Northern Ireland
Public Services
Ombudsman

Investigation Report

Investigation of a complaint against the Belfast Health and Social Care Trust

NIPSO Reference: 201912943

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The Role of the Ombudsman

The Northern Ireland Public Services Ombudsman (NIPSO) provides a free, independent and impartial service for investigating complaints about public service providers in Northern Ireland.

The role of the Ombudsman is set out in the Public Services Ombudsman Act (Northern Ireland) 2016 (the 2016 Act). The Ombudsman can normally only accept a complaint after the complaints process of the public service provider has been exhausted.

The Ombudsman may investigate complaints about maladministration on the part of listed authorities, and on the merits of a decision taken by health and social care bodies, general health care providers and independent providers of health and social care. The purpose of an investigation is to ascertain if the matters alleged in the complaint properly warrant investigation and are in substance true.

Maladministration is not defined in the legislation, but is generally taken to include decisions made following improper consideration, action or inaction; delay; failure to follow procedures or the law; misleading or inaccurate statements; bias; or inadequate record keeping.

The Ombudsman must also consider whether maladministration has resulted in an injustice. Injustice is also not defined in legislation but can include upset, inconvenience, or frustration. A remedy may be recommended where injustice is found as a consequence of the failings identified in a report.

Reporting in the Public Interest

This report is published pursuant to section 44 of the 2016 Act which allows the Ombudsman to publish an investigation report when it is in the public interest to do so.

The Ombudsman has taken into account the interests of the person aggrieved and other persons prior to publishing this report.

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SUMMARY
I received a complaint about the actions of the Belfast Health and Social Care Trust (the Trust) in relation to the care and treatment the staff of the Belfast City Hospital (BCH) provided to the complainant's brother (the patient). The patient had Downs Syndrome and also suffered from dementia. The complainant also raised concerns about the Trust's handling of her complaint.

The anxiety and stress associated with being in hospital is particularly acute for people with a learning disability and is compounded by difficulties they may have in being understood and making their needs known, such as expressing levels of pain or discomfort. A number of research reports (Heslop et al., 2013) and independent inquiries (LeDeR, 2017) have highlighted the persistent difficulties encountered by people with a learning disability and their families within general hospital services. It is regrettable that some of these well documented and preventable difficulties were experienced by the patient and their family despite the availability of tools and other resources designed to support the effective care for patients with a learning disability.

GAIN Guidelines set out clearly the levels of care expected for patients with a learning disability. Two areas of focus have particular relevance to this investigation - ensuring that communication is timely and sensitive to the needs of the person and providing person centred care, which is safe and respectful.

The investigation found a significant number of failures in the care and treatment of the patient overall and in the following areas;

Nutrition and Feeding the patient – contrary to guidance which highlights the importance of high quality nutritional care based on individual assessment of needs with appropriate planning and monitoring, this investigation found the following failings:

- The feeding of porridge contrary to Speech and Language Therapy advice on 3 and 4 December 2016 and offering other foods contrary to advice;
- The recording who fed the patient porridge;
- The identification that the recommended diet was not provided and the taking of appropriate action;
- The recording of foodstuffs in a consistent manner; and
- The reporting and recording of adverse incidents in relation to the feeding of porridge on 3 and 4 December 2016.

Communication & Reasonable Adjustments – safe, person centred care is underpinned by effective communication. When caring for a patient with a learning disability communication must be timely and sensitive to the needs of the person and involve the family when appropriate. This is particularly essential in relation to pain management and when a patient is non-verbal. This investigation found the following significant failures:

- Failure to use any kind of pain tool to assess and record the patient's possible pain or distress. This issue is of particular importance as the patient was unable to verbalise his pain levels; and
- Failure to ensure the care of the patient was consistently tailored for a person with dementia and learning disabilities in accordance with GAIN Guidelines.

The investigation also established further failings in relation to:

- A failure to ensure there was a coordinated approach between the Palliative Care and Care of the Elderly teams;
- A lack of coordinated communication between the family, Palliative Care and Care of the Elderly teams and;
- The over prescribing of paracetamol to the patient on Ward 3 South due to the inaccurate estimation of the patient's weight.

The investigation established maladministration in relation to:

- The failure of the Trust to show regard for the patient's human rights by failing to appropriately support or record the assessment of the patient's possible

pain or distress; and to ensure the care of the patient was not consistently tailored for a person with dementia and learning disabilities;

- The failure to report overprescribing of paracetamol in line with the Trust's 'Adverse Incident Reporting and Management Policy', April 2014 and it's 'Guidelines for the administration of intravenous (IV) Paracetamol', December 2014; and
- The failure to inform the complainant and her family of the overprescribing of paracetamol in line with the Trust's 'Being Open Policy', February 2015

The poor management of complaints has been highlighted in many of the reports and inquiries that have examined the care of people with a learning disability in hospitals. Opportunities were missed in this complaints handling process to provide the family with empathetic and timely responses which may have helped resolve their concerns locally and prevented them having to use time and energy in approaching the Public Services Ombudsman.

