

Case reference: HS-232166

Health Service Commissioners Act 1993

Date of Final Report: 18 November 2016

Final report by the Health Service Ombudsman for England into a complaint made by

Mr Khalid Mahmood and Ms Laila Khalid

On behalf of

Mrs Shamim Mahmood

Complaint about

Nottingham University Hospitals NHS Trust (the Trust)

Summary

1. Mr Mahmood and his daughter, Ms Khalid (the complainants), complain about the care and treatment provided to his late wife, Mrs Mahmood, for her liver disease between 2011 and 2013. They complain specifically:
 - The Trust did not perform a liver and kidney transplant despite positive results from transplant investigations in April and May 2011.
 - The Trust did not carry out a biopsy on the tumours on Mrs Mahmood's liver.
 - When Mrs Mahmood was in hospital at the end of her life, the Trust stopped her medication and did not perform any tests or observations between 3 and 7 October 2013.
2. The complainants say as a result, Mrs Mahmood's condition deteriorated between October 2011 and October 2013 and the Trust wrongly denied her a transplant. They believe the Trust could have prolonged Mrs Mahmood's life if she had received a transplant or if the Trust had carried out a tumour biopsy and provided treatment. They also say the alleged failings caused them distress and a loss of faith in the Trust, as they did not believe it was doing everything it could to prolong Mrs Mahmood's life. Mr Mahmood says the family have suffered significantly due to the early death of his wife.
3. Mr Mahmood and Ms Khalid would like a written apology from the Trust and a financial remedy.

Our decision

4. We have partly upheld this complaint. This is because there is evidence the Trust should have started investigations into Mrs Mahmood's suitability for liver transplant sooner, and it failed to record a rationale for its decision in January 2012 that she was not suitable. However, if the Trust had started investigations sooner, on the balance of probabilities, this would not have led to her having a transplant. We recognise the failings meant the family did not have clarity or reassurance about Mrs Mahmood's care and treatment. The Trust has not yet acknowledged the failings or addressed the impact they had. We have made recommendations to the Trust.

5. We did not find any failings relating to the lack of biopsy or in the care and treatment the Trust provided to Mrs Mahmood during her last hospital admission.

Background

6. Mrs Mahmood (aged 53 at the beginning of the period of complaint) had hepatitis C¹ related liver cirrhosis² acquired through a blood transfusion in 1979. She had significant co-morbid medical conditions including poorly controlled type II diabetes; progressive diabetic nephropathy³ leading to final stage kidney failure; a previous stroke; obesity; previous meningitis causing sepsis which required an intensive care admission; osteoarthritis⁴; and general frailty. She had failed to clear her hepatitis C virus following 18 months of therapy in the 1990s.

7. Mrs Mahmood had established liver cirrhosis since at least early 2011 for which she was under regular review at the Trust. She started developing complications of ascites⁵ in 2011. She developed a significant bleeding episode from oesophageal varices⁶ in October 2011. Mrs Mahmood continued to deteriorate with worsening ascites over the next two years.

8. At a January 2012 clinic appointment, a hepatology specialist registrar told Mrs Mahmood she was not fit for a liver transplant. In January 2013, scans showed she had developed tumours on her liver. At this time, the Trust decided to formally assess if she was suitable for a liver transplant. It did an assessment in February 2013. By this point, her kidney function had deteriorated and the Trust considered a joint liver and kidney transplant. It decided against this in April 2013 due to her poor performance status and overall frailty. She had ongoing problems with recurrent

¹ Hepatitis C is a virus that can infect the liver.

² Cirrhosis is scarring of the liver caused by continuous, long-term liver damage.

³ Diabetic nephropathy is a type of progressive kidney disease that occurs in people who have type 1 or type 2 diabetes.

⁴ Osteoarthritis is a condition that causes joints to become painful and stiff.

⁵ Ascites are the accumulation of fluid in the peritoneal cavity, causing abdominal swelling.

