

The investigation of a complaint by Mrs A and Mr B against Abertawe
Bro Morgannwg University Health Board

A report by the Public Services Ombudsman for Wales

Case: 201001670

Contents

Introduction	- 1
Summary	- 2
The complaint	- 4
Investigation	- 5
Relevant legislation, background information, local policy and guidance	- 5
The background events	- 7
Mrs A and Mr B's evidence	-14
The Home Manager's evidence	-16
The UHB's evidence	-17
Professional advice	-21
Analysis and conclusions	-26
Responses to draft report	-30
Recommendations	-30

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 complainants as Mrs A and Mr B.

Summary

Mrs A and Mr B complained about the Abertawe Bro Morgannwg University Health Board (“the UHB”) in relation to the care provided to their brother Paul in hospital during late 2008/early 2009. They explained that Paul had severe learning disabilities. He had been admitted to hospital for a serious bowel problem. Surgeons operated on Paul soon after his admittance. Paul sadly died in hospital about three weeks later due to respiratory problems involving excess secretions in his bronchial airways.

Mrs A and Mr B complained about many aspects of Paul’s nursing and clinical care. They provided papers which showed that the nursing care had been strongly criticised in a Protection of Vulnerable Adults (“POVA”) investigation run by the former NHS Trust. However, they remained unconvinced that the resulting action plan was adequate. Moreover, they considered that the investigation had not focussed on clinical care. Their main clinical concerns were that Paul had contracted pneumonia whilst in the Intensive Therapy Unit (“ITU”), been transferred prematurely to a general ward (“the Ward”) and that his care on the Ward in the days leading to his tragic death was poor.

The Ombudsman’s investigation did not focus on nursing care, as the POVA process had been thorough in that regard. However, he found that Paul’s nursing care on the Ward had been very poor and when combined with his clinical care, had produced an unacceptable level of treatment. With regard to Paul’s clinical care, he did not agree with every aspect of Mrs A and Mr B’s complaint. However, he concluded that the clinical care was generally well below a reasonable standard. In the investigation, he found that that there was:

- a lack of outreach support to the Ward from the ITU
- an over reliance on the assumption that Paul’s symptoms were psychological rather than clinical
- a lack of involvement of the consultant in charge of Paul’s care
- a failure to supervise junior doctors
- inadequate examinations of Paul
- failure to ensure that vital suctioning care was provided

- an inability among doctors to notice that nurses were not recording Paul's observations properly.

The Ombudsman also concluded that the hospital had failed to comply with the provisions of the Disability Discrimination Act regarding Paul, primarily by not making reasonable adjustments to its service to cater for his special needs.

The Ombudsman strongly upheld the main aspect of the complaint, concerning Paul's clinical care. Finally, he stated that his view was that reasonable nursing and clinical care might have altered the outcome for Paul, although this was uncertain.

The Ombudsman made a number of recommendations. These included a payment of £1500 to both Mrs A and Mr B for the uncertainty that they have to endure over whether Paul may have survived with adequate care. He recommended learning disability awareness training for staff; many reminders for staff about appropriate care and relevant audits and inspections. The Ombudsman also recommended that the matter be discussed at a full meeting of the UHB with regard to how it can best ensure that it complies with the Equality Act. The UHB agreed to implement his recommendations.

The complaint

1. With the help of the Community Health Council ("the CHC"), Mrs A and Mr B complained about Abertawe Bro Morgannwg University Health Board ("the UHB"). The complaint concerned treatment provided to their brother, Paul, whilst he was a patient at a hospital managed by the former Abertawe Bro Morgannwg NHS Trust ("the Trust"). On 1 October 2009, as part of NHS re-organisation in Wales, the UHB took over the responsibility of the Trust in relation to the hospital.

2. Mrs A and Mr B explained that their brother suffered brain damage at birth. As a result, he had severe learning difficulties. Paul also suffered from epilepsy and other physical problems. He attended hospital and had vital surgery to treat a serious bowel problem in late 2008. However, sadly Paul died in hospital on 23 January 2009, aged 53 years. The cause of death was an excess of secretions in his upper airways. Paul had contracted pneumonia whilst in hospital.

3. Mrs A and Mr B and advocates for Paul raised serious concerns about hospital care, particularly in relation to nursing issues. The Trust investigated the complaints via its Protection of Vulnerable Adults ("POVA") procedures. The POVA investigation found a number of important systemic and specific shortcomings in Paul's nursing care. The POVA report made numerous recommendations. The Trust produced an action plan to address the problems that it had identified. It also arranged a local resolution meeting involving the family and Paul's advocates and carers.

4. Mrs A and Mr B said that they remained dissatisfied despite the investigation and the meeting. They raised a large number of specific issues in their complaint to my office. Many related to nursing care. Notwithstanding the complainants' continued disquiet about aspects of nursing care, I decided to investigate complaints concerning the family's further misgivings about a range of clinical issues. These concerned:

- the hospital's role in Paul contracting pneumonia
- the treatment of Paul's pneumonia
- the decision to transfer Paul from the Intensive Therapy Unit ("ITU") to a medical ward ("the Ward")

- the practicalities of the transfer
- Paul's overall clinical care, especially whilst on the Ward.

5. Mrs A and Mr B also expressed dissatisfaction about the UHB's handling of local resolution. They said that the process did not provide answers to their clinical concerns.

6. Mrs A and Mr B stated that they believe their brother would be alive today if his clinical (and nursing) care had been adequate. They consider that vital questions remain unanswered concerning Paul's clinical care. That combined with knowledge that the nursing care was so poor, has caused them great distress. This added to the bereavement with which they have also had to cope.

Investigation

7. The investigation started on 23 December 2010. My Investigator obtained comments and copies of relevant documents from the UHB. I have considered those in conjunction with the evidence provided by Mrs A and Mr B. I have decided that, although clinical issues were the focus of this investigation, the investigation and report needed to give due recognition to matters of nursing care and the overlap between those and Mrs A and Mr B's clinical complaints. I have taken due account of the advice of two of my professional advisers: a Clinical Adviser and a Nursing Adviser. The Clinical Adviser is a Consultant in respiratory medicine. He is a former acute NHS Trust Medical Director. His name is Charles Turton. The Nursing Adviser is a Senior Nurse with extensive experience in acute care. Her name is Rona Mckay. Mrs A and Mr B and the UHB have had an opportunity to comment on a draft version of this report.

