: Management of Diabetes, in that he was assessed as normal and, therefore, did not require referral to a Chiropody/Podiatry service. The Board also referred to SIGN 55 in relation to liver and kidney function, and explained that kidney function tests are normally done annually but that liver function tests are not part of a patient's routine annual review of diabetes. The Board concluded by saying that :

> '[Mr C] was given verbal encouragement and education at each session with all the clinicians he saw. This education would have been further supported by the education sessions however, [Mr C] declined this offer.'

The copies of written information provided to me by the Board included comprehensive information on all of the areas noted by Mrs C in her complaint.

15. The Adviser's view was that to an extent there had been a breakdown in the relationship between Mr and Mrs C and Nurse 1 and the Dietician, given Mrs C's comments, which related to broader issues of the need for trust between patients and National Health Service staff. The Adviser also noted and agreed with Nurse 1's comments that it would have been advisable to reinforce the relevant messages to Mr C about living with and managing Type 1 diabetes. However, the Adviser concluded that there was nothing in the records to conclude that Nurse 1 was not competent in carrying out her job or had failed in relation to her care for Mr C. The Adviser also noted the issue of a protocol for care for new diabetic patients after discharge from hospital.

Conclusion

16. It is clear that this was and, given current circumstances, continues to be a very difficult and distressing time for Mr and Mrs C. Mrs C claimed that neither she nor her husband were provided with information relating to the control, treatment and care of diabetes at the time of, or after, Mr C's diagnosis and she contrasted her husband's experience with her own. She was also unhappy about one particular incident during a visit to their home in January 2006 when Nurse 1 discussed Mr C's prospects for returning to work. In relation to that incident, I cannot reach a finding on this specific point as there were no independent witnesses to corroborate what was said by whom, and Mrs C's and Nurse 1's accounts differ, though it should be noted that in responding to the complaint Nurse 1 offered an apology for any misunderstanding and the Director offered an apology for any distress caused.

17. There are clear differences of opinion between Mrs C and the Board in relation to the above incident, on whether or not Mr C was given written information on managing diabetes, and whether or not Mr C was offered and refused education sessions. It is regrettable that there is no written record of Mr C being given the insulin start pack or that he was given the colour-coded pages at the appropriate times, and the Board have confirmed that they can find no such records. However, there are records of Mr C being given written information in relation to diet and nutrition. The Board have outlined how, in their view, Mr C's care followed the SIGN 55 guidelines, where appropriate, given the clinical assessment of his condition, and the Adviser's view supports this. However, the Board also acknowledged that there were issues with the communication between Board staff and Mr and Mrs C, as their decision to partly uphold Mrs C's complaint demonstrates, and the Board expressed their regret that Mr and Mrs C felt let down by the service. It is important to note that the Board's records show that Mr C did not wish to be referred to the clinic earlier in 2006 and had refused education sessions, in contrast to Mrs C's assertions that this was not the case.

18. There are problems with the records kept by the Board, which has made it difficult to find corroboration for the Board's view of the support that was offered to Mr and Mrs C. The record of Mr C's visit to the diabetic clinic in October 2006 shows that he was managing his diabetes well, but I cannot determine whether or nor this was wholly due to the support from Board staff or due to Mrs C's apparent intervention by having her husband attend the

education sessions she was using for her Type 2 diabetes. However, despite omissions in the records, in that not all entries state when, where, how and by whom education was given to Mr C, it appears that he was offered some support and diabetic education. Entries in SCI-DC were not always clear on who was making them, or if entries were reporting other clinicians' comments. In assessing the specific role of the Dietician, I can find no problems with the records, which support her view of events. With regard to the role of Nurse 1 I must concur with the view of the Adviser, but the incomplete records do suggest that there were issues regarding clarity of communication, which Nurse 1 had reflected on herself. There is certainly a lot of evidence of contact between staff and Mr and Mrs C. However, it must also be said that patients must take responsibility for contacting Board staff if they feel that they need further advice.

19. Given the deficiencies in record-keeping, which appear to have contributed to a lack of clarity in communication, and Nurse 1's own reflection on the benefit of an education update for Mr C, balanced against the available records that do show some education and advice was provided to Mr C, that there are no issues with the Dietician's role, and the view of the Adviser, I partially uphold this complaint.

20. The proposed version of this report had three recommendations. The Board informed me that they have already acted to resolve one of the recommendations. The original recommendation (ii) was that the Board:

> 'remind staff working in the Diabetic Specialist Nursing Unit of the importance of complete records including names, dates, locations and reasons why decisions were taken or what information was passed to patients, and confirm how and when this has been done.'

The Board told me that this report has been discussed with the Diabetes Specialist Nursing Team in order to reiterate the importance of accurate and complete communication, and that this formed part of the Board's ongoing commitment across the whole organisation to, through audit and review, ensure the standard of record-keeping is improved and this improvement is maintained.

Recommendations

21. The Ombudsman recommends that the Board:

(i) apologise in writing to Mr and Mrs C for the deficiencies in record-keeping and the lack of clarity of communication; and

(ii) consider introducing a protocol for post-discharge care of patients with diabetes to reduce the potential for confusion as illustrated by this complaint, in particular, in instances where more than one Board is involved in patient care.

22. In relation to recommendation (ii), the Board informed me that improvements to working practices have been made and that they are happy to consider a range of options to make certain that the care, on discharge, of patients suffering from Diabetes is consistent, irrespective of which Board is responsible for the care of the patient.

23. 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 implemented.

Annex 1

Explanation of abbreviations used

Mrs C	The complainant
The Board	Tayside NHS Board
Nurse 1	A Diabetic Specialist Nurse assigned to advise Mr C
Mr C	The aggrieved, Mrs C's husband
The Adviser	One of the Ombudsman's medical advisers
The Practice	Mr and Mrs C's GP Practice
The Dietician	A dietician assigned to advise Mr C
The Director	Director of Nursing, Single Delivery Unit
SCI-DC	Scottish Care Information Diabetes Collaboration. The diabetes database used by Board staff
Nurse 2	A Diabetic Specialist Nurse who saw Mr C
The Consultant	Mr C's Diabetic Consultant
SIGN	Scottish Intercollegiate Guidelines Network

Glossary of terms

Diabetes	Diabetes is a chronic condition caused by too much glucose (sugar) in the blood. The blood sugar level can be too high if the body does not make enough of the hormone insulin. Insulin is produced by the pancreas (a gland behind the stomach) and moves glucose out of the blood and into cells, where it is broken down to produce energy. If diabetes is not treated it can cause long-term health problems because the high glucose levels in the blood damage the blood vessels. There are two types of diabetes.
HGB A1C	A blood test for Hemoglobin A1c, or Glycosylated Hemoglobin, to monitor the average plasma glucose (blood sugar) concentration over prolonged periods of time.
Type 1 diabetes	Also known as insulin-dependent diabetes. In type 1 diabetes, the body produces little or no insulin. Someone with this type of diabetes needs treatment for the rest of their life.
Type 2 diabetes	Also known as non-insulin dependent diabetes. In type 2 diabetes, the body does not make enough insulin, or cannot use insulin properly. This is called insulin resistance.

Annex 3

List of legislation and policies considered

SIGN 55: Management of Diabetes