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PUBLIC SERVICES OMBUDSMAN FOR WALES

The investigation of a complaint against Cardiff and Vale University Health Board

A report by the
Public Services Ombudsman for Wales
Case: 202003539

Contents

Introduction

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

In accordance with the provisions of the Act, the report has been anonymised so that, as far as possible, any details which might cause individuals to be identified have been amended or omitted. The report therefore refers to the complainant as Mr D. Relevant staff involved are referred to by their posts/designations.

Summary

Mr D complained about the care and treatment he received at the University Hospital of Wales during a scheduled admission for surgery to remove the right side of the colon. Mr D complained that:

1. Clinicians suggested that his diseased colon was the result of either Crohn's Disease ("CD") or appendicitis but never provided him with a definitive diagnosis.

2. Clinicians were slow to identify that he suffered a post-operative bleed and required further, emergency surgery.

3. Clinicians were aware that he suffered with Asperger's Syndrome ("AS") but failed to make appropriate adjustments to how information was conveyed to him.

4. Nurses who conducted home visits to assist Mr D in managing a temporary stoma provided inappropriate, ill-fitting stoma bags and unreasonably declined to obtain alternatives; they also failed to adequately treat excoriated skin around the stoma.

The Ombudsman upheld complaint 1. The Health Board said that surgery was conducted on the presumption that Mr D had CD but that surgical findings later suggested complex chronic appendicitis. However, the Ombudsman, through his Surgical Adviser, found that Mr D's pre-operative condition did not meet the threshold for surgery for either of these conditions. He also found that it should have been clear from the intra-operative findings that there were no surgical grounds for proceeding to remove even a limited amount of bowel tissue. The Adviser said that the risk to Mr D of performing surgery was not acceptable and that physicians should have employed a 'watch and wait' approach in which his condition would probably have settled without surgical treatment.

The Ombudsman upheld complaint 2. He found that there was no record of observations taken for a number of hours during the night following Mr D's surgery. This, along with Mr D's physiological condition at the time at which his post-operative bleed was detected, suggested that his

post-operative deterioration might have been detected sooner. Though the Ombudsman accepted that it was not clear whether earlier identification of Mr D's deterioration would have changed the subsequent series of events, it nevertheless exposed him to substantial risk.

The Ombudsman also upheld complaint 3. He found that clinicians did not make reasonable adjustments to accommodate Mr D's AS (and his difficulties with processing information). He also found that a specific request Mr D made to be seen by a mental health clinician was not arranged.

The Ombudsman did not uphold complaint 4. He found that efforts made by Stoma Nurses to obtain and fit appropriate stoma bags (and to treat excoriated skin) were reasonable given the complex nature of Mr D's stoma.

The Ombudsman recommended that Mr D be provided with a detailed apology and, in recognition of the avoidable trauma that he underwent and the distress that this report's findings will give rise to, a redress payment of £10,000 (a sum reflecting the nature and degree of injustice to him). The Ombudsman further recommended that:

- This report is shared with the Clinical Director responsible for the physicians involved in Mr D's care and that its findings are directly discussed at their appraisals and revalidation.

- These physicians undergo relevant training/revision in the management of CD and chronic appendicitis

- This report is shared with the relevant Director of Nursing and directly discussed with those nurses involved in Mr D's care.

- That the nursing team revise/reflect on the importance of conducting and documenting post-operative observations and of preparing accurate and relevant care plans; and, that both hospital and community-based nursing staff receive relevant training in the care and management of patients with Asperger's Syndrome.

The Complaint

1. Mr D complained about the care and treatment he received at the University Hospital of Wales ("the Hospital") during a scheduled admission for surgery to remove the right side of the colon (a right laparoscopic hemicolectomy). Mr D complained that:

- Clinicians suggested that his diseased colon was the result of either Crohn's Disease ("CD" - a chronic inflammatory disease of the intestines) or appendicitis (inflammation of the appendix) but never provided him with a definitive diagnosis.

- Clinicians were slow to identify that he suffered a post-operative bleed and required further, emergency surgery.

- Clinicians were aware that he suffered with Asperger's Syndrome ("AS" - a developmental disorder characterised by impaired social-interactional skills and difficulty in adapting to changing situations) but failed to make appropriate adjustments to how information about clinical findings and treatment plans were conveyed to him.

- Nurses who conducted home visits to assist in managing his temporary stoma (a surgically created opening in the abdomen through which the content of the bowel is diverted) provided inappropriate, ill-fitting stoma bags and unreasonably declined to obtain alternatives; they also failed to adequately treat excoriated (sore) skin around the stoma.

