

The investigation of a complaint by Miss O against
Abertawe Bro Morgannwg University Health Board

A report by the Public Services Ombudsman for Wales

Case: 201200787

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Introduction

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

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 Miss O, and her father, the aggrieved, as Mr O.

Summary

Mr O had a diagnosis of dementia. He was admitted to Cefn Coed hospital in 2009 and remained there until his death four months later. His daughter, Miss O, complained about aspects of his care towards the end of his life.

Mr O was assessed as 'at risk' of developing a pressure sore. Despite this, he was not re-assessed until after he developed significant pressure sore two months later. Had assessment and further preventive measures been taken, it is possible that the pressure sore might not have happened.

There was a lack of nutritional assessment, and Mr O was not referred to a dietician. Further, he should have been referred to a Speech & Language Therapist for a swallow assessment. Without regular nutritional assessments and without the input of a dietician and SALT, it is reasonable to conclude that the provision of food and fluid to Mr O was not as good as it could have been.

No end of life care pathway was in place at the time of Mr O's death, and his end of life care did not comply with the principles of palliative care. Nor was his pain management reasonable or consistent with guidelines. It therefore seemed likely that his pain management was insufficient on occasions.

My investigation identified patterns of failures to assess (pressure care, nutrition), to refer (to SALT, to a dietician, to palliative care), and to plan (end of life care). My office has issued two other reports to the Health Board this year¹ both which concerned elderly patients and in which some similar failings were identified, albeit at a different hospital and where the events occurred in 2008 and 2011. For that reason, I have referred this report to Healthcare Inspectorate Wales for it to take into account in planning its future inspections.

¹ Ombudsman case references 201100120 and 201101689.

I made a range of recommendations to the Health Board to prevent similar failings happening again. I also recommended that the Health Board apologise to Miss O and her family, and pay her £2000 for the distress exacerbated by failures in care during her father's last weeks of life. The Health Board agreed to implement all my recommendations.

The complaint

1. Mr O had a diagnosis of dementia. He was admitted to Cefn Coed hospital on 9 November 2009, and remained there until his death on 10 March 2010. Miss O has complained about aspects of her father's care towards the end of his life, and that he died in pain and distress. My investigation considered the following:

- pressure management;
- feeding and swallow assessment; and
- pain management and end of life care.

Investigation

2. My investigator obtained comments and copies of relevant documents, including Mr O's clinical records, from Abertawe Bro Morgannwg University Health Board and I have considered those in conjunction with the evidence provided by Miss O. I have not included every detail investigated in this report but I am satisfied that nothing of significance has been overlooked.

3. I obtained independent clinical advice from Dr M Puliyl, a consultant geriatrician, and from Ms L Onslow, a senior and experienced nurse. Their advice is summarised within this report, and is attached in full at **Appendices 1 and 2**.

4. Both Miss O and the Health Board were given the opportunity to see and comment on a draft of this report before the final version was issued.

Cefn Coed Hospital

5. Mr O was initially admitted to Ward A, a 9 bedded assessment unit at Cefn Coed hospital. He was transferred to Ward B, also at Cefn Coed, a 20 bedded ward providing continuing care to elderly male patients with mental health needs.

6. Cefn Coed Hospital is due for closure within the next five years.

The background events and evidence

Cefn Coed hospital – Ward A

7. Mr O had lived at home with his wife. He was known to have dementia, and was becoming increasingly confused with reports of some aggression. He attended a day centre on 9 November 2009 from where he was admitted to Ward A for assessment. An initial care plan/summary of needs assessed his Waterlow score² as eight, and his nutritional risk³ as three.

8. While on Ward A, Mr O was often confused, restless and agitated, especially at night, and had limited mobility. Throughout November and into December, he continued to have good and bad days and there was discussion about a long term care placement for him.

9. On 17 November, his Waterlow score was re-assessed and increased to 12 (at risk). His nutritional risk remained at three. These assessments remained the same when reviewed on 7 December.

10. On 9 December, the family attended a meeting with the consultant psychiatrist and other staff. They agreed that Mr O would be transferred to Ward B for long term care and assessed in 12 months' time.

11. On 15 December, his Waterlow score was re-assessed at 11 (at risk). His nutritional risk remained at three.

Cefn Coed Hospital – Ward B

12. Mr O moved to Ward B on 17 December.

² Waterlow scoring is a method of assessing the risk of developing pressure areas. 10+ = at risk, 15+ = high risk, 20+ = very high risk

³ Assessed using the Health Board's own nutrition risk tool. 0-2 = low risk, 3-6 = moderate risk, 7-29 = high risk

13. On 7 February 2010, Mr O was 'floppy and unresponsive'. He was reviewed by the on call doctor who considered that he may have had a TIA (Transient Ischaemic Attack, or mini-stroke). On 10 February, the family say that Mr O seemed chesty. Nursing entries on 11 February record that Mr O was having difficulty swallowing and was eating and drinking very little. From 12 February, he was believed to have a chest infection and possible CVA (Cerebrovascular Accident, or stroke). The plan was for assessment by a Speech and Language Therapist (SALT) and regular chest physiotherapy.

14. An entry by nursing staff at 6.30am on 14 February records the identification of a pressure sore as follows: 'Handed over by day staff that [Mr O] had been up all day in a chair. When night staff put [Mr O] to bed it was observed that [Mr O's] buttocks have started to break down and look very sore. ... Buttocks remain very sore this morning ...'. He was to remain in bed and a pressure mattress and cushion were to be obtained. Later that day he was moved to a bed with an air flow mattress. His Waterlow score was re-assessed as 18 (high risk).

15. Mr O was seen by a doctor on 15 February who noted '... pressure area in sacral region 5x3cm lesion, poor blood supply and ?gangrenous area. [Plan] ... urgent referral to Tissue Viability Nurse ...'. Family members were told of the pressure sore when they visited on 15 February.