The investigation established failings in the Trust's handling of the complaint namely:

- The failure to meet with the family prior to completing any investigation;
- The failure to share minutes of the meeting, held on 21 September 2018, with the complainant for comment;
- The delay in issuing minutes of the meeting, held on 21 September 2018, to the complainant;
- The delay in providing a final response to the complainant;
- The failure to provide regular and informative updates to the complainant;
- The failure to ensure coordination between the complaints team and the service area and;
- The failure to recognise the sensitivities around arranging a venue for the meeting with the complainant on 21 September 2018.

The investigation did not establish failings in the patient's care and treatment in relation to:

- The decision to carry out the procedure of oral suctioning on the patient on the night before he died;

- The vitamin drip being administered after the patient was deemed End of Life on 6 December 2016;
- The reducing pain relief without consent; and
- The anaesthetics care of the patient on 10 November 2016.

The investigation was unable to make a determination as to whether the vitamin drip was administered prior to the administration of paracetamol on 9 December 2016.

I concluded that that the maladministration and failures in care and treatment by the Trust in not appropriately supporting or recording the assessment of the patient's possible pain or distress; and in not consistently tailoring the care provided to meet the needs of a person with dementia and learning disabilities, caused the patient to experience the injustice of distress. I am also satisfied that the maladministration and failures in the care and treatment I identified caused the complainant and her family to experience upset, frustration, uncertainty and loss of opportunity for an adverse incident investigation into the over prescribing of paracetamol.

These investigation findings highlight the need to continue to raise awareness and improve practice for some of the most vulnerable patients within the hospital system. In this case, the failings in relation to the treatment and care of the patient were compounded by the added distress for the family arising from poor complaints handling.

I recommended that the Trust provides the complainant with a written apology for the injustice caused as a result of the maladministration and failures in care and treatment I identified. The Trust have been asked to engage an independent Learning Disability specialist to carry out a review of the issues raised within this complaint to identify any further opportunities for learning. I also have made recommendations for service improvements in relation to end of life care, coordination of care between the Palliative Care Team and Medical teams, record keeping and training provision for staff.

I acknowledged and welcomed the learning already identified and implemented by the Trust to: provide printed instructions regarding each Speech and Language

Therapy recommendation, for reference, on all Older Peoples Wards; to make available a Learning Disability resource on the Belfast Trust Internal Web site; to make available a resource pack, for staff, within all Older Peoples Wards; additional training and the rolling out of the hospital passport used in Adult Learning Disability services to all known service users where possible.

THE COMPLAINT

1. I received a complaint about the actions of Belfast Health and Social Care Trust (the Trust) in relation to the care and treatment the staff of Belfast City Hospital (BCH) provided to the complainant's late brother, (the patient). The complainant also raised concerns about the Trust's handling of her complaint.

Background

2. The patient, who had Downs Syndrome[1] and also suffered from dementia[2], was admitted to Ward 3 South, BCH on 9 November 2016 under the care of the Urology[3] Team for insertion of a suprapubic catheter.[4] On 25 November 2016 Care of Elderly reviewed the patient and he was transferred to Ward 7 North.

3. The complainant believed the patient did not receive appropriate care and treatment on Ward 7 North. A chronology detailing the events leading to the complaint is enclosed at Appendix six to this report.

4. The complainant also raised concerns about the Trust's handling of her complaint. In particular, she believed the complaints process was not carried out within the relevant timeframes and was carried out in an insensitive manner with the process lacking compassion. The complainant also believed the Trust's response was not coordinated.

5. A chronology detailing the complaint handling process is enclosed at Appendix seven to this report.

Issues of complaint

6. The issues of complaint accepted for investigation were:

Issue 1: Whether the care and treatment received by the patient in Ward 7 North,

[1] A chromosomal abnormality resulting in a variable degree of learning difficulties and a characteristic physical appearance.
[2] A condition characterised by a deterioration in brain function. The main symptoms are progressive memory loss, disorientation, and confusion.
[3] The branch of medicine concerned with the structure, functioning, and disorders of the urinary tract in males and females, and of the reproductive system in males.
[4] A hollow flexible tube that is used to drain urine from the bladder.

Belfast City Hospital, between 25 November 2016 until 10 December 2016 was appropriate and reasonable? In particular:-

a) **The appropriateness of the patient's diet while on the ward and compliance with Speech and Language Therapy instructions.**
b) **The coordination of end-of life care between the Palliative Care and Geriatric teams.**
c) **The appropriateness of carrying out oral suctioning on the patient.**
d) **Concerns that the patient was not given appropriate pain relief and suffered unnecessarily.**

Issue 2: Whether the complaint was investigated according to policy and procedure?