Investigation

2. My Investigator obtained comments and copies of relevant documents from Cardiff and Vale University Health Board ("the Health Board") and these were considered in conjunction with the evidence provided by Mr D. Clinical advice was obtained from 3 of my Professional Advisers: Mr Misra Budhoo, a Consultant Colorectal & General Surgeon, Ms Elizabeth Onslow, a Senior Registered Nurse, and

Ms Jacqueline Peck, a Colorectal Nurse Specialist with expertise in stoma care. I refer to them throughout the report as, respectively, the Surgical Adviser, the Nursing Adviser and the Stoma Nurse ("SN") Adviser.

3. The Advisers were asked to consider whether, without the benefit of hindsight, the care or treatment had been appropriate in the situation complained about. As Ombudsman, 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 in this report every detail considered during the investigation, but I am satisfied that nothing of significance has been overlooked.

4. Both Mr D and the Health Board were given the opportunity to see and comment on a draft of this report before the final version was issued. Mr D did not comment on the draft report but the Health Board responded in some detail to the identified failings. However, the Health Board's comments have not led me to alter or amend my findings or recommendations.

Clinical guidance and policies

5. Reference is made in this report to the following clinical guidance documents:

- British Society of Gastroenterology (BSG) 'Consensus guidelines on the management of inflammatory bowel disease in adults' (2019) – "the BSG Guidance".

- Nursing & Midwifery Council (NMC) 'The Code: professional standards of practice and behaviour for nurses and midwives' (2018) – "the NMC Guidance".

- Welsh Assembly Government (WAG) 'Passing the baton: A practical guide to effective discharge planning' (2008) "the WAG Discharge Guidance".

- Association of Stoma Care Nurses (ASCN) 'Stoma Care National Clinical Guidelines' (2016) – "the ASCN Guidance".

Relevant background information and events

6. Mr D was referred to the Hospital by his GP on 5 September **2018** with a 2-month history of intermittent, lower right-sided abdominal pain and weight-loss. Physicians initially suspected appendicitis or Inflammatory Bowel Disease ("IBD" – a broad term that includes CD and ulcerative colitis - conditions characterised by chronic inflammation of the gastrointestinal tract). Investigations, which included abdominal X-rays, stool sample analysis and a CT scan (a computer-enhanced X-ray), identified 'abnormalities' within the lower right abdominal area indicative of either recurrent appendicitis (with inflammatory appendix mass), or of inflammation at the junction of the small intestine and colon (the terminal ileum) - possibly associated with CD.

7. A colonoscopy was performed (examination of the colon with a flexible fibre-optic camera) which obtained biopsy samples from the terminal ileum and from sections of the colon. The terminal ileum appeared normal but biopsy analysis identified chronic inflammation of the glands in the lining of the intestines. Whilst this was suggestive (though not diagnostic) of CD, it was also suggestive of inflammation from delayed appendicitis presentation. A stool sample test recorded a very elevated level of faecal calprotectin (a protein found in the stool indicating intestinal inflammation).

8. A Consultant Colorectal Surgeon ("the Consultant") reviewed Mr D and agreed that he could be discharged with antibiotics pending further outpatient review and discussion of the biopsy results. At this review (on 20 December) the Consultant explained that the biopsy results were not conclusive and that he had sought a second opinion from a consultant gastroenterologist. The Gastroenterologist subsequently agreed that surgery would be the preferred option (for presumed CD) and this was conveyed to Mr D on 7 February **2019**.

9. Mr D was admitted to the Hospital's colorectal ward ("the Ward") on 12 November and signed a pre-operative consent form that specified the risk of post-operative bleeding and the possibility of requiring a temporary or permanent stoma. The following day, the Consultant performed the right, laparoscopic hemicolectomy but recorded that, once visualised, the

terminal ileum "…did not look obviously as if it had CD". He consequently removed less of the colon than was anticipated and constructed an anastomotic join (the reconnection of the 2 remaining ends of the intestines after a section is removed) using surgical staples.

10. Mr D was taken back to the Ward at 19:00 to recover. However, after some time, he began to feel very unwell. By 03:00 his blood pressure had fallen alarmingly and his NEWS[1] had significantly increased. A Surgical Team review was conducted and a major post-operative bleed was suspected. He was taken back to theatre at 05:30 where a midline laparotomy was performed (where the incision runs down the middle of the abdomen) and about 2 litres of blood was removed from the abdominal cavity. Surgeons decided, as a precaution, to disconnect the anastomosis and form a temporary stoma i.e. a 'double barrelled ileostomy/colostomy' (where the ends of the small and large bowel are bought up to the surface of the abdomen, side by side).

11. Mr D was taken to the Critical Care Unit (CCU) to recover and was visited, the following day, by the Consultant who recorded that Mr D was clearly shocked by his experience. Mr D was transferred back to the Ward on 18 November. He was referred to (and seen by) the Hospital's stoma nurse on 19 November and received instructions and information on self-managing the stoma. He was discharged on 22 November. Following discharge, Mr D received home visits from district nurses ("DNs") and stoma nurses ("SNs"). The ileostomy/colostomy was successfully reversed on 3 March **2020**.

