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

A report by the
Public Services Ombudsman for Wales
Case: 202302939

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Introduction

This report is issued under s.23 of the Public Services Ombudsman (Wales) Act 2019.

We have taken steps to protect the identity of the complainant and others, as far as possible. The name of the complainant and others have been changed as well.

Summary

Mrs Y complained about the care and treatment her late mother, Mrs W, received from Cwm Taf Morgannwg Health Board. Mrs Y complained that informed consent was not appropriately obtained for an Endoscopic Retrograde Cholangiopancreatography procedure ("ERCP – an examination of the pancreatic and bile ducts using a thin tube with a light and camera on the end). Mrs Y complained that her mother did not receive appropriate post-operative care, including monitoring, pain relief and oral care. Mrs Y also complained that the decision making process for a Do Not Attempt Resuscitation decision ("DNACPR" - which informs clinicians that a patient is not to be resuscitated) was not undertaken appropriately.

My investigation found that the ERCP consent form was lost and it was not possible to determine if Mrs W had been provided with sufficient information to make an informed decision. This caused ongoing uncertainty to her family and this complaint was upheld. My investigation also found that Mrs W did not receive appropriate post ERCP observations, that the documentation of assessment of pain was below standard, and there were missed opportunities to ensure she received appropriate oral care. While these failings did not alter the outcome for Mrs W, this resulted in uncertainty about the timeliness of pain relief Mrs W received and this complaint was also **upheld**. Finally, my investigation found that the DNACPR decision was clinically reasonable and undertaken at the appropriate time. This complaint was **not upheld**.

I recommended that within **1 month** of this report the Health Board should:

a) Apologise to Mrs Y for the failings identified.

b) Remind relevant staff of the importance of record keeping and ensuring patient records are retained.

c) Remind relevant staff of the post ERCP procedure pathway monitoring requirements.

d) Remind staff of the “Adult Mouthcare Assessment”, “My Mouthcare Plan” and “Personal Care Monitoring Form”, and the need to re-assess a patient’s needs following a change in their condition.

I recommended that within **2 months** of the date of the final report the Health Board should:

e) Provide the Ombudsman with an update of the ward monthly pain assessment audits and action taken to address any issues identified.

f) Undertake an audit of the ward completion of the post ERCP procedure pathway monitoring and identify suitable actions to address any issues identified.

g) Bring this report, and the reasons I have issued it as a public interest report, to the attention of the Chair of the Quality and Safety Committee.

The Health Board was given a number of opportunities to comment on a draft of this report but it has not done so. The Health Board has therefore not confirmed if it accepts these recommendations and for that reason this report has had to be issued as a public interest report.

The Complaint

1. Mrs Y complained about the care and treatment provided to her late mother, Mrs W, by Cwm Taf Morgannwg University Health Board ("the Health Board") at the Royal Glamorgan Hospital ("the Hospital"). Specifically, she complained that:

a) Informed consent was not appropriately obtained for an Endoscopic Retrograde Cholangiopancreatography procedure ("ERCP" – an examination of the pancreatic and bile ducts using a thin tube with a light and camera on the end).

b) Mrs W did not receive appropriate post-operative care including insufficient monitoring, pain relief and oral care.

c) The decision-making process was not appropriately undertaken for a Do Not Attempt Resuscitation decision ("DNACPR" – this informs clinicians that a patient is not to be resuscitated) as attempts were not made to consult with Mrs W or her family.

Investigation

2. My investigator obtained comments and copies of relevant documents from the Health Board and considered those in conjunction with the evidence provided by Mrs Y. They also obtained professional advice from 2 of my professional advisors, Ms Amanda Pagett, a registered general nurse ("the Nurse Adviser") and Professor Stephen Ryder, a consultant hepatologist ("the Hepatology Adviser"). The Advisers were asked to consider whether, without the benefit of hindsight, the care or treatment had been appropriate in the situation complained about. I determine whether the standard of care was appropriate by making reference to relevant national standards or regulatory, professional or statutory guidance which applied at the time of the events complained about. I have not included every detail investigated in this report, but I am satisfied that nothing of significance has been overlooked.

3. Both Mrs Y and the Health Board were given the opportunity to see and comment on a draft of this report before the final version was issued. Despite a number of opportunities the Health Board did not provide any comments on the draft report or confirm its agreement with the recommendations I have made.