⁶ Oesophageal varices occur often as a consequence of portal hypertension, commonly due to cirrhosis

ascites requiring repeated ascitic drain⁷ insertions throughout the rest of her life. She received palliative care from mid to late 2013.

9. On 1 October Mrs Mahmood attended the ED feeling ill. She was admitted, diagnosed as dehydrated with gastritis⁸, diarrhoea and vomiting with some haematemesis⁹. She remained in hospital until her death on 14 October. Her death certificate shows the cause of death as 1a encephalopathy¹⁰, 1b liver cirrhosis, 1c Hepatitis C, 2 hepatocellular carcinoma¹¹ and diabetic nephropathy.

Evidence we considered

10. We have considered the following evidence during our investigation.

- Information provided to us by Mr Mahmood and Ms Khalid
- Information provided to us by the Trust, including its complaint file
- Letters exchanged between Mr Mahmood and the Trust
- Relevant entries in Mrs Mahmood's clinical records
- Advice from an experienced consultant physician and nephrologist¹² (our physician adviser)
- Advice from an experienced consultant gastroenterologist with a subspecialty in hepatology¹³ (our hepatology adviser)

What we found

11. We explain our findings on each of the complainant's concerns separately below.

Consideration of transplants

12. The complainants are unhappy that the Trust did not consider Mrs Mahmood for liver or kidney transplants earlier. They also complain that, despite positive results from the assessment in 2013, the Trust did not offer her a transplant.

⁷ An ascitic tap or drain is a medical procedure where a needle is used to drain fluid that is trapped in an internal body cavity, most commonly the abdomen (belly).

⁸ Gastritis is inflammation of the lining of the stomach.

⁹ Haematemesis the vomiting of blood.

¹⁰ Encephalopathy is a disease in which the functioning of the brain is affected by some agent or condition (such as viral infection or toxins in the blood).

¹¹ Hepatocellular carcinoma is the most common type of liver cancer.

¹² A nephrologist is a physician who studies and deals with nephrology. Nephrology is the adult and paediatric study of the kidneys and its diseases.

¹³ Hepatology is a branch of medicine concerned with the study, prevention, diagnosis and management of diseases that affect the liver, gallbladder, biliary tree and pancreas.

13. Mrs Mahmood was at stage 3¹⁴ kidney disease in late 2011. Our hepatology adviser said that at this stage, she did not meet the criteria for assessment for a kidney transplant. There is evidence Mrs Mahmood had liver failure throughout 2011.
14. Our physician adviser said at Mrs Mahmood's March 2011 liver review the records show she had just recovered from meningitis, which is a very serious illness. Therefore, she was not suitable to be a candidate for liver transplant at this time, despite exhibiting signs of liver failure.
15. Our hepatology adviser explained the right time to start considering the possibility of transplant was at her liver review in November 2011, in line with British Society of Gastroenterology (BSG) guidance¹⁵. This was when Mrs Mahmood developed decompensation of her liver disease as evidenced by her oesophageal variceal bleed and her development of difficult to control ascites. There is no evidence the hepatology team considered the possibility of a transplant at this time, which we consider to be a failing.
16. If the team had considered this, Mrs Mahmood would have needed to undergo a formal work up assessment to determine her suitability for transplant, in conjunction with a transplant centre. At a clinic appointment in January 2012, a hepatology senior registrar told Mrs Mahmood she was not a candidate for a liver transplant. Our physician adviser said this was the latest point at which the Trust should have started to investigate Mrs Mahmood for a potential liver transplant. However, there was no formal assessment at this point. The notes of the clinic consultation say the registrar had a '*frank discussion*' with Mrs Mahmood. The notes do not clearly specify the reasons why she was not suitable, although our hepatology adviser said they imply it was her co-morbidities and general poor fitness. Our hepatology adviser said none of the factors mentioned, such as kidney impairment or poorly controlled diabetes, were an absolute contraindication in isolation. Therefore, formal assessment was imperative to make a thorough and evidence-based decision about her suitability.
17. There is no reference to the Trust considering transplant again until a consultant hepatologist did so in September 2012. The Trust decided to carry out pre-transplant investigations in January 2013. By this stage, Mrs Mahmood's kidney disease had progressed significantly. Therefore, it investigated her suitability for a joint liver and kidney transplant in February 2013. The outcome of this was positive for her cardiac¹⁶ investigation results, but Mrs Mahmood ultimately could not be listed for transplant as further consideration and review appointments showed that, by April, she had become too unwell.

