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The investigation of a complaint

by Mrs P

against Betsi Cadwaladr University Health Board

A report by the
Public Services Ombudsman for Wales
Case: 201405067

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Introduction

This report is issued under section 16 of the Public Services Ombudsman (Wales) Act 2005 ("the PSOW Act").

In accordance with the provisions of the PSOW 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 P and to the Betsi Cadwaladr University Health Board[1] as "the Health Board".

[1] The operational name adopted by Betsi Cadwaladr University Local Health Board

Summary

Mrs P complained about her late husband Mr P's treatment in what were his final weeks and about the handling of her complaint. Specifically, she complained about a delay in Mr P being seen on admission to hospital due to a bed shortage, a failure in diagnosing his brain cancer from a scan performed, and failures in his care and treatment (including being given a drug of limited prognostic benefit). Mrs P also complained about how Mr P was afterwards discharged home to her care without appropriate plans and services in place. She further complained about his discharge with medication (about which no advice or guidance had been offered) and also about a letter written to her by the Consultant treating Mr P after his death, which had caused her further distress.

Following an examination of clinical records, and advice from the Ombudsman's clinical advisers, the following aspects of the complaint were **not upheld**: Whilst Mr P's brain cancer had not been diagnosed from the scan this was within acceptable clinical practice on the part of an average radiologist, given the type of cancer was rare. However, given Mr P's ongoing symptoms, consideration should have been given to a second opinion from a Neuroradiologist. Whilst recognising Mrs P's distress in receiving the letter, at an emotional time, the Consultant had written it with the best of intentions. It was not, to the objective eye, insensitive or meant to cause her distress.

The following complaints were **upheld**: There had been a delay in Mr P's admission. The course of clinical treatment offered to Mr P at that stage of his illness was not reasonable (given its slow response rate) in comparison with a treatment he could have been offered which may have prolonged his life expectancy even for a short time. Mr P was discharged home without proper arrangements in place. The discharge lacked effective communication with both Mr and Mrs P, and raised serious concerns surrounding controlled medication. The complaint handling concern was also upheld. The following recommendations were made, all of which the Health Board agreed to implement in full:

(a) A written apology to Mrs P and an offer of redress of £3,000 for her distress, time and trouble in pursuing her grievances and complaint handling delays.

(b) The preparation of an action plan dealing with the nursing care failings identified by the Ombudsman's clinical adviser (relating to clinical care, patient discharge and record keeping).

(c) The case should be discussed at both Radiology and Cancer services meetings as a learning point, taking into account the critical comments of the Ombudsman's clinical advisers. An action plan to deal with resulting actions to avoid recurrence should be prepared and shared with the Ombudsman.

The complaint

1. Mrs P complained about the care and treatment afforded to her late husband, Mr P, after admission to Glan Clwyd Hospital ("the hospital") in the weeks before his passing, and about the way in which her subsequent complaints had been dealt with. She had a number of specific concerns as set out below:

(a) There was a delay in Mr P's being admitted to the ED / a bed found in AMU[2] when he was referred by his GP for admission on 22 April 2014 and a failure in his active care (hydration and sickness issues) whilst waiting for a bed

(b) A failure (and consequent delay) in diagnosing Mr P's brain cancer from the scan performed during this admission

(c) Concerns about commencing Mr P on a course of clinical treatment which would be of little prognostic benefit to him (the drug regime known as Ipilimumab)

(d) Concerns about the safety of Mr P's discharge home on 19 May 2014, in particular:

(i) No MDT[3] to discuss his discharge home with Mrs P took place when the previous plan was to discharge him to a hospice

(ii) Failing to ensure suitable caring arrangements were in place given his high risk of falls and confusion and

(iii) Supplying a controlled drug, and other medications, on discharge with insufficient advice or guidance to Mr or Mrs P about their administration

[2] ED – Emergency Department. AMU – Acute Medical Unit, sometimes also called the Medical Admission Unit (MAU), which is a short stay department with patients either being discharged or admitted and transferred to a ward for further management and treatment

[3] MDT – Multi Disciplinary Team – a meeting involving a number of professionals (including clinicians and social workers)

(e) The above failures resulted in emotional distress to Mr and Mrs P and, in Mrs P's view, contributed to Mr P's further decline, resulting in a reduction in his quality of life in his final weeks that might have been avoidable and

(f) Comments in a letter from the Consultant Oncologist that Mrs P found insensitive, and delays in the handling of her complaint.