Relevant legislation

4. The following law and guidance was considered:

- The Mental Capacity Act 2005 ("MCA").
- The Health Board's ERCP integrated care pathway 2017 ("the ERCP pathway").
- The NHS Wales Clinical Policy for Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) for Adults in Wales, reviewed 2022 ("the DNACPR guidance").
- All Wales model policy for consent to examination or treatment, adapted by the Health Board, in draft form in 2022, approved May 2023 ("the consent guidance").

The background events

5. On 13 June **2022** Mrs W attended the Hospital with symptoms of vomiting, being unable to eat and drink, weight loss and feeling weak. On 15 June an ultrasound ("USS" - the use of high-frequency sound waves to create an image of the inside of the body) of Mrs W's abdomen confirmed she had a fatty liver, gallstones (small stones usually made of cholesterol that form in the gallbladder) and a dilated bile duct (the small tubes that connect the liver to the small intestine). On 16 June a computerised tomography scan ("CT scan" - the use of X-rays and a computer to create an image of the inside of the body) of Mrs W's thorax, abdomen and pelvis showed an abnormality within the bile duct which was suspicious of cholangiocarcinoma (cancer of the bile duct).

6. On 17 June an endoscopy (an examination of the inside of the body using a thin tube with a light and camera at the end) was performed and identified that Mrs W had a hiatus hernia (when an internal part of the body pushes through a weakness in the muscle or tissue wall). It was also noted that Mrs W would be referred to the upper gastro-intestinal ("UGI") multi-disciplinary team ("MDT").

7. Following discussion with a consultant hepatobiliary surgeon (who specialises in surgery of the liver, bile ducts and pancreas) at a hospital outside of the Health Board area, a plan was agreed for Mrs W to undergo an ERCP. On 21 June it was documented that Mrs W and her family had been updated that an ERCP would take place and Mrs W had been listed for local and regional MDT reviews.

8. On 22 June Mrs W had a magnetic resonance imaging scan ("MRI" - the use of strong magnetic fields and radio waves to produce detailed images of the inside of the body) of her pancreas with contrast which concluded she had probable metastatic cholangiocarcinoma (meaning the cancer had likely spread). On 23 June a UGI clinical nurse specialist met with Mrs W and noted that she was fully aware of her diagnosis, her case had been discussed at the UGI MDT that day, and Mrs W was expecting to undergo the ERCP the following day.

9. On the morning of 24 June Mrs W underwent the ERCP. Following the procedure Mrs W returned to the ward. She was reviewed at 13:00 where her presentation was discussed with a consultant haematologist, and it was planned that she would be discharged that day. However, following this review Mrs W's condition deteriorated. At 14:30 Mrs W was noted to be experiencing abdominal pain and vomiting. It was considered she likely had pancreatitis (when the pancreas becomes inflamed and swollen) and a plan was made for her to receive intravenous ("IV" - directly into the vein) antibiotics and IV anti-emetics (anti-sickness medication). The plan also included for blood tests to be undertaken, a discussion with the on-call doctor, a request for a surgical opinion, a catheter to be put in place, fluid input/output monitoring, a further CT scan, and ongoing review.

10. On 25 June at 14:30 Mrs W was reviewed by the Critical Care Outreach Team. They recorded a plan which included for Mrs W to be observed closely, frequency of observations to be increased if there was concern, staff to encourage deep breathing with pain relief and if pain relief was insufficient, to consider tramadol (a strong opioid painkiller). Her blood sugars were to be monitored. It was also noted that if Mrs W showed signs of increased pain or her blood pressure dropped, she was for escalation to the Intensive Therapy Unit ("ITU").

11. On 26 June Mrs W was reviewed by an advanced nurse practitioner ("ANP") at 11:20. The ANP asked for a stool chart to be completed, a chest X-ray and referral to the on-call medics. Mrs W was reviewed at 12:10 by a medical speciality registrar. They discussed Mrs W's presentation with a surgical registrar and then with the ITU.