16. Mr O was seen by a tissue viability nurse (TVN) on 16 February. She noted '...unable to determine extent of damage at present until devitalised tissue lifted. [Impression]: deep tissue injury resulting from ↓ in skins tolerability to pressure during the early stages of [chest infection] whilst sat out. ...'. The family took a photograph of Mr O's pressure sore at this time and subsequent pictures appeared to show it worsening.

17. On 19 February, the family met for the first time with the doctor managing Mr O's care, described by the Health Board as an experienced staff grade doctor. I will refer to him as Dr S. The family report he explained that Mr O had Alzheimer's and vascular dementia, and that towards the end of his life, possibly in about six months, he would need TLC (Tender Loving Care)⁴ with the administration of fentanyl (a strong painkiller). This is not recorded in the limited note of the meeting. A pain chart was to be started. [Note. The pain chart was maintained daily from 19 February until Mr O's death.]

18. A nutritional risk assessment appears to have been conducted on 20 February and Mr O's risk score increased to 12 (high risk). Entries in the nursing records from 17 to 23 February show that Mr O was accepting fluids. Also, food charts for 17, 18, 20, 21 and 22 February (the only food charts that were maintained on Ward B) record that he was eating a little.

19. On 19 and 20 February, Mr O was noted to be in considerable pain when the pressure area was cleaned. The family queried pain management on 21 February. On 22 February, a nurse noted 'in obvious pain being cleansed around sacral area'. The TVN reviewed the pressure sore on 23 February.

20. The family say that Mr O was brighter on 22 and 23 February; he ate some ice cream and drank some juice. Dr S saw Mr O on 24 February. The family say Dr S told them that the TLC pathway would start. They were shocked by this. Dr S noted that Mr O was to have a fentanyl patch every 72 hours (he prescribed a 25mg patch) and that pain charting was to continue. A nurse noted that the family would have open visiting from this time. The family contend that food was stopped from this time. They continued to give him thickened

⁴ A term used to denote the approach of keeping a patient comfortable and cared for. The medical adviser has commented on the use of the term in Appendix 2 (page 18)

fluid through a syringe which they say seemed to comfort him. The nursing notes for subsequent days record that Mr O was taking small sips of fluid.

21. On 26 February, a 50mg fentanyl patch was applied. The family believed Mr O was in pain.

22. On 27 February, a nurse carried out a 'review of care plan and problem list' and noted '[Mr O] has deteriorated rapidly over the past [2 weeks]. He is now no longer accepting food, and only small sips of liquid. ...'. The nurse also noted continued pressure wound care, and the plan for pain management – fentanyl patch 50mg with oramorph (a strong painkiller provided orally) for breakthrough pain.

23. The family remained concerned about pain management and on 1 March, they met again with Dr S. He agreed to raise the fentanyl patch dose to 100mg. The family recall him saying that Mr O had only days to live. Following that, Mr O was given oral oramorph regularly but the family still believed that he was in pain. On 3 March, Dr S increased the fentanyl patch to 125mgs. On 7 March, a 'marked deterioration' was noted in Mr O's condition. On 8 March, Dr S increased the fentanyl patch to 150mgs and noted 'continue TLC'.

24. On 8 March, Mr O was reviewed by the consultant old age psychiatrist, Dr R, who noted the view of nursing staff that Mr O experienced pain during nursing interventions. She gave instructions for the dosage and administration of oramorph, but noted that his care to date had not been inappropriate. She spoke to family members.

25. On the evening of 9 March, nursing staff contacted the on-call doctor to review analgesia as they were concerned that Mr O may not be swallowing oral medication. The doctor attended at 7.25pm and

noted 'syringe driver not available/not an option'⁵. The doctor sought advice from the palliative care team who recommended a medication regime. Mr O sadly died soon after in the early hours of 10 March.

The complaint/POVA⁶ enquiries

26. Miss O complained to the Health Board on 30 August 2010. The Health Board decided that the complaint merited a POVA enquiry. The POVA group undertook a review, including obtaining statements from Dr R and Dr S.

27. Dr R's statement included '... [Mr O] was not put on a formal end of life care pathway - this was not in use at this stage but the principles of terminal care were applied.... TLC is not exactly commenced, it is not a pathway There was no specific change in the care, [Mr O] was still receiving medication as prescribed.'

28. Dr S wrote: 'I prescribed [Mr O] pain killers according to the pain ladder, pain chart observations by nursing staff and also by my own observation of [Mr O's] discomfort.' He explained the progression of pain relief through paracetamol, co-codamol, to fentanyl patches and oramorph for break through pain. He said he had used the term TLC which means to keep a patient pain free and comfortable until the end of their life.

29. The POVA report was dated November 2010. It addressed the issues raised by Miss O; it had not defined its own terms of reference, and appears to be written like a complaint response, for example it referred to 'our staff'. Dr R was a member of the POVA group as was the manager of Ward B. The report identified no failings in Mr O's care.

⁵ A syringe driver gives a continuous dose of pain relieving medication through a needle under the skin.

⁶ Protection of Vulnerable Adults – policy and procedures to safeguard vulnerable adults produced in 2004. (This was replaced by the 'Wales Interim Policy and Procedures for the Protection of Vulnerable Adults from Abuse' in November 2010.)

30. Regarding end of life care, the POVA report included: 'The assessment and observation made that [Mr O] was in the terminal stages of his illness was made by the multi-disciplinary team'⁷. Also, '... The End of Life pathway was not being used in Ward B at the time of [Mr O's] ... death. Nursing staff were aware of the pathway but were unable to use it until they had attended appropriate training. Ward B staff ... and [Dr S] accessed the "End of Life pathway" training on 19 May 2010 Until that time the principles of terminal care were applied.'⁸ It goes on to say that the care given was in keeping with the Health Board's End of Life Pathway and The All Wales Last Days of Life Care Pathway (July 2010).⁹

31. Miss O pursued her complaints, with responses from the Health Board on 18 February 2011, 24 June 2011 and 6 March 2012. Across its three responses, the Health Board's position was that:

- with regard to pressure care, the Health Board acknowledged in its later correspondence that Waterlow assessments had not been reviewed on a regular basis;
- with regard to nutrition, the Health Board said that food and fluids had not been withheld from Mr O. It said that Mr O would tolerate small amounts of fluids and nutritional supplements but that on occasions he refused or was unable to take them. The Health Board apologised that fluid balance charts had not been used, and said it was unfortunate that the matter of nutrition had not been discussed in more detail with the family;
- with regard to pain management, the Health Board conveyed Dr S's opinion that Mr O had not suffered unnecessary pain and distress. The Health Board said that Mr O was 'comfortable and pain free on most occasions'. A pain assessment tool had been used, advice had been sought from a palliative care

⁷ Page 14 of the POVA report. I have not seen a record of such a multi-disciplinary meeting.