Investigation

2. I obtained comments and copies of relevant documents from the Health Board. I considered those in conjunction with the evidence provided by Mrs P. The Health Board did not provide any specific comments, so I shall include the information it gave Mrs P in response to her initial complaint as part of the background where appropriate.

3. I obtained advice from three of the Ombudsman's Professional Advisers. Dr Nagui Anton is an experienced Consultant Neuroradiologist at a major teaching hospital being its lead radiology consultant for neurosurgery and oncology MDT ("the First Adviser"), Ms Liz Onslow who is a senior Nurse with a breadth of community and acute hospital experience including palliative and end of life care ("the Second Adviser"), and Dr Paul Nathan who is a Consultant Oncologist specialising in Melanoma with significant experience of oncology palliative care ("the Third Adviser"). I asked all of them to consider the clinical records and answer questions posed in relation to Mr P's care.

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

Relevant legislation, policies and guidance

5. My jurisdiction requires that I consider complaints in terms of whether the management and care afforded to a patient falls within the bounds of acceptable clinical care and practice, and so is reasonable. I consider matters based on what was known (or should have been known) at the time events happened and so cannot reach conclusions with the benefit of hindsight.

6. The advisers and I have had regard to a number of regulatory and good practice guidance documents in considering this case, including the following:

- The National Health Service (Concerns, Complaints and Redress Arrangements) (Wales) Regulations 2011 (also known as "Putting Things Right" (PTR)
- Nursing and Midwifery Council (NMC) Standards of Conduct
- NMC Record Keeping Guidance
- National Institute for Health and Care Excellence (NICE) Guidelines.

The background events

Background

7. I shall not include all details from the clinical records. All parties are familiar with them. Below are the most relevant clinical entries about the complaints made and some background for context.

8. In **1992**, aged 37, Mr P was diagnosed with malignant melanoma (a skin cancer) and in **January 2012** underwent surgery for a mass in the oropharynx. The oropharynx is the part of the throat directly behind the mouth, including the soft palate, which helps with speech and swallowing. Consequently, Mr P had to be fed via a PEG - a tube through the stomach to provide nutrition and hydration to those unable to eat properly (either temporarily or permanently). In **August**, abdominal nodes were found, and further metastases (secondary cancer) in **October 2013**, as well as cancer cells in ascites in the pelvis. Ascites is fluid accumulation in those suffering from advanced cancer. Mr P also suffered a bowel obstruction requiring surgery in **2013**. The records noted that Mr P was "Fully aware that he cannot be cured but keen to explore all options...and keen to avoid hospitalisation".

9. More chemotherapy followed (the regime about which Mrs P complains), after a documented discussion between Mr P and a Consultant Oncologist ("the Consultant") at a clinic (in **November**) which was recorded as follows:

> "I have explained the diagnosis...we will send the sample for BRAF testing...if he has a BRAF[4] mutant cancer he will benefit from Vemurafenib. He is currently asymptomatic and fit so I have offered him [another regime type] ... explained that although systemic treatment does not cure cancer ... [we] aim to control his disease. Response to these treatments is not guaranteed ... The response rate to chemotherapy is 10-20%. We are planning to give him 2 cycles ... we will discuss further management after that ... I have also given him leaflets on [the regime], Ipilimumab and Vemurafenib ..."

10. A report of a sample taken from Mr P (in his clinical records dated **3 December**) noted that the samples " ... have detectable mutation BRAF which increases the likelihood of response to BRAF inhibition therapy ..." On **8 January 2014**, Mr P attended a review clinic with the Consultant having already completed two cycles of the chemotherapy regime offered to him earlier. The record noted as follows:

> "...he is generally well and asymptomatic ... I offered him Ipilimumab. I have explained the way immunotherapy works ... Response rate for this treatment is around 50% and a response is usually delayed ... He has signed the consent form and his first cycle will be on 22 January".