12. Mrs W was reviewed again at 14:40. It was recorded that she did not require ITU support at that time and that referral from a consultant to the ITU Consultant was needed if there was a plan for escalation of her care. Mrs W was reviewed by another medical speciality registrar ("the Registrar") at 22:15 following a rapid response call to the ward. Mrs W was declining observations and not keeping her oxygen mask on. The Registrar spoke with Mrs Y. The Registrar did not feel that level 3 care (intensive care) would be in Mrs W's best interests, they would consider level 2 ("HDU"-high-dependency unit) care and they would re-discuss this with both the Medical and ITU Consultants. Mrs W's family were spoken to and were noted as being upset and concerned. They said that they were not aware of how unwell Mrs W was, had not been informed of the outcome of the MDT meeting and felt that staff on the ward had not been able to manage the severity of Mrs W's illness. They also felt that, given Mrs W's fitness prior to admission, she should be transferred to the ITU and remain for resuscitation. The Registrar then spoke with the On-Call consultant ("the Consultant"). The Consultant spoke with an ITU consultant and contacted Mrs W's family. A plan was made for transfer to the HDU for monitoring, but that Mrs W was not for level 3 (ITU) care. It was noted that the DNACPR decision would be re-visited in the morning. Following this it was recorded that Mrs W's family were at her bedside.

13. On 27 June an ITU consultant reviewed Mrs W and spoke with her family. It was explained that Mrs W had 3 problems which individually could be serious and not survivable. Best and worst case scenarios were explained and it was confirmed that at that point, any treatment that she required could be provided on the ward. A plan was recorded which included regular review and consideration for transfer for level 2 care. She was not for CPR and if she deteriorated then a syringe driver (a pump which delivers medication under the skin at a constant rate), and end-of-life care pathway would be implemented.

14. Mrs W was transferred to the HDU later that day. Sadly, Mrs W died on 29 June.

Mrs Y's evidence

15. Mrs Y said that she did not consider Mrs W was given appropriate information about the ERCP procedure and the consent process was completed without anyone there to support her mother. She said, as Mrs W had just been told she was dying, she did not believe Mrs W had the capacity to make this decision.

16. Mrs Y said the Health Board failed to monitor and act on her mother's condition. She said when she visited on 24 June at approximately 14:30, she found Mrs W in an appalling state and had to inform staff that her mother was covered in vomit and in extreme pain. She said her mother did not receive appropriate care following the ERCP, including observations, appropriate pain management and oral care. She said Mrs W was left in a side room with the door shut and her deterioration was only picked up after Mrs Y raised concerns. She therefore questioned how long her mother had been left in that condition without anyone noticing.

17. Mrs Y said she was unhappy with the DNACPR decision making process. Mrs Y said that she received a call from the Registrar to say her mother had taken "a turn for the worse" and they were making a DNACPR decision. She said she was shocked this decision was made over the telephone and there was no discussion, rather they were informed the decision had been made. She then travelled to the Hospital, and on the way the Consultant rang her to discuss this further. She said she informed

him she was on the way to the Hospital and would prefer to discuss the decision with him in person. She said she was extremely upset to find that the Consultant was not at the Hospital and therefore had not seen Mrs W or clinically assessed her in person. She said that she remained deeply upset that she never had a choice.

18. Mrs Y said that if Mrs W had received appropriate care following her surgery, she would have been in less pain and had a more dignified death. Mrs Y also said that as a result of these events, she had become clinically depressed and suffered with post-traumatic stress disorder. She said she did not want another family to go through what her family had.

19. On commenting on a draft of this report, Mrs Y said that she accepted her mother had capacity to consent to the ERCP decision, she said that as her mother had been given very difficult news it could have impacted her ability to retain information and staff could have easily asked for a family member to be present. Mrs Y also said that her mother was provided with incorrect information on the procedure as the leaflet she was given was for a "fit person", whereas her mother was not well, and it was out of date. She provided a copy of the leaflet which was dated 2014.

The Health Board's evidence

20. In its initial complaint response, the Health Board said that at the time of Mrs W's admission, her liver enzymes showed that her bilirubin (a pigment found in bile) level was elevated. This increased until the time of her ERCP and then returned to normal. This showed that Mrs W's bile duct had been blocked by the tumour and the stent that was fitted during the procedure was effective. It said that unfortunately Mrs W developed pancreatitis on 24 June, which was a recognised complication of ERCP.