8. I have not included every detail investigated in this report but I am satisfied that nothing of significance has been overlooked.

Relevant legislation, background information, local policy and guidance

9. Section 21 of the Disability Discrimination Act 1995 states that service providers must make, "reasonable adjustments" to cater for the needs of disabled people. (Please note – the Equality Act 2010 has

replaced the Disability Discrimination Act. It has streamlined and enhanced discrimination legislation generally. The Equality Act includes the main elements of the Disability Discrimination Act.)

10. In 2009, the Health Service Ombudsman and Local Government Ombudsman in England issued a report called “Six Lives: the Provision of Public Services for People with Learning Disabilities”. The report used the experiences of six people to illustrate general problems that were apparent regarding the provision of public services to people with learning disabilities. The report highlighted many failures and made recommendations. My colleague, the Health Services Ombudsman in England, Ann Abraham said:

“Six Lives has highlighted distressing failures in the quality of health and social care services for people with learning disabilities. No investigation can reverse the mistakes and failures but if the NHS and social care leaders take positive steps to deliver improvements in services, this may bring some small consolation to the families and carers of those who died.”

11. There are many other reports such as the 2007 “Death by Indifference” publication by Mencap, the campaigning charity, which indicate that people with learning disabilities do not have fair treatment in the NHS.

12. NHS figures suggest that there are 1.5 million people in the UK with learning disabilities. The UHB’s own figures say that 14% of the general population need acute hospital care in the UK every year. The figure is 26% for people with learning disabilities.

13. In 2010, the UHB introduced its Traffic Light System to help care for patients with learning disabilities. It involves the creation of a document for each patient that indicates:

- a. key information about the patient such as medication (red)
- b. useful information about the patient such as preferred communication method (amber)
- c. details that would improve the patient’s stay such as food choices (green).

14. In 2003, the Welsh Assembly Government issued its guide to handling NHS complaints in Wales. This is called, "Complaints in the NHS". (Please note that new arrangements have come into force in April 2011). Section 1.12 of Complaints in the NHS states that:

"Where a complaint indicates that a child or vulnerable adult may have been abused, the Child Protection/Vulnerable Adult Procedures should be followed not the complaints procedures. The NHS Complaints Procedures should not be used to investigate allegations of abuse."

The background events

Introduction to events

15. The following chronology is a brief outline of the main events in Paul's care and the complaint that followed. It will not set out a detailed description of Paul's time in the hospital. However, it provides a summary of the main events in question.

Paul's time in the hospital

16. On 31 December **2008**, Paul was admitted to hospital due to symptoms of abdominal pain. Clinical staff found that Paul had a perforated bowel with faecal peritonitis, which is a severe infection. Paul underwent surgery later that day under the care of a consultant surgeon ("the Surgeon"). The Surgeon remained responsible for Paul's care until he died three weeks later. After surgery, Paul was transferred to the Intensive Therapy Unit ("ITU"). Paul became very ill with multi system failure caused by the severe infection evident in his faecal peritonitis. Paul then developed pneumonia whilst in the ITU. Staff treated him for the condition.

17. On 16 January **2009**, staff moved Paul to the High Dependency Unit ("HDU"), a part of the ITU.

18. On 19 January, staff removed Paul's tracheostomy on the instructions of doctors. A tracheostomy is a surgically created opening in the neck leading directly to the trachea (the breathing tube) to help a person breathe.

19. An entry in the clinical notes by a doctor, timed at 10.45am on 20 January, said that Paul had required oxygen, "last night". The notes said that staff continued to, "suction his chest". Suctioning is necessary if a patient cannot clear secretions from the back of their throat. It would therefore, prevent a patient from choking on the secretions or the airways becoming blocked. The notes added that the plan was for Paul to be relocated to the Ward later that day.

20. On 20 January, Paul was transferred to the Ward. The next day, Paul moved into a single room.

21. At 08.30am on 21 January, the Surgeon reviewed Paul. He noted that Paul was doing well generally. He added that Paul required, "intensive chest physiotherapy".

22. At 04.30pm on 21 January, a Speech and Language Therapist ("SALT") visited Paul. Among other comments, the SALT noted that staff should monitor Paul's chest "closely".

23. On 21 January, Paul was suctioned on two occasions by physiotherapy staff.

24. At 09.30am on 22 January, a doctor reviewed Paul. He noted that Paul's observations were "stable".

25. At 10.30am on 22 January, Paul was suctioned by physiotherapy staff.

26. At 12.30pm on 22 January, a SALT reviewed Paul. The entry in the notes started with the comment, "notable upper airway secretions today".

27. At 03.00pm, physiotherapy staff examined Paul and decided that suctioning was not necessary.

28. At 10.30pm on 22 January, Paul's observations showed that his oxygen saturation was 87%. Normal oxygen saturation for a healthy person is between 95-100%. Paul's overall observations reached a

score of four on the Trust's scoring chart. This score indicates the need for input from senior colleagues.

29. An untimed entry on 22 January (which I believe to have related to events that took place at about 10.50pm) referred to an interaction between a doctor and Paul. The notes said that nurses had requested that the doctor replace Paul's feeding tube, which had come out. The notes confirmed that the doctor did this. The doctor's notes indicated that Paul was "agitated" but there had been no change in that regard. His medical notes entry appears to state that the plan was to call for help if Paul deteriorated.

30. At around 11.15pm on 22 January, Paul's carer sought medical help. He spoke to the same doctor who replaced the feeding tube, who was near the Nurses' Station at the time. (Note – this interaction is not referenced in the medical records). The doctor did not visit Paul.

31. At 12.30am on 23 January, according to the nursing notes, nurses changed Paul's shirt, as it was damp. The nursing notes show that staff gave Paul sedatives. The drugs chart shows that the sedative was prescribed by the same doctor who replaced Paul's feeding tube an hour or so earlier. The nursing notes also said that staff administered mouth care for Paul, "as patient had thick phlegm" in his mouth.

