Scottish Parliament Region: Lothian

Case 201300063: Lothian NHS Board

Summary of Investigation

Category

Health: Hospital; Oncology

Overview

The complainant (Mrs C) raised a number of concerns that treatment decisions, communication and level of support by healthcare professionals were not of a reasonable standard following her husband (Mr C)'s cancer diagnosis.

Specific complaints and conclusions

The complaints which have been investigated are that Lothian NHS Board (the Board):

(a) failed to provide a reasonable standard of care and treatment to Mr C following his cancer diagnosis (*upheld*); and

(b) failed to clearly communicate with Mrs C regarding Mr C's prognosis and provide an adequate level of support to help Mrs C cope with his illness (*upheld*).

Redress and recommendations

The Ombudsman recommends that the Board:	*Completion date*
(i) provide a plan detailing the changes they have made to: prevent a recurrence of failing to store medical records securely; and meet Scottish government emergency department targets;	30 May 2014
(ii) confirm the learning gained as a consequence of this complaint and provide details of how this has been passed to and considered by relevant staff;	30 May 2014
(iii) provide a plan detailing the changes they have made to prevent a recurrence of failings in their communication with Mr and Mrs C regarding chemotherapy treatment;	30 May 2014
(iv) ensure their responses to complaints are meaningful and appropriate in tone, use of	30 May 2014

language etc; and

(v) further apologise to Mrs C for the failures identified and offer to meet her to discuss in more detail the response she received to her complaint. 30 May 2014

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

Main Investigation Report

Introduction

1. Mr C was seen by an oncologist (the Consultant) at the Western General Hospital (the Hospital) on 30 October 2012. He was subsequently diagnosed with lung cancer. (He was also diabetic and had heart disease.) Mr and Mrs C agreed to chemotherapy treatment believing this would give him up to a year of life. However, he deteriorated significantly after the first course of chemotherapy treatment and he subsequently had several admissions to the Hospital. At Mr C's out-patient appointment on 8 January 2013, the Consultant admitted him again to the Hospital. Mr C was taken by a porter to an assessment ward and he waited on a trolley for a bed. After seven to eight hours, Mrs C became very concerned because they had no diabetes medication or food and so she approached staff on a number of occasions asking for insulin and some bread. Mrs C said that staff told her they did not have any food or insulin and there were no beds. Eventually, staff provided some insulin. Around 23:30, Mr C was given a room in another assessment ward, which was cold and had no heating. He was eventually moved to an oncology ward, but was not offered further chemotherapy treatment. Shortly before his discharge on 16 January 2013, the Consultant told Mr and Mrs C that Mr C had around two weeks to live. Mr and Mrs C were shocked and grief stricken. Mr C was discharged home to the care of his medical practice that day. Sadly, he died shortly after, on 25 January 2013.

2. Mrs C complained that the treatment decisions in relation to chemotherapy were unreasonable and that the admission arrangements on 8 January 2013 when Mr C waited around 11 hours on a trolley for a bed was extremely distressing and unacceptable in light of Mr C's physical condition. Mrs C also complained that Lothian NHS Board (the Board) failed to communicate with them in a reasonable way about Mr C's prognosis. Finally, Mrs C was concerned about what she said was an unreasonable level of support provided to them particularly when he was discharged on 16 January 2013.

3. Mrs C complained to the Board by letter, which they received on 24 April 2013. The Board responded on 30 May 2013. Mrs C was unhappy with their response and brought her complaint to us on 10 June 2013. We agreed to investigate her complaint about the standard of care and treatment provided by the Board to Mr C following his cancer diagnosis.

4. The complaints from Mrs C which I have investigated are that the Board:

(a) failed to provide a reasonable standard of care and treatment to Mr C following his cancer diagnosis; and

(b) failed to clearly communicate with Mrs C regarding Mr C's prognosis and provide an adequate level of support to help Mrs C cope with his illness.