21. The Health Board said that the ERCP pathway outlines that observations post procedure should be completed quarter hourly for the first hour, half hourly for the next 2 hours, followed by hourly until 4 hours had passed. It said that, unfortunately, Mrs W's ERCP pathway document could not be located in her medical notes and therefore it could not comment on the frequency of observations for the 2 hours immediately post procedure. It said, from the other medical records, it could confirm that following the

procedure, at 11:00 a nurse was advised Mrs W could have sips of water, progressing to a soft diet. At this time her National Early Warning Score ("NEWS" - a standardised scoring system for monitoring patients and identifying deterioration, with the higher the score the greater the level of concern) was 0. It was noted that observations were taken hourly until 13:00. Mrs W's NEWS was 0 at 15:00 and 18:00. It said, therefore, Mrs W's observations post procedure remained stable and there was early detection when her NEWS increased, and she became unwell. It said there was no delay in the diagnosis and management of Mrs W's treatment.

22. The Health Board commented that the door to Mrs W's side room was closed at her request. However, regular contact was maintained with her. It apologised to Mrs Y that on her arrival to the ward she had to bring to the attention of staff that Mrs W had vomited.

23. The Health Board said that all of Mrs W's prescribed medication, including pain relief, was administered appropriately. No concerns regarding pain management were identified and an appropriate plan was in place should pain have not been managed. This was not required. However, it did identify that pain charts were not updated.

24. The Health Board said that Mrs W's oral care assessment, completed on her admission, stated she was independent with oral care. However, this was not re-assessed when she deteriorated. It said she received oral care as part of her personal care plan, but re-assessment should have taken place when her condition changed.

25. The Health Board said that decision making around resuscitation is the responsibility of treating clinicians. It said it is expected in most situations that this would be discussed with the patient, if appropriate, and those closest to them. It apologised for the shock Mrs Y experienced when she was informed of the decision on 26 June.

26. In response to this investigation, the Health Board said that there were no concerns about Mrs W's capacity, and she was deemed to have capacity to consent to the ERCP in line with the MCA. It said that while being informed of a diagnosis of cancer would be distressing, it did not mean there was a lack of capacity to consent to a procedure. It said that Mrs W did not

have a cognitive impairment and did not experience delirium. It said if a patient was deemed to have capacity to consent to a procedure and indicated they were willing to do so, it is not common practice to routinely involve family members unless it is specifically requested. It said Mrs W's family were updated about the need for ERCP and a clinical nurse specialist also met with Mrs W and did not record any concerns raised about the procedure. The Health Board also confirmed that the ERCP would not have taken place without consent having been confirmed and checked by all team members present. However, unfortunately, the consent form for the procedure could not be located or shared with the Ombudsman.

27. The Health Board reiterated that while the ERCP pathway document had been lost, and observations appeared not to have been completed in line with the pathway, it considered this would not have altered Mrs W's management as she was reviewed based on new clinical symptoms at 14:30, when her observations at this point were unremarkable. While the completion of the ERCP pathway documentation was below standard, it did not consider this influenced the management or outcome for Mrs W.

28. The Health Board said that Mrs W's condition deteriorated on 26 June, and she was reviewed on a number of occasions by the Medical Registrars on call and the ITU Outreach team, as well as being discussed with the Consultant and an ITU consultant. It said that given she was deteriorating, and her prognosis was poor, it would not have been in her best interests to undergo aggressive treatment in the ITU setting. It said the Registrar had a detailed conversation with Mrs W's family, after which the Consultant also spoke with the family. The following day an ITU consultant also spoke with Mrs W's family to explain her prognosis and it was documented the DNACPR decision was made and Mrs W's family agreed with the decision and management plan. The Health Board confirmed that, while the discussions around the DNACPR decision were documented, unfortunately, the DNACPR form itself could also not be located.

29. The Health Board said that pain management was a key focus for improvement on the ward. It said it had been requested that pain scores were recorded during morning and afternoon medication rounds to ensure

assessment did not exceed 12 hours. The Pain team also now undertake monthly pain assessment audits. Ongoing training was also facilitated about the care and management of a deteriorating patient.

30. The Health Board was sent a draft version of this report on 11 April 2024. It was asked to provide comments on the report, including whether it accepted my recommendations, by 2 May. On 20 May the Health Board requested an extension in providing comments to 31 May, which was agreed. Following this, no comments have been provided nor further requests for an extension. Further reminders were sent by my office, including issuing a letter to the Health Board's Chief Executive on 25 July which advised that if a response was not provided by 1 August, I would have no choice but to publish this report. No response to this letter was received.

