Investigation of a complaint against the Belfast Health & Social Care Trust

Report Reference: 202002619

The Northern Ireland Public Services Ombudsman
33 Wellington Place
BELFAST
BT1 6HN
Tel: 028 9023 3821
Email: nipso@nipso.org.uk
Web: www.nipso.org.uk

The Role of the Ombudsman

The Northern Ireland Public Services Ombudsman (NIPSO) provides a free, independent and impartial service for investigating complaints about public service providers in Northern Ireland.

The role of the Ombudsman is set out in the Public Services Ombudsman Act (Northern Ireland) 2016 (the 2016 Act). The Ombudsman can normally only accept a complaint after the complaints process of the public service provider has been exhausted.

The Ombudsman may investigate complaints about maladministration on the part of listed authorities, and on the merits of a decision taken by health and social care bodies, general health care providers and independent providers of health and social care. The purpose of an investigation is to ascertain if the matters alleged in the complaint properly warrant investigation and are in substance true.

Maladministration is not defined in the legislation, but is generally taken to include decisions made following improper consideration, action or inaction; delay; failure to follow procedures or the law; misleading or inaccurate statements; bias; or inadequate record keeping.

The Ombudsman must also consider whether maladministration has resulted in an injustice. Injustice is also not defined in legislation but can include upset, inconvenience, or frustration. A remedy may be recommended where injustice is found as a consequence of the failings identified in a report.

Reporting in the Public Interest

This report is published pursuant to section 44 of the 2016 Act which allows the Ombudsman to publish an investigation report when it is in the public interest to do so.

The Ombudsman has taken into account the interests of the person aggrieved and other persons prior to publishing this report.

TABLE OF CONTENTS

Page

Case Reference: 202002619
Listed Authority: Belfast Health and Social Care Trust

SUMMARY

This complaint is about the care and treatment the Belfast Health and Social Care Trust (the Trust) provided to the complainant's father (the patient) from November 2016 to February 2017.

The patient was admitted to the Royal Victoria Hospital (RVH) in early February 2017 to repeat a procedure relating to his liver cancer diagnosis and discharged three weeks later.

The investigation found the patient's drug treatment should have focused more on relieving the patient's distressing abdominal symptoms by considering and administering medications avoiding the gastrointestinal tract. It found there was a failure to commence a food chart, to make a referral to dietetics for 15 days and a failure to fully consider refeeding syndrome. The investigation also found a failure to adopt a more patient centred approach to the patient's care and that he should have received or been copied into a discharge and clinic letters. Additionally, I found a failure in record keeping regarding the carrying out of an OGD. I consider these failings to represent a failure in the care and treatment afforded to the patient.

I recommended the Trust apologise to the complainant for the injustice sustained. I also recommended that the Trust undertake a review of procedures in place to ensure that the patient's voice is heard and that it should ensure relevant staff are given the opportunity to reflect on the findings of this report.

THE COMPLAINT

1. This complaint is about the care and treatment the Belfast Health and Social Care Trust (the Trust) provided to the complainant's father (the patient) from November 2016 to February 2017.

Background

2. The patient was admitted to the Royal Victoria Hospital (RVH) on 28 November 2016 to 1 December 2016 for a medical procedure relating to his liver cancer diagnosis. On 1 Feb 2017, at an outpatient appointment, it was decided to repeat the procedure. The patient was admitted to the RVH on 7 February 2017. The procedure was cancelled twice but subsequently carried out on 10 February 2017, although it was not fully effective. The patient was discharged on 22 February 2017. Sadly, the patient died in a hospice on 6 April 2017.

Issues of complaint

3. I accepted the following issue of complaint for investigation:

Was the care and treatment provided by the Trust between 28 November 2016 and 22 February 2017 appropriate. The investigation considered,

- the prescribing and administration of medication;
- food intake monitoring and referral to dietetics;
- the diagnosis and treatment of hepatoma in the context of previously decompensated liver cirrhosis to include the two TACE[1] (Trans arterial chemoembolization) procedures;
- the level of communication provided to the family and the timeliness of referrals for palliative care and social work support;
- provision of pain relief following readmittance to the RVH on 7 February 2017, the provision of laxatives and control of diabetes;
- completion of an OGD[2]; and
- the discharge from RVH on 15 February 2017.

[1] A procedure to give chemotherapy directly to the cancer site, most often in the liver. It is a non surgical and minimally invasive procedure
[2] Oesophago Gastro Duodenoscope looks at the upper part of the gut with a narrow flexible tube

INVESTIGATION METHODOLOGY

4. In order to investigate this complaint, the Investigating Officer obtained from the Trust all relevant documentation together with its comments on the issues the complainant raised.

Independent Professional Advice Sought

5. After further consideration of the issues, I obtained independent professional advice from the following independent professional advisors (IPA):

- A Consultant hepatologist and Gastroenterologist (H IPA) trained in dealing with patients with advanced liver disease, including decompensated liver disease and diagnosis and treatment of hepatocellular carcinoma from 2008; and
- A Dietician, BSC Hons Human Nutrition and Dietetics, Masters in Public Health and PhD Researcher (D IPA) with extensive experience within the NHS of older persons services, nutritional support, end of life care and policy review.

I enclose the clinical advice received at Appendix two to this report.

6. The information and advice which informed the findings and conclusions are included within the body of this report. The IPAs provided 'advice'. However, how I weighed this advice, within the context of this particular complaint, is a matter for my discretion.

Relevant Standards and Guidance

7. In order to investigate complaints, I must establish a clear understanding of the standards, both of general application and those specific to the circumstances of the case. I also refer to relevant regulatory, professional, and statutory guidance.

The general standards are the Ombudsman's Principles[3]:

- The Principles of Good Administration

8. The specific standards and guidance referred to are those which applied at the time the events occurred. These governed the exercise of the administrative functions

[3] These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.

and professional judgement of those individuals whose actions are the subject of this complaint.

