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PUBLIC SERVICES OMBUDSMAN FOR WALES

The investigation of a complaint against Cwm Taf Morgannwg University Health Board and Swansea Bay University Health Board

A report by the
Public Services Ombudsman for Wales
Case: 201905294 and 202000972

Contents

Introduction

This report is issued under s23 of the Public Services Ombudsman (Wales) Act 2019.

In accordance with the provisions of the Act, the report has been anonymised so that, as far as possible, any details which might cause individuals to be identified have been amended or omitted. The report therefore refers to the complainant as Mrs W and her husband as Mr W.

Summary

Mrs W complained about the care provided to her husband, Mr W, by Abertawe Bro Morgannwg University Health Board, following his oesophageal (relating to the food pipe between the throat and stomach) cancer surgery in February 2018. Mrs W said that Mr W never really recovered after his surgery; he struggled to eat and became emaciated, immobile, incontinent and depressed. Although palliative support was eventually arranged, this was only arranged just 2 weeks before Mr W died in September 2018.

The Ombudsman found that Mr W should have been given psychosocial support and specialist dietetic support before, during and after his surgery. He was unable to reach any conclusions about whether the frequency and standard of telephone support offered by a Specialist Nurse was clinically appropriate because no records were maintained. During the same period, Mrs W also approached a charity for support and wrote twice to the Health Board to request contact, explaining that Mr W was very unwell, rapidly losing weight and struggling to eat. In addition, a Dietician identified that Mr W was malnourished and lost 19% of his bodyweight. No action was taken by the Health Board until Mrs W escalated her concerns to the NHS Wales Chief Executive, which should not have been necessary in light of Mr W's prognosis and his deteriorating condition. The Ombudsman therefore concluded that there was no evidence that the Health Board provided adequate and appropriate post-discharge care and support to Mr W and that it had failed to deal with Mrs W's requests for contact and support promptly.

He also found that Mr W and his wife were not advised on symptoms of recurrence or informed of Mr W's prognosis after an analysis of the tissue removed during his surgery indicated that Mr W's cancer had not been fully removed. There was no evidence that Mr and Mrs W were told of the high likelihood that Mr W's cancer would recur and that, if it did, it would probably be systemic. Therefore, the Ombudsman concluded that the Health Board failed to keep Mrs and Mr W fully informed about Mr W's condition, his prognosis and what to expect. The evidence in this case and in previous cases considered suggested that this failure was the result of a systemic issue relating to full and appropriate communication with patients, across the Health Board area.

The Ombudsman also found that, whilst Mr W's terminal diagnosis was not apparent until his symptoms recurred, palliative care should have been offered once the outcome of the surgery, and Mr W's poor prognosis, was known. The failure to do so meant that Mr and Mrs W were unable to access appropriate support and review promptly when Mr W's symptoms did recur. As a result, the Ombudsman found that the Health Board failed to provide suitable end-of-life care to Mr W.

After the events leading to this complaint, changes took place to NHS provision in the local government area of Bridgend, which was transferred from the former Abertawe Bro Morgannwg University Health Board (re-named Swansea Bay University Health Board) to the former Cwm Taf University Health Board (re-named Cwm Taf Morgannwg University Health Board). **Swansea Bay** and **Cwm Taf Morgannwg** agreed to implement the Ombudsman's recommendations respectively.

The Ombudsman recommended that, within **1 month** of the date of this report, both Swansea Bay and Cwm Taf Morgannwg should:

(a) Provide an apology to Mrs W for the shortcomings identified in this report.

(b) Share this report with all staff throughout the relevant service areas, for them to reflect on the findings and conclusions.

He also recommended that, within **3 months** of the date of this report, both Swansea Bay and Cwm Taf Morgannwg should:

(c) Review current practice on the recording of telephone support offered by the Specialist Nurse Service, to ensure that it is compliant with the NMC Code and standards on record keeping and remind all relevant staff of those standards.

(d) Conduct a random sampling Patient Opinion Survey to establish an understanding of patients' experiences of UGI cancer care. Repeat this survey a year later to establish whether there has been any improvement and, if any issues around communications are identified as prevailing, take further steps to address them.

Further, he recommended that, within **6 months** of the date of this report both Swansea Bay and Cwm Taf Morgannwg should:

(e) Ensure that the first Surgeon, the second Surgeon, the Oncologist and the Specialist Nurse consider and reflect on my findings as part of their regular supervision.