Professional Advice

The Nurse Adviser

31. The Nurse Adviser said that although the ERCP pathway documentation was missing, from reviewing Mrs W's medical notes, the ERCP time was recorded as 09:40 on 24 June. She said, if this was the case, post-procedure observations should have commenced at 15 minute intervals, been half hourly until 12:40 and hourly until 16:40. She said there was no evidence that they were.

32. The Nurse Adviser said that, while the nursing notes recorded "observations were taken every hour until 13:00", this was not reflected in the NEWS chart which had observations recorded at 11:00, 15:05, 18:10 and 20:20. While the NEWS during these times were between 0-2, which would not have triggered escalation to medical staff, the nursing records do provide good evidence of nursing staff recognising and reporting Mrs W's new clinical symptoms and deterioration to medical staff. The first occasion where the NEWS alone would have triggered escalation to medical staff was not until 25 June at 14:15.

33. The Nurse Adviser said that, although the standards fell below those expected in relation to compliance with the directed post-procedure observations, this did not appear to have influenced Mrs W's outcome as there was evidence of nursing staff recognising and reporting new clinical symptoms to medical staff before the NEWS would have triggered this.

34. The Nurse Adviser said the first recording of Mrs W complaining of pain following the ERCP was at 14:15. This was escalated to medical staff and a plan documented. From this point until Mrs W was transferred to the HDU, Mrs W underwent regular review, multiple times per day, by medical staff, ANP and/or the Critical Care Outreach team. The Nurse Adviser said that within the contemporaneous records there were recordings of the severity of pain Mrs W experienced such as "severe abdo pain", "ongoing abdo pain", "denying pain", "appears settled". There were also entries such as "pain killers given to good effect", "Oramorph given for pain" and "no complaints of pain", along with a suggestion to use patient controlled analgesia ("PCA" - a pain management system which allows the patient to administer pain medication when they need it) if necessary. However, the Nurse Adviser said that while the medication records demonstrated Mrs W was receiving regular pain relief prior to her transfer to the HDU, without a formal pain score chart it was difficult to consistently track the varying levels of Mrs W's pain, determine whether pain medication was administered in a timely manner, whether it was effective or whether PCA would have been more appropriate.

35. The Nurse Adviser said that a pain assessment option was contained in the nursing documentation, but this was not robustly completed. It was often populated with ticks which gave no indication of Mrs W's pain assessment or management. There was also a lack of a designated care plan for pain management.

36. The Nurse Adviser said that Mrs W underwent an "Adult Mouthcare Assessment" on 14 and 17 June and was deemed independent. Mrs W also had a mouthcare plan which was completed on 14, 17 and 18 of June. Both these documents state they should be repeated if a patient's condition changes but they were not. In addition, the intentional rounding tool (a structured approach to nursing checks on patients) and the personal care monitoring form could have been used to document the provision of oral care

support, but this was lacking. Therefore, the Nurse Adviser said that there was a lack of evidence that Mrs W underwent appropriate oral care assessment and support. Re-assessment did not occur when her condition changed possibly resulting in missed opportunities for Mrs W to receive the support she required when she needed it.

The Hepatology Adviser

37. The Hepatology Adviser considered whether Mrs W's observations not being undertaken in line with the ERCP pathway had any impact on her or her prognosis. The Hepatology Adviser said that the observations being performed more frequently or at a different time would not have had any impact. Mrs W's pancreatitis developed a few hours after her ERCP, which he said was commonly the case, and presented with symptoms of vomiting and abdominal pain. The Hepatology Adviser said there would have been no early warning with a change in observation timing and nothing could have been done to prevent the pancreatitis.

38. The Hepatology Adviser considered Mrs W's pain management. He said she deteriorated quickly after she developed pancreatitis. She had vomiting and experienced abdominal pain on 24 and 25 June, and by 26 June she had become agitated and confused which became the main issue rather than pain. He said the medication charts for the 24 and 25 June showed oramorph being administered at regular intervals of a few hours suggesting pain was being asked about and responded to. In Mrs W's medical notes there were also entries on 25 June saying "settled" and "pain 6/10 on moving". However, the Hepatology Adviser said that on the NEWS chart from 24 and 25 June there was only 1 entry recorded for pain, and although the nursing notes provide more evidence that pain assessments were undertaken, these were one-off statements rather than ongoing observations.