32. At 1.30am on 23 January, Paul sadly died after the Cardiac Arrest Team had attempted CPR. The medical records show that the complainants were very unhappy with the standard of care that staff had provided to Paul. The notes stated that the family wanted a, "full investigation" of the events leading to Paul's death. The notes indicated that a staff member told them that they would need to write to the Trust.

Events after Paul died

33. On 1 April, a staff member from one of Paul's caring agencies sent a complaint letter to the Trust. The letter set out various issues including:

- the decision to transfer Paul to the Ward from the ITU
- numerous and detailed aspects of nursing care

- the response of nurses and doctors to Paul's deteriorating condition during 22 January including the failure to act after the doctor was approached at the Nurses' station

34. Also on 1 April, a Consultant Intensivist who had been involved in Paul's care whilst he was in the ITU sent a statement to the Trust's headquarters regarding the pending inquest. That clinician leads in the UHB on Critical Care matters. I shall call him the Intensivist. The statement said that he had drawn up the statement from the medical notes, as he had, "no memory of the actual events". The statement outlined Paul's care whilst he was in the ITU. He added:

"I saw him on the 20 January at 10.45 hours – I thought his general condition was improving and he was needing less oxygen. Based on the fact that he was requiring very little nursing intervention and on my assessment that he was at low risk of sudden deterioration, I decided that he was suitable for discharge to the general surgical ward."

35. On 16 April, a Strategy Meeting took place within the Trust. This followed discussions regarding the complaint and a decision to address the matters raised under the Trust's POVA procedures. Attendees agreed that the Head of Nursing would lead the POVA investigation. At the Strategy Meeting, it was noted that awareness sessions for nursing staff about learning disabilities should form part of the action plan.

36. On 20 May, the Trust received a letter from Mrs A and Mr B. The letter included dissatisfaction about many aspects of Paul's care. They raised numerous nursing issues. Mrs A and Mr B also expressed concern about some of the clinical issues that they later raised in their complaint to me. They drew the conclusion in their letter that if Paul had stayed in the ITU, in which they said Paul's care had been very good, until his pneumonia had been fully resolved, he would not have died in hospital.

37. On 21 May, the Trust acknowledged Mrs A and Mr B's letter of 20 May. The letter expressed condolences. It explained that a POVA investigation had been deemed necessary. The letter said that once POVA began, the NHS complaints procedure was "suspended".

38. In August 2009, Paul's family received the post mortem report. The report concluded that the reason for Paul's admittance to the hospital and the operation itself did not seem to be a likely contributory factor in Paul's death. It said that the pathologist's opinion was that Paul died due to respiratory problems. The report added:

"I am...struck by the extent of secretions present throughout the airways which strongly suggests that retention of secretions has played a role in causing respiratory failure."

39. In January **2010**, the Head of Nursing issued the POVA investigation report. The terms of reference were set out in the report. It said that these were to investigate the, "basis and reasonableness" of the concerns raised by the various complainants regarding, "several aspects of the general nursing care and medical care by staff at [the hospital]". I will set out the "conclusions" to the POVA report in full below:

"The Investigating Officer believes that there were a number of processes that were not in place to ensure that [Paul] received the most appropriate nursing care. Examples include absence of individual care plan and nursing tools such as a nutritional or pressure area assessments. Observations were not undertaken as instructed and the [Patients at Risk or PAR] scoring was not always assessed. Nurse/patient contact appeared to be ad hoc and there were occasions when the carers were left to perform nursing interventions for which they were untrained. Mental capacity issues were not addressed and, given [Paul's] severe learning disabilities, gave rise to significant advocacy issues.

A predisposing factor, contributing to these events is the Ward environment in which [Paul] was nursed. The Ward is a busy and complex area where staffing levels did not reflect the complexity of the Ward and it appears that the number of nurses on duty per shift were inadequate to deal with the demands of patient care. [Note – the matter of staff shortages was mentioned earlier in the report, where it said that it had been raised by Ward staff on occasions.] Whereas this is not raised as an excuse, its bearing

needs to be acknowledged in the overall consideration of POVA investigation.

The Investigator believes that the nursing care provided was less than adequate as there is no documented evidence to suggest otherwise. The acts of omission include:

- Individualised Nursing assessment not undertaken.
- Individual care plan not devised on admission to Ward, resulting in fundamentals of care not being delivered by the nursing team.
- Observations/monitoring not being undertaken as per [ITU] discharge pathway.
- Concerns raised by family/carers not recorded or acted upon, including in the hours before Paul died.

The Investigator can, therefore, find failings by the staff on [the Ward] and the POVA complaint is upheld.”

40. The POVA investigation report noted a number of changes that the Trust (by now the UHB) had already made and added further recommendations. Improvements noted or recommended included: addressing nursing team attitudes; providing training on assessments and observations; introducing further patient observational tools; increasing staffing levels on the Ward; electronic audits of fundamentals of care to take place; reviewing and auditing nursing documentation and introducing verbal and written systems for nursing handover of patients from ITU to wards. The report also referred to the need to arrange awareness sessions regarding learning disability but this did not form part of the action plan.

41. On 26 January, there was a meeting at the UHB involving Paul's family and carers, Paul's advocate from Mencap, the Head of Nursing, the Surgeon, the Intensivist and other UHB staff. The meeting notes state that the purpose was for Paul's family to find out why Paul had survived surgery and a lengthy stay in the ITU, only to die on the Ward. The official UHB notes of the meeting stated that it was established that Paul died of an, “excess of secretions in his chest”. The

Family stated their concerns during the meeting. They expressed particular dissatisfaction about the following issues:

- the removal of Paul's tracheostomy on 20 January 2009
- the timing of Paul's transfer from the ITU to the Ward
- the failure to consult with the family about the transfer
- neglect of Paul on the Ward and nursing issues
- poor clinical response to Paul's deteriorating health near the end of his life.