(f) Implement compulsory training for all doctors and nurses treating and managing patients with gastro-intestinal cancer, covering advanced communication skills and the need for patient involvement in care, including exploring patients' expectations and values around their personal diagnosis and prognosis, as well as the human rights issues identified in this case.

(g) Take steps to ensure that patients with upper GI cancer have access to nutritional assessment, tailored specialist dietetic support and psychosocial support, in line with the NICE guidance.

Finally, the Ombudsman recommended that, within **9 months** of the date of this report:

(h) Swansea Bay should consider the care in this case through a process akin to that provided in the Complaints Regulations, to decide whether there is any qualifying liability arising from any harm that arose from any breach in the Health Board's duty of care as a result of the failings identified.

(i) Within 6 months of reminding relevant staff of the NMC standard of record keeping, both Swansea Bay and Cwm Taf Morgannwg should conduct an audit of a reasonable sample of Specialist Nurse records in the service, to determine the standard of compliance with NMC Code and take action to address any shortcomings.

The Complaint

1. Mrs W complained about the care provided to her husband, Mr W, by Abertawe Bro Morgannwg University Health Board ("the Health Board"), following his cancer surgery in February 2018. Specifically, Mrs W complained that the Health Board failed to:

(a) Provide adequate and appropriate post-discharge care and support, with particular input from:

i. the District Nursing Team
ii. a Dietician
iii. a Specialist Nurse keyworker.

(b) Keep Mrs and Mr W fully informed about Mr W's condition, his prognosis and what to expect.

(c) Deal with Mrs W's requests for contact and support promptly.

(d) Take prompt and appropriate action to provide suitable end-of-life care when Mr W's terminal cancer recurrence was diagnosed.

Investigation

2. On 1 April 2019, after the events leading to this complaint, changes took place to NHS provision in the local government area of Bridgend, which was transferred from the former Abertawe Bro Morgannwg University Health Board (re-named Swansea Bay University Health Board – "Swansea Bay") to the former Cwm Taf University Health Board (re-named Cwm Taf Morgannwg University Health Board – "Cwm Taf Morgannwg"). The care in this case was provided by the Department of General and Upper Gastro-Intestinal Surgery and delivered across both the Bridgend and Swansea areas. Therefore, this report is issued against both Swansea Bay and Cwm Taf Morgannwg to take forward the recommendations made, respectively.

3. I obtained comments and copies of relevant documents from the Health Board, including Mr W's health records, relevant policies applicable at the time and telephone logs. I considered this information in conjunction with the evidence provided by Mrs W.

4. I sought advice from Nick Everitt, a Consultant in General and Upper Gastro-intestinal Surgery ("the Adviser"). The Adviser was asked to consider whether, without the benefit of hindsight, the care and treatment had been appropriate. I determine whether the standard of care was appropriate by referencing relevant national standards or regulatory, professional or statutory guidance which applied at the time.

5. I considered the last peer review into Upper Gastro-intestinal Cancer Services in the Health Board ("the Peer Review"), which was conducted by the Wales Cancer Network in November 2016. The Peer Review stated that there was an ongoing need for patient involvement in care, including exploring patients' expectations and values around their personal diagnosis and prognosis. It also found that there was reduced capacity for a specialist nurse service and for a dedicated dietetic service. It noted that these issues had also been present 3 years earlier.

6. I have also had regard to previous investigations conducted by my office. In 2016, I partially upheld a complaint against the Health Board relating to poor communication around the terminal nature of a patient's disease and the rapid deterioration of his condition.[1] Another, similar case was upheld in 2019.[2] In May 2020 I settled a complaint when the Health Board acknowledged failures relating to informed consent, including ensuring access to test results which should have informed the patient's prognosis.[3]

7. Mrs W and both Health Boards were given an opportunity to see and comment on a draft of this report before the final version was issued. I have not included in this report every detail investigated, but I am satisfied that nothing of significance has been overlooked.

[1] See previous decision 201501765
[2] See previous decision 201804041
[3] See previous decision 201905514

Relevant legislation

8. The National Institute of Health and Care Excellence Guideline NG83: Oesophago-gastric cancer: assessment and management in adults (January 2018 – "the NICE Guidance") states that patients should be informed of the symptoms of recurrent disease as well as what to do and how to access rapid review if any of those symptoms develop. Psychosocial support should be offered to help patients to understand the potential impact on family life, uncertainty around prognosis and where they can access further support. It also states that nutritional assessment and tailored, specialist dietetic support should be offered before, during and after radical treatments (such as surgery).