INVESTIGATION METHODOLOGY

7. In order to investigate the complaint, the Investigating Officer obtained from the Trust all relevant documentation together with the Trust's comments on the issues raised by complainant. This documentation included information relating to the Trust's handling of the complaint.

Independent Professional Advice Sought

8. After further consideration of the issues, I obtained independent professional advice from the following independent professional advisors (IPA):

- **Consultant Geriatrician**, MB MSc MD FRCP FRCPE FRCPI Dip Card Lond, a consultant physician for over 30 years and an accredited geriatrician since 2001. (G IPA)
- **Consultant Nurse**, RGN, BA(Hons), MSc, PGCert(HE), specialising in the care of frail older people, including people with dementia, with experience across acute care and community. (N IPA)
- **Consultant Anaesthetist,** MBChB, MA (Med. Ethics and Law) PgDip (Med.

Education) FRCA, with over 22 years experience in providing anaesthesia for urological surgery. (A IPA)

9. The information and advice which informed my findings and conclusions are included within the body of my report. The IPAs provided me with 'advice'; however how I weighed this advice, within the context of this particular complaint, is a matter for my discretion.

Relevant Standards

10. In order to investigate complaints, I must establish a clear understanding of the standards, both of general application and those which are specific to the circumstances of the case. I also make reference to relevant regulatory, professional and statutory guidance.

The general standards are the Ombudsman's Principles[5]:

- The Principles of Good Administration
- The Principles of Good Complaints Handling
- The Public Services Ombudsman Principles for Remedy

11. The specific standards and guidance referred to are those which applied at the time the events occurred. These governed the exercise of the administrative functions and professional judgement of those individuals whose actions are the subject of this complaint.

The specific standards and guidance relevant to this complaint are:

- The General Medical Council's (GMC) Good Medical Practice, as updated April 2014 (the GMC Guidance);
- The Nursing and Midwifery Council's (NMC) Code: Professional standards of practice and behaviour for nurses and midwives, March 2015 (the NMC Code);

[5] These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.

- The National Institute for Health and Care Excellence's (NICE) Quality Standards [QS13] End of life care for adults, November 2011 (NICE QS13);
- The Guideline and Audit Implementation Network (GAIN) Guidelines on Caring for People With a Learning Disability in General Hospital Settings, June 2010 (GAIN Guidelines);
- The Department of Health, Social Services and Public Safety's (DHSSPS) Improving the Patient and Client Experience Standards, January 2012, (the DHSSPS Standards);
- Belfast Health and Social Care Trust's Policy and Procedure for the Management of Comments, Concerns, Complaints and Compliments v 3 (the Trust's Complaints Policy); and
- The Department of Health, Social Services and Public Safety (DHSSPS) Complaints in Health and Social Care: Standards and Guidelines for Resolution and Learning, April 2009 (the DHSSPS Complaints Procedure).

12. I did not include all of the information obtained in the course of the investigation in this report but I am satisfied I took into account everything that was relevant and important in reaching my findings.

13. A draft copy of this report was shared with the complainant and the Trust for comment on factual accuracy and the reasonableness of the findings and recommendations.

INVESTIGATION

Issue 1: Whether the care and treatment received by the patient in Ward 7 North, Belfast City Hospital, between 25 November 2016 until 10 December 2016 was appropriate and reasonable? In particular:-

a) The appropriateness of the patient's diet while on the ward and compliance with Speech and Language Therapy instructions.
b) The coordination of end-of life care between the palliative care and geriatric teams.

c) The appropriateness of carrying out oral suctioning on the patient.
d) Concerns that the patient was not given appropriate pain relief and suffered unnecessarily.

Detail of Complaint

14. The complainant raised concerns about the care and treatment the patient received on Ward 7 North of BCH. In particular she said that the patient received foodstuffs contrary to Speech and Language Therapy (SLT) instructions. This included the feeding of porridge, on at least two occasions, as well as other staff leaving food for the patient or offering the family food for him when he was nil by mouth. The complainant also believed there was a conflict and lack of coordination between the Geriatric[6] and Palliative Care[7] teams resulting in poor care of the patient. She also complained about the procedure of suctioning[8] being carried out on the patient on the night that he died. She believed this to be a painful procedure that was not required and caused him distress.

15. The complainant also raised concerns that the patient was not given appropriate pain relief. This included reducing his pain relief without consent, the administration of a vitamin drip, on 9 December 2019, prior to being given paracetamol to reduce temperature, as well as the patient continuing to receive a vitamin drip after he was deemed End of Life on 6 December 2016. As a result the complainant stated the patient suffered unnecessarily. The complainant also said staff did not use an appropriate tool for assessing the patient's pain.