⁸ Page 11-12 of the POVA report

⁹ Page 19 of the POVA report

- consultant, and medication had been given for any break through pain;
- with regard to end of life care, the Health Board said the decision that Mr O was in the terminal stage of his illness was made by the multi-disciplinary team and then conveyed to the family on 19 February. The term TLC had been used to indicate the intention to keep Mr O pain free and comfortable until the end of his life. In its letter of 6 March 2012, the Health Board said that it was developing a more structured process to communicate with families about the condition, prognosis and treatment of their family member.

32. The Health Board drew up an action plan as a result of Miss O's complaints. It included the need for:

- full re-assessment of patients' care plans and needs on transfer between wards – a new protocol was circulated to the wards in July 2011;
- on-going assessments of Waterlow scores on Ward B (this was included in the protocol above, and discussed at a ward managers' meeting in April 2011); and
- a review of specialist seating (for pressure relief).

Professional advice

33. The clinical adviser's reports are attached in full as Appendices. In summary, the view of the Ombudsman's medical adviser is that there was no recognisable end of life care pathway, that Mr O's pain was not appropriately managed, and that advice should have been sought from the palliative care team much earlier. Also that Mr O's ability to swallow should have been assessed after a stroke was noted on 12 February. There was insufficient discussion with the family about feeding Mr O or about the move to 'TLC', a term which the adviser considered out of date.

34. The view of the nurse adviser is that there was a serious failure to assess Mr O's risk of developing pressure sores, and staff did not act to minimise his pressure sore risk after his deterioration on 11 February. However, the pressure wound was appropriately managed. Mr O was not referred to SALT as he should have been, and his nutrition risk was not reviewed on Ward B until 20 February, despite his dietary intake being noted as poor from 25 January. While his intake reduced, this was not discussed with the family, although there is no evidence to suggest that nutrition was withheld. The nurse adviser shares the medical adviser's concern that Mr O was not referred earlier to palliative care, although notes that Mr O's pain was assessed and monitored. The nurse adviser queries why a syringe driver was not used. The nurse adviser comments that the Health Board's action plan is inadequate to address the failings in Mr O's care.

Analysis and conclusions

35. In reaching my findings, I have been guided by the thorough and helpful analyses of the clinical advisers. This investigation has considered three elements of Miss O's complaints and I address each of these below.

Pressure management

36. Mr O was assessed as 'at risk' of developing a pressure sore on 15 December 2009. Despite this, there was no re-assessment until after the pressure sore was identified on 14 February – a period of two months. Pressure sore assessment is a basic part of nursing care and it is difficult to understand how it was overlooked, more so as Mr O was already known to be as being at risk. Further, Mr O became unwell from 11 February, increasing his susceptibility to pressure damage, and still no assessment was done. This was simply unacceptable, and was, as the nurse adviser has said, a serious failing. The worst case scenario subsequently ensued with

Mr O, an ill and vulnerable patient, developing a serious and painful pressure sore. Had assessment and further preventive measures been taken, it is possible that the pressure sore might not have happened.

37. Like the family, I was shocked at the photographs taken of Mr O's pressure sore, both the extent of it and at its apparent worsening. However, I have been reassured by the explanation and advice from the nurse adviser that the sore, once identified, was properly managed and was starting to heal. I therefore conclude that there were no failings in wound care. However, I **uphold** this complaint for the failure to assess him.

Feeding and swallow assessment

38. The family has been extremely concerned about Mr O's food and fluid intake, and I have considered a number of issues relating to this - whether he was provided with sufficient food/fluid, whether food/fluid were deliberately withheld from him towards the end of his life, and whether he was able to swallow what he was given.

39. First, I note a lack of nutritional assessments. Mr O was assessed on Ward A on 12 December when he was noted to be in the 'moderate risk' category. However, he was not reassessed on Ward B until 20 February by which time he had moved into the 'high risk' category. The nurse adviser has identified that at this time Mr O should have been referred to a dietician. He was not.

40. While only limited information is recorded about Mr O's intake in the nursing notes, there is reference to provision of fortified food and fluids until 22 February. The family contend that after that, food was withdrawn. The shared view of the advisers is that there is no evidence that food and fluids were deliberately withheld from Mr O. Also that a lack of intake was likely to be a part of the progression of his illness. This should have been better explained to the family.

41. Mr O was a patient with dementia who had suffered a likely stroke. Both of these conditions could affect his ability to swallow. The medical adviser has highlighted that problems with his ability to swallow were noted on 11 February and that Mr O was to be referred to SALT for an assessment. The nurse adviser has explained why a SALT assessment was important¹⁰. That referral should have happened and did not. The Health Board has offered no explanation as to why.

42. Without regular nutritional assessments and without the input of a dietician and SALT, it is reasonable to conclude that the provision of food and fluid to Mr O was not as good as it could have been. I **uphold** this complaint, although not that food/fluid was deliberately withheld.

Pain management and end of life care

43. One of the family's abiding concerns is that Mr O unnecessarily suffered pain and distress towards the end of his life. They have also raised questions about the move to 'TLC', and I will address this first.