39. The Hepatology Adviser said the notes from the Critical Care team, on 26 June, suggested the consideration of subcutaneous pain relief (injected into the skin) if needed. There were no entries suggesting significant pain after this. By 27 June the main problem was agitation and confusion, and appropriate medication changes were made to treat this.

40. The Hepatology Adviser said that, overall, while there were deficiencies in the recording of pain assessment, there was evidence that pain was asked about and responded to. There were no entries to suggest that giving oral medication was not working and the potential switch to subcutaneous treatment was not undertaken as it was not deemed necessary. He therefore considered Mrs W's pain management was adequate.

41. The Hepatology Adviser was also asked to consider the DNACPR decision making on the 26 and 27 June, based on the medical notes as the DNACPR form could not be located. He said that on 26 June at 14:40 there was clear documentation that the Clinical team were aware of Mrs W's deterioration and sought senior advice about the escalation of care plan. There was a further discussion at 18:30 with the Consultant and a plan that, if there was significant deterioration, escalation would not be appropriate and a DNACPR order should be put in place. A detailed note was recorded at 22:15 when Mrs W's NEWS deteriorated, and she was seen by the Registrar. Mrs Y was contacted, and a discussion documented about the severity of Mrs W's illness and prognosis. This included a discussion about what escalation of care was appropriate. When Mrs Y expressed her unhappiness at the decision, the Consultant also spoke with her.

42. The Hepatology Adviser said that the documented discussions with the Consultant, by staff present on the ward, were of high quality and by the time he spoke with Mrs Y the Consultant was in full knowledge of the situation and clinical options available. He said this was clearly sufficient to put him in a secure place clinically to institute a DNACPR decision. The Hepatology Adviser also said that the decision was entirely clinically appropriate as CPR would have had no chance of success and would therefore have been futile and distressing.

43. The Hepatology Adviser said there was an excellent entry by the ITU Consultant on the 27 June which fully documented a discussion with Mrs W's family. This covered all the required elements, Mrs W's diagnosis and there being no chance of CPR being successful. He said he would regard this as exemplary practice.

44. The Hepatology Adviser also considered Mrs Y's comments on the draft report, specifically whether the information leaflet provided to Mrs W was appropriate. The Hepatology Adviser said that the leaflet was fit for purpose. He confirmed that it contained information that was still current in terms of indications, the option of doing nothing and complications.

Analysis and conclusions

Whether informed consent was appropriately obtained for the ERCP

45. Mrs Y believed that it was not appropriate to gain consent from Mrs W as she felt that she lacked capacity due to recently being told of her cancer diagnosis. I have seen no evidence in the medical notes that there were concerns about Mrs W's capacity or that Mrs W lacked capacity to make the decision at that time, and consider it was appropriate for consent to be obtained from Mrs W in line with the MCA. However, it is of concern that the consent form for the procedure cannot be located. Without the form there is no record of what information was shared with Mrs W, such as the risks associated with the procedure. While I accept there is evidence that clinicians spoke with Mrs W regarding the procedure, she was in agreement for this to proceed, and note the Health Board's comment that the procedure would not have taken place without consent being confirmed, the loss of the consent form is a service failure. I also accept that a leaflet was given to Mrs W about the procedure which contained appropriate information. This is not sufficient evidence that Mrs W was given the opportunity to discuss the content of the leaflet or any concerns she may have had. Mrs Y has expressed concern about whether Mrs W was given appropriate information, and the loss of the consent form will leave Mrs Y with ongoing uncertainty. Therefore, to this limited extent, I **uphold** this complaint.

Whether Mrs W received appropriate post-operative care including sufficient monitoring, pain relief and oral care.

46. There is no evidence that Mrs W was monitored in line with the ERCP pathway following the procedure. This is a service failure. I accept the advice that her deterioration was likely to have come on rapidly, with no early warning signs, and that the lack of observations did not alter the outcome for Mrs W. Appropriate action was also taken when staff became aware of her

deterioration, this was escalated to the Medical team and appropriate reviews took place. However, it was Mrs Y who found Mrs W covered in vomit and highlighted this to staff. Therefore, Mrs Y is left with uncertainty about how long her mother had been in this condition, or would have remained in this condition, due to the observations not being recorded at the appropriate frequencies.