11. For some time Mr P had been complaining of persisting headaches. In early **March** 2014, and in later weeks, he suffered several short lived neurological episodes of weakness and slurred speech, considered to be "mini strokes".

12. On **22 April**, his GP saw Mr P and requested that he be admitted by ambulance to the hospital's AMU. Mr P was very dehydrated, with a history of nausea and vomiting. He arrived at hospital just before 10.30pm that evening. However, Mr P spent some time waiting at the ED before he was seen or found a bed on the AMU (in total over four hours). Intravenous (IV) fluids, antibiotics and pain relief were administered and further investigations planned. The assessment also recorded that Mr P had been suffering headaches for over eight weeks and that he "maintains headache all over the head".

[4] BRAF is a human gene which has been shown to be faulty, mutating in some cancers. Certain drugs (inhibitors) have been developed that target BRAF mutating cancer

13. Mr P underwent a number of investigations including an ultrasound and an MRI of his brain on **24 April** (this is the MRI about which Mrs P has complained, having been told later by the hospice Mr P was admitted to that it portrayed brain cancer). An MRI in this instance would be a scan that demonstrated details of brain soft tissues, as well as the brain coverings and skull, in contrast with an X-ray of the head which would only show the bones. The MRI was said to be "normal" with "no evidence of metastases". A CT scan (a detailed type of scan) on **28 April**, showed progression of Mr P's abdominal cancer and liver metastases. On **1 May,** Mr P developed symptoms suggestive of a mini stroke similar to earlier events (see paragraph 11 above). The palliative team noted that it might **"**be worth discussing the recent MRI with radiology" to see if there was any meningeal disease, but that discussion noted there was none on the MRI. On **2 May**, a Stroke Consultant was of the opinion that Mr P's symptoms did "not look vascular in origin".

14. Whilst Mr P's headaches had continued, by **13 May**, they were noted to be more under control. He was "anxious to go home" unless a bed could be found at the local hospice. There were none available. As he had vomited a few times, Mr P was kept in until an abdominal X-ray could be performed (it was feared he may have another obstruction). On **16 May**, it was recorded that Mr P had suffered a fall but had not lost consciousness. The X-ray performed showed no evidence of significant bowel abnormality. Mr P went home on weekend leave whilst arrangements for enhanced home care could be put in place for his formal discharge. Mrs P said that the weekend trial was not successful. Mr P was delirious, agitated and confused, having no conception of time. He was also unsteady on his feet and so at risk of falls.

15. Mr P returned to the ward as planned. On **19 May**, Mrs P said she went to the hospital for what she had understood was an MDT to discuss Mr P's discharge home. On arrival, she said she was told the meeting had been cancelled, that Mr P was already discharged and ready to be taken home. Mrs P said she was given a bag of medication containing ampoules of morphine although said these were not on the prescription list with his discharge notification. She added that his discharge papers were also dated for 14 May to the hospice, when Mr P was discharged home to her care that day. Furthermore, Mrs P said that she was given no information about how frequently steroids were to be administered or patches for Mr P's pain were to be changed. The clinical records showed Mr P's discharge notification to the

GP was dated 14 May indicating the place of discharge as the hospice. It listed ampoules of morphine to be given by injection as part of Mr P's discharge prescription.

16. While at home Mr P suffered a number of falls, about which Mrs P complains (see below). Thereafter, Mr P deteriorated, was unsteady on his feet and "acting out of character", having little cognition. District Nurses considered that he needed 24 hour supervision and that Mrs P would not be able to manage. On **27 May**, a bed was found at the local hospice and Mr P remained there until he passed away on **10 June**.

17. Mrs P first complained to the Health Board about the above issues on **28 May**. On **8 September**, she e-mailed the Health Board stating:

> "... I have had ... nothing from you since 19 July saying you were sorry it hadn't been answered within 30 days standard ... I feel ... that the investigation and my complaint are not important ... and you do not see this as a priority.
>
> I also received a letter from my husband's Oncologist [the Consultant] saying my husband was his star patient. I feel this was very insensitive for me to receive after his death as I now believe he was used as a guinea pig for this immunotherapy. The very fact that you have failed to respond has given me more distress in what is already a very upsetting period in my life and that of the family ..."