Clinicians at the meeting dealt with the points raised. They said that the removal of the tracheostomy was, "normal procedure". They stated that the timing of Paul's transfer might have been "premature" with "hindsight". However, at the time it was reasonable. They noted that ITU beds were in demand. The Surgeon explained that, "lessons had been learned". He added that nobody else would experience the same, "lack of care". The Head of Nursing explained that the POVA investigation had made a difference. She added that Pauls' "neglect" would not be repeated. The family expressed the view that the NHS had let them down and that Paul would not have died if he had stayed longer in the ITU or had better care on the Ward.

42. On 6 April, Mrs A and Mr B wrote to the UHB. The letter referred to the meeting that had taken place in January. However, the complainants said that there was an outstanding need for a full investigation into decision-making and care in relation to Paul's stay in hospital at the end of 2008 until his death in January 2009. The letter included a list of 40 questions, which Mrs A and Mr B said required answering. They noted that they had submitted these questions prior to the local resolution meeting of January. The questions were mainly regarding nursing care. However, a number concerned clinical decision making as later put to me.

43. On 22 April, the UHB wrote to Mrs A and Mr B. The writer said that she had sent their letter to the General Surgery Directorate and requested a written response.

44. On 30 April, according to UHB records, Mrs A telephoned the UHB to request that it take no further action regarding their letter at that time. She was noted as saying that she and her brother wanted to discuss matters with the CHC and were considering complaining to me.

45. On 4 November, the CHC submitted the complaint to my office on behalf of Mrs A and Mr B.

Mrs A and Mr B's evidence

46. Mrs A and Mr B acknowledged that the POVA investigation was very critical of the nursing care that staff provided to Paul on the Ward. They said that they accepted that my investigation would focus on clinical matters. However, they stated that they remained sceptical about the adequacy of the UHB's action plan. They considered that the POVA process had been thorough and many changes had apparently resulted. Nevertheless, they commented that the failures outlined in the POVA report were so damning that there should be independent inspections to check on progress.

47. In outlining their concerns relating to Paul's clinical care as set out earlier, Mrs A and Mr B said that a major theme was that, "nobody listened". They stated that Paul's carers and family expressed various strong misgivings about aspects of his care whilst he was in hospital. Mrs A and Mr B maintained that there was a general lack of knowledge among staff of the problems of people with learning difficulties. In submitting the complaint on their behalf, the CHC said:

"The family feels very strongly that nurses and doctors in secondary care are ill-equipped and untrained in dealing with patients with learning difficulties and feel that this should be rectified."

They said that the Six Lives report had shown that this was a widespread problem.

48. Mrs A and Mr B were very unhappy with the nursing care that Paul received. Their views are well documented and informed the POVA process. In commenting on a draft of this report, they said that the

nursing care was even worse than it seemed. They commented, for example, that the nursing notes said that Paul's T shirt was changed on the night of 22/23 January 2009. However, they claimed that this only happened because the attending carer requested it. Mrs A and Mr B commented that the inadequacy of nursing care did not excuse clinicians. They queried the hospital's role in Paul contracting pneumonia. Mrs A and Mr B expressed concern about how clinicians treated Paul's pneumonia generally. They strongly asserted that Paul was transferred prematurely from the HDU to the Ward. They said that Paul's tracheostomy was his "lifeline" and it was taken away too early. Mrs A and Mr B stated that they believed it was unreasonable to transfer Paul to the Ward so soon after staff removed the tracheostomy. They added that some sort of, "cooling off period" should have been applied, particular for a patient such as Paul who had special needs.

49. Mrs A and Mr B said that the transfer to the Ward was not done correctly, as the discharge form failed to mention the need for continued suctioning. They said that doctors did not notice that nursing staff were mishandling Paul's observations. They stated that doctors failed to examine him properly from 20-23 January. Mrs A and Mr B maintained that the doctor failed to act appropriately when Paul's carer approached him at the Nurses' Station on the evening of 22 January. In general, they said that crucial aspects of Paul's clinical care were inadequate. In their view, the combination of these clinical failures and nursing shortcomings meant that Paul was let down by the NHS and died as a result.

50. Mrs A and Mr B said that the UHB's local resolution response failed to explain all the issues fully. They noted that clinical issues remained outstanding. They also stated that at the meeting of 26 January 2010, clinicians were very candid in accepting that Paul would not have died with good quality care. However, the meeting notes did not reflect that. They supplied their informal notes of the meeting that took place on 26 January 2010. The Mencap advocate who had attended that meeting had compiled the notes. This version of the notes reported the Surgeon saying that, "he believed that Paul might still be here" if matters had been handled better from around the time Paul left ITU.

51. Mrs A and Mr B said that the process has left them with many unanswered questions, which they had posed in their letter of 6 April 2010. Mrs A and Mr B acknowledged that at the time, they were confused about the complaints process. However, they said that they did not want the UHB's local resolution investigation to stop despite the UHB's record of a telephone conversation that indicated this. They said that there must have been a misunderstanding on that point.

52. Mrs A and Mr B said that it was "heartbreaking" to see Paul in his last days, deteriorating but unable to explain how he felt. They commented that the family knew how serious Paul's condition was around the time of his operation. However, they said that he had fought back from the surgery and overcame postoperative complications before being transferred from the ITU to the Ward. Mrs A and Mr B explained that the events in question have caused the family continuing distress over and above their bereavement at the loss of a much-loved family member. Mrs A and Mr B maintained that Paul died because of poor care and treatment. The CHC explained that:

"Paul's family are devastated by the untimely loss of their brother and feel that if correct and appropriate care and treatment had been provided he would still be alive today."

The Home Manager's evidence

53. The Manager of the care home in which Paul lived provided evidence for the investigation. The Home Manager said that Paul had 24-hour carer support, even in hospital. He was on duty during the late evening and night of 22/23 January 2009. He said that he arrived around the time that two doctors were changing Paul's NG tube, which was about 10.50pm. The Home Manager stated that at that time, Paul was agitated. He was very concerned about Paul's condition. He explained that he spoke to the same doctors who had replaced the NG tube at about 11.15 at the Nurses' station. One was male, who had taken the lead role and one female. The Home Manager maintained that he told them that Paul was very unwell, breathless, clammy and, "very flat". He said that the male doctor suggested that he tell the nursing staff to administer Diazepam (a sedative) to Paul. The doctors

did not visit Paul then or later. The Home Manager added that nursing staff also did not appear to act on his concerns around that time and later. He said that after Paul's death he felt, "frustrated and appalled" about Paul's care during his last hours.