9. The Cancer Delivery Plan for Wales 2016-2020, drawn up by the Wales Cancer Network (November 2016 – "the Delivery Plan"), states that the Health Board should offer patients timely, high quality and accessible information about their condition, including honest and open discussion regarding treatment outcomes.

10. The NHS Wales National Optimal Pathway for Oesophageal Cancer: Point of Suspicion to First Definitive Treatment in Adults (aged 16 and over) (September 2019 – "the Pathway") was developed after the time of the events. It recommends that patients should receive consistent information and support, tailored to meet their needs, and be introduced to a Dietician at the time of their diagnosis.

11. The Nursing and Midwifery Council Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates ("the NMC Code") provides the standards of record keeping that apply to "the records that are relevant to [the individual's] scope of practice". It states that records must be completed at the time or as soon as possible after the event and should identify any risks or problems that have arisen as well as the steps taken to deal with them.

12. The Health Board's Standard Operating Procedure for the District Nursing Service confirmed that there was a mixed model of referral into that team across the Health Board area ("the referrals process").

Referrals in the Swansea area were made through a single point of access telephone service. However, referrals in the Bridgend area were made through the GP Practice or to the District Nursing Team directly.

13. All public bodies must comply with the Human Rights Act 1998 ("the HRA"), which incorporated the European Convention of Human Rights ("the Convention") into UK law. The Convention sets out individuals' rights in a number of "Articles". Article 8 provides individuals with the right to respect for private and family life, home and correspondence. This is relevant to the management of patients with terminal illness and the wider needs of the patient and their relatives as part of family life. Case law indicates that patients should be given the information, about their condition and treatment, to which they would assign significance. It is not my function to make definitive findings about whether human rights have been breached, but I will identify where they arise and comment upon a public body's regard for them.

14. The NHS Concerns, Complaints and Redress Arrangements (Wales) Regulations 2011 ("the Complaints Regulations") places a duty on the Health Board to consider whether any failings identified amounted to a "qualifying liability in tort". This is where a person has suffered a personal injury or loss arising from a breach of duty of care that is owed to that person. A breach of duty of care is defined as being where someone has failed to act with the same reasonable care that would be provided by another person in the same circumstances, but also that the failure has caused significant harm. Where it is identified that some harm was caused, the Health Board can offer redress which includes a detailed response and explanation, an appropriate apology, financial compensation and information regarding actions which is being undertaken to minimise the possibility of a reoccurrence of events.

The background events

15. In August **2017**, at 77 years old and living in the Swansea area, Mr W was diagnosed with oesophageal (relating to the food pipe between the throat and stomach) cancer. He received pre-operative chemotherapy (which can shrink tumours before they are removed, thereby making it easier for the surgeon to distinguish between normal and cancerous tissue and potentially improving post-operative recovery) on 1 and 22 November,

which did not have any significant impact on Mr W's tumour. Owing to available capacity, Mr W was referred to a Consultant Surgeon based in the Bridgend area ("the first Surgeon") for surgery to remove it.

16. During surgery on 31 January **2018** all visible cancer and affected lymph nodes (part of the immune system responsible for filtering and breaking down harmful cells) were removed and sent for analysis ("the tissue analysis"). It is usual practice for removed cancerous tissue to be analysed to see whether the rim of the tissue (known as the margin) is clear of cancer cells. Where a tumour is removed with a margin of normal tissue around it, this can indicate that the cancer has been fully removed. The presence, or absence, of cancer cells at the margin can also influence decisions about what, if any, further treatment is required.

17. On 2 February the first Surgeon told Mr and Mrs W that the operation had been successful and that all the cancer had been removed. Mr W was discharged on 5 February with plans for follow up from a Specialist Nurse from the Bridgend area ("the Specialist Nurse") and a doctor's review at the hospital in 3 to 4 weeks. A referral was sent to Mr W's GP, requesting that the District Nurse Team see him for wound management. This was not received by the District Nurse Team. Instead, Mr W's GP Practice Nurses assisted him with wound care. The Specialist Nurse telephoned Mrs W on 9 and 13 February but there were no notes made of what was discussed.