Investigation

5. My complaints reviewer examined a copy of Mr C's available medical records and the Board's complaint file in addition to the information Mrs C provided. When we asked the Board for a copy of Mr C's medical records, they sent a copy of the letters and notes that had been computerised saying that his medical and nursing notes could not be traced. The available records included copies of detailed discharge letters to Mr C's medical practice relating to all of Mr C's admissions to hospital. My complaints reviewer also obtained independent advice from advisers who specialise in oncology and nursing (the Medical Adviser and the Nursing Adviser respectively). The advisers considered that they were able to provide advice on the basis of the available records.

6. 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

7. Mr C was seen as an out-patient by the Consultant at the Hospital on 30 October 2012 with a seven month history of cough, increasing shortness of breath on exercise, difficulty in swallowing and right hip pain. He was subsequently diagnosed with lung cancer, which had spread to his liver. (He also had a complex medical history including diabetes and heart disease.) Mr C was admitted to the Hospital on 7 November 2012 with shortness of breath, reduced mobility and confusion. He was treated with intravenous antibiotics. Mr C then underwent chemotherapy treatment from 14 November 2012 until 16 November 2012, but his condition deteriorated significantly. On 26 November 2012, Mr C was admitted to the Hospital with light-headedness and hypoglycaemia, and tests showed a degree of renal injury. On 29 November 2012, Mr C was discharged, but was re-admitted on 10 December 2012 with breathing difficulties. He was once more hypoglycaemic and had a diabetic and cardiologist review. In light of his

temperature, he was prescribed antibiotics and was discharged on 17 December 2012.

8. At Mr C's out-patient appointment on 8 January 2013 with the Consultant, he was admitted again to the Hospital because his breathing difficulties had worsened. Around mid-day, Mr C was taken by a porter to an assessment ward and he waited on a trolley for a bed. At approximately 23:30, Mr C was given a room in another assessment ward. After five days on this ward, he was moved to a breast ward, then an oncology ward. Mr C was not offered further chemotherapy treatment. He was discharged on 16 January 2013 to the care of his medical practice and he died on 25 January 2013.

Relevant targets

9. Health improvement, efficiency, access to services and treatment (HEAT) targets introduced by the Scottish Government states that 98 percent of patients will wait less than four hours from arrival to admission, discharge or transfer for accident and emergency treatment.

(a) The Board failed to provide a reasonable standard of care and treatment to Mr C following his cancer diagnosis

10. Mrs C raised concerns about the Consultant's decision to treat Mr C with chemotherapy, which she believed caused his condition to deteriorate further, and that the treatment was subsequently withdrawn. Mrs C was also concerned about Mr C's admission to the Hospital on 8 January 2013 in that Mr C had to wait approximately 11 hours on a trolley before he was given a bed in a room, which she described as cold and sparse. During this period, Mr and Mrs C became distressed because they had no diabetes medication or food for him as the canteen was closed and Mrs C approached staff on a number of occasions outlining her concerns that Mr C would become hypoglycaemic, but Mrs C said staff told her that they had no food or insulin and there were no beds available. Eventually, Mrs C told staff that she would take Mr C home, and staff then provided some insulin and Mrs C's daughter managed to get something for Mr C to eat from the supermarket. Mrs C believed that staff failed to treat Mr C with dignity.

Board response

11. The Board said that Mr C was first seen by the Consultant in clinic on 30 October 2012 given his symptoms. He was diagnosed with extensive lung cancer including multiple liver metastasis (cancer had spread to the liver). The

prognosis of the disease untreated would be a few months at most. About half of patients would be expected to respond to chemotherapy with survival being prolonged by a few months, but there would be no long-term survivors and for the remainder, the prognosis would be unchanged. The Board explained that chemotherapy has a significant risk of side-effects and mortality in five to ten percent of patients. These risks would be increased for Mr C given his extensive medical conditions. The Consultant commenced chemotherapy treatment for Mr C on 14 November 2012, which was concluded on 16 November 2012.

12. The Board explained that the Consultant decided to determine at an out-patient appointment on 8 January 2013 whether further chemotherapy treatment was safe. When the Consultant saw Mr C then, he admitted Mr C to the Hospital given his breathing difficulties had worsened. Investigations suggested it was a progression of the cancer rather than heart failure. Given this was within two months of chemotherapy treatment, it suggested a disease that was resistant to treatment and an extremely poor prognosis. The Consultant agreed that chemotherapy probably did make things worse given Mr C's other medical conditions and the cancer's lack of sensitivity to chemotherapy, which could not have been foreseen. The Consultant met Mr and Mrs C on 14 January 2013 to discuss the possibility of hospice care given that prognosis was very short and for discharge home on 16 January 2013.