Mr D's evidence

12. In emails to the Health Board of 15 January and 29 July 2020, Mr D complained, through his partner, that he was led to believe that his hemicolectomy would be a routine operation and that he had been assured during the consenting process that the risk of post-operative complications was negligible. However (and contrary to the Health Board's account of the matter), Mr D said he began to feel unwell shortly after his return to the

[1] NEWS: National early warning score - a scoring system based on observations of pulse, temperature, blood pressure and other physiological indicators which identify and monitor deterioration in a patient's condition.

Ward and, by 23:00 informed nurses that ‘something was wrong’. Mr D said that, during this time, he developed worsening abdominal pain and became cold and clammy (despite sweating profusely). Mr D said that he was checked by nurses who took his temperature (only) and kept assuring him that ‘everything was fine’. He said that it was a further 4 hours before staff realised that he had had a major bleed and a further 2 hours before he was taken to theatre. The emergency surgery he underwent left him with a large scar, an ileostomy and an enduring psychological trauma.

13. Additionally, Mr D said that:

- His partner was not informed that he had been taken back to theatre for emergency surgery (contrary to his expressed wish that she should be informed of any emergency developments).

- The meaning of a ‘stoma’ was not adequately explained to him. When told it was temporary, he believed that meant it would be reversed before discharge.

- Clinicians were slow to refer him to the Hospital’s stoma nurse. This limited the time available for him to learn how to change the stoma bag.

- He was repeatedly served meals which were unsuitable for his condition. This continued to occur despite him bringing it to the attention of staff.

- He requested to discuss his traumatic experience and the anxiety it gave rise to with an appropriate mental health professional. However, this did not happen, despite an assurance that it would be arranged.

- A senior ICU nurse suggested he might wish to visit the Hospital’s public concourse. No consideration was given to how his AS made this difficult. He became disoriented which led to him suffering a panic attack.

- He was told (on the morning of 22 November) that he would be discharged later that day. This ran contrary to the assurance he was given that he would receive 24 hours' notice of discharge.

- He was told that both the DNs and the SNs would telephone before arriving, but they later explained that this is not something they ever do.

- The SN advised Mr D to use paper towels instead of medical dry wipes to clean his stoma and recommended calamine lotion for the skin irritation. However, information he obtained online advised against this.

- The SN declined to order products that were not made or supplied by one particular manufacturer. It appeared that this company sponsors and/or financially compensates SNs for using its products.

- On visiting the Stoma Clinic, a SN identified that some staples or stitches had been left in place around the stoma which should have been removed before discharge. Nurses advised that they would work their way out through the skin 'naturally' but this has resulted in additional pain and discomfort.

14. Mr D was unhappy with the Health Board's response to his complaint and wrote a further email specifying where he felt his complaint issues had not been adequately addressed. He emphasised that the Health Board had never provided him with a definitive diagnosis, and it remained unclear to him whether his diseased colon was the result of appendicitis or CD.

15. In a letter to my office, Mr D said that, before his initial operation he was led to believe that he had CD. However, despite this, he was given no treatment to manage this condition while he waited for his operation. Subsequently (when in hospital for his reversal), he was told that he had in fact been suffering from 'complex chronic appendicitis'. Mr D said that it appears therefore that he was incorrectly treated as a CD patient and may have had a large amount of tissue removed unnecessarily. This had "massively" affected his life. He said that he had been unable to attend

work (or carry out everyday activities) with the stoma because of concern about leakage, and had suffered pain, extensive scarring and severe depression.

The Health Board's evidence

16. In its first complaint response of 20 April 2020, the Health Board offered Mr D its apologies for:

- The confusion/failings surrounding his dietary status and the inappropriate foods that he was offered.
- Any confusion/lack of clarity surrounding the nature of the stoma and the precise meaning of 'temporary'.
- The failure of staff to refer him to hospital based mental health clinicians for support and counselling.
- The confusion and panic that he suffered after becoming disorientated in the Hospital's concourse.
- Incorrectly informing Mr D that SNs would contact him in advance of home visits to give a precise calling time.
- The initial difficulties with measuring, checking and adjusting the stoma bag template.

17. With regard to Mr D's complaint about the failure of staff to contact his partner prior to his return to theatre, the Health Board said that it had been specifically recorded in Mr D's notes that he did not wish staff to do this and that his preference was, rather, to contact his partner himself once out of theatre. To that end, staff had ensured that he took his mobile phone with him to theatre and that it was available to him in recovery.

18. The Health Board added that:

- Mr D was referred to the Hospital Stoma Team on 19 November and received stoma-care training until 22 November. On that day it was recorded that he was self-caring with all stoma activities.