18. On 20 February the Upper Gastro-Intestinal Multidisciplinary Team ("the MDT") reviewed the tissue analysis; all but 1 of Mr W's lymph nodes were affected and cancerous cells were detected at the margins of the tissue removed. The MDT noted there was a very high chance that Mr W's cancer would recur and spread throughout his body. It decided not to offer Mr W treatment to suppress the formation of another tumour because the pre-operative chemotherapy had been ineffective.

19. Mr W was reviewed by the first Surgeon on 28 February. He noted that Mr W was recovering well, eating normally and reported no adverse symptoms around his chest or stomach. Mr W had lost 1 stone and 5.4 pounds in weight since before his operation. The first Surgeon wrote to Mr W's GP, stating that he had explained the findings of the tissue analysis and that the MDT had decided not to offer further treatment. He planned to review Mr W in 3 months' time.

20. The Specialist Nurse telephoned Mr and Mrs W for 5 minutes on 13 April and for 3 minutes on 21 April, but she made no record of what was discussed. When Mr W was reviewed by a hospital doctor on 23 May he was noted to be doing well with no reported symptoms. He had lost a further 6.8 pounds since February.

21. In June Mrs W approached a community cancer charity ("the Centre") for support. The Centre referred Mr W to a Dietician ("the Dietician"), noting that Mr W appeared to be generally unwell and had lost 2 stone and 7 pounds since the previous November. The Health Board received the referral form on 5 July.

22. On 2 July Mrs W wrote to the first Surgeon "in sheer desperation with regard to [Mr W's] health". She said that they had received no post-operative support, no input from a Dietician or the District Nurse Team, and no medical advice regarding Mr W's deterioration since his operation. Mrs W reported that Mr W had lost 3 stone and 7 pounds in total and asked whether this was normal following surgery. She also said that she had left several messages for the Specialist Nurse and with the first Surgeon's Secretary, requesting contact, but received no response. The first Surgeon later said that he did not receive this letter because he was away from work for most of July and August. It was passed to the Specialist Nurse, who telephoned Mrs W twice on 10 July – once for 3 minutes and once for 2 minutes – but she made no telephone notes of the conversation.

23. The Dietician's initial assessment on 20 July noted that Mr W had lost 19% of his body weight and was suffering from malnutrition. He was struggling to eat enough calories despite a prescription for nutrition supplements, so she wrote to Mr W's GP to request an increase in his prescription. On 26 July the Specialist Nurse telephoned Mrs W. The call lasted 9 minutes but no record was made of what was discussed.

24. On 6 August Mrs W wrote to the Director General for Health and Social Services and NHS Wales Chief Executive ("the Director"), enclosing a copy of her letter to the first Surgeon. She asked whether it was "normal practice" to leave a patient with no monitoring, advice or support from a specialist cancer service. She said that Mr W had gone from weighing 13 stone and 7 pounds to weighing just 9 stone and 10 pounds; she

believed he was now critically ill and needed medical attention but his next appointment with the first Surgeon was not until 12 September. On 7 August the Specialist Nurse telephoned Mrs W for 9 minutes but no record was made of what was discussed.

25. On 9 August Mrs W telephoned the Dietician reporting further deterioration; Mr W had lost nearly a further 7 pounds in the previous month, his dietary intake had decreased again, and he was unable to tolerate the full amount of nutrition supplements prescribed. The Dietician wrote to Mr W's GP and copied her letter to the Specialist Nurse.

26. Mrs W's letter to the Director was forwarded to the Health Board on 13 August and passed to the Specialist Nurse because the first Surgeon was not due to return to work until September. On the same day the Dietician recorded that the Specialist Nurse had telephoned her, told her about Mrs W's letter to the Director and expressed concern that things appeared to have suddenly escalated. The Dietician noted that the Specialist Nurse said no issues had been raised previously and that she (the Specialist Nurse) had thought Mrs W was very anxious and struggling to come to terms with the impact of Mr W's surgery.

27. The Specialist Nurse telephoned Mr and Mrs W 3 times between 15 and 17 August before she received an answer on 17 August; this call lasted 12 minutes but no telephone note was made of the conversation to confirm what was discussed. She subsequently arranged an urgent CT scan for Mr W, which took place on 23 August.

28. On 28 August the MDT noted that the CT scan confirmed Mr W's cancer had recurred. Palliative chemotherapy and services were recommended. The Specialist Nurse asked a Surgeon in the Swansea area ("the second Surgeon") to see Mr and Mrs W, in the absence of the first Surgeon, to explain the results.