18. The Health Board responded by a detailed letter on **15 October**. Some of what it had to say is included below. It said that Mr P had been treated with Ipilimumab and had been made aware that the response rate to this "was around 50% and that its response rate was usually delayed".

19. Mrs P was dissatisfied with the response and so complained to me. She was concerned that Mr P had repeatedly complained about headaches and that this ought to have been an indication that something was wrong – the unidentified brain cancer. Mrs P remained distressed and unhappy at

being placed “in a vulnerable position” when Mr P was discharged on 19 May, adding:

> “...If my husband had been cared for effectively in hospital and not unsafely discharged he would not have had such a traumatic time leading up to his death; in fact he may have lived longer...”

Mrs P’s evidence

20. Mrs P, in relaying the above events, said that she had felt very unsupported after Mr P’s discharge and had contacted MacMillan and the District Nursing service herself. She said that no arrangements were put in place by the time Mr P was sent home with her on 19 May. She questioned why Mr P had been discharged without the planned MDT given the earlier weekend trial had not been successful because Mr P was so unsteady on his feet and disorientated. Mrs P said that she found the experience extremely stressful and upsetting. She felt the Health Board had failed Mr P in not identifying the cause of his severe headaches and could have done more.

The Health Board’s evidence

21. The Health Board, when responding to Mrs P (letter 15 October 2014) , acknowledged that there had been a delay in Mr P being seen and that he had been sent back to the ED to wait. It said this was because the hospital was particularly busy that night with a number of patients waiting for beds – the AMU had a shortage of beds. The Health Board apologised, adding that the AMU had now moved to a new building so the unit could now “accommodate 15 patients, rather than the 5 spaces that were available at the time”. This, it said, had alleviated the waiting problems experienced by Mr P.

22. The Health Board said that the ampoules of morphine were for additional pain relief, if required by Mr P, and to be administered by District Nurses. It apologised “unreservedly for the confusion” and said that the reason for them should have been clearly explained to Mr and Mrs P. In future, to avoid a recurrence, it said that discussions with a family about controlled medication to be given by District Nurses would take place with a Pharmacist before discharge. It added that a Discharge Liaison Nurse at the hospital said that she had suggested to Mrs P a referral to Marie Curie would

be appropriate for a rapid response service at home (who could contact her the evening of discharge) and that Mrs P would also be able to contact the Out of Hours GP service (OOHGP). It acknowledged that this had not been adequately explained to either Mr or Mrs P. It had also transpired, when it investigated, that the referral had not been entered on the relevant system so the Marie Curie service was completely unaware of the need to contact Mrs P.

23. The Health Board said that it had reflected on events and acknowledged that there should have been an MDT involving Mrs P (as originally planned) before discharging Mr P to "ensure full support could be given to you both at home". It apologised that the support arrangement had broken down, adding that it accepted "...these failings caused you and your husband unnecessary anxiety and distress". The Consultant said he had only written the letter to Mrs P, referring to Mr P as his "star patient", because he admired how he had dealt with his illness. He had not intended to cause Mrs P distress.

Professional advice

24. I am grateful to all the advisers for their review of documentation and the advice they gave. They consider aspects of clinical care on the same basis as me. I summarise what each had to say below.

25. On examination of the MRI performed on 24 April 2014, the **First Adviser** explained that the image taken included both a routine image and one after the injection of the contrast medium gadolinium - material that will highlight certain vascular and abnormal structures. Accordingly, this Adviser said that the imaging was of good quality and was a complete examination. The routine image showed some minor changes in certain areas albeit no obvious evidence as one would expect to see with metastases of the brain.