The specific standards and guidance relevant to this complaint are:

- General Medical Council (GMC). The professional duty of candour (June 2015, updated March 2022);
- The General Medical Council's Good Medical Practice, April 2019 (GMC Guidance);
- Academy of Medical Royal Colleges (AMRC), Please write to me, writing outpatient clinic letters to patients. Guidance (September 2018);
- National Institute for Clinical Care and Excellence (NICE) CG32 (2006) Nutritional Support for Adults Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition;
- British Dietetic Association (2016) Model and Process for Nutrition and Dietetic Practice;
- British Dietetic Association (2008) Guidance for Dietitians for Records and Record Keeping;
- ESPEN practical guideline: Clinical Nutrition in cancer;
- Diabetes UK (2018) Evidence-based nutrition guidelines for the prevention and management of diabetes; and
- ESPEN (2020) ESPEN practical guideline: Clinical nutrition in liver disease

9. I did not include all information obtained in the course of the investigation in this report. However, I am satisfied I took into account everything I considered relevant and important in reaching my findings.

10. A draft copy of this report was shared with the complainant and the Trust for comment on factual accuracy and the reasonableness of the findings and recommendations. The complainant supplied a comprehensive response detailing her concerns with the content of the draft report. The Trust also supplied its comments in addition to further observations from a clinician and additional dietetic records, not previously supplied. As a result, I sought additional independent medical advice from professional advisors. I gave careful consideration to the further comments and advice received and provided both the Trust and the complainant

with a further report in draft form. Following receipt of further comments, I made amendments the content of the report where I felt it appropriate to do so.

THE INVESTIGATION

Was the care and treatment provided by the Trust between 28 November 2016 and 22 February 2017 appropriate.

a. The prescribing and administration of medication

Detail of Complaint

11. The complainant said no one appears to have understood or taken appropriate action to address the worsening symptoms her father experienced after swallowing his tablets (or eating food). She complained there was a failure to consider other methods of drug administration in order to alleviate symptoms. The complainant highlighted that staff refused the IV administration of drugs. She said taking oral medication caused abdominal pain, discomfort, bloatedness and nausea, however this did not change the decision as to how medication was administered.

Evidence Considered

I considered GMC Guidance.

The Trust's response to investigation enquiries

12. The Trust explained during the patient's second admission to the RVH Liver Unit, '*gastro-intestinal symptoms are documented in his medical, nursing and palliative care notes'* and that efforts were made to manage these symptoms by adjusting his medication. The Trust considers the patient received appropriate input from the palliative care team, with focus on symptom management. Following the TACE, the patient was generally unwell and as a result, he was not able to take a number of his oral medications. *'Most of these medications including oral hypoglycaemic agents (diabetic drugs) and anti-hypertensives[4] do not have intravenous alternative.*' The Trust stated '*many of his oral medications were not essential and therefore missing them for several days was not a critical issue. There is evidence from his drug*

[4] Blood pressure medication

Kardex that as he recovered, he was managing all of his oral medications from 20 February up until the time of discharge'.

13. The Trust stated, in relation to the use of laxatives, '*the patient's constipation might have been contributing to poor appetite, weight loss and bloating as well as a degree of intolerance to iron supplements. It was suggested stopping the iron supplements and starting a laxative. It is probable that bile acid malabsorption*[5] *and radiation proctitis*[6]*/enteritis*[7]*, which were previously established diagnoses, may have been contributory to the symptoms the patient was experiencing'.*

Relevant Independent Professional Advice

14. The H IPA advised the abdominal symptoms which the patient experienced were *'clearly challenging'* explaining that the patient had previous radiation, previous fluid in the abdomen, a very scarred/cirrhotic liver with very widespread cancer and a previous diagnosis of bile salt malabsorption. He advised when abdominal discomfort becomes so predominant this is often due to '*extensive cancer*' and can be difficult to treat. He advised that management, with someone such as the patient should be focused on improvement of abdominal symptoms with '*avoidance of oral medication if this made symptoms worse'.*

15. The H IPA advised that most of the drugs used do have '*alternatives avoiding the gastrointestinal tract'* and he provided examples of these.

Analysis and Findings

16. The context of the overall complaint refers to the care and treatment the patient received during the period 7 to 22 February 2017. The patient was 80 years of age with a history of prostate cancer, diabetes, elevated blood pressure, a heart pacemaker, ascites[8] and liver cirrhosis[9]. He had been diagnosed with liver cancer in late 2016 and had a TACE procedure carried out on 29 November 2016. The patient

5 Bile acids (salts) that are not absorbed properly into the small intestine pass to the large intestine where they trigger diarrohea symptoms.
6 Inflammation of the lining of the rectum
7 Inflammation of the small intestine
8 The buildup of fluid between the lining of the abdomen and the abdominal organs
9 Scarring of the liver caused by long term liver damage.

was aware the TACE procedure was with palliative rather than curative intent, that is, with the hope of prolonging life rather than being a cure.

17. In January 2017, a follow up scan revealed the liver tumour was more extensive than first thought and was progressing. A second TACE procedure was carried out on 10 February 2017, which was only partially successful. The discharge letter to the patient's doctor dated 22 February 2017, documented that he developed Post TACE syndrome[10]. He remained in hospital until discharge on 22 February 2017.

18. The complaint is that the patient's gastric symptoms were not adequately controlled through medication following the second TACE procedure and that there was a failure to consider other methods of drug administration to alleviate his symptoms. The clinical notes document that for much of his stay during February 2017 in hospital, the patient complained of pain and bloating in his stomach, feeling bilious and nauseous, although I note that the records indicate this somewhat reduced in the days prior to discharge on 22 February 2017. I accept the H IPA's advice that *'the abdominal symptoms of the patient were clearly challenging'.* The patient's liver disease and his extensive liver cancer would all have contributed to the symptoms which he was reporting, and I accept that in this situation these are difficult symptoms to control and treat successfully.