Evidence Considered

Legislation / Policies / Guidance

16. I considered the following guidance and standards:

- the GMC Guidance
- the NMC Code
- NICE QS13
- GAIN Guidelines

[6] Relating to old people
[7] Care for the terminally ill and their families
[8] Procedure used to maintain patients' airways by removing mucous secretions and foreign material.

- the DHSSPS Standards

Relevant extracts of the guidance and standards referred to are enclosed at Appendix three to this report.

The Trust's Response to Investigation enquiries

17. In response to enquiries about the patient's diet and SLT recommendations the Trust explained *'A review of [the patient's] medical records was undertaken and can confirm he was fed porridge on the 3 and 4 December 2016. There is no other documentation in the records that evidence [the patient] was fed other inappropriate food.' The Trust note however, 'The SLT records on 6 December 2016 have recorded that 'pt. was offered a minced meat dinner and porridge on sat & sun morning' (3 and 4 December 2016).* It went on to explain *'We are unable to identify who fed [the patient] porridge, as this is not recorded in nursing records. As such, it is not possible to have the opportunity to discuss why this occurred. However, we accept that there was clearly a breakdown in communication between the nursing staff involved in providing [the patient's] care that resulted in him being fed porridge, which was contrary to the Speech and Language Therapy recommendations.* The Trust *'…unreservedly, apologise for the distress this caused to [the patient's] family.'* The Trust also explained it had reviewed the Datix system, which retains a record of all incidents, and confirmed that there was *'…no record of an adverse incident being reported…in relation to this incident. The Trust acknowledges that this should have happened and this was reinforced with staff…'*

18. The Trust went on to explain the Deputy Sister at the time *'…raised the issue with nursing staff and reinforced the specific SLT recommendations…* as well as liaising *'…directly with the Speech and Language Team to ensure that staff were aware of the correct consistencies as recommended by the team. All wards within our service now have written advice available to staff detailing the correct food types for each consistency as a further reinforcement of best practice. The SLT Service facilitates training for all nursing staff on a rolling basis. Printed instructions regarding each SLT recommendation are displayed, for reference, on all Older Peoples Wards within Belfast City Hospital to include those foods, which must be avoided.'*

19. In relation to enquires about the coordination of end of life care between the Palliative Care and Geriatric teams the Trust *'acknowledged…that the ward fell short of the standards expected and there was an absence of a coordinated approach in the provision of [the patient's] care.' 'The medical records evidence extensive input for Care of older people and Palliative Care Teams. There is no record of a joined up review of [the patient's] care or evidence of direct discussion between the two teams however the records would indicate that both teams were aware of each other's inputs.'*

20. In relation to the complaint that the patient was suctioned on the night that he died causing him distress the Trust explained that *'It had been noted on 08 [sic] December 2016, by the Chest Physiotherapist, that nasal suctioning should not be carried out due to distress this caused. [The patient] received oral suctioning in the hours prior to his death. The notes document that during this time [the patient] had significant secretions that are known to cause distress. The rational for completing this was to optimise comfort.* The Trust further explained that oral suctioning *'…occurred on 9 December 2019 [sic] on 3 occasions on 05:50, 08:00 and 16:00…'* and is *'…a procedure undertaken by registered nurses following a clinical assessment of need.' 'The oral suctioning was undertaken to alleviate distress caused by accumulating secretions.'* It went on to explain that registered nurses are not trained to undertake nasopharyngeal suction (NP)[9]*'…and there would be no circumstances where nursing staff would undertake this within Older People's wards.'*

21. In response to enquiries about reducing the patient's pain relief the Trust explained *'The patient was on 2mg on [sic] morphine. This was reduced to 1mg on the 26 November 2016. Prescription charts for the syringe driver note the dosage was reduced from Morphine Sulphate 2mg to 1mg at 15:00 on 26 November 2016. This was then discontinued at 21:00 and changed back to Morphine Sulphate 2mg at 21:05, 26 November 2016*…'

[9] Technique used by respiratory physiotherapists that involves using the airway of the nose to remove secretions from the upper airways when the patient is unable to do so themselves.