13. Finally, the Board apologised that Mr C had a ten hour wait on a trolley which did not meet the standard of care aimed for and also if the room he was admitted to was cold and had no heating.

Advice received

14. The Medical Adviser explained to my complaints reviewer that the type of cancer Mr C had (small cell lung cancer) was an aggressive one. At an extensive stage, it spreads to other organs; in Mr C's case, this was to the liver. Untreated, the survival of this type of cancer was an average of six weeks and with chemotherapy the average was eight to ten months. The treatment worked well in some cases, but not all and there was a significant risk of side-effects sometimes resulting in death that was well recognised particularly following the first cycle of treatment. There was no other treatment that either prolonged life or improved survival. Even when patients have other medical problems and were relatively frail, the nature of the disease warranted consideration of

chemotherapy. Mr C's medical records documented his other medical problems and stated that 'the aim [of chemotherapy] is to improve quality of life and hopefully extend with the treatment'. The Medical Adviser said that the decision to provide chemotherapy treatment in the first instance to Mr C was reasonable.

15. The Medical Adviser went on to say that following his first round of chemotherapy, Mr C's condition subsequently deteriorated and he was admitted to the Hospital with renal impairment at the end of November 2012. In December 2012, he was admitted to the Hospital again with heart failure and for diabetes control. His final admission to hospital was on 8 January 2013 as he was generally unwell and, as the disease was found to be progressing, further chemotherapy was not advised. The Medical Adviser said that if small cell lung cancer progressed in spite of chemotherapy, then the prognosis was very poor and there was no evidence that additional chemotherapy would help. Furthermore, Mr C's general condition had deteriorated significantly and he was deemed unfit for further treatment. The Board's decision not to provide a second round of chemotherapy treatment was, said the Medical Adviser, appropriate and reasonable.

16. In relation to end of life care, the Medical Adviser said that the discharge letter of 16 January 2013 indicated that Mr C's family believed he would manage satisfactorily at home and referred him to community palliative care. The Medical Adviser said that given the relevant agencies appeared to be involved, the Board provided a reasonable standard of care and treatment.

17. My complaints reviewer asked the Nursing Adviser whether it was reasonable that Mr C was left on a trolley for around 11 hours on admission to the Hospital on 8 January 2013. The Nursing Adviser said that the targets were introduced to address this issue and ensure that patients received optimal care in a hospital bed in an appropriate ward where staff were best placed to provide this. What happened to Mr C did not meet these standards. Furthermore, the Nursing Adviser went on to say that it was totally unacceptable that Mr C, who had lung cancer and insulin-dependent diabetes, had been left on a trolley for this length of time. Finally, the Nursing Adviser said that the care and treatment provided was also contrary to the Patient Charter, in relation to patients' rights to access to treatment and services appropriate to their needs and to be treated as individuals with dignity and respect.

(a) Conclusion

18. Mrs C complained that the Board failed to provide a reasonable standard of care and treatment to Mr C following his cancer diagnosis. Mrs C was very concerned about the decision to provide chemotherapy in the first instance given the significant adverse impact on Mr C's condition and then the subsequent decision not to provide further chemotherapy. However, the advice I have accepted is that the treatment decisions in relation to the provision of chemotherapy were reasonable. Having said that, there are issues around the communication of these decisions and I go on to address this under complaint (b).

19. Turning now to Mr C's admission to the Hospital on 8 January 2013 when he was left on a trolley for an unacceptable length of time, the Board acknowledged that this did not meet the standards required. Moreover, Mrs C said that during this time staff also failed to provide any food or insulin within a reasonable time. In the absence of nursing and medical notes, there is no evidence to contradict her account, which I find credible. Therefore, this was not just a failure to meet expected standards, which the Nursing Adviser said meant that Mr C was not assessed and treated in a timely manner, but also a failure to show care to Mr and Mrs C and treat Mr C with respect and dignity. This exacerbated what was already a very distressing situation given Mr C's serious and deteriorating condition. I am very critical of this. I am also very critical of the fact that the Board have been unable to provide me with Mr C's medical and nursing notes. Given the significance of these failures, I uphold the complaint. I am making recommendations to address the missing medical records and to ensure that there is no recurrence of the failings identified.