- It was not possible to provide Mr D with 24 hours' notice of his discharge. Mr D was however given notice of his afternoon discharge following the SNs morning review on 22 November.

- The SNs confirmed that peri-stomal excoriation (soreness around the stoma) can be relieved by the use of calamine lotion and that paper towels may reasonably be used to absorb fluid leakage.

- The SNs, regardless of where their funding comes from, are bound by the NMC (Code of Conduct) Guidance and must be impartial in the sourcing of products. There is no evidence to suggest that they acted improperly in this regard and the records confirm that products were obtained from a range of suppliers.

19. The Health Board responded to Mr D's email of 29 July on 13 November. The Health Board said that, with regard to the specifics of his diagnosis, surgery was carried out on the basis of "presumed CD". It said that the Consultant and the Gastroenterologist "…were both in agreement that surgery would be the better option for presumed CD, rather than medication". However, on the basis of the Consultant's findings during surgery, the Health Board said he: "…was able to identify that Mr D did not have CD but in fact was suffering from a complex chronic appendicitis, [however] the inflammation markers, biopsies and review of diagnostic imaging were all consistent with the initial CD diagnosis".

20. The Health Board said it did not agree that there was a delay in identifying that Mr D was deteriorating after his initial operation. It emphasised that Mr D's post-operative symptoms of low blood pressure (BP), abdominal pain, pallor and sweating were first noted at 03:00 and he underwent a senior surgical review at 04:30. Following blood transfusions and medication to restrict bleeding, he was taken to theatre at 05:30.

21. With regard to Mr D's AS, the Health Board emphasised that he gave no indication that he was experiencing self-harming thoughts or a depressive episode. The Health Board confirmed that "…all of the clinicians involved in Mr D's care were aware of his diagnosis of AS" but they "…did not feel that he required support from a mental health clinician or that he required a mental health assessment".

22. The Health Board concluded by emphasising that stoma product samples may be sent to patients, but where there is no identified clinical need for them, such products may be rejected by the SNs. However, there was no indication that products were refused by the community SN in this case.

Professional Advice

Surgical Adviser

23. The Surgical Adviser began by considering the lack of clarity surrounding Mr D's diagnosis and his complaint that he may have been "incorrectly treated as a CD patient". He said that, with regard to Mr D's admission in September 2018, there were few recorded details of how his abdominal pain started and progressed. He noted that a CT scan of the abdomen had shown a right-sided 'inflammatory mass' that was considered to be either the result of chronic appendicitis or of CD. However, he said there were no clear indications of CD on the scan. The Surgical Adviser noted that a colonoscopy was performed which identified the terminal ileum as normal in appearance, and the right colon as having increased folds - appearances that, again, were not typical of CD. He also noted that the biopsy of the terminal ileum was normal. The Surgical Adviser added that:

- The results of the CT scan, the colonoscopy and the biopsy analysis were suggestive only of an inflammatory process.

- Mr D's raised calprotectin level (a test that was not repeated) can occur with inflammatory processes other than CD.

- The Consultant's intra-operative notes recorded findings not seen on the scan taken a year earlier, but no other scans (such as an MRI – a more discriminating computerised X-ray) were performed before surgery.

- CD would normally be associated with a thickened bowel, increased blood vessels, enlarged glands and 'fat wrapping' (a coating of fatty tissue) around the colon. However, none of these features were present.

- The adhesions located around the caecal pole (where the large intestine begins) were indicative of recovery from the delayed presentation of appendicitis.

24. The Surgical Adviser said that the decision to proceed to a right hemicolectomy (or any surgery) for CD is a radical one and is normally taken when medical treatment has failed or when a patient's symptoms become so severe that they are admitted as an emergency. Equally, it is very unusual for appendicitis to require such extensive surgery (other than in the most complex cases). The Surgical Adviser said that, given this, he would have expected the operation to have been performed as an exploratory, diagnostic laparoscopy. Moreover, it should have been clear from the Consultant's intra-operative findings that there were no surgical grounds for proceeding further and the rationale behind the decision (made during the operation) to remove even a limited amount of bowel tissue was not clear. The Surgical Adviser said that Mr D's symptoms did not meet the threshold for surgery and there appears to have been no recorded discussion of the option of medical treatment.

25. The Surgical Adviser said that the decision to perform even an abridged resection, involved considerable risk to Mr D (in terms of potential post-operative complications) which was not outweighed by any risk attached to leaving the colon intact. He was clear that, in the absence of a definitive diagnosis, physicians should have employed a 'watch and wait' approach and/or attempted to treat Mr D's condition medically. He added that, alternatively, surgeons might have considered performing an

appendectomy (the removal of the appendix). He concluded that "…the decision, on balance, to proceed to surgery and perform a right hemicolectomy had little merit and was not reasonable".