19. Nonetheless I accept the H IPA's advice that there should have been more focus on the '*improvement/palliation of his abdominal symptoms with avoidance of oral medication if these made his symptoms worse'*. The H IPA advised most of the drugs administered do have alternatives which avoid the gastrointestinal tract, such as medication which dissolves under the tongue, or which can be administered via intravenous, subcutaneous or intramuscular routes. These alternatives do not appear to have been seriously considered. I am satisfied based on the evidence that in a palliative setting medications for diabetes, cholesterol and blood pressure do not have to be as tightly controlled, which should have allowed other oral medication to be rationalised.

[10] A complication after TACE treatment typically presenting with symptoms such as abdominal pain, nausea, fever and elevated liver enzymes

20. I note omeprazole[11] was omitted from the patient's medication for a period of five days. I accept the H IPA's advice this omission would be unlikely to cause lasting damage; however I also accept his advice that the continuation of this acid blocking medication would have improved the patient's wellbeing and could have been prescribed in a form which dissolves under the tongue.

21. Overall, regarding this element of complaint, I accept the H IPA's advice, that in the face of the patient's extensive and progressing liver cancer, his drug treatment should have focused more on relieving the patient's distressing abdominal symptoms by considering and administering medications avoiding the gastrointestinal tract. I consider this to constitute a failure in the care and treatment afforded to the patient. I consider the patient sustained the injustice of a loss of opportunity to potentially control his symptoms better. I also consider it led to an injustice to the complainant of upset and uncertainty regarding the treatment the patient received. Therefore, I uphold this element of the complaint.

b. Food intake monitoring and referral to dietetics

Detail of Complaint

22. The complainant raised concerns about food charts and the Trust accepted that it failed to commence a food chart and make a referral to dietetics following the patient's admission on 7 February 2017. A referral was made to the Nutrition and Dietetics' team on 21 February 2017 and the Nutrition and Dietetics' team assessed him on 22 February 2017. The complainant believed this delay caused a detrimental effect to the patient.

Evidence considered

23. I considered the NICE Guidance, the ESPN Guidance and British Dietetic Guidance.

The Trust's response to investigation enquiries

24. The Trust explained on admission on 7 February 2017 the patient had a Malnutrition Universal Screening Tool (MUST) assessment completed. He scored one on this

[11] A medication to reduce the amount of acid made in the stomach, used to treat indigestion and acid reflux.

assessment indicating he was medium risk of malnutrition. This indicated the patient's food intake should be monitored for three days, and a referral made to dietetics. The clinical notes for 7 February 2017 show under the heading plan '*Dietician R/V ?supplements'* Unfortunately, a food chart was not commenced and a referral to dietetics was not made. The Trust apologised for this as part of local resolution and stated MUST assessments and actions are now a focus on the ward with compliance being audited three monthly, which I welcome. Following receipt of sight of this report in draft form, the Trust provided additional dietetic records. The Trust's response to a second draft report on this complaint contradicted information previously supplied and accepted relating to dietetics. The further response stated that a MUST score of 1 does not indicate a referral to a dietitian, that weight loss was also likely to have occurred prior to admission given the patient's weight history and queried the findings on refeeding syndrome. I comment on this in the findings and analysis section below.

Relevant Trust records

25. Reference is made to relevant extracts of clinical notes relating to this element of complaint at Appendix two following the D IPA advice.

26. **Dietician Independent Professional Advice**

27. The D IPA provided advice on the patient's dietary care. The D IPA's initial advice together with supplementary advice provided after consideration of the additional dietetic records is enclosed at Appendix two to this report.

Analysis and Findings

28. Irrespective of the Trust's further comments, I note that it failed to commence a food chart for the patient or make a referral to dietetics for 15 days following admission on 7 February 2017. I note the entry in the clinical notes for 7 February 2017 stating the plan was '*Dietician R/V ?supplements'* I accept the D IPA's advice that whilst it is not possible to definitively quantify the impact this delay had on the patient's physical health, it is clear that he was a vulnerable patient who was, in addition to having a serious life limiting condition, experiencing weight loss and poor appetite. I am therefore satisfied that there was potential at that time, for the patient to benefit from

a referral to a dietitian. I also note the patient likely lost weight prior to admittance and whilst on the ward, from the dietetic assessment, of approximately 6.5kg, or 7.5%, which is a significant weight loss in a short period of time. I accept the D IPA's advice that this delay in commencing dietetic oversight and treatment would have put the patient at increased risk of weight loss and muscle loss.

29. The Trust stated, referring to refeeding syndrome, due to the level of calorific intake, being on anti-nausea medication and the criteria for refeeding, the patient would not be 'deemed a refeeding risk'. Nonetheless, I accept the D IPA advice that refeeding risk would have been present prior to anti -nausea medication being prescribed, the fact of the patient having poor oral intake and weight loss and that more consideration should have been given to this syndrome.

30. Overall, I accept the D IPA's advice that the dietetic assessment carried out on 22 February 2017, was largely satisfactory when compared to national standards and guidelines. This included the use of an estimation of dry weight in its estimations, the recording of estimated nutritional requirements, the noting of biochemistry, a hospital dietary history and record of sip feeds.

31. Having said that, I consider the acknowledged failure to commence a food chart for the patient, to make a referral to dietetics for 15 days and insufficient consideration being given to refeeding syndrome, to constitute a failure in the care and treatment afforded to the patient. I consider the patient sustained the injustice of a loss of opportunity to be provided with the optimum care and treatment. I also consider it to have led to an injustice to the complainant of upset and uncertainty regarding the treatment her father received. I therefore partially uphold this aspect of the complaint.