44. The medical adviser has explained that TLC is an outdated term. It is not a proper or recognised care pathway; the POVA report notes that such a pathway was not in place on Ward B until May 2010. Dr S appears to have moved Mr O to TLC, or to palliative care only, on 24 February when he started introduced stronger pain relief in the form of fentanyl. There is no explicit statement to this effect or reasoning for the decision in the records. I cannot fully address the gap between Dr S's decision at that time and the family's contention that Mr O was showing some signs of improvement as Dr S has not documented his reasoning. However, I note the nursing review on 27 February that Mr O had deteriorated rapidly over the previous two weeks, that is from the time of his stroke.

¹⁰ See page 29

45. Dr S increased Mr O's pain relief on 24 February when he started the fentanyl patches. It is documented several times in the records that Mr O experienced pain during nursing interventions and when he was turned. The family believe that he was in pain on many occasions and they often had to ask for additional pain relief for him. They sought meetings about this with Dr S on 1 March and Dr R on 8 March. The Health Board has said that a pain assessment tool had been used, medication had been given for break through pain, and palliative care advice had been sought. Dr S has said that he had given pain relief according to the 'pain ladder'¹¹. The medical adviser disagrees. He has commented that the management of pain was unsatisfactory, it was not consistent with conventional guidelines, the dosage of oramorph for break through pain was inadequate, and a referral should have been made to the palliative care team much sooner. I agree with his views.

46. The clear advice I have received is that Mr O's end of life care did not comply with the principles of palliative care. Nor was his pain management reasonable or consistent with guidelines. It therefore seems likely that his pain management was insufficient on occasions. I **uphold** this complaint.

Summary

47. Clear patterns have emerged here of failures to assess (pressure care, nutrition), to refer (to SALT, to a dietician, to palliative care), and to plan (end of life care).

48. My office has issued two other reports to the Health Board this year¹² both which concerned elderly patients and in which some similar failings were identified, albeit at a different hospital and where the events occurred in 2008 and 2011. These included poor pain relief at end of life, lack of pressure sore assessment, lack of nutritional assessment or referral to dieticians. This is clearly of

¹¹ See page 20 of the medical adviser's report at Appendix 1 for an explanation.

¹² Ombudsman case references 201100120 and 201101689.

concern, and for that reason I will be referring this report to Healthcare Inspectorate Wales for it to take into account in planning its future inspections.

49. I would also comment that although Cefn Coed hospital is due for closure, for the time that it remains open it should be expected to deliver the highest standards of care to those patients who continue to need its services.

50. Finally, given the significant findings of this investigation, I am surprised and disappointed that the POVA process found no failings in Mr O's care. In my view, the POVA report simply offered up the views of the clinicians; there was no proper analysis of the care provided. It appeared to defend the actions of the Health Board, which is not its function.

Recommendations

51. I make the following recommendations:

Within **a month** of the issue of the final version of this report, the Health Board should:

- a) offer a genuine and fulsome apology to Miss O and her family for the failings I have identified in this report. It should subsequently keep Miss O informed of what actions are being taken as a result of these recommendations;
- b) make a payment of £2000 to Miss O for the distress exacerbated by failures in care during her father's last weeks of life;
- c) confirm to me that the End of Life care pathway introduced in 2010 includes the need to consider timely referral to the palliative care team.

Within **three months** of this report, the Health Board should:

- d) arrange for this report to be discussed between Dr R and Dr S and their clinical appraisers to ensure that learning is confirmed;
- e) arrange refresher training for nursing staff on the end of life care pathway, including palliative care referrals and the use of specialist equipment (for example, syringe drivers);
- f) provide my office with evidence of steps taken to improve nutritional care;
- g) either introduce referral pathways to SALT and dieticians and palliative care OR audit the effectiveness of existing pathways;
- h) ensure that staff are fully trained in the use of the referral pathways.

Within **four months** of this report, the Health Board should:

- i) audit compliance with the end of life care pathway and the appropriateness, or not, of palliative care referrals.

In light of the Health Board's own action plan, I also ask the Health Board to confirm to me:

- j) that the key worker update form has been devised and that training has been delivered to Ward B nurses on care planning and responsibilities; and
- k) how senior nurses monitor care delivery on ward B.

52. I further ask the Health Board to note my concerns about the POVA enquiries, and to consider whether any action needs to be taken as a result.

53. I am pleased to note that in commenting on the draft of this report the Health Board has agreed to implement these recommendations.

Peter Tyndall
Ombudsman

1 February 2013

MEDICAL ADVICE

Clinical Adviser's Name and Qualifications

M Puliyei MB MSc MD FRCP Dip Card

Relevance of qualifications and/or experience to clinical aspects

of this case: I am accredited in both internal medicine and in geriatrics. I have experience in the areas covered by this case and so I am competent to comment on this case.

Conflict of Interest (clarification of any links with body or

clinicians complained about): I do not know any of the parties concerned. I have no conflict of interest to declare.

Background and Chronology:

Mr O, a 77 year old, who lived at home with his wife of 53 years was diagnosed with mixed dementia (Alzheimer's disease + vascular dementia) and had declining memory, agitation and panic attacks. There is documentary evidence that he was manifesting aggression to his wife with delusions of spousal infidelity as far back as April 2005.

After attending a day centre on 9/12/09 he was admitted the same day to the Ward A, Cefn Coed Hospital, Swansea for assessment. He was transferred to Ward B on 17/12/09 and by that time he became incontinent and unable to walk. A CT scan on 5/1/10 showed generalised brain shrinkage which was consistent with a diagnosis of dementia.

Mr O developed a sacral pressure sore which was first noticed on the evening of 13/2/10 after he had been seated in a chair all day. This was reviewed by periodically by the tissue viability nurse. He went downhill and seemed to deteriorate after the sacral pressure sore developed. The ulcer appeared to cause him pain which distressed his family.

He stopped eating and became less responsive. On 24/2/10 he was started on a "TLC pathway" and fentanyl (a strong opioid) patch was applied to the skin to relieve pain from the sacral sore.

He passed away on 10/3/10. Cause of death was certified as: "End stage dementia".

Questions and Responses:

1. Mr O appears to have declined from 10 February 2010; what was the diagnosis and prognosis at this time?

There is no entry dated 10/2/10 in his medical notes. So one is unable to comment on what happened specifically on that date.