The UHB's evidence

54. The UHB provided Paul's relevant medical records, POVA and complaint papers and various general comments about aspects of the complaint. It also responded to specific questions. The UHB attributed some of the comments to key staff members as I will outline below.

55. The Head of Nursing drew attention to the POVA investigation and report. She re-iterated why a POVA investigation was the appropriate response to carer and family concerns about Paul's care on the Ward. She said that POVA had upheld the "allegations" made by Paul's carers and family members. The Head of Nursing commented on Mrs A and Mr B's complaint about how Paul was treated in the last few hours of his life. In that context, she stated that the POVA investigation found:

"The Nurses present...appeared not to have responded to the carer's concerns when [he] raised these with the nursing team."

She said that the nurses and the doctor who replaced Paul's feeding tube all felt that Paul's "clamminess" was caused by his "agitation".

56. The Head of Nursing explained that the UHB had implemented the action plan to address the issues that the POVA investigation had identified. She said that there had been cultural change on the Ward. This was in addition to positive developments based on education and training of staff and procedural upgrading.

57. The UHB said that it has not been able to appoint a new permanent sister for the Ward. It had interviewed in May 2011 but did not identify a candidate with the "calibre" for the job. It later said that the post was filled and the new Ward Sister started work in August.

58. The UHB reported that it had reviewed the Ward staffing levels. It said:

“The staffing establishments have been increased by resetting the budgets and using assessment tools for ratio of nursing staff to patients.”

59. The UHB confirmed that it had no specific policy on caring for patients with learning disabilities. However, the UHB indicated that its new Traffic Light System should help in the care of future patients. The UHB said that the system would facilitate an individualised and robust care plan to be created for each patient.

60. In Paul’s case, the UHB accepted that his learning disabilities were not taken into account as the POVA report had found. It stated that nursing care, “fell short of what he deserved”. It added:

“It is clear that the individual needs of [Paul] were not addressed and the fact that [Paul] had physical and mental disabilities was not taken into account. The care was not individualised and the nursing team failed to act on the concerns raised by the family. With this in mind the care did not meet the provisions of the Disability Discrimination Act.”

61. The UHB referred to the decision at the Strategy Meeting of 16 April 2009, to provide learning disability awareness training for nurses. It said that in response to that decision it had provided Ward staff with training on assessing patients, safeguarding adult provisions and issues of giving care with dignity and respect.

62. The UHB acknowledged that the POVA investigation should have considered clinical issues. However, it said that nursing care concerns were the priority of the complainants. In addition, they had the opportunity of discussing clinical matters with key staff at the local resolution meeting of 26 January 2010.

63. The UHB responded to some of the clinical issues raised in the complaint and interim advice from my Advisers. The Intensivist said that he believed that Paul’s pneumonia was caused by aspiration of the

stomach contents. This means that stomach contents entered Paul's trachea or lungs.

64. The Intensivist explained that a tracheostomy could be useful for short-term control of secretions. He added that they have "drawbacks". He said that they can impair the swallow reflex and in Paul's case, this would have made his basic problem worse. The Intensivist stated that if Paul could not have coughed, the tracheostomy was vital to keep him alive. He said that later Paul's cough was observed to be "effective". He commented that he was able to clear secretions from his windpipe into his mouth. The Intensivist said that provided Paul did not take the secretions into his trachea it did not matter that he swallowed them. He did not regard Paul as having pneumonia around 19 January 2009. Therefore, the Intensivist considered that it was appropriate for clinicians to remove the tracheostomy and transfer Paul out of the ITU.

65. The Intensivist stated that, "the ITU discharge pathway" relating to Paul included that he could be re-admitted to ITU in the event that his condition deteriorated. He added:

"...we would review the patient on the ward if we were requested to.

This is the Patient's safety net. Many of our discharged patients have a high risk of deterioration over the following days. We depend on adequate standards of monitoring on general wards to ensure the safety of our discharged patients."

The Intensivist said that at that time there was no ITU outreach service in place. He noted that a, "pilot system" has been underway during the last year. He added that the UHB has appointed specialist nurses into that role.

66. The Intensivist stated that staff did not seek agreement with Paul's family regarding the transfer as, "it is not our habit or our obligation to discuss every change of treatment with the family of patients."

67. The Intensivist discussed the issue of suctioning. He said that the instructions for regular suctioning were recorded in the medical notes but not on the ITU discharge form. He called this an “oversight”. The Intensivist explained that the discharge form should have made Paul’s suctioning requirement clear. He remarked that the medical notes said Paul, “needs regular suctioning”. He added that this was open to interpretation but would most likely mean anything from two to four hours.

68. The doctor who reviewed Paul at 09.30am on 22 January 2009 provided his comments. He said that this was his only interaction with Paul. In short, he said that he relied on a nurse who had told him that Paul’s observations were unchanged. Therefore, he documented this in the medical records. The doctor said that he found Paul, “a little restless”. However, he did not think that this represented a change in his condition.

69. The UHB explained that the Surgeon would have been invited to comment but he had left the authority and was no longer resident in the UK.

70. The UHB failed to identify the doctor who replaced Paul’s feeding tube on 22 January and saw the Home Manager soon after.

71. Finally, the Intensivist analysed Mrs A and Mr B’s comment that Paul would have survived with reasonable care. The UHB summarised his view as follows:

“...patients with defective swallow reflexes nearly always pass away (of aspiration and drowning in secretion) and their life expectancy is very short for this reason. [The Intensivist] remembers that admissions were made that ward care had not been of the standard that we would expect and that it is reasonable to make the assertion that [Paul] may have survived longer if care had been better, but probably not much longer.”