32. Additionally, I would also bring to the Trust's attention the learning/service improvements suggested by the D IPA. These are provided to illustrate and emphasise good practice in nutrition and dietetics.

    - Volumes and quantities to be included in diet history records, such as ml in cup sizes

- Records of oral nutritional supplement intake to be provided in more detail, including the number being offered per day, the amount accepted and the length of time these had been provided
- Refeeding risk to be noted and considered in cases of weight loss and poor oral intake
- Ensuring that the clinical record is more comprehensive and an accurate representation the full dietetic assessment – it may be useful for this to be recorded via a proforma or standardised form to ensure all relevant detail is included in the clinical record.

c. The diagnosis and treatment of hepatoma in the context of previously decompensated liver cirrhosis to include the two TACE procedures

Detail of Complaint

33. The complainant said the patient did not receive holistic care during his 2nd admission in February 2017, rather he received care only for what he was admitted for - the 2nd TACE Procedure and subsequent complications. The TACE procedure was cancelled twice, with her father having to fast from midnight on two occasions and with his medication stopped. She stated no account was taken of her father's underlying health in this regard, including his diabetes.

Evidence considered

The Trust's response to investigation enquiries

34. In relation to the overall issue of holistic care, the Trust stated that during the patient's hospital admission from 7 February 2017 to 22 February 2017 he was '*assessed by a range of members of the multidisciplinary team including doctors, nurses, palliative care nurses, physiotherapists, occupational therapists, social workers, dietician and diabetic specialist nurse, thereby ensuring a holistic approach. The focus was on management of complications of the TACE procedure and symptom management. A significant proportion of Liver Unit patients receive palliative treatment, either in the context of end-stage liver disease or cancer (hepatoma, pancreatic cancer, cholangiocarcinoma) and as such they do have considerable experience of providing holistic care'*.

Relevant Independent Professional Advice

35. The H IPA advised '*a TACE procedure is a procedure whereby a cannula is placed through a peripheral artery) into the cancer to give chemotherapy directly into the cancer*. The HIPA clarified his initial advice stating '*In this case* w*ith progressive disease, the management should have been for palliative management which means that the aim was to relieve symptoms (rather than to control the cancer for as long as possible which is the aim of TACE in other patients). Already before the first TACE treatment, the approach was described to be palliative, the TACE at best prolonging life rather than cure, and with the new finding of rapid progression the treatment should have concentrated more on symptom relief.*

36. The H IPA further advised '*The CT liver of 4 January 2017 showed progression of disease from the scan in November 2016. Discussion at MDT and with the patient with regards to the treatment aims would have been more appropriate rather than being too focused on and following the radiology advice. In general, a radiologist can suggest further investigations or be involved in further management. However, a decision on whether palliative chemoembolization is still appropriate (when the patient might have been borderline suitable for this when the diagnosis was made) should be made by the multidisciplinary team and certainly in discussion with the hepatologist. From the notes, there was no review of the images and clinical situation and a conscious decision to continue with the plan of proactive treatment with TACE'*.

Analysis and Findings

37. The complainant believed the patient did not receive 'holistic care' during this admission. I have taken this to be a concern that while the patient received the TACE and treatment for the symptoms as they occurred, insufficient regard was given to looking at the person as a whole. Based on my review of the records the patient was assessed and treated by a large number of members of the multidisciplinary team including doctors, nurses, dieticians, physiotherapists and that he was under the care of the appropriate teams and professionals at all times.

I comment on this element of the complaint further under the heading 'communication' below, which will include my consideration of how the patient was

treated holistically. At this juncture I am of the opinion that the dominant focus of the clinicians treating the patient was on the management of complications following the TACE procedure and the associated symptoms.

38. The complainant's is concerned the TACE procedure was cancelled twice, and her father had to fast on two occasions. I note the patient was admitted on 7 February 2017 with the intention that the TACE procedure be carried out the next day. Unfortunately, this was cancelled on both 8 and 9 February 2017, being carried out on 10 February 2017. The Trust stated due to winter pressures and the sheer volume of sick patients in the hospital at that time, its Interventional Radiologists were required to perform several procedures on an emergency basis and hence the patient's procedure could not be accommodated. The Trust stated that his blood sugars were appropriately monitored and recorded and remained stable during both periods of fasting.

39. I make no criticism of the Trust for the fact that the TACE procedure was cancelled on two consecutive days. I accept the unfortunate fact that both currently and historically the health system has faced unprecedented pressures both in relation to staffing levels and numbers of patients to be treated. This has led to the regrettable situation whereby sometimes procedures have to be prioritised. In this case, I note that the patient remained medically stable whilst waiting two days for the TACE to be performed and while I understand the complainant's worry during this time, I am satisfied the two-day delay did not indicate a failure in the patient's care and treatment. Therefore, I do not uphold this element of the complaint.

d. Communication and family involvement

Detail of Complaint

40. The complainant said there was very little family inclusion in the patient's care and the family were not listened to when they tried to explain the issues / symptoms the patient was experiencing. I also have examined how the patient was treated holistically.