22. It explained that the rationale for the decision to reduce the dose of morphine is not clear from the review of the notes entry *'…although concerns had been raised relating to constipation in the previous medical review on 25 November 2016. The Consultant responsible for this decision making recalls noting the previous entry by the palliative care team…that abdominal cramps had improved with hyoscine. The Consultant recalls considering [the patient's] abdominal cramps may have been related to constipation which can be a side effect of Morphine and further more could have had a contributory effect to drowsiness at this time. For this reason the dose of Morphine was reduced at this time, Hyoscine was continued.'*

23. The Trust also explained in addition to pain relief via the syringe driver the patient was also *'…prescribed 'as required' medication 1mg morphine sulphate…'* from 24 November 2016. *'This additional pain relief, could have been administered if the nursing or medical team assessed him as being in pain subsequent to the change on the syringe driver dose.'* The Trust stated this 'as required' medication 1mg morphine sulphate was administrated *'…on 8 December 2016 (11:25) and on two occasions 9 December 2016 (11:40 & 16:30)…'*

24. When asked if any attempt was made to consult the family or the palliative care team about this reduction the Trust explained *'A clinical decision to reduce the morphine by 1mg was made on the assessment of [the patient's] condition. At the time of this dose change discussion with the Palliative Care Team was not felt necessary. The team did discuss this with the family later that evening and the dose was readjusted to the original dose and rate.'*

25. In relation to the complainant's reference about the administration of a vitamin drip the Trust explained *'… this treatment was not related to pain relief. [Dr A] commenced the vitamin drip known as Pabrinex 26 November 2016 following the initial ward round. As [the patient] was nil by mouth and consideration was being given to the insertion of a nasogastric tube the intravenous Pabrinex (vitamin drip) was commenced in line with this.*

26. The Trust also explained *'…[the patient] was prescribed IV paracetamol to be administered four times daily from 26 November 2016. Prior to this date [the*

patient] was prescribed and received oral paracetamol on a regular basis. The route of administration was changed due to nil by mouth status. The medical drug records evidences that paracetamol was administered as prescribed with exception of 2 occasions…'

27. The Trust explained *'As learning from the complaint GAIN Guidelines on Caring for People with Learning Disability in General Hospital Settings has been shared with all wards and have been discussed at team meetings. A Learning Disability resource is now available for all staff on the Belfast Trust Internal Web site and all wards have been provided with information regarding this. In addition, a resource pack is now available within all Older Peoples Wards to ensure staff are familiar with the appropriate assessment tools and guidance. The Learning Disability service was contacted to review current training available for staff within acute areas in preparation for a proposed link nurse type role that will support best practice within each ward. A formal request for training has been made through the Nursing Learning and Development Team for courses to be commissioned for Care of Elderly staff to access Learning Disability courses relating to Dementia to enable teams to ensure best practice…'*

Clinical Records

28. The patient's clinical records were considered. Relevant extracts form the clinical records are enclosed at Appendix four to this report.

Relevant Independent Professional Advice

29. The G IPA was asked to comment on the impact on patients of receiving inappropriate foodstuffs when suffering from aspiration pneumonia and if there was such an impact on a patient. In response to the impact on patients, he advised *'Aspiration pneumonia may get aggravated…'*

30. As to the impact on the patient he went on to advise *'He had impaired swallow and SALT recommendation was that he should have only textured B thin, pureed food and stage 2 custard thick fluid This is recorded by SALT as "a recommendation with acknowledged risk that aspiration is possible" still. He allegedly received non-*

approved food porridge. He was said to have developed aspiration. However it is not easy to prove a clear cause and effect given the fact that he was already prone to aspiration. That he was offered porridge is accepted by the Trust and thus there was a breach of SALT advice.'

31. The G IPA was asked to comment on the coordination of the patient's end of life care. He advised *'…there is no record that there was lack of coordination between palliative care and geriatric team as regards end of life care. Their findings/opinions are recorded correctly and chronologically in the clinical Multiprofessional Notes.'* The findings and recommendations of the Palliative Care team were *'…properly recorded in the notes and have been acknowledged by the geriatric team.'* He also advised *'…There is no evidence in the medical records of any disagreement or discord.'*

32. The G IPA advised *'The palliative care team was at first concerned in the main with symptom control. There was an expectation initially among the geriatricians that he might get better once his aspiration pneumonia was treated with antibiotics. It was not an unreasonable expectation for a young man aged 59, though of course he had significant co-morbidities…However when it became obvious that [the patient] had reached the end of his life, active treatment with antibiotics was withdrawn and the accent changed to keeping him comfortable based also on the recommendations of the palliative care team…That was around the time when the idea of finding him a place in a hospice was mooted but no beds were found soon enough for [the patient]…'*

33. The G IPA also advised *'Though it was probably recognised that [the patient] was nearing the end of his life, active treatment with fluids and antibiotics was still being administered on 3/12/16. It was only on 6/12/16 that the Palliative care team mentions for the very first time the phrase, "likely end of life care"…Advice from the palliative care team on 28/11/16 was for a "parallel plan for future care" while saying that if he deteriorates then hospice care would be appropriate. Therefore they had not made/taken any clear decisions regarding EoL[End of Life] care at that point. It can be argued that [the patient] should have been started on EoL care much earlier.*

That actual decision to launch into EoL care was however not made by the palliative care team (who were aware that he was still on intravenous antibiotics) till 6/12/16.'