26. The Surgical Adviser additionally noted that the operation records made no mention of checks conducted (at the end of the procedure) to ensure that the anastomotic joins were viable and that there was no significant bleeding. Also, no mention was made of the device used to divide and ligate (tie-up) blood vessels. The Surgical Adviser considered these to be important omissions from the documentation.

27. With regard to Mr D's post-operative bleed, the Surgical Adviser said that this is an uncommon but important early complication that can be detected via careful observations of BP, pulse and urine output. He said that the drop in BP over the period of time since recovery (12 hours) indicated a loss of blood volume in the region of 40%. This implies a blood loss of approximately 200-300mls an hour which Mr D's body would have attempted to compensate for by, primarily, increasing his heart rate. He would also have become cold and clammy, with increasing abdominal pain and decreased urine output. The Surgical Adviser said that, eventually, Mr D's compensatory mechanisms failed, at which point his condition became a medical emergency requiring fluids and urgent blood transfusion.

28. The Surgical Adviser noted that these measures were promptly instigated at 03:30. However, whilst the Surgical Team recorded being called to see Mr D because of his elevated NEWS, there were no NEWS charts included in the records for the period 20:00 – 03:00. The Surgical Adviser said that a rising pulse followed by a reduced urine output should have triggered concern and that these signs would have preceded the drop in blood pressure and would have been detectable. The Surgical Adviser therefore concluded that it was likely that this monitoring did not take place and that early diagnosis of bleeding and prompt action was therefore delayed. He added, however, that it was uncertain whether an earlier identification of Mr D's deterioration would have changed the subsequent series of events.

29. In conclusion, the Surgical Adviser stressed that:

- The decision to conduct surgery was based on limited evidence and ran contrary to the expectation that surgery is only undertaken when disease is sufficiently significant (as outlined in BSG Guidance).

- Neither scans nor colonoscopy were supportive of CD and insufficient attention was paid to the more likely possibility of delayed appendicitis.

- The findings made during surgery should have limited the operation to either a diagnostic laparoscopy or an appendectomy.

- Pre-operative scans were not performed.

- Mr D was effectively exposed to serious risk which was not justified by the clinical and radiological evidence.

- The Surgical Adviser said "…it is most likely that, within 4 months of his original presentation… Mr D would have settled without surgical treatment, and [further] imaging would have likely demonstrated this".

Nursing Adviser

30. The Nursing Adviser began by considering whether nurses were slow to identify and escalate Mr D's post-operative bleed/deterioration. She noted that a retrospective entry made in Mr D's nursing records suggested that, between 20:00 and 03:00, he appeared to be free of pain or nausea and that he had "…walked to the toilet and settled to sleep". However, the entry also noted that, at 01:30, Mr D was given a prescribed intravenous infusion of Gelofusine (a blood plasma replacement used to increase fluid volume in blood loss or dehydration). This appears to have been given when Mr D's urine output fell below 100mls per hour (in accordance with an instruction written on the prescription chart).

31. The Nursing Adviser said that the records provided by the Health Board did not contain NEWS charts or any other record of observations taken between 20:00 and 03:00. She observed that nowhere in the Health Board's correspondence with the family or with my office was this omission explained and, moreover, its narrative account of the events of that night (in its complaint response letters) notably omitted any reference to this period. Whilst the Nursing Adviser could not definitively state that Mr D's post-operative observations (prior to 03:00) were not, therefore, conducted, this would appear to be the case on the basis of the available evidence. As such, this runs contrary to the NMC Guidance.

32. With regard to the question of whether nurses made reasonable adjustments (particularly in the area of communication) to accommodate Mr D's AS, the Nursing Adviser firstly noted that there are no specific nursing standards or guidelines governing this issue. However, given that clinicians were aware of Mr D's AS and his social anxiety, consideration should have been given to how these factors impacted on him, especially given the unfamiliar environment in which he found himself. Mr D struggled to talk to strangers and seemed to have had a poor understanding of some clinical issues and of his plan of care. The Nursing Adviser said that his problems with social anxiety meant that going to a busy concourse in the Hospital by himself, would have been challenging and likely to have increased his anxiety. She added that all of these factors should have been clearly identified in his care plan but were not.

33. The Nursing Adviser said that NMC Guidance require nurses to "…make a timely referral to another practitioner when any action, care or treatment is required". When Mr D was reviewed on 21 November it was recorded that he appeared "shell-shocked" from recent events and the possibility of psychological/psychiatric referral was queried. However, there was nothing to indicate that this idea was pursued by either medical or nursing staff or discussed further with Mr D. This was a failing of care.

34. With regard to Mr D's complaint that nurses failed to contact his partner to inform her that he had been taken back to theatre as an emergency, the Nursing Adviser said that it was clearly recorded that Mr D did not want his partner informed prior to surgery and that he would contact her via telephone when he was in recovery. To that end, Mr D took his

mobile phone with him to theatre. The Nursing Adviser said that the Health Board's response therefore accurately reflects documented entries in the clinical records and clinicians in that situation could not have gone against Mr D's stated wishes.