Evidence considered

I considered AMRC Guidance and GMC Guidance

The Trust's response to investigation enquiries

41. The Trust stated a '*Palliative Care Nurse Specialist, reviewed the patient almost every day, thus providing continuity of care. Medical review took place daily, with at least four consultant-led ward rounds per week. The symptoms he described are documented in the medical notes and efforts were made to manage these symptoms to the best of the Trust's ability. The complainant also met with doctors involved with the patient's care on at least four occasions during his admission to hospital in February 2017 and they have documented her concerns.*

42. The Trust also explained *'The Regional Liver Unit has a robust handover process… Each in-patient in the Liver Unit is discussed in detail and plans are made regarding ongoing management. As much as is possible, the Hepatology team attempt to ensure continuity of care with junior doctors over the course of the working week, however this is not always possible given the requirements of the on-call rota and leave commitments...'.*

43. *In addition, the patient's daughter was also present at both his outpatient appointments. There is evidence that the patient's daughter was contacted by telephone on several occasions by both doctors and nurses to provide an update of his condition'.*

Relevant Independent Professional Advice

44. The H IPA advised *'MacMillan support was mentioned in his last admission and they were key in treating the symptoms following the second TACE procedure. Although difficult to determine from the notes, it seems that there was not much listening and not much finding out what priorities the patient had for the last phase of his life. The feeling is that the communication between the doctors and the family was more "to provide an update on his condition'……On reviewing the patient's clinical deterioration with significant symptoms and the newly discovered extensive liver infiltration, I would have expected that in the context of palliative management*

(TACE) they would have discussed with the hepatologist and the patient whether this was still appropriate and would have likely helped change the focus of the patient's management to more active palliation of symptoms.

45. The H IPA further advised that from reading the notes, '*the documentation of communication was rather concerned with technical issues rather than patient's priorities and concerns. From the beginning of the patient's management, the doctors should have written the clinic letters to the patient (or at least copied the patient into the communication)* *https://www.aomrc.org.uk/reports-guidance/please-write-to-me-writing-outpatient-clinic-letters-to-patients-guidance/ (Academy of Royal Medical Colleges). In this family this would have significantly improved communication and understanding of the family of the issues. From the discharge letter (which also was not sent to the patient), the patient had a complication during his TACE procedure (dissection of segment 3 artery). Due to duty of candour it would have been important for the patient to get a copy of the letter (https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/candour---openness-and-honesty-when-things-go-wrong/the-professional-duty-of-candour). The complication should have been made clearer to the patient and his family'*.

Analysis and Findings

46. During the period 7 February to 22 February 2017, the complainant said there was very little family inclusion in the patient's care and of a feeling the family were not listened to when attempts were made to explain the symptoms the patient was experiencing. I note the content of the clinical notes which documents contact and discussions with family members during this time. The notes document conversations relating to the patient's condition on 10,11,15,19 and 20 February 2017 with the main ones being on 15, 19 and 20 February 2017.

47. The records indicate the patient's condition was discussed with the family members with their concerns regarding the current treatment being fully documented. The complainant and her brother attended a complaints meeting on 20 February 2017 along with a consultant, the nurse manager, the palliative care nurse and a staff nurse. This meeting was held following complaints from the family members relating to the patients care and what they regarded as failures in this care. The patient's

medical history and current condition were discussed and the future plans for the patient. The family also expressed their concerns over the patient's symptom management. During all these meetings and discussions, the family had the opportunity to ask questions and present their concerns. I appreciate the complainant remained dissatisfied with the level of communication regarding the patient's care and treatment and in particular complains that it was not made more explicit the terminal consequence of the progression and growth of the disease present. However, I am satisfied that a number of meetings did take place at which the family were informed of the patient's condition, his ongoing treatment and that the concerns they raised were fully and properly documented.

48. Regarding the treatment of the patient holistically I note and accept the H IPA's advice that overall, there is *'not enough evidence of the patients voice being heard'.* Following the first TACE in November 2016 the patient had a CT scan on 4 January 2017. This scan revealed the patient's liver cancer was much more extensive than had been thought at the time of the first TACE procedure in November 2016 and was still progressing. The first TACE procedure, which was purely palliative in intent, had minimal effect. The Trust state that a telephone conversation took place with the patient's next of kin on 11 January 2017, who indicated that as the initial right sided TACE had been adequately tolerated, clinicians and the family were happy to proceed with the left sided TACE subsequently arranged for February 2017. I note the meeting record held on 20 February 2017 documents that a third TACE was still being considered. I accept the H IPA's advice that, while this was a challenging situation for the medical team, a time comes when it is important to 'stop and think' about what is important to the patient and what his wishes and priorities would be in his final days. I agree with the H IPA that a pausing and reflection on the aim of management should have taken place when it became apparent that the liver cancer was more extensive than first thought and that it was progressing quickly. This should have been in a more detailed discussion among the medical team and the patient, and should have been held with the patient present or the patient's wishes in mind after ascertaining his views. The H IPA felt that '*throughout the period in February 2017 there is not enough evidence of the patient's voice being heard*'.

49. I therefore accept the H IPA's advice 'the *documentation of communication was rather concerned with technical issues rather than patient's priorities and concerns'* and consider this to constitute a failure in communication and to represent a failure in the care and treatment received. I note the CT scan of 4 January 2017 indicated much more extensive and progressing disease being present. I acknowledge that a second TACE was recommended by radiology and that the family were happy to proceed on the basis that the first TACE had been adequately tolerated by the patient. However, there is no evidence of a discussion among clinicians regarding the changing situation, i.e. more extensive and progressing disease. The complainant maintains that she was unaware of the progression of disease and of its aggressive nature as revealed in the CT scan prior to and even after the outpatient appointment held on 17 February 2017. She states that this information could (her emphasis) have altered her father's decision to go ahead with the second TACE. I consider that the results of the CT scan on 4 January 2017, notwithstanding the radiology recommendation, to have represented a time when 'stop and think' as suggested by the H IPA was warranted, an opportunity to note the change in circumstances and perhaps possible management adjustment in line with the patient and family wishes. It is possible that the family may have been happy to proceed with the left sided TACE but that would have been after a fully informed discussion and in full knowledge of the rapid progression of the patient's disease.