However, it is stated on 11/2/10 at 2.45 p.m. that he "required suctioning soon after dinner as he appeared to have difficulty swallowing." The physiotherapist has written at 4.00pm that he was "leaning heavily to the right, unable to sit unsupported and flaccid [=floppy] right arm".

There is a later entry on 11/2/10 by the junior doctor, "Nursing staff also report R [=Right] arm not moving → difficult to assess, slumped to R [=Right] → seen by the duty doctor Sunday [7/2/10] c [=with] ?TIA [*transient ischaemic attack - a mini-stroke*]". And the diagnosis of the junior doctor on 11/2/10 was ??CVA [=stroke].

The notes on 11/2/10 indicate that he had suffered a further stroke around that time. As regards prognosis - it is recorded (in the medical notes from April 2005) that previously he had a stroke in

1997. It can be assumed, given his presentation of mixed dementia (Alzheimer's disease + vascular dementia) that he had suffered multiple small strokes in the past, leading to loss of brain cells causing shrinkage of the brain and contributing to vascular dementia. Therefore, prognostically a further stroke would have impacted adversely on his dementia.

2. Were there any signs of improvement after 10 February? The family say he was showing small signs of improvement (their letter of complaint of 30/8/10) - smiling, recognition.

The entry in the medical notes for 12/2/10 states, "Pt [=patient] reviewed. Seems settled. Is his usual self (informed by nursing staff)... moving all 4 limbs today."

The medical notes do not refer to "the quick signs of recovery, smiling and talking, eating ice cream!" mentioned in the family's complaint letter dated 31/8/10. But the information reported by nursing staff on 12/2/10: "Is his usual self" is consistent with the family's report of improvement.

Yet the next day, 13/2/12 it says, "Up in specialised chair for a few hours. Continues to look poorly". Subsequently when he was put to bed that evening a pressure sore was spotted on his lower back.

Mr O's limb weakness from the stroke improved quickly while problems with swallowing persisted. He deteriorated rapidly when he developed the sacral pressure sore and the pressure ulcer continued to get worse.

3. Is it appropriate to use the term 'TLC' with the family?

TLC [=tender loving care] was used in the past to imply "keeping the patient comfortable". That abbreviation is no longer in vogue in medicine but it appears to have been in usage in this unit in 2010. TLC was recognised as being patronising, pejorative and inappropriate. It has been discarded from palliative care parlance.

TLC has been replaced by the term “palliation” signifying symptom control without curative intent.

4. Why was he moved to TLC?

The new stroke around 11/2/10 would have impacted adversely on his mental health and dementia. Development of the pressure sore would have brought on pain because the ulcer exposed nerve endings. On 21/2/10 “...family concerned about pain and asked how the staff were assessing this...” At that point he was being given simple analgesia (paracetamol). In a demented patient who is not able to communicate staff should have been alert to non-verbal clues as regards his pain. And on looking at the nursing notes, this appears to have been taken on board.

Once the pressure sore appeared, he was started to be turned two-hourly. The turning itself may have been a painful process. Staff were mindful of this. On 22/2/10 it says:

“[Mr O] has slept well, disturbing and becoming distressed during intervention - turned 2 hourly. In obvious pain when being cleansed around sacral area”.

On 22-23/2/10, “has not experienced any signs of pain since given cocodamol tablets as prescribed”.

On 24/2/10, “Deterioration. ↓ [=reduced] activity. Not vocalising. C/o [=complaining of] pain during movement. C/o breathlessness. Spoke to daughter... discussed fentanyl patch.”

On 25/2/10, “[Mr O] has deteriorated rapidly over the past 2/52. [2 weeks; i.e. from 11/2/10]. He is no longer accepting food and only small sips of liquid...”

The decision to palliate may have been based on overall deterioration though this does not appear to have been negotiated properly with the family and so documented, as it should have been.

5. Was a recognisable end of life pathway instigated?

No, not till the last evening of his life. Fentanyl patches do not constitute end-of-life pathway. Its absorption is varied and erratic and as it is applied on to the skin for 72 hours at a time, it does not lend itself to the fine titration that is called for in order to achieve pain relief.

In this instance, it would appear that he was put on the strong opioid (fentanyl) while at the same time he continued to be on the weak opioid (cocodamol). That is pharmacologically illogical. Further, for breakthrough pain he was offered 2.5 mls oramorph which represents inadequate dosing in someone who is already established on the strong opioid fentanyl. He should correctly have received 5 -10 ml oramorph rather than 2.5 ml in each dose.

Principles of palliative care were ignored except on the last evening of his life. The management of his pain was not consistent with conventional guidelines. The WHO analgesic ladder which specifies step-wise increase with more potent painkillers was not used. [*The World Health Organization three-step analgesic ladder comes of age. Palliat Med April 2004 18: 175-176*].

There is mention on 9/3/10 that a “syringe driver [=a syringe pump which can be set up to infuse drugs for pain relief under the skin, round the clock] was not available/not an option”.

6. Did ‘TLC’ involve withdrawal of food? If so was this appropriate?

Palliation implies symptom control. The notes state that on 25/2/10 he was not eating and having very little liquid of his own volition.

Denial of food and drink is not a part of the regime of palliation. However, if the patient does not eat or drink of his own accord, it is not usual practice to “force-feed” or to resort to “tube-feeding” etc especially if death is imminent. Often the terminal, dying patient loses appetite, is no longer hungry and therefore refuses food and drink. In the circumstances it would be inappropriate to feed forcibly. However this is a negotiated decision and one is usually guided also by the patient’s wishes (when he has capacity or has expressed wishes previously) or that of the family.

Comfort rather than nutrition is the priority at the stage of end of life. It may suffice at that point to simply moisten the mouth and lips for comfort or offer ice cubes to suck.