34. The G IPA went on to advise *'…Overall based on the available evidence/standards prevailing in 2016 the care provided to [the patient] cannot be greatly faulted.'*

35. In relation to the use of oral suctioning the G IPA advised *'[The patient's] swallow was impaired. Uncoordinated swallow was putting him at risk of developing aspiration pneumonia. Secretions could easily trickle down the windpipe because his swallow reflexes were not working properly*. *When the medication that was being used was not sufficient to effectively dry up the secretions (hyoscine was being administered continuously over 24 hours via the syringe driver precisely for this purpose), there was the risk that accumulated secretions in the mouth and windpipe could cause [the patient] to choke / become breathless/ develop aspiration pneumonia… Additionally, secretions in the upper airways might cause (to the listeners who are present in the room – the family, for instance) a disturbing rattling sound as air that he breathes bubbles though the secretions...'* The G IPA went onto advise *'…It is a safety decision to use suctioning and was being done in [the patient's] best interests to provide comfort and also to reduce the risk of developing pneumonia.'*

36. The G IPA was asked to comment on the reduction of morphine sulphate levels given to the patient. He advised that on '*On 25/11/16 it was suggested that a trial of continuous subcutaneous infusion [CSCI] of morphine sulphate 2mg and hyoscine butylbromide 20 mg over 24 h.'* be given. '*Additionally [the patient] was to receive on as required basis: hyoscine 20 mg subcutaneously and morphine 1 mg subcutaneously 2-4 hourly.'*

37. The G IPA advised '*Morphine is an exceedingly constipating drug. Morphine slows the transit time in the gut allowing the intestine to absorb the water/fluid during the slow passage of stools, thus causing constipation. That constipation contributes to/aggravates delirium is well recognised*.'

38. The G IPA went on to advise *'…Dr [A] at his ward round on 26/11/16 has suggested changing the dose of morphine sulphate in the CSCI to 1 mg/ 24 hrs. The reasoning is not recorded. However it can be surmised that the rationale was to explore if by reducing morphine, his constipation and resulting delirium would improve. It is not standard practice to record rationale behind every change in the dose of a drug…morphine sulphate 1 mg via syringe driver was started at 1500 hrs on 26/11/16. This order was however scored out 6 hours later and the original dose of 2 mg/24 hours was restored. He also advised that the '…dose of 2 mg morphine sulphate was then continued unchanged, every day on 26/11/16, 27/11/16, 28/11/16, 29/11/16 and subsequently till 9/12/16. Therefore in effect [the patient] continued to receive the originally prescribed dose of 2 mg morphine sulphate via the syringe driver over 24 hours except for a 6 hour hiatus on 26/11/16.'*

39. The G IPA advised '*Reducing the dose was only a trial to ascertain if that would overcome his delirium which may have been aggravated by morphine induced constipation.' 'The decision to reduce the dose of morphine was reversed within six hours due to the concerns expressed by [the patient's] sisters. It was not unreasonable to restore original dose of morphine as the family were so unhappy.'*

40. The G IPA was asked to comment on whether a consultation should have taken place with the Palliative Care Team prior to a reduction in morphine levels. He advised *'…it is not essential because the geriatrician is well versed in medical matters at the end of life. The clinician is therefore perfectly competent to prescribe and alter dose of morphine.'* The G IPA also made comment on if a consultation ought to have taken place with the family in relation to the same matter. He advised *'No. It is reasonable for the geriatrician [sic] make clinical decisions in the best interests of his patient…it was not a huge reduction in dose that was being proposed. 2 mg morphine over 24 hours is actually in itself a very small dose.'*

41. In relation to the 'as required' 1mg morphine sulphate the G IPA advised the patient *'… was prescribed as required morphine sulphate subcutaneously. BUT this was only administered once, presumably because it was not needed except on that occasion. The only occasion it was administered was just once at 1125 hrs on 8/12/16.'*

42. The G IPA commented on the level of paracetamol the patient received. He advised *'...the maximum dose of paracetamol that [the patient] could have safely had was only 2.7 g.'* He advised '*The dosing of paracetamol has been an issue in the case of [the patient]. This was because he was initially prescribed and administered full adult dose of paracetamol, usually 4 g/day. However since he was under 45 kg body weight, the usual dose of 4 g/day would have been excessive…' 'IV paracetamol 1 g four times daily was initially prescribed on 9/11/16 on as required basis, up to a maximum prescribed dose of 4 g daily oral/iv…This prescription was re-written on 13/11/16 as 1 g four times daily po'.* On 25 November 2016 the prescription was *'…re-prescribed as 500 mg IV four times daily with a note to say that the dose reduction was being made because of low body weight. This was the correct step.'* At this time *'…actual weight was taken into the reckoning in determining the dose of paracetamol.'*