26. The Adviser said that after the gadolinium was injected there was still no evident abnormality within the brain structure to indicate metastases. However, there was abnormal thickening and enhancement of the leptomeninges (the tissue covering the brain). This involved three of the four right brain lobes (and to a much lesser extent to one of the left lobes) and so

was extensive. Whilst non-specific in appearance, and other conditions could have been the cause, these were not likely in Mr P's case. As a patient with known malignancy, the Adviser commented:

> " ... there is no doubt that these appearances would be indicative of intracranial malignant spread involving the brain covering but not the brain parenchyma (functional parts of the brain) ... The abnormalities ... were only seen on one sequence ... following the ... gadolinium ... The abnormal enhancement is not in the brain tissue which makes it more difficult to detect by general radiologists. The appearances, however, are rather typical and would be more readily detected by a specialised neuroradiologist. This does not imply that the majority of general radiologists would not be able to detect these changes. There is certainly a failing here but more of a mistake of omission rather than negligence or of lack of knowledge".

27. The First Adviser added that malignant melanoma was one of the common tumours to cause brain metastases. That said, in a large study of patients with brain cancer only 11% involved the brain covering as in Mr P's case, so it was less common and also not as readily detectable as in the functional areas of the brain itself. The level of care in Mr P's case, the Adviser felt, was thus within acceptable clinical practice. However, the First Adviser said that an MRI reported as "normal" did not tally with Mr P's clinical status at the time and so a radiology discussion through an MDT was warranted. This, he felt, could have led to Mr P being recalled for a repeat scan (with contrast medium) which might have led to an earlier diagnosis. This Adviser added that brain metastases from melanoma in patients where chemotherapy has not been effective (as in Mr P's case) "carries a bad prognosis". Given Mr P's poor general health, and the extensive nature of the spread to the brain covering, no intervention would have been possible. Even if the diagnosis had been made at the time of the MRI report, this Adviser said it would have:

> "... had no impact on the outcome, in terms of quality or length of remaining life, as it would not have changed any treatment options ..."

28. The **Second Adviser** was asked to comment generally on the level of nursing care and particularly to focus on the events surrounding Mr P's discharge home on 19 May (including issues about his falls and take home medication). This Adviser had some criticisms.

29. The Second Adviser said that Mr P's admission assessment identified concerns relating to pain and nutrition. Hydration was not identified (even though it was the reason for admission by his GP). Despite the assessed concerns, no care plans were generated about those matters as they should have been - e.g. Mr P had a PEG but there was no clear evidence about its management and whether this was his only means of nutrition / hydration or whether he also had an oral intake.

30. The falls risk on admission would not, on the score attributed, have triggered the implementation of a falls care pathway. However, Mr P's documented falls later, whilst in hospital, were not always taken into account on review of the falls risk assessments, as they should have been. In particular, the fall on 16 May would, if taken into account with all known falls evidence available, have increased the score to trigger a falls care pathway. This did not happen and was a failing. It in turn possibly impacted on future events at Mr P's discharge.

31. There was sufficient evidence, in this Adviser's view, to show that Mr P was experiencing difficulties with his balance and dizziness, having occasional confusion and disorientation. There was no evidence that this was discussed with Mr and Mrs P, or that these factors were taken into consideration in discharge planning – e.g. physiotherapy input might have helped with gait difficulties. An increased risk of falls would not itself prevent a patient's discharge home; no amount of supervision could guarantee preventing a person from falling. However, this Adviser felt that poor communication with Mr and Mrs P evidently left them "ill prepared to cope with the increased falls". Mr P wanted to go home (given there was no hospice bed available) but there was no evidence that this changed plan of care was discussed with Mrs P, so she had no opportunity to express her fears and anxiety. A case conference / MDT (as had been originally

intended) would have helped everyone and Mrs P, in particular, would have known exactly what could be provided and what the process was should Mr P's needs require increased care input (as a terminally ill patient). The Second Adviser added:

> "The importance of carer involvement in the discharge planning process, particularly in situations when a person is likely to continue to deteriorate at home, cannot be underestimated".