Professional advice

72. My Nursing Adviser said that the POVA report reflected, “a vigorous investigation”. She added that the recommendations that arose from it should improve the care that the Ward provides.

73. Notwithstanding my Nursing Adviser’s positive comments about the POVA investigation, report and action plan, she raised an issue which she regarded as outstanding. She stated that there is no evidence that the action plan has dealt with the issue of how senior staff react to concerns from junior colleagues. She explained that the POVA report made the point that Ward staff had raised the issue of staff shortages on occasions. My Nursing Adviser said that the action plan should have included recognition that senior staff must respond when concerns are reported. She said that this is set out in the guidance for managing risk as set out by the Nursing and Midwifery Code 2008, Standards of Conduct, Performance and Ethics for Nurses and Midwives.

74. My Nursing Adviser discussed the quality of nursing care that Paul received on the Ward. She made the following points of note:

- Paul’s observations were not recorded regularly enough
- when observations were taken, they were incomplete
- there was a failure to act when Paul’s observations demanded referral to senior nurses and clinicians, which contradicts the guidance in National Institute for Clinical Excellence guidance 50 called “Acutely Ill Patients in Hospital, Recognition of and Response to Acute Illness in Adults in Hospital”
- there is no evidence that nursing staff in the Ward suctioned Paul, although the records indicate that physiotherapy staff did so on occasions during the period 20-23 January.

My Nursing Adviser commented on this as follows:

“This is evidence that indicates a level of knowledge and care far below reasonable standards”.

75. My Clinical Adviser provided comments on all the clinical heads of complaint that I have summarised in paragraph 4. He explained that Paul had a very serious medical problem at the time he attended hospital in December 2008. He said that it was, “a very grave and life threatening situation”. This led to surgery to remove the large bowel. My Clinical Adviser said that Paul then required a high level of support to assist with breathing and circulation, which he received in the ITU. He said that Paul made slow progress. My Clinical Adviser said that it was not surprising that Paul suffered multi system failure after developing such a severe illness. He added that pneumonia is a “common” complication in the aftermath of situations like this. My Clinical Adviser said that the hospital had no case to answer in that regard. He added:

“...had it not been for timely initial resuscitation; appropriate investigation; skilled surgical intervention; and excellent intensive care post-operatively Paul would not have survived long enough to develop pneumonia.”

76. My Clinical Adviser stated that the care the ITU provided to Paul in treating his pneumonia was, “entirely reasonable”. However, this was not the case on the Ward. I will return to this below. My Clinical Adviser did not criticise the decision to remove Paul’s tracheostomy.

77. My Clinical Adviser explained his analysis relating to the decision to transfer Paul to the Ward. He said that this was a matter of clinical judgement and the UHB’s response to this point was reasonable. He added that Paul was breathing independently, appeared to be coping without the tracheostomy and seemed to be clearing secretions without support. However, he indicated that there was a context for these decisions. He explained:

“In an ideal world, complex patients like Paul who had just had a tracheostomy removed would be cared for in a high dependency setting for several days afterwards. But it is usual in the NHS for there to be intense pressure on intensive care capacity with conflicting needs of different patients being balanced on a daily basis. It would not be unusual for someone who appeared clinically stable to be transferred to a suitable ward area the day

after a tracheostomy was removed. Tragically in this case the assumption that the Ward area was safe for further care was ill-founded”.

78. My Clinical Adviser said that there were flaws in the practicalities of the transfer. He explained that the handover:

- took inadequate account of Paul’s special needs, probably not meeting the requirements of the Disability Discrimination Act
- did not clarify the frequency of suction required
- failed to include any plan for ITU follow-up.

My Clinical Adviser described these as, “substantial shortcomings”.

79. My Clinical Adviser provided a comprehensive analysis of his views on Paul’s general clinical care whilst in hospital. As I have stated, he has outlined aspects of Paul’s care that were good or reasonable. However, he set out a number of significant concerns. I will discuss these below.

80. My Clinical Adviser said that there was no follow up care from the ITU after he was transferred to the Ward. He stated that he would have expected such an outreach service to be in place and used in Paul’s case. However, he noted that the UHB had now introduced such a scheme.

81. My Clinical Adviser said that his understanding of the Disability Discrimination Act led him to believe that Paul’s care did not comply with it whilst he was on the Ward. He said that staff should have made reasonable adjustments, “to ensure equality”. My Clinical Adviser explained further:

“I would expect that the clinical team...should ensure maximum involvement of the carers and family who know better how the patient will react in different circumstances. So for example is agitation psychological, or an indication of pain or breathlessness or hunger or thirst or the need for personal care. It would be good practice to involve a learning difficulties nurse specialist in care”

82. My Clinical Adviser stated that Paul's care on the Ward relied, to some extent, on the assumption that his agitation was psychological rather than clinical. In that context, he was concerned about the use of sedation in Paul's case. He outlined his views as follows:

"The humanitarian reasons for considering sedation for agitation, distress and poor sleep are clear. But the concern about use in complex circumstances is that over sedation may further compromise the patient's ability to clear their chest secretions, also to respond to increasing secretion retention by manifesting further distress, potentially leading to critical retentions of secretions. There is a need for caution and careful observation, which is not necessarily easy in the general ward."

83. My Clinical Adviser was very critical about the clinical monitoring of Paul on the Ward. He described it as, "seriously inadequate". He made various criticisms in that regard. First, he said that the Surgeon, as the Consultant in charge, should have been more involved during Paul's days on the Ward. He said that he could find no evidence that Paul's case was discussed with a consultant after the morning of 21 January. My Clinical Adviser stated that there was evidence that junior doctors did not have appropriate supervision and that this was vital, as they appear to have, "lacked important skills".

84. My Clinical Adviser's second criticism of the clinical monitoring involved the routine review of Paul by a doctor at 09.30am on 22 January, which he did not regard as sufficiently robust. The doctor did not assess Paul's chest despite the SALT entry in the notes and the need for oxygen recently and failed to notice that observations were not being recorded properly.