43. The G IPA was asked to comment on the recalled weight of the patient, at the time of admission, and if this had any impact on comments already made about the dosing of paracetamol. He advised *'I assume that figure is unreliable…*' as other identified *'…anomalies only go to show how unreliable "recall" is, and misleading when medical decisions are based on wrong values.'*

44. The G IPA commented on the impact to the patient from receiving higher doses of paracetamol. He advised that prior to 26 November 2016 the patient *'…was getting large doses which could have been potentially toxic to his liver and later his kidneys too. However there is no evidence from the blood test results that he came to harm as result of overdosing with paracetamol.'*

45. In relation to the vitamin drip given to the patient the G IPA advised *'The vitamin infusion that the family mentions is probably referring to intravenous Pabrinrex® high potency solution for injection. This was prescribed on 26/11/16. Pabrinex® is often used when a patient who has not been eating but then starts feeding. This is standard practice and may be acceptable given the fact that [the patient] had not been made for end of life (EoL) care at that point.'*

46. The G IPA commented on the pain relief given to the patient during the period from 25 November 2016 to 10 December 2016. He advised '*There is no actual concrete evidence available that the pain relief was inadequate. The NEWS observation chart has recording of pain score, whenever recorded (as it has not invariably recorded) is marked as zero implying no pain. In any event he could not have been given more paracetamol due to low body weight. More morphine would have put him at risk of worsening delirium due to increased constipation. Therefore one must conclude that from 25/11/2016 he was on optimum drug dose for pain.'*

47. He went on to advise *'However there is an entry on 25/11/16 at 1215 hrs where the palliative care team suggest that they felt he may have been in pain based on "moaning, holding lower abdomen/bladder area reluctant to be examined." On the same day at 1530 hrs by the ST6 doctor from Care of Elderly says, "Appears in discomfort ?abdomen, facial grimacing, pulling at sheets over abdomen. Not keen on examination." The corresponding entries on the NEWS score on 25/11/16 at 0910 hrs, 1505 hrs and 2010 hrs have not recorded anything at all concerning the pain score.'*

48. The G IPA identified learning /service improvements which are enclosed at Appendix five to this report.

49. The G IPA concluded that *'Communication between the family and the two teams could have been better, especially as to their expectations for the patient and the aim of treatment. The dosing of paracetamol was excessive. Yet [the patient] did not suffer liver toxicity as a result. Recognition that [the patient] was dying should have happened earlier. The palliative care team should have initiated EoL care sooner because it was actually within their gift, rather than try and keep on top of his pain control.'*

50. The N IPA was asked to comment on the SLT instructions given in relation to the feeding of the patient, from 25 November 2016 to 10 December 2016, and how these instructions were conveyed to nursing staff. The N IPA advised that entries in both the SLT and multi-professional notes and references in the *'Daily evaluation of Nursing Care' '…all provided clear guidance on what consistency of diet and fluids*

to offer. There is evidence that the SALT spoke directly to the nursing team as well as recording entries in the multiprofessional record and providing BED Signs with clear instructions.' She advised that *'… SALT used an appropriate combination of written and verbal records and instructions to communicate with the nursing staff as well as the wider team. The specific advice is clearly written up in multi-professional notes with reference to discussion with the nursing team. The bed sign dated 2nd December was deployed appropriately…'*

51. In relation to the bed sign dated 2 December 2016, which sets out swallowing recommendations, the N IPA advised the sign was *'…clearly written and in large letters.'* She advised that a *'…relative had tampered with the sign…Fortunately, this did not alter the key point of the sign, or contradict entries in the multi-professional record. However it did remove additional information that was presumably intended to support the ward team in preparing the correct consistency using what was provided by the kitchen. Regardless of this, the nursing team would be expected to know what a Texture B diet is, and that porridge was not the correct texture.*

52. The N IPA was asked to comment if the patient received any foodstuffs contrary to the SLT advice. She advised that *'There are no specific food charts in the records. Entries are made ad hoc either in the nursing records or on the fluid chart…there is evidence that [the patient] received foodstuffs contrary to SALT advice on at least 3rd and 4th December 2016.'*

53. The N IPA advised *'There is no information in the records about who fed the porridge to [the patient]'*… however...*'The Registered Nurse is accountable overall for this aspect of care. The failure to provide the recommended diet should have been picked up by the Registered Nurse, and recorded in the Daily Evaluation of Nursing Care. The Registered Nurse would be responsible for assessing [the patient] for signs of possible aspiration eg breathlessness, wheeze, coughing and to have recorded NEWS observations. They should then have discussed the outcome with the medical team. There is no record that this happened. The Registered Nurse would also be responsible for reviewing the incident with the person who incorrectly fed [the patient], advising them on the correct procedure, and identifying if additional training or other measures were required in order to prevent the*

situation recurring. An incident report should have been completed because the treatment plan was not correctly followed and harm could potentially have occurred. None of these actions are recorded.'