(a) Recommendations

20. I recommend that the Board:	*Completion date*
(i) provide a plan detailing the changes they have made to: prevent a recurrence of failing to store medical records securely; and meet Scottish government emergency department targets; and	30 May 2014
(ii) confirm the learning gained as a consequence of this complaint and provide details of how this has been passed to and considered by relevant staff.	30 May 2014

(b) The Board failed to clearly communicate with Mrs C regarding Mr C's prognosis and provide an adequate level of support to help Mrs C cope with his illness

21. Mrs C was concerned about the failures in communication by the Board about Mr C's prognosis in that she said they were led to believe that chemotherapy treatment would give Mr C up to one year of survival. They were, therefore, shocked and grief stricken when the Consultant told them that Mr C only had a few weeks left to live. Mrs C also asked if care equipment could be arranged so that Mr C could be properly cared for at home, but she said that the Consultant told them there was no point as it would be too late by the time it took to get the equipment. As a result, Mrs C was unhappy with the level of support provided.

Board response

22. The Board said that chemotherapy had a significant risk of side-effects which could lead to death in some patients and that these risks would have been increased for Mr C given his extensive additional medical problems. The medical records showed that Mr C was told at the clinic on 30 October 2012 that treatment was not curative (and of the risks of infection) but not that prognosis or treatment-related death was discussed. Normally patients in Mr C's situation were given leaflets which reiterated the risks, but did not quantify them.

23. The Board went to say that during Mr C's first admission to the Hospital on 7 November 2012 an oncology registrar (the Registrar) discussed the risks of chemotherapy treatment. The medical records showed that the Registrar repeated the risks of injury, possible fatal infection and blood clots (which may damage the heart) and clarified the prognosis saying that on average three months without chemotherapy and eight to 12 months with chemotherapy was the survival rate. She stated that Mr and Mrs C were keen to go ahead 'notwithstanding risks'. The Consultant also started chemotherapy on 14 November 2012 believing that Mr C understood the risks and wished to go ahead with the treatment.

24. The Board went on to say that the Consultant met Mr and Mrs C on 14 January 2013 to discuss future plans including the possibility of hospice care. The discussion was documented retrospectively by another doctor the day after. The note stated the family were happy with discussions and for discharge home on 16 January 2013. During the discussions, the Consultant

indicated that prognosis was very short and that any re-admission would appropriately be to hospice. He also said that waiting for a full package of care and equipment would have delayed discharge to the point that discharge would not be possible and Mr C would not get home. The Consultant believed all concerned were happy with this. He apologised that Mrs C found the information so shocking and that he had not been able to provide the support he would have liked in the short lifetime Mr C had left. The Board said the discharge was considered safe in so far as Mr C was walking, not at risk of falls, providing most care for himself and had many family members around. The Board told Mrs C that the discharge would not have happened if she had been uncomfortable with it.

25. The Board explained that the Consultant had gone through Mr C's illness and confirmed to them that Mrs C understood the 'up to one year survival' the Registrar had discussed in November. Unfortunately, the Board said it was clear the Registrar and the Consultant did not emphasise enough or ensure that Mrs C understood the very significant risks of treatment and that this outcome was possible but not likely.