47. While the pain management plan put in place for Mrs W was reasonable, the documentation of pain assessment was not to a reasonable standard. This is also a service failure. Although there is evidence that Mrs W received regular pain relief, without the adequate documentation it is not possible to determine that all the pain relief she received was in a timely manner, was effective or whether other methods of administering it would have been appropriate. This ongoing uncertainty is an injustice to Mrs Y who is distressed that her mother may have been in pain unnecessarily.

48. The advice I have received is that there were also missed opportunities to ensure Mrs W had appropriate oral care support as she was not re-assessed at the appropriate time and the documentation in this area was also below standard. This was an injustice to her.

49. For the reasons outlined, I therefore **uphold** this complaint.

Whether the decision making process was appropriately undertaken for a DNACPR decision

50. The advice I have received, and accept, was that it was clinically appropriate that a DNACPR decision was made. While I do not underestimate the shock and distress it caused to Mrs Y and her family, it was appropriate that this decision was made based on Mrs W's presentation, and detailed recordings were documented in Mrs W's medical notes regarding this decision. I also appreciate Mrs Y's concern that the Consultant had not seen her mother when he spoke to her about the DNACPR decision. However, this conversation took place after Mrs W had been reviewed in person by members of the clinical team and this information had been shared with the Consultant. I accept the advice that this was clinically reasonable.

51. A DNACPR decision is a clinical decision but guidance states that it should be discussed with a patient, if possible, and if not their family. Mrs Y feels she was informed of the decision, rather than having a choice. While I cannot comment on the exact words that were used during the discussions with her, there is evidence that she was spoken to at the appropriate times and following her concerns, she had a further discussion with the Consultant, before also discussing this decision with an ITU consultant the following day. I therefore consider that it was appropriate that the DNACPR decision was made at this time and Mrs W's family were appropriately contacted about the decision. On this basis, I **do not uphold** this complaint.

52. While I note the Hepatology Adviser said that the documentation regarding the DNACPR decision making in the medical notes was appropriate, even referring to the ITU Consultant's note as exemplary, it is of concern that the DNACPR form could also not be located, along with the other documents that have been mislaid in this case. My predecessor issued a thematic report "Justice Mislaid: Lost records and lost opportunities"[1] which highlighted that it is a fundamental principle of information governance that public sector bodies, especially those responsible for providing health and social care services, can easily identify, locate and retrieve information relating to their service users. It is therefore of concern that 3 separate documents relating to Mrs W have been lost by the Health Board.

53. It is also very disappointing that, despite a number of opportunities to do so, the Health Board has not responded to the draft version of this report. This has left me with no choice but to publish this report as the Health Board has not confirmed it accepts my recommendations. In addition, this lack of response has caused further frustration to Mrs Y, at an already difficult time. It is also very concerning that this is not a standalone case. I am currently liaising directly with the Health Board's Chief Executive on delays in responding to my office's requests for information across a large number of cases.

[1] PSOW Thematic report Justice Mislaid -Lost Records and Lost Opportunities https://www.ombudsman.wales/app/uploads/2020/03/Thematic-report-E.pdf

Recommendations

54. I **recommend** that within 1 month of this report the Health Board should:

a) Apologise to Mrs Y for the failings identified.

b) Remind relevant staff of the importance of record keeping and ensuring patient records are retained.

c) Remind relevant staff of the post ERCP procedure pathway monitoring requirements.

d) Remind staff of the "Adult Mouthcare Assessment", "My Mouthcare Plan" and "Personal Care Monitoring Form", and the need to re-assess a patient's needs following a change in their condition.

55. I **recommend** that within 2 months of this report the Health Board should:

e) Provide the Ombudsman with an update of the ward monthly pain assessment audits and action taken to address any issues identified.

f) Undertake an audit of the ward completion of the post ERCP procedure pathway monitoring and identify suitable actions to address any issues identified.

g) Bring this report, and the reasons I have issued it as a public interest report (as set out in paragraph 53), to the attention of the Chair of the Quality and Safety Committee.

MM. Morris.

29 August 2024

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