¹⁴ Kidney disease is measured in stages measured from 1-5. 1 indicates normal kidney function but suggestions of kidney disease, and 5 indicates very severe kidney disease. Stage 3 indicates moderately reduced kidney function.

¹⁵ BSG (2000) *Indications for referral and assessment in adult liver transplantation: a clinical guideline*

¹⁶ Cardiac in this sense is relating to, or affected with heart disease.

18. In its response, the Trust said its initial priority was managing Mrs Mahmood's hepatitis C and that it could only consider the possibility of liver transplant at the point Mrs Mahmood had liver failure. However, our physician adviser said there is no evidence in the records that the Trust did treat Mrs Mahmood for her hepatitis C during this period. As explained previously, there is evidence Mrs Mahmood had liver failure in 2011. Therefore, the Trust's explanation for the timing of its decision to start formal investigations of Mrs Mahmood's suitability for treatment is not supported by the records.

19. In summary, there were failings in how the Trust managed the consideration of Mrs Mahmood's suitability for transplant surgery. In line with the BSG guidance, it should have started formal investigations between November 2011 and January 2012. It did not do this. The hepatology registrar made a decision that she was not fit for transplant in January 2012, but this was not based on investigations and there is no record of an appropriate rationale. We find this a failing in record keeping as we would expect any reasoning for significant decisions in a patient's care to be recorded. This failing means we cannot be certain whether the Trust made the decision appropriately. This has caused uncertainty for Mrs Mahmood's family as to why the Trust decided she was not suitable for a transplant at that point.

20. There was a delay of 14 months (from November 2011) before the Trust made the decision to send Mrs Mahmood for pre-transplant investigations and 15 months until she actually had them in February 2013. The Trust has not provided an accurate and evidence based explanation for its actions.

Impact of the failings

21. As the Trust did not do the initial investigations to assess Mrs Mahmood's suitability for transplant, we cannot know what the results would have been. Our hepatology adviser explained that the Trust could not have made the decision to transplant on the basis of the investigation results alone. It would have had to take into account numerous other factors, such as Mrs Mahmood's fitness, her ability to look after herself and exercise tolerance. As we mentioned earlier, between November 2011 and February 2013, there was no single factor that would have absolutely ruled out a transplant. It was positive that Mrs Mahmood was relatively young at 53. However, there were a number of relative contraindications, including her clearly documented poorly controlled diabetes, progressive renal failure, limited mobility and need for regular assistance. Our hepatology adviser said that some, but not all of Mrs Mahmood's symptoms may have improved after transplant, if she had survived the initial post-transplant period. However, the decision would be made on her overall suitability at her assessment.

22. Due to a severe shortage of organs, transplant centres have to weigh up a patient's probability of survival along with their likely extension of life. Our

hepatology adviser said most causes of death after a liver transplant relate to co-morbid factors such as diabetes and hypertension, both of which Mrs Mahmood had, leading to a significantly increased risk of stroke or heart attack. She was only 53 but her functional age¹⁷ was older. Mrs Mahmood's extension of life was likely to have been considerably less than for other patients with fewer co-morbidities.

23. Our hepatology adviser said that, based on the available information, and on the balance of probabilities, if the Trust had started the formal assessment of Mrs Mahmood's suitability for transplant between November 2011 and January 2012, it would have been unlikely to consider her appropriate for a transplant.