32. In so far as discharge medication was concerned, this Adviser said the nursing records showed an entry "medication checked and given" on 19 May but no indication that any explanation was given about them or that either Mr or Mrs P understood what to do with them – e.g. the interval of changing the slow release opioid patch Mr P had. In particular, there was no evidence of any explanation given about the morphine ampoules, which are a controlled drug only to be given by a Registered Nurse (in this case the District Nursing services). The Second Adviser was extremely concerned that the records also showed no evidence of communication with the District Nurses about when the opioid patch should be changed. She added, "The potential for a serious medication error, because of these failings, cannot be underestimated".

33. The nursing records relating to hydration matters, falls risk assessments, and how these issues affected Mr P's discharge, were "poor" in the Adviser's view. They were not in accordance with the required NMC standards for record keeping (see paragraph 6). This Adviser described them as "considerable failings in record keeping [that] have not been acknowledged or addressed by the Health Board". That meant this Adviser could not with confidence say whether (and if so to what extent) this had impacted on Mr P's wellbeing.

34. In conclusion, the Second Adviser said:

> "... There were a number of failings in the discharge process which could have caused considerable distress to Mr and Mrs P at a time when they were particularly vulnerable. Appropriate apologies have been offered for acknowledged failings in the discharge planning

process. Some failings in record keeping do not appear to have been recognised by the Health Board. There is no available action plan and no indication of how the Health Board proposes to monitor progress towards quality improvement in this aspect of care."

35. The **Third Adviser** echoed the First Adviser in saying that brain metastases was always a risk from melanoma. However, he said that there had only recently (in 2014) been professional agreement about the need for surveillance of patients, such as Mr P, who were at high risk of recurrence. National guidelines existing in 2012, for example, did not demand brain imaging in asymptomatic patients by way of surveillance and so most hospitals would not have performed routine brain scans without any symptoms warranting a scan. The scan in Mr P's case had initially been reported as normal. However, the Third Adviser said that as Mr P's symptoms continued (headaches, etc as set out above), it would have been appropriate to have arranged a repeat scan after a few weeks. If that had also been reported as normal it would have been reasonable to make a referral to a neurologist**.**

36. The Third Adviser said that in his opinion, on his admission in May, this was the latest point at which Mr P should have been offered another palliative drug (Vemurafenib). The drug about which Mrs P complained (Ipilimumab), in his view, ought not to have been continued. With respect to the latter, this Adviser also commented that it was not a drug intended for palliative use in advanced cancer as its response rate was low – durable disease control in 15% of patients, not the 50% cited by the Consultant and the Health Board. The drug Vemurafenib, however, inhibited the activity of "the BRAF gene" which was a mutated gene found in some 50% of melanomas. The BRAF gene was present in Mr P's case. In such patients Vemurafenib produced shrinkage of tumour and an improvement in cancer related symptoms in 90% of patients. It was also an active drug in brain disease and so could provide benefit for up to six months before the cancer also became resistant to it. The Third Adviser said he could see no evidence that this drug was offered in Mr P's case as an alternative, or that the pros and cons of both drugs were fully discussed with Mr P, so he could make an informed decision.

37. This Adviser further commented as follows:

> "The palliative oncological care of this patient should have included treatment with a BRAF inhibitor. The fact that it did not, and that the oncologist waited in vain for the rare possibility of a delayed response to Ipilimumab whilst treatment with Vemurafenib was an option is a cause for concern ...
>
> [Mr P] should have been offered Vemurafenib at a point where he was becoming symptomatic with no evidence of benefit from Ipilimumab. Given the disease burden many specialists would not have offered Ipilimumab at all and would have offered Vemurafenib as a first line treatment although this is more subjective. Treatment with Vemurafenib would have been likely to improve quality of life and may have prolonged life, albeit for a short time. I find the fact that the drug was not offered, despite the BRAF status of the tumour being known, a cause for significant concern ...
>
> I believe that the clinical management of metastatic melanoma in this case falls significantly short of the standard that I would expect ..."

Analysis and conclusions

38. Mrs P's complaint centres on the care afforded to her husband in what were to be his final weeks before his passing. It raises a number of issues that concern me. Whilst guided by the advice I have received, I stress that the conclusions reached in this report are mine.