7. Could Mr O swallow?

On 11/2/10 when he had the stroke, Mr O was clearly not able to swallow. The notes say that his breathing passages had to be suctioned after feeding because food had tracked into his bronchial tubes. At that time he was correctly started on thickened feeds [*=which are easier to swallow when the muscles required to initiate and complete swallowing are weakened by the stroke*]. The notes do mention that he was not particularly fond of thickened feeds. On 11/2/10 reference is made in the plan for a “SALT [*Speech And Language Therapist*] assessment” in order to assess his swallowing reflex, which sometimes gets lost during stroke. However there was no evidence that SALT had visited Mr O to perform this assessment.

His ‘Daily Food and Fluid Record Chart’ for 17/2/10, 18/2/10, and also from 20/2/10 to 22/2/10 show that he had some considerable oral intake on those days. These post-date the stroke on 11/2/10 and do actually document a fairly substantial oral intake on those dates.

There is an entry on 9/3/10 saying, “Staff concerned that pt [=patient] is not swallowing oral medication - not benefiting from oral analgesia....” This was the day before he died.

8. Were his symptoms and pain appropriately managed? The family are concerned that he wasn’t able to swallow oral medication - was this a well founded concern?

Impaired swallow is a recognised symptom in patients with vascular dementia. In addition, the stroke that he had around 11/2/10 could have affected his swallow too. Staff were mindful of the fact that he needed to be on “thickened” feeds.

It is documented that he was not able to swallow on 9/3/10 at 7.25pm. Advice was sought for the first time from the palliative care specialist registrar and on-call palliative care consultant. Appropriate palliative care was prescribed overnight. The patient passed away at 1.30am on 10/3/10.

Management of pain was unsatisfactory. It would have been good if advice had been sought from the palliative care team much earlier. Not doing so was contrary to General Medical Council’s Good Medical Practice which specifies the duties of a doctor: “Work with colleagues in the ways that best serve patients’ interests”, “Referral involves transferring some or all of the responsibility for the patient’s care, usually temporarily and for a particular purpose... care or treatment that is outside your competence.” [http://www.gmc-uk.org/static/documents/content/GMP_0910.pdf]. In the event, he got access to proper palliative care advice only on the evening before he died.

9. Was there any time he should have been referred to an acute ward?

Mr O had a background of mental health issues dating back to at least 2005 according to the records. His dominant problems were

relating to old age psychiatry. There were no “acute” medical needs that would have warranted transfer to an acute medical/geriatric ward.

However his medical need for pain relief/palliative care was not being met on this ward. So it would have been appropriate for him to be referred to a palliative care ward or at least a palliative care team.

Other issue noted

The onset of pressure sore was documented as an Adverse Incident Report (AIR) on 16/2/10 at 9.30am. There is no evidence that this AIR was duly processed. One is not clear whether the learning from this incident would be used to prevent recurrence.

Conclusions

1. Given Mr O’s long standing severe dementia it was possible that death was inevitable. However, the terminal care that he received was sub-optimal.
2. Development of sacral pressure sore was potentially avoidable.
3. His pain control in the final fortnight of his life may have been better if there was early involvement of the palliative care team once the decision to embark on the route of palliation was made.

NURSING ADVICE

Clinical Adviser's Name and Qualifications:

L Onslow MSc BA (Hons) RN

Relevance of qualifications and/or experience to clinical aspects of this case

I am a Senior Nurse with particular expertise in the care of older people in both acute and primary care settings. I currently work as a specialist nurse in an older person's outreach team. Clinical aspects of this case fall within my expertise and I thus feel competent to offer advice on these matters.

Conflict of Interest

None

Background

Mr O lived at home with his wife. He had a diagnosis of mixed vascular/ Alzheimer's Dementia and was experiencing episodes of increased confusion and reports of some aggression. He attended a day centre on 9 November 2009 from where he was admitted to Ward A at Cefn Coed hospital for assessment. Mr O began to deteriorate physical and mentally and by 8 December he had become doubly incontinent and unable to walk. At an assessment meeting, on this date, it was agreed with the family that Mr O would be transferred to Ward B (a continuing care ward) and assessed in 12 months' time.

Mr O was transferred to Ward B on 17 December 2009. On 11 February 2010 he became 'chesty' and was commenced on antibiotic therapy for this. On 14 February, it was observed that Mr O's

buttocks were beginning to break down. At 1.30pm he was transferred to a bed with an air flow mattress as a temporary measure whilst awaiting delivery of an air mattress and cushion, ordered for him from the bed company that were contracted to provide the equipment.

Mr O was seen by a tissue viability nurse (TVN) on 16 February 2010, and a plan of care was implemented. He was reviewed again on 23 February and improvement in his pressure sore was noted.

From 20 February onwards, Mr O's condition was evidently deteriorating, and he was experiencing pain, that at times was difficult to control. Advice was sought from the palliative care team on 9 March. Mr O died on the following day.

Questions and responses

I have been asked to provide nursing advice on Mr O's pressure area care and management, nutritional care, pain management, and to consider the reasonableness of the record keeping. I consider that I am competent to answer the questions identified for consideration by a wound care nurse. In order to provide clarity in my advice I will address each of the issues separately.

Wound Care

Had Mr O's pressure sore risk been appropriately assessed?

Were appropriate preventative measures in place?

Could/should the pressure wound have been identified earlier?

I will consider these questions together as they are clearly linked.

National Guidance recommends:

- Patients should receive an initial and on-going risk assessment in the first episode of care (within 6 hours).
- The pressure ulcer grade should be recorded using the European Pressure Ulcer Advisory Panel (EPUAP) Classification system

- Patients should receive an initial and on-going pressure ulcer assessment. This should be supported by photography and/or tracings.
 - All those who are vulnerable to pressure ulcers should as a minimum be placed on a high specification foam mattress.
 - All pressure ulcers graded 2 or above should be documented as a local clinical incident.
 - Patients with a grade 3-4 (as per EPUAP classification) pressure ulcer should as a minimum provision be placed on a high specification foam mattress with an alternating pressure overlay, or a sophisticated continuous low pressure system.
 - The optimum wound healing environment should be created using modern dressings.
- (NICE 2005 CG 29 The prevention and treatment of pressure ulcers Quick reference guide page 1).