29. The second Surgeon reviewed Mr W on 29 August. He noted that Mrs W expressed unhappiness that they had not been told about the results of the tissue analysis immediately following Mr W's operation, but said he had explained that there would have been nothing gained by telling them about that because it would depress their mood when they are in

recovery from a serious operation. The second Surgeon made a referral to an Oncologist ("the Oncologist") to consider palliative chemotherapy and told the GP that Mr W would need full palliative input including access to cancer support nurses.

30. On 6 September the Oncologist reviewed Mr W but concluded that he was too unwell to receive chemotherapy. She noted that the District Nurse Team was already involved and made a referral to the Palliative Care Team. She later wrote again, noting that Mrs W remained distressed about Mr W's condition and their experience since his surgery. She said that whilst the tissue analysis was important for the clinical team to know, to inform and plan future treatment options, it would not have increased the frequency of Mr W's follow-up reviews. Sadly, Mr W died on 14 September.

Mrs W's evidence

31. Mrs W said they were not advised that Mr W's chemotherapy in November had had no effect, or of the poor prognosis from the tissue analysis, and that they were unaware Mr W's cancer had recurred and was terminal until they saw the second Surgeon in August. She said the descriptions of Mr W at his reviews in February and May did not reflect the significant deterioration of her husband's health and that they were not advised about what kind of weight loss that might be expected after surgery. She noted that her requests for contact went unanswered until she wrote to the Director.

32. Mrs W explained that Mr W never really recovered after surgery; he struggled to eat and became emaciated, immobile, incontinent and depressed. She said that she had to seek care from the Out of Hours Service and, although palliative support was eventually arranged, this was just 2 weeks before Mr W died. Consequently, relevant palliative care aids, such as a commode and a hospital bed, were still in the process of being delivered and installed and Mr W never had the benefit of them. Mrs W said that witnessing her husband's slow deterioration and death as his sole carer and without advice or support left her with feelings of pure terror and helplessness that would stay with her forever and she could not understand why Mr W was not given the help and support that he needed and deserved.

The Health Boards' evidence

33. The Health Board said that Mr and Mrs W appeared to have interpreted the first Surgeon's comments on 2 February, that the operation had been successful, as meaning that he was cured. It suggested that Mr and Mrs W might not have directly asked about Mr W's prognosis and acknowledged that there was no evidence that the implications of the tissue analysis and the MDT's decision not to offer further treatment were explicitly explained. The Health Board also acknowledged that there should have been more robust documentation of Mr W's presentation at his review appointments and that he should have received tailored specialist Dietetic support.

34. The first Surgeon said he had explained that the tissue analysis revealed Mr W's cancer was aggressive, and that there were cancer cells at the margins, at Mr W's review on 28 February. However, he also said that he would not usually discuss with a patient how long they might have to live. Additionally, the second Surgeon stated that there would have been no benefit to have told Mr W about his poor prognosis because it was far from certain that his outlook was likely to be poor. The second Surgeon went on to say that it is his usual clinical practice to only inform patients of relevant survival rate statistics if their prognosis is particularly good or if the patient specifically asks for that information.

35. The Specialist Nurse said that it was not routine practice for a Dietician to be assigned. She recalled that there were occasions when her phone calls were not answered but that she had some lengthy, friendly conversations with Mrs W, during which it appeared that Mr W was having a good amount of varied foods. She said that she had received Mrs W's letter in July and attempted to make contact but believed that she had been unsuccessful because Mr and Mrs W were going out in the afternoons. She said this had reassured her that Mr W was undertaking normal activities until August, when she became aware that Mr W was lethargic, losing weight and experiencing low moods.

36. The Health Board said that the Specialist Nurse can be called on her phone in many clinical areas which made it difficult to maintain written telephone notes, but it acknowledged that this might also impede comprehensive assessment and evaluation of a patient's condition. It also

said that patients like Mr W can expect to lose 2-3 stone following surgery and provided a dietary advice sheet which stated that patients who undergo oesophageal surgery should continue with a liquid diet for the first week after discharge, moving onto “sloppy” foods in the second week and then solid foods in the third week. It confirmed that this progression should be guided by patient’s recovery and supported with contact from a Specialist Nurse each week.