50. I also accept the H IPA advice that clinic letters and the discharge letter should have been provided to the patient which I consider would have assisted both the family and the patient in their understanding of the issues involved. I accept the point made by the Trust that guidance quoted by the H IPA from the Royal Academy of Medical Colleges was published in September 2018, more than one year following the circumstances of this complaint has been referenced. However I am satisfied that sending clinic letters and collaboration with families has been good practice/habit for much longer, for example General medical Practice (GMC) 2013 has a section on Communication, Partnership and Teamwork which references providing patients with information they want or need to know. I welcome the fact that in recent years it has become RVH Liver Unit practice to copy patients into clinic and discharge letters and that an initiative developed by NHS Scotland 'What matters to you' was adopted and launched by the Trust in September 2017.

51. I am satisfied that the complainant did receive updates on the patient's condition; however overall, I consider the failure to adopt a more patient centred approach and to receive important letters to represent a failure in the care and treatment provided to the patient. I consider the patient sustained the injustice of a loss of opportunity to have his views fully explored and to have a more patient centred holistic approach. The complainant also sustained the injustice of uncertainty because the patient's situation was not considered holistically Therefore, I partially uphold this element of the complaint.

e. Pain relief

Detail of Complaint

52. The complainant said when the patient was admitted on 7 February 2017, he was not prescribed adequate and timely pain relief.

Evidence considered

The Trust's response to investigation enquiries

53. The Trust stated that during his admission in February 2017 the patient's analgesia requirements were continuously monitored. Due to ongoing symptoms of pain, he was prescribed Oramorph[12] 2mg as required on 10 February 2017.

Relevant Independent Professional Advice

54. The H IPA advised that '*commenting on adequacy of pain relief is always difficult since pain is very subjective. This is especially true for patients with advanced intraabdominal cancer and ascites. These patients, in their advanced stage of disease, frequently complain about significant intractable abdominal discomfort which is often very difficult to control and, depending on the quality of the medical history, the patient does not necessary call "pain" as such… The patient was prescribed pain relief and the pain score was "0" a lot of the time, but there were a couple of days (10 February to 12 February), when the pain score was reported as up to 7. Pain medication would have been better prescribed as regular rather than for as required use which meant that the patient had to ask for it. Also, other*

[12] Pain medication

medication for the patient's discomfort might have been more adequate than traditional medication for (acute) pain and would have possibly made life more tolerable for the patient and would have improved the patient's quality of life. Especially at the end stage, quality of life depends on numerous additional factors other than pain and I feel that the palliative team could have improved these more if they had appreciated his likely more complex discomfort and symptoms better. Overall, I feel that the severity of the patient's condition in terms of discomfort was maybe not appreciated by the medical team which was too fixed on getting the TACE procedure done'.

55. Regarding the use of laxatives and the control of diabetes, the Hepatologist IPA advised that the '*constipation of the patient is in the context of abdominal pain and nausea as part of his abdominal discomfort he experienced. Sometimes this feeling can not be improved but is a sign of advanced cancer. He was given a laxative, but not enemas. With regards to diabetes control, I think it is right for the team to not concentrate too much on this…. his diabetes control was reasonable for the circumstances'.*

Analysis and Findings

56. I note the content of the clinical notes whereby the complaint raised the issue of the patient's pain levels and his discomfort. On 19 February 2017 in a discussion with a doctor, the complainant said that her father was '*in extreme pain and discomfort and that the medical staff were refusing to listen'*. The record also documents '*she explained to myself that he refuses pain relief when he is feeling bad'.* The following day, 20 February 2017, in a discussion with the palliative care nurse, the patient discussed his pain level. The record documents '*No c/*o (complaint of) *pain, on careful questioning [the patient] admitted that he was having some mild discomfort…. And stated that 'I would not call this pain'.* I note that the patient was prescribed pain medication 'as and when required' on 10 February 2017.

57. I note for the later part of the patient's admission his pain score on a scale of 1-10 on his observation charts was recorded as nil, with it elevated to 4-7 in the days after the TACE procedure on 10 February 2017. I accept the H IPA's advice that commenting on the adequacy of pain relief in individuals is difficult as the level of

pain experienced by differing people can be very subjective. I accept the advice many patients in the advanced stages of disease complain of 'discomfort' rather than pain as such. I also note the complainant's description of the patient as being a '*stoic gentleman'* who did not want to create a fuss and who was also wary of taking additional medication which might increase his abdominal discomfort.

58. I note that while the patient's pain score might have been recorded as nil, I do not necessarily consider this to represent a situation whereby he was not in any 'discomfort'. I accept the H IPA's advice the severity of the patient's condition in terms of the discomfort he was experiencing may not have been fully appreciated. In these circumstances, I accept the H IPA advice and I am satisfied that pain medication would have been better prescribed as regular rather than on an as required basis, which meant that the patient had to specifically ask for it. I consider this to constitute a failure in the care and treatment afforded to the patient. I consider the patient sustained the injustice of a loss of opportunity to receive optimum pain relief throughout his admission. I also consider it to have led to an injustice to the complainant of upset and uncertainty regarding the pain relief treatment the patient received. I uphold this element of complaint.

f. OGD

Detail of complaint

59. The complainant believed blame was assigned to her for telling a junior doctor that her father had difficulty swallowing, a fact she denies, which resulted in an unnecessary OGD being performed. She also complained that informed consent was not obtained.

Evidence considered

I considered the GMC Guidance.

The Trust's response to investigation enquiries

60. The Trust stated that following the Consultant Hepatologist's review of the patient on 12 February 2017, he arranged an OGD to investigate his upper gastro-intestinal symptoms, which were documented as including abdominal pain, which was worse after eating, nausea, dyspepsia and difficulty swallowing. These are all symptoms

that would suggest an OGD was indicated. The Consultant Hepatologist carried out the OGD on the day following his review (13 February 2017) and the findings offered a degree of reassurance in that serious pathology was excluded. The Trust also stated there was clear evidence the Doctor completed a consent form with the patient who had capacity to make the decision.