39. I have set out above, in some detail, both relevant events and the advice received, meaning I can be relatively brief in my analysis, albeit Mrs P deserves a full explanation to all aspects of her concern. The Health Board has already acknowledged the delay in Mr P being allocated a bed and his wait at the ED (which his GP had sought to avoid by asking for a direct AMU admission). The Second Adviser also commented that despite being admitted due to vomiting and dehydration this was not noted as an issue in the assessment of Mr P, which was wrong. **I uphold** complaint **(a)**.

40. In relation to diagnosing Mr P's brain cancer, this is a more finely balanced issue. Being confined to the brain covering, as opposed to within the brain structure itself, means Mr P's cancer was rarer and so more difficult to detect by a radiologist (as opposed to a neuroradiologist – a specialist discipline). I have set out above what standard the Ombudsman is required to consider. There was a failure to diagnose Mr P's condition from the scan, but being heavily guided here by what the First Adviser had to say, the failure was not beyond reasonable clinical practice. In other words, taking into account what the First Adviser has said, and the rarity of the cancer, a number of radiologists may have reached the same conclusion in similar circumstances. Having said that, the palliative team was on the right track when it wondered if there was evidence of "meningeal disease" (see paragraph 13 above). It was assured the radiologists could see no such evidence. The First Adviser considers that an MDT should have discussed the matter further at this stage. This is why I say my finding here is finely balanced, but I am persuaded by what the First Adviser has said. I **do not uphold** complaint **(b)** as made out.

41. Turning to the Third Adviser's comments, however, whilst the initial scan was felt to be "normal", he makes the point, and I agree, that given Mr P's continuing symptoms it would have been reasonable to refer him for a repeat scan, or consider a referral to a neurologist. This did not happen. It should have, not least as both the First and Third Advisers clearly agree that brain metastases is well known in patients who have previously suffered from melanoma. It is possible a second scan may have been interpreted differently. As no further scan was performed we cannot know if it may have been possible at that point to make the diagnosis. Mr P's documented ongoing symptoms of headaches, dizziness, gait and balance issues, plainly, in my view, warranted serious consideration being given to more specialist advice, such as the scan being passed to a neuroradiologist for an opinion or making a referral to a neurologist.

42. From what the Third Adviser had to say, and from the documented discussions with Mr P which I have set out above, it is clear that Mr P had been made aware that the drug regime (Ipilimumab) carried no guarantee of success. The clinical record and the Health Board's complaint response both, wrongly, cite 50% as the response rate. My Adviser says it is 15%,

which is significantly different. That said, Mr P was said to be keen to explore all options, not unnaturally given his situation. As the patient, that was his decision to take, so long as he was fully aware of what the treatment entailed, its response rate, and of all options available to him.

43. The Third Adviser comments that there is no evidence that Mr P was told about another treatment option which he considers would have been the better option for the clear reasons he gives. The success rate figures he quotes in both cases (see above) make it clear it would have been the preferred drug given the BRAF gene mutation in Mr P's case. Whilst Mr P, from the clinical records, gave informed and proper consent to undergoing the regime about which Mrs P complains, it was limited to the extent of the options presented to him. There is no evidence that he was told about the significantly better response rate to Vemurafenib, as compared to, what the Third Adviser calls, the wait "in vain for the rare possibility of a delayed response to Ipilimumab". In that context, Mr P was not in possession of all relevant facts when he consented to the cycle. It is all the more alarming given that the test in December 2013 had identified the BRAF gene and the report clearly indicated that it would be responsive to Vemurafenib (see paragraph 10 above).

44. On that basis, whilst in a slightly different way from how Mrs P saw matters, I **uphold** complaint **(c)**. In the Third Adviser's view, this drug choice also impacted on Mr P's quality of life for a period of time and, potentially, the alternative Vemurafenib may have prolonged his life expectancy, even if by a short time. Whilst it is impossible to know with certainty, any additional time with a loved one is precious and I do not underestimate the loss of that for Mrs P and the additional distress I am certain she will face again on learning this.