It is also important to note that pressure sore risk assessment is necessary to inform a person centred plan of care. As well as identification of the type of mattress being used I would expect to see evidence of positioning and repositioning interventions, frequency of change of position and skin inspection (particularly those areas vulnerable to breakdown for example; heels, elbows, ears and sacrum) and consideration of the time that Mr O should have spent sitting in the chair. Other factors such as nutritional support and assessment of all surfaces used by Mr O should be documented. Particular attention should have been paid to the suitability of the chair that he was using and whether it required additional pressure relieving equipment (for example; a cushion). (NICE CG 29 The prevention and treatment of pressure ulcers Quick reference guide Pages 2 and 3).

Mr O's pressure sore risk was not assessed on admission to ward B and as a consequence no care plan was generated in response to any identified risk. The nursing care records do not provide any evidence of interventions employed to minimise the risk of the

development of pressure sores - these are serious failings in nursing care. In the absence of risk assessment and care planning, it is not possible to state whether the pressure sore should have been identified earlier. It is clear however, that regular attention was paid to Mr O's personal hygiene needs and management of incontinence and if there had been any deterioration in his skin integrity this should have been noted during these episodes of care delivery. There is no indication to suggest that this was the case.

Could the wound have deteriorated as quickly as identified on the incident form on 16 February 2010?

As I have previously advised there is no indication of any strategies implemented to minimise the risk of the development of pressure sores. On 14 February 2010 at 6.30am a nurse has noted '*[Mr O] had been up all day in a chair. When night staff put [Mr O] to bed it was observed that [Mr O's] buttocks had started to break down and looked very sore*'. The nurse has not identified the grade of pressure sore present at the time. Given the fact that Mr O had become acutely unwell on 11 February 2010, with a chest infection, his general inability to recognise early pressure damage (for example; pain), the fact that he was doubly incontinent and had a reduced dietary intake, it is clear that his skin was less able to tolerate the pressure when sitting out in the chair. The combination of these factors would have caused his pressure area to deteriorate this quickly. It is important to emphasise that nursing staff should have been alert to the potential risk of deterioration in his pressure areas as a consequence of these factors and should have implemented actions to minimise the risk- they did not do so and this is a serious failing in care.

Was the wound appropriately managed?

Actions taken when the pressure sore was identified were appropriate. A pressure cushion and appropriate pressure relieving mattress were utilised and a regular two hourly repositioning regime was implemented and maintained. According to the clinical records,

there was no delay in obtaining a specialist mattress because, Mr O was *'moved to bed (next door) with air flow mattress until Huntleigh (provider of specialist mattresses/beds) contacted tomorrow'* (entry 14 February 2010 1.30pm). Advice was sought from an appropriate expert practitioner. This reflects Nursing and Midwifery Council Guidance that states *'you must consult and take advice from colleagues where appropriate'* and *'you must make a referral to another practitioner when it is in the best interests of some-one in your care.'* (NMC 2008 The Code: standards of conduct, performance and ethics for nurses and midwives page 5 sections 26 and 28).

The TVN reviewed Mr O on 16 February 2010 and prescribed a plan of care. This plan of care was followed by nursing staff. Intrasite (this is a gel used to remove devitalised tissue) was used in order to enable the identification of the extent of the tissue damage. This was an appropriate wound care product. A further review by the TVN on 23 February 2010 notes a significant reduction in the wound size (approx 5cm x 5cm) and that debridement of the wound (removal of dead tissue), using the Intrasite had been effective. The plan of care was revised with a change of wound care products to assist in further protection of the sore and reduce the risk of faecal contamination. It is evident that nursing staff followed this revised plan of care.

I have reviewed the photographs provided and dated by the complainant. I can understand that, from a lay perspective, the wound would look as if it was worsening. This is not actually the case. Wound healing is a complex series of physiological events which occur in a predictable sequence. It is important to support a wound healing environment that encourages progression from one stage to the next. Wound bed preparation is of key importance and focuses on controlling and optimizing the wound environment for healing. (The Royal Marsden hospital manual of clinical nursing procedures 2008 Chapter 48 page 943). In Mr O's situation, when first reviewed by the TVN, he had a great deal of devitalised tissue that needed to be removed (debridement) in order to determine the extent of tissue

damage and promote wound healing. The wound care products utilised were appropriate and the photographs provide evidence that these were effective; the pressure sore was serious but was responding to the treatment provided. It would, however, have taken a considerable amount of time to heal. There is no evidence of any serious flaws or omissions clinically in the management of Mr O's pressure sore.

Nutritional Care

Were his nutritional needs identified and appropriately identified?

Should his ability to swallow have been assessed; should he have been referred to SALT?

I will consider these two questions together as they are clearly linked.

Nutrition is a basic human need and a fundamental aspect of nursing care. National guidance recommends:

- All hospital patients should be screened for malnutrition or risk of malnutrition on admission to hospital and screening should be repeated weekly or when there is clinical concern (for example; unintentional weight loss, fragile skin, poor wound healing, impaired swallowing).

The guidance goes on to state that people with any obvious or less obvious indicators of dysphagia (swallowing difficulties) should be referred to healthcare professionals with relevant skills and training in the diagnosis, assessment and management of swallowing disorders (NICE 2006 CG 32 Nutrition support in Adults. Quick reference guide page 10).

The Health Board's own guidance recommends that those patients at High Risk of Malnutrition should be referred to a dietician (see nutrition risk tool in the clinical records). The risk assessment should inform a person centred plan of care.

A nutritional risk assessment was undertaken on 12 December prior to Mr O's transfer to ward B on 17 December 2009. He was identified to be in a moderate risk category. Actions identified in response to this risk included the requirement to review in three days. This did not happen and I can find no evidence of any further nutritional risk assessments being undertaken until 20 February 2010 when Mr O was identified as being at high risk of malnutrition. Reference is made to Mr O's nutritional care on the reviewed care plan and summary of needs dated 15 December 2009. This identifies that Mr O's dietary intake was not reported to be problematic, that he required food to be cut up for him, the use of a plate guard and that he eats with a spoon. It was also identified that he needed prompting at times and that he might need to be fed by staff as he had recently become confused and distracted by hallucinations.