24. Therefore, we do not consider different action would have led to the Trust offering Mrs Mahmood a liver transplant at an earlier stage. We can understand that because the Trust did initial investigations in early 2013, this has led Mr Mahmood and his family to question what the outcome would have been if this had happened sooner. If the Trust had formally investigated her suitability in late 2011 or early 2012, the likely result would have been to refer her for palliative care (symptom relief) only, but this would have allowed the family more certainty and clarity. Because it did not, this caused them significant distress and confusion about the Trust's actions.

25. The Trust has not yet acknowledged what went wrong in its management of Mrs Mahmood. Therefore, it has not taken any action to recognise how this affected Mr Mahmood and his family or to make sure the failings do not happen again. We have made recommendations to address this at the end of the report.

26. We recognise that the Trust's failings mean Mr Mahmood, Ms Khalid and their family will always be left with an element of doubt about whether the outcome could have been different. Therefore, we would like to share some further comments our hepatology adviser provided to help them understand the situation.

27. Our hepatology adviser said a patient in Mrs Mahmood's condition, who is suitable for transplant, would need a live beating donor organ and the average waiting time on the transplant list is nine to 18 months. A patient will be taken off the list if their condition deteriorates and they are no longer fit for transplant. Therefore, if the Trust had carried out a formal assessment at the time it should have, and even if this had shown Mrs Mahmood was suitable for liver transplant, she would have faced a wait of nine to 18 months. We know her disease was rapidly progressing and she developed liver cancer and more significant kidney failure in 2013. Therefore, even if Mrs Mahmood had been assessed as suitable for transplant in

¹⁷ The term for a person's age, that is determined as a measure of their functional capabilities as a combination of physiological, psychological and social age. This means if a person has poor physical health, their functional age would be higher than their chronological age.

2012, there is a good chance she may not have reached the top of the waiting list before she became too ill to receive a donor liver.

Biopsy of liver tumours

28. The complainants say that the Trust did not carry out a biopsy on the tumours on Mrs Mahmood's liver. They believe this was a missed opportunity to provide treatment.

29. There is evidence in Mrs Mahmood's medical records that she did have tumours on her liver. Scan results show they developed at some point between January 2012 and January 2013. There is no record of Mrs Mahmood having a liver biopsy.

30. Our physician adviser said it was highly likely that Mrs Mahmood's tumours were a cancer. He said the decision about whether or not the Trust should have done a biopsy is down to clinical judgment. There is a serious risk of biopsy spreading potentially cancerous cells to other parts of a patient's body. Our physician adviser said a biopsy is only done when there is either a reasonable doubt in diagnosis, or a reasonable chance that it would lead to successful treatment. Mrs Mahmood's diagnosis was not in doubt and our physician adviser said there was probably no treatment the Trust could offer her.

31. We appreciate Mr Mahmood's concerns about the lack of biopsy. However, there is evidence the Trust made an appropriate diagnosis for the liver tumours without the need for a biopsy and it was most likely that a biopsy would not have led to treatment. Therefore, it was right that the Trust did not to perform a biopsy and expose Mrs Mahmood to the associated risks of spreading cancerous cells. We have not identified any failings in relation to this part of the complaint.

32. We note that, reassuringly, there is no evidence to suggest Mrs Mahmood's condition deteriorated because she did not have a biopsy.

End of life care in September and October 2013

33. The complainants are concerned Mrs Mahmood's paracentesis appointment on 27 September 2013 was not performed correctly and could have led to her deterioration in health on 1 October 2013 when she was admitted as an emergency.

34. There is no evidence of concern in the medical records regarding the paracentesis drain on this date.

35. Our physician adviser said there is no evidence that the Trust performed the paracentesis incorrectly. He said the Trust carried out the procedure as per

guidelines¹⁸ and there is no suggestion this contributed to the deterioration of Mrs Mahmood's condition days later.