45. It is clear from what the Second Adviser in particular has said that the arrangements for Mr P's discharge home in May did not go as they should have done. Whilst appreciating that Mr P wanted to go home, decisions were taken in haste with no proper thought to the consequences for either Mr or Mrs P. The lack of communication with both Mrs P and the District Nurses, about the drugs in particular, could have resulted in serious consequences – opioid toxicity (overdose) given the patches were opioid based and the ampoules contained morphine (an opioid). This is a matter of serious concern and may have been ameliorated had the planned MDT taken place.

That is where all issues could be discussed when planning a patient's discharge – falls, medications and additional care input. The Second Adviser also commented that the records were at some points so poor that it was impossible to say if this impacted on Mr P's care, which itself is a significant concern. **I uphold** all components of complaint **(d).**

46. From what I have already said above, I do not doubt that all events caused both Mr and Mrs P distress at the time. The failing identified by the Third Adviser in particular means that, whilst not affecting the overall outcome for Mr P, there is a possibility his life may have been prolonged and his symptoms better controlled for a short period had the other drug been offered to him. He describes Mr P's clinical management in that respect as falling significantly short of the standard expected. I **uphold** complaint **(e).**

47. In relation to the Consultant's letter it is possible that Mrs P has allowed events to colour her views. I do not criticise her for that. It was a highly emotive time, witnessing her husband's decline and the frustration she had felt at events set out above. The Consultant has explained why he wrote as he did – he admired Mr P's resilience and did not intend to cause Mrs P distress. Obviously only she knows how it made her feel but, to the impartial reader, the Consultant's letter does not appear insensitive of itself. To the contrary, it is full of admiration for Mr P and I'm sure the Consultant had the best of intentions in writing it. He hoped that it might help and be of some comfort to Mrs P. In the context of what I have found above, however, this is unfortunate, but I **do not uphold this part** of complaint **(f)**. With respect to complaints handling, it is clear that Mrs P had to wait longer than was reasonable for a response - some four and a half months and only after she had chased for a reply. Whilst acknowledging some concerns, the Health Board has not found failings to the same extent I have set out above. **I uphold** the remaining **part of (f).**

48. The different failings identified in this investigation give a cause for serious concern for a number of reasons. It highlights a concern about the quality of documentation, diagnostic issues, lack of beds for terminally ill patients, hurried and ill considered discharge of seriously ill patients together with avoidable medication concerns. Additionally, there remains the question of why the far better palliative option was not considered in Mr P's case. For these cumulative reasons I have taken the decision that the case raises issues of public interest.

49. I hope the above does provide Mrs P with answers to her concerns - even if I do not uphold all the complaints to the extent she might have wished. I do not doubt the events she describes were very distressing for her and that this has tainted her memories and the final weeks of her time with Mr P. I am sorry that what I say above may distress her further. I have some recommendations to make in light of the failings found, although the Health Board has already introduced some changes that would minimise or avoid recurrence in some instances. Before making my recommendations I want to stress to Mrs P that the amount of redress I recommend below relates purely to the failures in relation to complaint handling, her time and trouble in pursuing her grievances, and an element for the distress caused to her which I recognise that I could never adequately quantify. It is in line with sums I have recommended in previous cases.

Recommendations

50. I **recommend** that the following be undertaken within one month of the issue of this report unless specified differently:

1) The Health Board should apologise in writing to Mrs P for the shortcomings identified.

2) The Health Board should further offer Mrs P redress of £3,000 in terms of her time and trouble in pursuing her grievances and additional distress caused as a result of events and the failings identified (payable within six weeks of the issue of this report).

3) The Health Board should provide me with an action plan as suggested by the Second Adviser to demonstrate how it intends to deal with the nursing care failings identified (within 2 months of the issue of this report).

4) This case should be discussed at both the next Radiology meeting and the Cancer services meeting as a means of recognising the failures identified and of learning (taking into account the comments of the First and Third Advisers as set out above). The Health Board should provide evidence to me within one month of both meetings

taking place that this has happened, and also provide me with details of any resulting actions that may be identified.

51. I am pleased to note that in commenting on the draft of this report Betsi Cadwaladr University Health Board has agreed to implement all these recommendations.

Nick Bennett
Ombudsman

30 September 2015

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