35. The Nursing Adviser said that Mr D was not given adequate notice of the plan to discharge him, and the Health Board's response gave no indication of there being any discussion with him (and/or his partner) about his preparedness for discharge. The Nursing Adviser stressed the key to effective discharge planning is the involvement of patients and carers so that they can make informed decisions and choices (as is made explicit in the WAG Discharge Guidance). On that basis, Mr D was not given sufficient notice about his proposed discharge.

36. Finally, the Nursing Adviser said that, on balance, Mr D's referral to the Hospital's stoma nurse was not delayed. She said that it was reasonable that he was not expected to self-manage his stoma-bag while in CCU (given that his IV fluid and analgesia lines might have hindered this).

The SN Adviser

37. The SN Adviser began by considering whether, on referral, (community) stoma nurses (SNs) were aware of Mr D's AS and whether they made reasonable adjustments to accommodate his needs (such as providing him with advance notice of their visits). The SN Adviser said that, having reviewed the documentation, she could find no evidence that Mr D's diagnosis of AS was communicated to the community team or that he had specific communication needs. This ran contrary to ASCN Guidance which stipulates the importance of history taking in establishing patient background information as early on as possible.

38. The SN Adviser said that, whilst it is not always possible for community nurses to confirm their time of arrival at the patient's house, the patient should be aware of the date of the visit as stated in ASCN Guidance. She added that, where a patient has a specific communication or medical need, it would be appropriate to consider these and to provide the patient with, at least, an approximate time of arrival.

39. With regard to Mr D's concern that SNs advised him to use paper towels (instead of medical dry wipes) to clean his stoma and calamine lotion to soothe the excoriated peri-stomal skin, the SN Adviser noted that, on 2 December, SNs recorded in some detail that Mr D had a slightly inflamed suture line and some peristomal skin soreness. The record indicated that Mr D was advised to apply calamine lotion (there was no reference made to the use of paper towels). The SN Adviser said that this was acceptable and that ASCN Guidance advocates the use of calamine lotion for superficial redness or, alternatively, non-sting stoma barrier wipes.

40. With regard to Mr D's concerns about leaks from ill-fitting stoma bags, the SN Adviser noted that SNs recorded that the stoma was producing some mucus and had a 'dip' on its left side which caused it to leak. This did not imply that the bag was not cut to an appropriate size. The SN Adviser said that the visiting SN consequently ordered samples of a 1-piece drainable bag that had a gentle curve, designed to fit securely over an uneven stoma. The SNs notes confirm the order requirements per month of this was suitable. The SN Adviser said that the SN acted in accordance with ASCN Guidance on this point.

41. The SN Adviser then considered the suggestion made by Mr D that, contrary to good practice, SNs favoured one stoma product manufacturer over others. She said that SNs initially utilised this manufacturer's products but, following problems with adhesion and leaks (as a function of the unevenness of the stoma), ordered a number of products from alternative sources. The SN Adviser said there was, therefore, no evidence to suggest that SNs improperly favoured one source of stoma products over another.

42. With regard to Mr D's concern that there were staples or stitches left in place around his stoma (which should have been removed before he was discharged), the SN Adviser said that an ileostomy is stitched in place and usually stitches are dissolvable in 7–14 days. However, the SN Adviser noted that, following his attendance at the Stoma Clinic on 8 January, it was recorded that Mr D had 'pimples' at the '12 o'clock' and '6 o'clock' positions, which were felt to be suture material that had not absorbed. The SN Adviser did not consider it unreasonable that Mr D was advised that this material would eventually work its way out or be broken down by the body.

43. With regard to the Health Board's responses to Mr D's specific questions, concerns and complaints about his stoma care, the SN Adviser said:

- Details of the problems Mr D referred to in ordering supplies should have been appropriately recorded in the daily (visit) record but were not.

- It may have been useful to have explained to Mr D that the stoma size would change as he recovered from surgery. However, the SNs reviewed him regularly and arranged an appointment at the hospital for resizing.

44. In conclusion, the SN Adviser said that the medical notes provide no assessment of Mr D's specific needs in relation to his AS. Had this been done and properly documented, a more tailored approach to his care would have been possible. Many of Mr D's complaints related to his difficulty with communication and learning. Additionally, the SN documentation is limited in terms of recording Mr D's concerns and the responses and solutions to them (including the documentation given to him).