Advice received

26. The Medical Adviser said the medical notes available showed that the common side effects of chemotherapy were discussed and that the risk of serious infection associated with a low blood count was stressed. Providing chemotherapy booklets and specific sheets about drugs given was expected standard of care throughout the NHS for chemotherapy treated patients. The aim of the treatment was to improve quality of life and hopefully extend it. The Medical Adviser said that for patients with small cell lung cancer, 60 percent of them responded well to treatment. However, it was one of the most challenging aspects of oncology to communicate the likelihood or otherwise of benefit to patients particularly in terms of prognosis. Before treatment, the evidence (from the discharge letters to the medical practice) showed that the Registrar had clearly indicated a survival of three months without treatment and eight to 12 months with chemotherapy. She also reiterated the risks of life-threatening complications. The Medical Adviser said their experience was that often patients misheard or misunderstood clearly quoted timescales at a time when they were in shock from the diagnosis. However, there was clear evidence that the potentially poor prognosis was discussed with Mr and Mrs C. In their opinion, the consent process was appropriately taken over more than one visit to the Hospital and the benefits and risks were clearly explained.

27. The Medical Adviser went on to say that in relation to the discharge on 16 January 2013, the discharge letter indicated that Mr C's family thought he would manage satisfactorily home, he was seen by the clinical nurse specialist and referred to community palliative care. It appeared to the Medical Adviser that communication with the family was good. The Medical Adviser concluded that there was evidence of effective consent, communication and support for Mr and Mrs C and that the Board provided a reasonable standard of care and treatment.

(b) Conclusion

28. Mrs C complained that the Board failed to communicate clearly with her regarding Mr C's prognosis and failed to provide her with an adequate level of support to help her cope with his illness. Turning first to communication, she said that when she and Mr C agreed to the first round of chemotherapy, they believed that with this treatment he would survive 12 months. The Medical Adviser said there is evidence that before Mr C consented to treatment, both of them were told that with chemotherapy Mr C could expect to survive eight to 12 months and that the risks of the treatment were stressed. However, the Medical Adviser also said that many patients and their families were unable to comprehend and remember such details in these extraordinary and stressful circumstances. Moreover, the Board stated that the healthcare professionals failed to sufficiently emphasise or ensure Mr and Mrs C understood the risks of treatment and that it was unlikely Mr C would survive a year. I am satisfied that the risks of treatment and prognosis were explained, but it is my view that the healthcare professionals who discussed these with Mr and Mrs C did not take sufficient care to ensure that Mr and Mrs C not only heard what the healthcare professionals were saying, but that they fully understood. This led to a personal injustice to Mr and Mrs C in that they were shocked and extremely distressed when the Consultant told them in January 2013 that Mr C only had weeks left. Mrs C continues to be extremely distressed by this.

29. Related to this, the Board's full response to Mrs C's complaint refers in considerable detail to technical and medical terms and much of it is difficult for a lay person to understand. This, together with the lack of statement of condolences, makes the response appear uncaring. This is inappropriate and insensitive in light of the nature of the complaint.

30. Turning now to the level of support offered to Mr and Mrs C when Mr C was discharged from the hospital, the advice I have accepted is that this was reasonable. Mrs C felt let down by the Hospital at a very difficult time, but there is evidence that appropriate arrangements were made to ensure that Mr C was cared for after he was discharged. However, in light of the shortcomings around communication (see paragraph 28), which had such a devastating effect, I uphold the complaint.

(b) Recommendations

31. I recommend that the Board:	*Completion date*
(i) provide a plan detailing the changes they have made to prevent a recurrence of failings in their communication with Mr and Mrs C regarding chemotherapy treatment;	30 May 2014
(ii) ensure their responses to complaints are meaningful and appropriate in tone, use of language etc; and	30 May 2014
(iii) further apologise to Mrs C for the failures identified and offer to meet her to discuss in more detail the response she received to her complaint.	30 May 2014

32. 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.

Annex 1

Explanation of abbreviations used

Mr C	the complainant's husband
the Consultant	a consultant in oncology at the hospital
the Hospital	Western General Hospital
Mrs C	the complainant
the Board	Lothian NHS Board
the Medical Adviser	one of the Ombudsman's advisers who specialises in oncology
the Nursing Adviser	one of the Ombudsman's advisers who specialises in nursing
the Registrar	a registrar in oncology at the hospital

Annex 2

Glossary of terms

Hypoglycaemia	abnormally low level of sugar in the blood
Metastasis	the spread of cancer from the initial site of the disease to another part of the body
Palliative care	care that focuses on relieving and preventing the suffering of patients at the end of their life
Renal failure or impairment	a condition where the kidneys are not working normally