Relevant Independent Professional Advice

61. The H IPA advised that the '*Initial plan was for an OGD to check for varices. There is a consent form for an upper gastrointestinal endoscopy signed by the consultant and dated 13 February 2017. The form is signed by the patient (on the back) and* ***not*** *dated by the patient which is not recommended practice. The indication on the consent form given is dysphagia. Reading the notes, it appears to me that the problem was more that the patient refused to take food in rather than the food going down his oesophagus and it seems like there was a miscommunication. According to the discharge letter the OGD (13 February 2017) was done for surveillance for oesophageal varices. This would not an appropriate indication without detailed discussion with the patient given how unwell he was.*

62. *The OGD showed signs of problems of the blood flowing through the patient's liver properly (portal hypertension), but nothing else of note, in particular no varices which are another (more severe) sign of problems with the blood flow through the liver. Consent was obtained from the patient, but there is no evidence that there was a full and proper discussion as to the reasoning for the OGD being carried out with the patient. There was nothing to suggest that oesophageal varices was mentioned to him. In the circumstances of a probable problem of the patient refusing food and abdominal symptoms / difficulties after swallowing rather than difficulty in swallowing (which I feel was a miscommunication), I feel that that an OGD was not appropriate without a detailed discussion having taken place with the patient, given how unwell he was. From the notes, there did not seem an urgent indication to do an OGD.*'

Analysis and Findings

63. The complainant believed the patient had an unnecessary OGD performed, and proper consent had not been obtained.

64. An examination of the clinical record reveals the first reference to an OGD was on 10 February 2017 when it was recorded '*appointment for surveillance OGD for oesophageal varices'*[13] *rescheduled for later date'*. The record for 12 February 2017 simply states *'? OGD tomorrow'*. The OGD was carried out on 13 February 2017, the reasons being given as '*abdominal pain and dysphagia*[14]*'* The report stated that no varices were seen in the stomach with barely noticeable varices being found in the oesophagus.

65. I note the discharge letter of 22 February 2017 to the patient's GP stated, *'patient underwent surveillance OGD for varices as inpatient on 13/2/17….'* I note this is in line with the record of 10 February 2017 which also referenced varices. However, it is not in line with the content of the consent form the patient signed which did not mention varices rather it gave dysphagia as the reason for the procedure.

66. Responding to the content of the draft report the Consultant Gastroenterologist and Hepatologist (CGH) who carried out the OGD provided comment. He stated that he met the patient on three occasions, on 11 and 12 February 2017 on ward rounds and on 13 February 2017 for the OGD. He recalled that on 12 February the patient was visibly struggling to swallow food when he (the CGH) was assessing him. It was for this reason that the CGH suggested a camera test of the stomach to which the patient agreed. He stated there was not '*a miscommunication with the patient for an OGD and I recall our interaction.'*

67. The CGH stated that the OGD was not taken as '*part of a follow up assessment of varices and was not undertaken as due to any comments made by the patients daughter or anyone else. The main reason for proceeding as an inpatient was the observed and reported difficulty swallowing'.* He said that the patient's upper abdominal pain would also have been an acceptable indication to proceed '*particularly in the context of having concurrent co-morbidity that increased his risk of stress ulceration.'* In addition he stated that there was no question in his mind as to the patients fitness to undergo the procedure.

[13] Varices are abnormally dilated veins which can rupture and bleed. Variceal bleeding refers to bleeding of varices found throughout the gastrointestinal tract
[14] Difficulty or discomfort in swallowing

68. The CGH accepted that the medical notes of his ward rounds were brief, and he accepted an '*inadequate record of the conversations that took place.'* He stated that the *'discharge letter was prepared by a junior doctor and is incorrect describing the indication as surveillance of varices'*. He accepted that this error '*has likely arisen due to the inadequate medical notes of 12 February 2017.'* The CGH apologised for his part in this failing and any distress it has led to.

69. The evidence shows the patient signed a consent form on 13 February 2017 for an upper gastrointestinal endoscopy (The CGH stated that it was he who dated the form). I accept the H IPA's advice that while consent was obtained from the patient for this procedure to be carried out, there is no evidence in the clinical record that there was a full and proper discussion as to the reason for it. Having said this and having carefully considered the matter I find that I cannot go as far as to state that the OGD carried out on 13 February 2017 was an unnecessary procedure. I accept that it was a clinical decision taken by the consultant following him directly observing the patient struggling to swallow food and in the face of the patient reporting abdominal discomfort.

70. Nonetheless I refer to the GMC Guidance which states you must 'Record your work clearly, accurately and legibly' and that 'Clinical records should include:

a. relevant clinical findings

b. the decisions made and actions agreed, and who is making the decisions and agreeing the actions

c. the information given to patients

d. any drugs prescribed or other investigation or treatment

71. The CGH has accepted that the medical records are brief and represent an inadequate record of the conversations which took place with the patient on 11 and 12 February 2017. I agree with this assessment. It is this failure to adequately document conversations and decisions made which directly led to the OGD procedure incorrectly being described as a surveillance of varices in the patients discharge letter. I consider a failure in maintaining accurate and contemporaneous records impedes the thorough, independent assessment of care provided to patients. I also consider that maintaining accurate and appropriate records affords protection

to those involved in providing patient care by providing a clear record of their actions and the treatment given, if questions are asked at a later time. I consider that the failure to record what was discussed with the patient regarding the reasoning for the OGD procedure to represent a service failure and to be contrary to GMC Guidance relating to the care and treatment afforded to the patient. I also consider it to have led to an injustice to the complainant of upset and uncertainty regarding the necessity of the patient undergoing the procedure the patient undertook.

I uphold this element of the complaint.