37. The Health Board apologised that there were shortcomings in its communication with Mr and Mrs W, and that appropriate specialist support services were not provided. It regretted that these shortcomings led to Mr and Mrs W feeling unsupported and unprepared for Mr W’s deterioration and death. It also confirmed that it was in the process of arranging Human Rights training for both clinical and governance staff to ensure that patients’ human rights are fully considered during clinical treatment and complaint handling. Swansea Bay also offered to reconsider the impact of the events in this case under a process akin to the Complaints Regulations.

Professional Advice

38. The Adviser noted that, before surgery, there was no evidence that Mr W’s cancer had spread to his lymph nodes or any other parts of his body so, at that point, although his stage of cancer was advanced, there remained the possibility of a cure. However, the tissue analysis showed that Mr W’s cancer was more aggressive than first thought and suggested that some cancer had not been removed during surgery. This indicated that Mr W’s prognosis was much worse than initially believed and was already at a stage whereby few patients survive for long after diagnosis.

39. The Adviser explained that patients should be provided with all relevant and significant information and placed at the centre of any decision making that involves them. This included communicating accurate information on prognosis, based on the likely outcome, whilst accepting that sometimes exceptions do occur. He said this meant that Mr W should have been told what he needed and wanted to know, not what the clinicians thought he should be told, about his prognosis and the likelihood that his cancer would recur.

40. The Adviser confirmed that there was no guidance on the appropriate frequency or duration of post-operative follow-up care. However, he said it was essential to contact patients following surgery to ensure that they are recovering as expected and to check whether they have any ongoing problems with eating and drinking.

41. The Adviser also said that:

- The quality of the discharge information was poor when Mr W left hospital because there was no management plan provided for how he would be monitored and reviewed going forward.

- There was no evidence that the lost referral to the District Nurse Team resulted in any clinical consequence for Mr W, in terms of his operation and wound care.

- It should not have fallen to the Centre to arrange dietetic input.

- Once the post-operative analysis was known, Mr W should have been told that his cancer was likely to be terminal and palliative care should have been offered. Even if it was not required until later, this would have provided Mr and Mrs W with a channel for support once he started to deteriorate.

- Mr W's clinic appointments were well-timed to provide adequate monitoring but, given that there was no treatment that could be offered to Mr W, there was nothing to be gained from assessing the progress of his disease until it made him feel unwell.

- As soon as Mrs W raised concerns about Mr W's condition, action should have been taken to review him because – given the stage of his cancer – any deterioration was worrying.

- If Mr W had been promptly and properly informed, he and Mrs W could have come to terms with his terminal diagnosis, prepared themselves for his likely outcome and planned his end-of-life care.

- Once the CT scan had identified recurrence of Mr W's disease, the actions taken to arrange palliative input and end-of-life care were timely and comprehensive.

Analysis and conclusions

42. When considering clinical decisions, I consider care in the context of the circumstances and what was known at that time to determine whether the care provided fell within the bounds of appropriate clinical practice. In order to uphold a complaint, it must be established that any identified shortcomings resulted in a significant, unresolved hardship or injustice. I have received clear and detailed advice, which I accept in full, although my conclusions are my own.

43. Mrs W complained that the Health Board failed to provide adequate and appropriate post-discharge care and support. This related to the District Nursing Team, a Dietician and the Specialist Nurse, and I will deal with each one in turn.

44. The District Nurse referral was sent to Mr W's GP. This was the correct pathway for the referrals process in the Bridgend area but, as Mr W lived in the Swansea area, this was not the correct pathway for the relevant District Nursing Team that should have supported Mr W. As a result, the District Nursing Team was unaware of the referral and Mr W's GP Nurses had to provide appropriate wound care and support to him instead. It seems to me that this kind of confusion is a risk when the referrals process is dependent on the area, within the same health board, in which the service will be delivered. However, the Adviser confirmed that there did not appear to have been any clinical impact from this omission. Therefore, I **do not uphold** this element of the complaint. However, I invite both Swansea Bay and Cwm Taf Morgannwg to consider standardising the mode of referral into the District Nursing Services across their respective health board areas.

45. The Specialist Nurse confirmed that it was not routine practice to assign a Dietician to patients such as Mr W. I also note that the Peer Review identified that there was reduced capacity to provide that service. However, the NICE Guidance states that dietetic input should be arranged before, during and after surgery. I agree with the Adviser that it should not

have been left to the Centre to arrange this. The failure to arrange appropriate dietetic input meant that Mr W's deterioration and weight loss were not identified or addressed until late July, and no investigation into the recurrence of his cancer took place until August. In addition, Mr and Mrs W received no advice or support in the meantime. These omissions constitute an injustice for Mr and Mrs W. Therefore, I **uphold** this element of the complaint.