85. The third aspect of poor clinical monitoring, as outlined by my Clinical Adviser, was that doctors did not ensure that Paul's suctioning regime was adequate. He noted that there was no care plan in place for Paul. He noted that the Surgeon and the SALT emphasised the need for regular suctioning for Paul. He added that suctioning by a skilled nurse or physiotherapist should have been implemented on the Ward. His view was that suctioning should have occurred every four hours. My

Clinical Adviser said that this could have been increased if necessary. He stated that the SALT review on 22 January referred to Paul having notable upper airway secretions earlier. My Clinical Adviser drew attention to the fact that the cause of death was retention of secretions within the bronchial airways. My Clinical Adviser stated:

“Inadequate attention was given to helping Paul clear excess...secretions with skilled physiotherapy and nursing care...despite the notes of the Surgeon and the SALT. Monitoring was insufficiently frequent...”

86. My Clinical Adviser’s final point about clinical monitoring concerned the attendance of a doctor at around 10.50pm on 22 January. He again found that a doctor failed to examine Paul’s chest despite the comments of the SALT earlier that day concerning secretions. The doctor did not react to problematic observations. Although the observations were not recorded adequately, they indicated that Paul was not stable. My Clinical Adviser could not find a record of the conversation between that doctor and the Home Manager, which apparently took place at about 11.15pm. However, he noted that there is an untimed prescription for a sedative on 22 January.

87. My Clinical Adviser summarised Paul’s clinical care from 20-23 January, in the context of the above analysis as:

“...very substantially below standards of basic care which would be reasonably expected.”

88. In forming the above critique of Paul’s care, my Clinical Adviser has noted positive comments in the UHB’s response to my investigator. He remarked that the UHB has acknowledged a number of shortcomings. He added that significant learning appears to have occurred because of Paul’s case.

89. My Clinical Adviser discussed the combined effects of the nursing and clinical failures in Paul’s case. He acknowledged the belief of the complainants that with proper care Paul would still be alive. He also acknowledged the comments of the Intensivist in that regard. My

Clinical Adviser said that if Paul's deterioration had been fully appreciated on 22 January, he would have required a tracheostomy once again and help with breathing. He stated that this would have proved very problematic for Paul, with a high chance of long term serious and life altering consequences. On balance, he considered that Paul would have been unlikely to survive this further deterioration in his condition. However, he suggested that with appropriate and robust nursing and clinical responses to his condition, it is possible that he would have survived, with a small chance of attaining a reasonable level of health thereafter. In drawing this conclusion, he said:

“The evidence is that Paul died with critical retention of chest secretions and that this was a potentially avoidable death.”

My Clinical Adviser pointed out that the Intensivist said that Paul was a candidate for re-admission to the ITU in the event of deterioration. Therefore, he said that this demonstrated that clinicians did not believe at the time that a relapse in Paul's condition would have led to a hopeless situation.

Analysis and conclusions

90. Paul's death and the circumstances that surrounded it, was a tragedy for him and the people who cared for and loved him. I offer my personal condolences through this report. For the Trust, Paul's care presented a major challenge, such was the nature of his illness and the extent of his learning disabilities. Despite aspects of Paul's care in the hospital being adequate or better, the NHS failed him. Below, I will set out my reasons for drawing that conclusion and the implications that this had for him.

91. The investigation did not focus on nursing care. However, my investigator has had to pay due regard to nursing issues to be clear about what, if anything, was outstanding after the POVA report was issued. Moreover, to understand Paul's clinical care, I have had to consider the interplay between the nursing and clinical responses. Therefore, I will begin my analysis and conclusions with a brief word about the nursing care Paul experienced on the Ward.

92. Paul's nursing care on the Ward was abject. I note that the Head of Nursing has used the term "neglect" in relation to Paul's nursing care on the Ward. My Nursing Adviser has concluded that Paul's nursing care was a long way below reasonable standards. She added that the POVA investigation that the Head of Nursing conducted was sound and the basis for significant change. I commend the UHB for its actions in that regard. However, it greatly concerns me that the dire level of nursing care to which Paul was subjected on the Ward, could have happened in the 21st century. It is vital that change is robust and long lasting. I agree with Mrs A and Mr B that an element of independent monitoring should be involved. Despite the thoroughness of the POVA investigation as far as nursing issues were concerned, it appears that there are two matters that the action plan did not address. I consider these to relate to the response of senior staff to reported problems and learning disability awareness training.

93. I will now turn to Mrs A and Mr B's specific complaints as outlined in paragraph 4 of this report. My comments are based on the advice of my Clinical Adviser, which I find thorough, plausible and measured. I note that the matters in question in this regard were not analysed in the POVA investigation report, as they should have been.

94. The first complaint listed in paragraph 4 concerns Paul contracting pneumonia. It appears that this was an unfortunate but common consequence of his acute illness. My Clinical Adviser has praised Paul's care in the ITU. Its staff were not to blame for Paul acquiring pneumonia. I do not uphold this complaint.

95. Mrs A and Mr B questioned the hospital's treatment of the pneumonia. Whilst Paul was in the ITU, that treatment was sound. In terms of the continuing effects of pneumonia whilst Paul was on the Ward, it was far from sound. I will deal with this below. To the extent that the complaint related to care in the ITU, I do not uphold this complaint.

96. Mrs A and Mr B's third head of complaint concerned the decision to transfer Paul from the ITU to the Ward. I regard this as a more contentious matter. My Adviser has not criticised the decision to remove

Paul's tracheostomy. However, he has remarked that in an ideal world, Paul would have remained in the ITU for a longer period after that had been done. We are not in an ideal world. NHS resources are limited. It appears that transferring Paul to the Ward was reasonable in that context. As my Clinical Adviser stated, the transfer was done on the basis that Paul would be looked after on the Ward. He was not. I understand that Mrs A and Mr B will always believe that Paul would have continued to recover if he stayed in the ITU, or at least any deterioration would have been overcome. They might be right. However, whilst having misgivings about the matter, I cannot uphold their complaint about the transfer for the reasons stated by my Clinical Adviser.