G. Discharge

Detail of complaint

72. The complainant questioned the decision that the patient was medically fit to be discharged on 22 February 2017.

Evidence considered

The Trust's response to investigation enquiries

73. The Trust stated '*Prior to discharge, the Medical Team, Nursing Staff, Physiotherapist, Occupational Therapist, Dietician, Diabetes Specialist Nurse, Social Worker and the Palliative Care Team all assessed the patient. The consensus at time of discharge was that the patient's symptoms were controlled, and he was at his baseline level of function and mobility with no requirement for Social Services input at that time.*

Relevant Independent Professional Advice

74. The H IPA advised '*The patient was reviewed prior to discharge. It seems like there was at the beginning an ongoing misunderstanding of the patient's priorities to get his intractable abdominal discomfort improved, and the teams aim to get the TACE done. At time of discharge, the criteria of the hospital for fitness was whether there was anything medical that the team could offer which couldn't be offered in the community and the patient was therefore regarded as "fit" for discharge. The family's view was clearly different expecting a resolution of his abdominal discomfort which seems wasn't adequately acknowledged in the reviews'.*

75. The H IPA advised that '*there was a difference in understanding between the medical team and the family / patient what "fitness" for discharge means in a palliative context. There was no test or procedure outstanding, but the medical team together with the palliative care nurses should have made a discharge and follow up plan for the patient which the patient and his family agreed with. This would have been at least some improvement in symptoms and a plan on priorities and management in the community which would have included further (parenteral) medication to try if the current medication fails. I would have expected that this would even include out of hours contact details and emergency medication for any of the patient's symptoms becoming unbearable. It seems from the complaints meeting there were already issues with communication and the team found it difficult to find out priorities of the patient and see how these could be addressed. Instead, the discharge process seemed like a tick box exercise whether mobility, pain and nutrition could be improved before discharge*.'

Analysis and Findings

76. In considering this element of the complaint, I note that the patient entered the hospital on 7 February 2017 for an elective TACE procedure with the intention that he be almost immediately discharged home with his continuing care to take place outside of a hospital setting. It was only through complications resulting from the TACE procedure, and the need for IV antibiotics that his stay lasted as long as it did.

77. I note the medical team reviewed the patient prior to discharge on 22 February 2017. This included nursing staff, the physiotherapist, the occupational therapist, dietician, diabetes specialist nurse, the social worker and the palliative care team. An update had been provided to the NI Hospice Community Clinical Nurse specialist for ongoing follow up and a discharge letter was sent to the patient's GP. I accept the H IPA's advice the patient at this time was 'medically fit for discharge' in that there were no procedures outstanding to take place in a hospital setting and nothing further to be done at that time which could not take place within the community. His observations were stable with pain and nausea scores at '0' although as referenced earlier this is not to say that he was not experiencing some abdominal discomfort.

78. As the H IPA referenced, it is apparent that the family's expectation was that there should be a marked improvement in the patient's abdominal discomfort before discharge. While I can understand the H IPA's comments that there could have been more communication regarding future plans, contact details and perhaps emergency medication should his symptoms become unbearable, I note the complainant's comments regarding the patients desire to be discharged and that he raised no concerns with the staff over the planned discharge. In these circumstances, with the patient having been reviewed by the appropriate clinical teams, his observations being stable, the fact that no clinical procedures were planned and the expectation that his continuing care could be covered in the community, I am satisfied that the patient was medically fit to be discharged and cared for in the community. Therefore, I do not uphold this element of the complaint.

CONCLUSION

79. I received a complaint about the care and treatment provided to the patient between 28 November 2016 and 15 February 2017. I upheld aspects of the complaint.

Following my investigation of this complaint, I consider

- The patient's drug treatment should have focused more on relieving the patient's distressing abdominal symptoms by considering and administering medications avoiding the gastrointestinal tract.
- There was a failure to commence a food chart for the patient, to make a referral to dietetics for 15 days and in the consideration of refeeding syndrome.
- There was a failure to adopt a more patient centred approach to the patient's care and that he should have received or been copied into a discharge and clinic letters.
- There was a failure in record keeping with regard to the decision to conduct an OGD procedure.

I consider these failings to constitute a failure in the care and treatment afforded to the patient and to have led to injustice to the complainant of upset and uncertainty regarding the care and treatment her father received.

80. I offer through this report my condolences to the complainant and her family for the loss of their father during what was undoubtedly a distressing time. I note, through my reading of the correspondence that her concern was always that the patient received the best care possible. While I acknowledge that my report may not answer all of the concerns she has had, I hope that it may go some way to address outstanding concerns about the care and treatment the patient received.

Recommendations

81. I recommend the Trust provides to the complainant a written apology in accordance with NIPSO's 'Guidance on issuing an apology' (July 2019), for the injustice caused as a result of the failures identified (within **one month** of the date of this report).

82. I recommend that the Trust review procedures in place to ensure that the patient's voice is heard and in doing so take note of the independent professional advice and learning appended to this report.

83. I recommend the Trust should ensure relevant staff are given the opportunity to reflect on the findings of this report and the full IPA's advice in consideration of their own practice. This should be discussed at staff's next appraisal and noted in appraisal documentation.

84. I recommend the Trust implements an action plan to incorporate these recommendations and should provide me with an update within six months of the date of my final report. The Trust should support its action plan with evidence to confirm it took appropriate action (including, where appropriate, records of any relevant meetings, training records and/or self-declaration forms which indicate that staff read and understood any related policies).

MARGARET KELLY
OMBUDSMAN **February 2025**

Appendix 1

PRINCIPLES OF GOOD ADMINISTRATION

Good administration by public service providers means:

1. Getting it right

- Acting in accordance with the law and relevant guidance, with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

2. Being customer focused

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to its commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

3. Being open and accountable

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.
- Stating its criteria for decision making and giving reasons for decisions
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for its actions.

4. Acting fairly and proportionately

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

5. Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

6. Seeking continuous improvement

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.