46. There is no guidance to define the level of follow-up that should have been offered to Mr W by the Specialist Nurse. The telephone logs indicated the number and frequency of attempted contacts, but I cannot establish with certainty what was discussed or whether the level of contact was appropriately informed by clinical assessment, because there are no notes available. This means that I cannot reach any conclusions about whether the frequency and standard of support offered by the Specialist Nurse was clinically appropriate. I consider, on the balance of the evidence available, that it is unlikely that Mrs W did not mention her concerns about her husband's dietary intake and weight loss, given her letter to the Consultant and Mr W's condition by the time he saw the Dietician in July. With no evidence to demonstrate that appropriate clinical assessment and review was offered, there is considerable uncertainty as to whether the actual recurrence of Mr W's cancer should have been identified sooner. In any event, Mrs W should not have had to escalate her concerns to the Director before Mr W's deterioration was addressed. This is a significant injustice to Mr and Mrs W, and I **uphold** this element of the complaint.

47. Mrs W complained that the Health Board failed to ensure that she and Mr W were fully informed about Mr W's condition, his prognosis and what to expect. I accept that all the visible cancer had been removed during surgery and that, from this point of view, the operation was a success. However, I also recognise that, to patients, this might sound like a cure. It is important, therefore, for clinicians to ensure that they clarify precisely what is meant, and what the patient (and their relatives) have understood. It is clear from Mrs W's actions in approaching the Centre and from the content of her letters that she was concerned about her husband's condition but that they did not understand what was happening.

Furthermore, both the second Surgeon and the Oncologist acknowledged that Mrs W raised concerns that they had not known that Mr W's cancer was likely to recur.

48. Mr and Mrs W should have been fully informed of the implications of the tissue analysis, and the MDT's decision not to offer further treatment, as soon as it was known. They should also have been given information on what symptoms of recurrence to look out for and how to access support in future. Whilst the first Surgeon recalled stating the results of the tissue analysis, there was nothing in the notes to confirm that he explained the implications of them or how Mr and Mrs W could request help if needed. There was a second missed opportunity to do so at the appointment in May, and more opportunities were missed each time the Specialist Nurse had a telephone conversation with Mrs W. As a result, Mr and Mrs W were isolated and unsupported by the Health Board, and scared and uncertain about what was going to happen at a time when they should have been supported to understand Mr W's prognosis and prepare for his eventual outcome. This was a serious injustice to Mr and Mrs W, and I **uphold** this element of the complaint.

49. I am also particularly concerned by the comments made by the second Surgeon, which seem to condone a practice whereby patients are not fully informed of the likely progress and outcome of their disease. The Health Board's formal response also acknowledged that it was not certain whether the implications of the tissue analysis had been fully explained, or whether Mr and Mrs W had asked about it. It is not reasonable to expect patients to know the specific questions to ask and the Adviser confirmed that such an approach, in which the clinician gives a patient only selected information they consider to be in a patient's best interests, is contrary to the NICE Guidance, the Delivery Plan and best practice. Furthermore, given the findings of the Peer Review and previous cases that have come to my attention (see paragraph 7), I am concerned that the failure to explain patients' prognoses may have been a systemic failing within the Health Board and across the Bridgend and Swansea areas.

50. Mrs W complained that the Health Board failed to deal with her requests for contact and support promptly. In the absence of any telephone notes, it is impossible to distinguish which incoming calls might have been Mrs W's messages requesting contact or, whether any attempt

was made to return them. In any event, Mrs W's letter to the Surgeon in early July clearly requested contact, explained Mr W's deterioration and asked for more support. The Adviser has confirmed that any deterioration should have been interpreted as a worrying sign and that a review should have been arranged as soon as symptoms of recurrence appeared. There were only 2 very short telephone calls logged after Mrs W's first letter, and the Specialist Nurse appears to have assumed that her calls were not answered because Mr and Mrs W were going out in the afternoons. It was not until Mrs W's letter to the Director had been forwarded to others in the Health Board that appropriate action was taken to engage with the Dietician and, ultimately, to arrange the CT scan. It should not have been necessary for Mrs W to escalate her concerns in that way before Mr W's deterioration was reviewed, and this constitutes an injustice to both Mr and Mrs W. Therefore, I **uphold** this element of the complaint.