36. There is no evidence of concern regarding Mrs Mahmood's paracentesis on 27 September, which was carried out appropriately. Therefore, we do not find failings here.

37. The complainants are concerned that, during Mrs Mahmood's final hospital admission, the Trust stopped her medication and did not perform any tests or observations between 3 and 7 October 2013.

38. Our physician adviser said it was appropriate for the Trust to start end of life care at this point, as Mrs Mahmood's condition had deteriorated significantly whilst she was an inpatient. He said it was appropriate for the Trust not to perform observations or tests at this time. Doing this on a dying patient is not good practice because it could cause unnecessary pain or discomfort at a point where there is no likelihood of any benefit.

39. It is clear that Mrs Mahmood's condition unexpectedly improved after 7 October. Therefore, it was appropriate for the Trust to reassess and restart tests and observations after this. However, Mrs Mahmood still had a very poor prognosis and sadly died in the hospital a week later.

40. We appreciate how distressing it must have been for Mrs Mahmood's family. However, there is evidence that the Trust's actions between 3 and 7 October were appropriate in reaction to her declining condition. We have not identified any failings in this aspect of the complaint.

Recommendations

41. There were failings in how the Trust managed its consideration of Mrs Mahmood's suitability for transplant. On the balance of probabilities, the outcome would have been the same even if it had managed this properly. However, we can see the failings caused the family doubt about the adequacy of her care and concern that she was denied the chance of a longer life. This inevitably caused them significant emotional distress and confusion.

42. There was also a failing in record keeping as the Trust did not record the reasoning why Mrs Mahmood was not suitable for a transplant in early 2012, although it recorded the decision. This has caused her family uncertainty and we are unable to assess whether the decision making was appropriate at the time.

¹⁸ K P Moore and G P Aithal. Guidelines on the management of ascites in cirrhosis Gut 2006;55;1-12

43. The Trust has not yet acknowledged the failings, recognised the impact on Mr Mahmood, Ms Khalid and their family, or taken action to improve its service. Therefore, we make the following recommendations:

- Within four weeks of the date of the final report, the Trust should write a joint letter to Mr Mahmood and Ms Khalid to acknowledge the failings we have identified and for the significant distress and confusion this caused them.
- Within four weeks of the date of the final report, the Trust should pay financial remedy of £250 to both Mr Mahmood and Ms Khalid individually (£500 in total) for the distress caused as a result of the missed opportunity for an earlier liver transplant and poor record keeping identified in the report.
- Within three months of the date of the final report, the Trust should develop an action plan to show how the Trust has learned from the failings in its consideration of Mrs Mahmood's suitability for transplant and the poor documentation of its decision making. It should send this to Mr Mahmood and Ms Khalid. The action plan should identify the reasons for the failings, where possible. It should explain the learning the Trust has taken from these issues; what it will do differently in future; who is responsible and timescales for each action; and how it will monitor these.
- The Trust should send us evidence it has complied with all our recommendations. It should also send an anonymised copy of our final report and the action plan to the Care Quality Commission (send to HSCA_Compliance@cqc.org.uk) and NHS Improvement (nhsi.enquiries@nhs.net)

Conclusion

44. We identified failings in how the Trust managed Mrs Mahmood's suitability for a liver transplant from November 2011 and in 2012, and how it recorded its decision making. We were persuaded that this did not have a negative impact on her prognosis, as on the balance of probabilities, she would not have been considered suitable for a transplant. However, the failing caused Mrs Mahmood's family distress and doubt about the adequacy of her care and treatment. We have made recommendations to recognise the impact on the family and to ensure the Trust makes systemic improvements.

45. We found the care and treatment the Trust provided during Mrs Mahmood's final hospital admission was appropriate and that it was right that the Trust did not carry out a biopsy. This is why we have partly upheld the complaint.

GRO-C

Catherine Olney-Falzon
Investigations Manager
18 November 2016