Analysis and conclusions

45. In reaching my findings I have had regard to the advice that I have received from my Advisers, which I accept. However, the conclusions reached are my own. The investigation has considered 4 complaint elements and I will address each of them in turn:

1) The lack of clarity surrounding Mr D's diagnosis and subsequent treatment

46. Mr D's concern about this matter centred on whether the surgery he underwent in response to "presumed CD" was appropriate to the retrospective diagnosis that he received of chronic, complex appendicitis and, therefore, whether a large amount of tissue was removed unnecessarily. I anticipate that Mr D will find the Surgical Adviser's view that the surgery he underwent was not appropriate and, moreover, that his condition did not warrant any form of surgery, extremely distressing.

47. In concurring with the Surgical Adviser on this point, I have had regard to the following considerations:

- There were no clear indications of CD on the CT scan, or from the colonoscopy, or from the biopsy analysis, or from the calprotectin test. These investigation results (none of which were repeated) were suggestive only of an inflammatory process.

- The adhesions located around the caecal pole were indicative of recovery from the delayed presentation of appendicitis – a condition that did not warrant extensive surgery.

- The threshold for surgical intervention (of any sort) was not met and the intra-operative findings gave no indication of the need to remove even a limited amount of bowel tissue.

- There was no evidence that the option of treating Mr D's condition medically was discussed or that a 'watch and wait' approach was considered.

- The decision to perform even an abridged resection involved considerable risk to Mr D which was not outweighed by any obvious benefit.

48. Given the above, I am satisfied that the surgery planned and conducted by clinicians in response to Mr D's presentation had, as the Surgical Adviser stated, 'little merit', and was not appropriate to his condition. This was a serious service failure. I am also of the view that it avoidably exposed him to a series of (potentially life-endangering) risks when his condition would, in all probability, have settled without surgical treatment within a matter of months. I consider that, consequently, Mr D suffered a number of disquieting injustices which included: the prolongation of pain, discomfort and anxiety while awaiting surgery; the disruption and trauma of being admitted to the Hospital and the numerous adversities that he faced as a patient with AS; the pain, discomfort and distress of the surgery he underwent; the development of potentially life-threatening post-operative complications and the further life-saving surgery he underwent; recovery from the further surgery and the management of a

stoma (with numerous associated problems) for several months; the impact of these matters on his mental health, his work, his everyday activities and his family life; the lack of clarity and failings of care that obliged him to submit complaints to the Health Board (and, subsequently, to my office).

49. For all of these reasons, **I uphold** this element of Mr D's complaint.

2) Clinicians were slow to identify that Mr D suffered a post-operative bleed and required further, emergency surgery

50. I concur with the Nursing Adviser's view that, from the available documentation, it is not possible to definitively establish if Mr D displayed clinical signs of deterioration between 20:00 and 03:00 on the night of 13/14 November (that would have been evident from his physiological observations). Whilst the sequence of events following 03:00 were recorded in some detail, the records did not contain NEWS charts or any other record of observations taken before this time, other than a (retrospective) summary of the night's events.

51. I note that, throughout its correspondence, the Health Board has made no reference to any recorded observations taken between 20:00 and 03:00. From this, I conclude that such observations were either not recorded or not carried out, the latter of which, I consider to be the more likely explanation, given that observations were recorded both before and after this period. Moreover, I am not persuaded that Mr D's condition gave no cause for concern prior to 03:00 given that:

- He was administered an intravenous infusion of a blood plasma replacement at 01:30 in response to a significant reduction in urine output.

- He recalled reporting to nurses that he was feeling unwell on several occasions.

- He recalled developing symptoms which closely correspond to the Surgical Adviser's description of the body's reaction to blood loss.

- The Surgical Adviser's assertion that Mr D's gradually rising pulse rate would have been evident and detectable.

52. Given these factors, I concur with the Surgical and Nursing Advisers that it is likely that the monitoring of pulse (in addition to temperature) did not take place and that early diagnosis of bleeding was therefore delayed. Whilst I accept that it is uncertain whether an earlier identification of Mr D's deterioration would have changed the subsequent series of events (in terms of the scheduling of his return to theatre), I am nevertheless of the view that:

- The failure to accurately monitor and record Mr D's observations during a critical period of post-operative recovery (in which he reported deterioration) is concerning and has not been adequately addressed by the Health Board.

- Whilst it remains unclear whether a delay in identifying Mr D's condition (and escalating it) led to any avoidable adverse clinical consequence, this failing nevertheless exposed Mr D to significant risk.

- On the basis of Mr D's recollection, he was placed in the position of having to persist in his efforts to "persuade" and prompt nurses into taking appropriate action.

53. I consider that these factors amount to a significant injustice to Mr D and, consequently, I **uphold** this element of his complaint.

3) Clinicians were aware that Mr D suffered with AS but failed to make appropriate adjustments to how information about clinical findings and treatment plans were conveyed to him

54. I concur with the Nursing and SN Advisers that, whilst clinicians were aware of Mr D's AS and his social anxiety, there was no indication within the records that these factors were incorporated into his care plan (contrary to ASCN and NMC Guidance). It is also concerning to note that Mr D's request to discuss his anxiety and trauma with an appropriate

mental health professional was not pursued. I am of the view that this was a missed opportunity, as many of Mr D's concerns might have been allayed by exploring them with a mental health practitioner.