97. Mrs A and Mr B said that the hospital mishandled Paul's transfer from the ITU to the Ward. They are correct. The UHB has acknowledged that the ITU discharge form did not include instructions for suctioning. My Clinical Adviser has added two further criticisms relating to the failure to take account of Paul's special needs and the lack of planning for ITU follow-up. These are serious failings, especially when combined with the lack of a care plan as highlighted in the POVA report. These failures were the starting point for Paul's care going wrong. Without them, it is reasonable to assume that Paul's care on the Ward would have been better. I uphold this complaint.

98. Mrs A and Mr B had many concerns about Paul's clinical care on the Ward. I share their views in large part, based on the analysis of my Clinical Adviser. He has said that clinical care was, "very substantially below" a reasonable standard. He has set out his views to that end and criticised:

- the lack of outreach support from the ITU
- a failure to ensure that Paul's care complied with the Disability Discrimination Act
- over reliance on the assumption that Paul's presenting symptoms were psychological rather than clinical
- lack of involvement of the consultant in charge of Paul's care
- a failure of supervision
- inadequate examinations of Paul by doctors

- failure to ensure that vital suctioning care was provided appropriately
- the apparent inability of doctors to notice that observations were not taken, not recorded properly or that alarming results were in evidence.

I would add that the doctor, who discussed Paul with the Home Manager at about 11.15pm on 22 January, should have examined Paul promptly after the latter had reported that Paul had deteriorated.

99. I am very concerned that this level of clinical inadequacy could have been allowed to occur. In short, Paul was supposed to be closely monitored and treated for the possibility that excess secretions would compromise his ability to breathe after a stay in ITU. I note that physiotherapists attended Paul and they suctioned Paul at times. It appears that nursing staff should also have been doing so regularly. They did not. At 03.00pm on 22 January, physiotherapy staff determined that Paul did not require suctioning. Therefore, it appears that Paul deteriorated during the later part of 22 January. Notwithstanding the catalogue of failures discussed in this report, it would be a reasonable assumption that if nurses had suctioned Paul in the later part of 22 January and/or a doctor had examined him thoroughly, the chain of events may have altered. The increase in secretions and his poor observations should have led to a recognition that Paul had relapsed. In the event, the UHB must take a good deal of the responsibility for the fact that Paul died of exactly what suctioning was meant to prevent. He did so without a reasonable level of care and skill in terms of professional intervention, both of nursing and clinical staff. That was devastating for him and the people who loved him.

100. I cannot be certain about what would have happened if staff involved in Paul's care on the Ward had looked after him properly. However, it seems to me that, on balance, Paul's likelihood of surviving with an acceptable life thereafter were reduced from low (with average care) to zero (with the care that he received). That knowledge and the distress that Paul's poor care has caused, represents a major injustice for Mrs A and Mr B. I uphold this part of their complaint.

101. Mrs A and Mr B were dissatisfied with the response of the UHB at local resolution. The local resolution in 2010 only involved a meeting. I note the discrepancies between the official notes and Mrs A and Mr B's perspective. I cannot adjudicate on that. Moreover, bearing in mind my findings, that Paul may have survived with appropriate care, I do not believe that the subtleties of this disagreement have much significance now. I cannot criticise the UHB for ending the local resolution process if Mrs A appeared to have asked it to do so. However, I consider that the UHB should have confirmed this in writing such were the circumstances of this case. Nevertheless, on balance, I cannot uphold this complaint.

102. Finally, I consider it vital that nursing and clinical care providers respond appropriately to the challenge that patients with learning disabilities present. The Six Lives and other reports, combined with the volume of people with learning disabilities that need to use the NHS, demonstrates the necessity of the NHS understanding the needs of those members of our society and making the adjustments that are required. This did not happen for Paul. Moreover, even without that understanding and a proper response to his particular needs, his care should have been far better. I hope I see no further cases like this.

Responses to draft report

103. I am pleased that Mrs A and Mr B and the UHB have accepted the draft report so positively. A representative of Paul raised an issue having read the draft report. The representative said that the case and aspects of the UHB's response indicate that staff did not comply with the Mental Capacity Act 2005 in relation to decision making about Paul's care and may not be fully aware of it now. I appreciate those misgivings. The comment re-inforces the need for awareness training. I have not altered my findings in the light of the response because I trust that issues relating to the Mental Capacity Act would need to be highlighted as part of learning disability awareness training. This is covered by item C of my recommendations below. I also note that the POVA investigation criticised Paul's care in that regard.

Recommendations

104. I recommend that within one month of the date of this report, or longer where specified, the UHB:

- A. sends an apology letter to Mrs A and Mr B from its Chief Executive for all the failings that are discussed in this report.
- B. pays Mrs A and Mr B £1500 each as an acknowledgement that their brother's care was so poor and the uncertainty over how that might have affected the sad outcome
- C. within four months draws up a comprehensive programme of learning disability awareness training for key nursing and clinical staff, which must include appropriate recognition of the role of family, carers and advocates in providing vital information to staff and in helping to make prudent decisions about care
- D. reminds its clinical staff that they should be aware about whether the patients in their care are having appropriate observations recorded **and** acted upon
- E. finds a suitable forum for a comprehensive discussion among consultants about the use of sedation in complex cases, in the light of my Clinical Adviser's comments
- F. reminds all its consultants of the need to ensure robust supervision of junior doctors
- G. within four months, carries out a quality audit of a suitable sample of ITU discharge documentation and takes appropriate action in response to the findings
- H. within four months, carries out a suitable review of patients dying on hospital wards after periods of intensive care and takes appropriate action in response to the findings
- I. takes appropriate action to remind relevant senior staff to react promptly and decisively to reports from junior staff, in the context of the analysis by my Nursing Adviser and relevant guidance
- J. within four months presents my investigation report to a full meeting of the UHB and ensures that a focussed, minuted discussion ensues concerning how its hospitals can best guarantee that it meets the provisions of the Equality Act in terms of patients with learning disabilities
- K. shares this report with Health Inspectorate Wales and requests that it carry out a timely and detailed inspection of the Ward to ensure that the UHB's action plan has been fully implemented and improved standards are being maintained.

105. The UHB has agreed to implement the recommendations above.

Peter Tyndall
Ombudsman

14 September 2011