On 25 January 2010 it was noted that Mr O's dietary intake was poor and it is evident that on several days following this his food intake remained poor. He lost a considerable amount of weight between 12 January 2010 and 31 January 2010 (69.7kg to 64.0kg). These facts did not prompt nursing staff to undertake a nutritional risk assessment or consider the need to refer Mr O to a dietician. He was drowsy on 4 February 2010. On 11 February 2010, Mr O was noted to be chesty, his dietary intake had been poor and he was having difficulty in swallowing. He was seen by a doctor who requested a referral to Speech and Language Therapy (SALT) for a swallowing assessment. This did not happen. This was a serious failing as a swallowing assessment was necessary in order to inform a plan of care. This would include for example; consistency of diet and fluids and positioning of Mr O when feeding. I do note that the doctor had recommended thickened fluids but the actual consistency of the fluids does have to be determined following a formal swallowing assessment. Nutritional supplements were prescribed by the doctor on 11 February 2010 - these were given as prescribed and on the occasions when they were not, the rationale for this is clearly

documented (usually because Mr O declined the supplements or was too drowsy to take them).

Food charts were commenced on 17 February and maintained until 22 February 2010. These clearly indicate that Mr O was not having sufficient dietary intake to meet his nutritional needs. It is important to note that his nutritional needs would have increased because of his recent chest infection and pressure sore (British Association of Parenteral and Enteral Nutrition 2003 The 'MUST' explanatory booklet page 3). There is no evidence of any multidisciplinary discussion, concerning this fact or consideration of a dietician referral. An entry in the clinical records on 27 February 2010 identifies the fact that Mr O's physical condition had deteriorated rapidly over the past two weeks and that he was no longer accepting food. There is no evidence of a discussion with the family concerning this fact. Anorexia, weight loss, and swallowing difficulties are common in patients with Dementia and these problems are often irreversible (British Geriatric Society 2009 Nutritional Advice in Common Clinical situations section 6). This information needs to be communicated sensitively to the family who may have difficulty accepting this fact. It is important to note that there is no evidence to suggest that nutrition was withheld from Mr O.

Pain Management

Was his level of pain monitored and appropriate action taken?

Pain is a subjective, personal experience, really only known to the person who suffers. All health care professionals should be alert to the possible presence of pain and should be in the possession of the skills and tools to assess pain. It is important to note that assessing pain is particularly challenging in the presence of severe cognitive impairment, when a person may be unable to articulate their pain and their ability to self report can become impaired or absent. (British Geriatric Society and British Pain Society 2007 Guidance on the

assessment of pain in older people page 6). In these circumstances it is particularly important that nursing staff are alert to the presence of non verbal signs of pain.

There is clear evidence that in response to Mr O's deteriorating condition, his pain was assessed utilising a tool that took into account all dimensions of pain assessment including feedback from the family. Analgesia was prescribed and administered and its effectiveness evaluated. Nursing staff responded promptly to concerns raised by family members and also sought medical advice when analgesia was not effective in relieving Mr O's pain.

Given the fact that there were difficulties in managing Mr O's pain and agitation I am surprised that advice from the palliative care team was not sought earlier. It is evident that his pain management was of concern to his family, particularly on 6 March 2010. Advice was not sought until 9 March 2010 at 7.25pm. Given the fact that Mr O was having difficulty in swallowing liquids and was requiring medication for strike through pain (pain that has broken through and reached a peak) I am surprised that a syringe driver was not used. The reason syringe drivers are so effective is that they provide a smooth and consistent release of pain-relieving medication over a period of time, therefore avoiding the 'peaks' and 'troughs' that occur with other methods of administering pain relief. With PRN doses, the very fact that they are required indicates that the pain has built up to a peak and 'broken through'. Once the dose is administered it causes a sedation effect, which can then cause an increase in agitation as it wears off. The idea behind a syringe driver is to avoid this and allow the patient to stay alert but calm. I note an entry in the clinical records on 9 March 2010 identifies that a syringe driver was not available. It is unclear why this was the case and/or if nursing staff would have been familiar with using this equipment.

Nursing records

Are the nursing records of a reasonable standard?

Despite the identified shortcomings in my response to the previous questions, when considered overall the nursing records are of a reasonable standard and comply with Nursing and Midwifery Council Guidance on record keeping (2009).

Observation/ monitoring

Was Mr O appropriately observed/ monitored on Ward B?

There is only one physiological observation chart available - this refers to the date when Mr O was transferred to Ward B and a subsequent set of observations undertaken three days later. It is not possible therefore to comment on the reasonableness of his physiological observations. However; it is evident that nursing staff were monitoring Mr O and that when his condition deteriorated on 11 February 2010, they appropriately raised concerns to medical staff. I have commented on other aspects of monitoring in my response to your previous questions and I have no additional comments to make.

Heath Board's action plan

I have reviewed the Health Board's action plan. Considering the seriousness of identified failings in care I am not reassured that sufficient action has been taken to minimise the risk of similar failings occurring in the future. I acknowledge that a protocol has been written and circulated to the wards concerning regular on going assessment following transfer to continuing care wards. I also note that a key worker update form has been devised and that training is being arranged for staff nurses on care planning and responsibilities. I am concerned that a time frame for implementation and completion of the training has not been identified. There are no specific actions identified to improve nutritional care, including dietician and SALT referral pathways.

There is no apparent recognition of the need to improve the knowledge and skills of nursing staff when providing end of life care, including palliative care referrals and the use of specialist equipment as for example; syringe drivers that would help to minimise the distress of both patients and family members.

The action plan does not contain any reference to on-going measurement and monitoring of care delivery on the ward or of Senior Nurse Involvement in this process.

Conclusions

I have identified a number of serious failings in the nursing care that Mr O received particularly in regard to risk assessment, care planning and referral pathways. These significant failings have not been sufficiently addressed in the Health Board's action plan.