55. I am of the view that these shortcomings amount to a failure (on the part of hospital clinicians and community nurses) to make reasonable adjustments to take account of Mr D's difficulties with communication and information management. This, in turn, may well have impacted on his understanding of key issues such as how and when his partner should be contacted, discharge arrangements, the meaning of a "temporary" stoma (and other matters relating to his care and treatment). In any event, I consider there was an abiding failure to acknowledge and accommodate Mr D's AS and I therefore **uphold** this element of his complaint.

4) Community SNs provided inappropriate, ill-fitting stoma bags and unreasonably declined to obtain alternatives; they also failed to adequately treat excoriated skin around the stoma

56. With regard to the question of how SNs treated Mr D's peri-stomal excoriated skin, I accept the SN Adviser's view (based on ASCN Guidance) that the use of calamine lotion was acceptable (along with non-sting stoma barrier wipes) and that paper towels may reasonably be used (optionally) to absorb fluid leakage.

57. I also accept the SN Adviser's view that, with regard to Mr D's concerns about leaks from ill-fitting stoma bags, SNs recorded that the stoma had a 'dip' on its left side which caused it to leak. The SN Adviser was satisfied that attempts to counter this by ordering a 1-piece drainable bag that had a gentle curve was a reasonable response to the problem and the SNs acted in accordance with ASCN Guidance on this point.

58. I have also carefully considered Mr D's concern that SNs favoured and/or promoted one manufacturer's products over others, but I am not persuaded that this was the case, given that a number of products were procured from alternative sources.

59. Having said this, I note that the SN Adviser was critical of SNs for not recording details of the problems Mr D encountered in ordering supplies (an apparently complex matter that should have been recorded in the daily-visit record). I also note her view that it would have been useful to explain to Mr D that the stoma size will change as a patient recovers from surgery requiring a process of resizing. Whilst I consider these matters amount to record-keeping shortcomings on the part of SNs, I do not intend to recommend that the Health Board takes further action. However, I **invite** the Health Board to raise these matters for discussion with the relevant SNs in the interests of learning.

60. Finally, I consider that the level of financial redress that I have set out in my recommendations (below) reflects the gravity of the service failures and the consequent injustices to Mr D that I have identified in this report. Specifically:

- Mr D underwent an initial (albeit abridged) hemicolectomy that was not warranted by his condition and which both unnecessarily removed a quantity of bodily tissue and exposed him to the risk of intra and post-operative complications.

- Mr D suffered serious post-operative complications which were only detected when they became life-endangering, and which required him to undergo further emergency surgery.

- Mr D's recovery was complicated by the need to manage a temporary stoma which gave rise to a number of associated problems. This impacted on his work, his everyday activities, his family life and his mental health.

- Mr D then underwent further surgery to reverse the stoma.

- There was an abiding failure by clinicians to record and accommodate Mr D's AS. This compromised his opportunity to fully understand the treatment that was being proposed.

Recommendations

61. I **recommend** that, within **1 month** of this report being issued the **Health Board**:

a) Provides Mr D with a fulsome written apology for the clinical care and communication failings identified in this report. This apology should make reference to the flawed diagnostic and surgical decisions that were made, to the distress and suffering that Mr D endured as a result of them, and to the further distress that this report's findings will give rise to. It should also make reference to the abiding failure to recognise and accommodate Mr D's Asperger's Syndrome in communications with him.

b) Makes a payment to Mr D of £10,000 in recognition of this distress.

62. I further **recommend** that, within **3 months** of this report being issued, the **Health Board** provides me with evidence that:

c) This report has been shared with the Clinical Director(s) responsible for the relevant Consultant Surgeon/Colorectal Team and the Gastroenterologist involved in Mr D's care and that its findings have been reflected upon and directly discussed with those physicians including at their appraisals and revalidation.

d) Steps have been taken to ensure that these physicians undergo training/revision in regard to the diagnosis, treatment and medical management of CN and recurrent appendicitis (with reference to the BSG Guidance).

e) This report has been shared with the relevant Director of Nursing and that its findings have been reflected upon and directly discussed with those nurses involved in Mr D's care.

f) The inpatient nursing team has revised/reflected on the importance of conducting and documenting post-operative observations and of preparing accurate and relevant care plans; and, that both hospital and community-based nursing staff receive relevant training in the care and management of patients with Asperger's Syndrome.

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

Nick Bennett 22 November 2021
Ombwdsmon/Ombudsman

ENDNOTE

This document constitutes a report under s.23 of the Public Services Ombudsman (Wales) Act 2019 and is issued under the delegated authority of the Ombudsman.

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