51. Mrs W complained that the Health Board failed to take prompt and appropriate action to provide suitable end-of-life care when Mr W's terminal cancer recurrence was diagnosed. I acknowledge that the results of the tissue analysis did not automatically mean that Mr W was in the terminal stages of his disease. Whilst Mr W's cancer was at a stage whereby few patients survive for long, there are a minority of patients who do recover. Ultimately, Mr W's terminal diagnosis was not apparent until his symptoms recurred and, for the reasons outlined, it was not conclusively established until the CT scan results were known in August. The treatment provided after this point was appropriate. However, palliative care should have been offered when the MDT confirmed that systemic recurrence was likely. The failure to do so meant that Mr and Mrs W were unable to access appropriate support and review promptly when Mr W's symptoms did recur, and this was a significant injustice to them. For this reason, I **uphold** this element of the complaint.

52. Where I find evidence of service failure which has caused injustice, it is appropriate for me to consider whether a person's human rights may have been engaged and/or compromised as a result. Given Mrs W's evidence in describing her husband's deterioration, and the effects of that experience without adequate or appropriate advice and support, I think that both Mr and Mrs W's human rights are likely to have been compromised in this case. They should have had the information and support to enable them to receive appropriate care when Mr W had symptoms of recurrence.

They should also have had the time to come to terms with Mr W's prognosis and to prepare for his eventual outcome both mentally and with suitable palliative care aids and support. The fact that they did not impacted on Mr W's rights as an individual, and on both his and Mrs W's rights as part of wider family life. This is particularly important at the end of someone's life and the failures identified therefore represent serious injustices to both Mr and Mrs W.

53. The care that was provided in this case was delivered by the Department of General and Upper Gastro-Intestinal Surgery across both the Bridgend and Swansea areas. I was pleased that Swansea Bay offered to reconsider the issues raised in this complaint through a process akin to the Complaints Regulations. As this service has now been separated by the changes introduced in April 2019 (see paragraph 2), it is also, in my view, incumbent upon both Swansea Bay and Cwm Taf Morgannwg to address the shortcomings identified above and ensure that any systemic failures do not continue.

Recommendations

54. I recommend that, within **1 month** of the date of this report, both Swansea Bay and Cwm Taf Morgannwg should:

(a) Provide an apology to Mrs W for the shortcomings identified in this report.

(b) Share this report with all staff throughout the relevant service areas, for them to reflect on the findings and conclusions.

55. I recommend that, within **3 months** of the date of this report, both Swansea Bay and Cwm Taf Morgannwg should:

(c) Review current practice on the recording of telephone support offered by the Specialist Nurse Service, to ensure that it is compliant with the NMC Code and standards on record keeping and remind all relevant staff of those standards.

(d) Conduct a random sampling Patient Opinion Survey to establish an understanding of patients' experiences of UGI cancer care. Repeat this survey a year later to establish whether there has been any improvement and, if any issues around communications are identified as prevailing, take further steps to address them.

56. I recommend that, within **6 months** of the date of this report both Swansea Bay and Cwm Taf Morgannwg should:

(e) Ensure that the first Surgeon, the second Surgeon, the Oncologist and the Specialist Nurse consider and reflect on my findings as part of their regular supervision.

(f) Implement compulsory training for all doctors and nurses treating and managing patients with gastro-intestinal cancer, covering advanced communication skills and the need for patient involvement in care, including exploring patients' expectations and values around their personal diagnosis and prognosis, as well as the human rights issues identified in this case.

(g) Take steps to ensure that patients with upper GI cancer have access to nutritional assessment, tailored specialist dietetic support and psychosocial support, in line with the NICE guidance.

57. I recommend that, within **9 months** of the date of this report:

(h) Swansea Bay should consider the care in this case through a process akin to that provided in the Complaints Regulations, to decide whether there is any qualifying liability arising from any harm that arose from any breach in the Health Board's duty of care as a result of the failings identified.

(i) Within 6 months of reminding relevant staff of the NMC standard of record keeping, both Swansea Bay and Cwm Taf Morgannwg should conduct an audit of a reasonable sample of Specialist Nurse records in the service, to determine the standard of compliance with NMC Code and take action to address any shortcomings.

58. I am pleased to note that in commenting on the draft of this report, both **Swansea Bay** and **Cwm Taf Morgannwg** have agreed to implement these recommendations respectively.

Nick Bennett 8 January 2021
Ombudsman

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