54. The N IPA advised that oral suctioning procedures can be *'…carried out by Registered Nurses for management of upper respiratory/ oral secretions. This is normal practice if the patient is distressed by the secretions, and assistance is urgently required… The Daily Evaluation of Nursing Care on 9 December records that the nurse carried out suction at 05:50, 08:00 and 16:00… This was a reasonable action and is appropriate for a nurse to carry this out for upper respiratory secretions.* The N IPA went onto advise that the management of secretions on 9 December, carried out by a registered nurse, was *'…in line with good practice.'*

55. The N IPA commented on any indication of distress caused to the patient by the oral suctioning. She advised that *'After the suctioning…on 9 December at 05:50 it is clear that the nursing team were monitoring [the patient] and attempted to assess NEWS although they record that the sisters "refused for me to check NEWS score". During the day the nursing staff subsequently administered appropriate treatment for comfort "prn dose of midazolam, morphine, buscopan, glycopyrronium all given". [The patient] was also reviewed by the palliative nurse*. The N IPA advised *'There is no evidence that the suctioning specifically caused distress on this occasion. Appropriate assessment was attempted following the procedure but was declined by the patient and his relatives.'*

56. The N IPA was asked to comment on the methods used to assess the level of the patient's pain/comfort. She advised that *'The Abbey Pain Tool[10] was developed for assessing pain in people with dementia who may have difficulty in verbally communicating their symptoms. Pain assessment tools are intended to support professional observation and judgement and do not replace this.'* The N IPA also advised that she *'…did not find any evidence of the Abbey Pain Tool being used by any of the multi-professional team or the visiting specialist palliative care team. There are a number of references to whether [the patient] appeared comfortable or*

[10] An observation pain assessment tool used in care of patients with dementia

in distress in the Daily Evaluation of Nursing Care, but these are not supported by use of a tool or scale.'

57. The N IPA advised *'…that the nurses and multi-professional team made professional judgements of whether [the patient] was in pain or distressed. Ideally this judgement would be supported by a measure such as a pain tool that has been designed for the person with communication and cognitive impairment such as that associated dementia and learning difficulties. This would support professional judgement in interpreting his symptoms, quantifying his need, evaluating his response to treatment and recording his progress. Pain score on NEWS was completed on a number of occasions, but this was not appropriate.'* The N IPA also advised '…*In all cases where a score is given it is 0.'* The pain scores *'…usually relies on the person being able to describe their level of pain and to report a score. It is unlikely that [the patient]…would have been able to cooperate with this effectively…'*

58. The N IPA commented on the differences between the Abbey Pain Tool and the other assessment tools, namely the DisDat[11] tool, and which would be considered more appropriate in the care of the patient. She advised the DisDat tool is *'…designed to assess non-verbal signs of distress (as a symptom that includes but is not specific to physical pain) …It was designed …for working with people with learning disabilities. It principally assesses non-verbal signs such as vocalisation and tongue/jaw movement but does also include an item on skin appearance. The Abbey Pain Scale was developed specifically for assessment of pain in dementia, and is similar to the DisDat in looking for non-verbal signs, but goes further in assessing physiological and physical signs, such as blood pressure reading, skin damage, that might indicate that the person could be in pain.'*

59. The N IPA also advised *'[The patient] was physically ill as well as having long-term problems with learning disability and dementia. Acute problems such as constipation and infection, as well as degenerative joint change could have contributed to pain and could be assessed through physical examination and/or observation. The Abbey Pain Scale would have been more likely to capture all*

[11] Used for assessing distress in people with severe communication difficulties.

these factors including potential physiological triggers in acute care, therefore may have been marginally more useful than the DisDat in this circumstance.'

60. The N IPA was asked to comment if adequate pain assessments were carried out on the patient for pain/comfort and if appropriate follow-up action taken as necessary. She advised, that following a review of the medical notes, *'… that although pain assessment should have been supported by a pain score appropriate for the person with dementia and learning difficulties, professional judgements were made about [the patient's] level of comfort and appropriate follow up action was taken if pain or distress was detected.'*

61. The N IPA commented on whether the IV[12] paracetamol was administered as prescribed. She advised that the *'…Medicines Administration Record confirms [the IV paracetamol] was given with exception of 2 and 7 December midday… No reason is given for the paracetamol not being given on the two occasions. Otherwise it has been administered regularly as prescribed.'*

62. In relation to any impact on the patient as a result of not receiving IV paracetamol on the two occasions the N IPA advised, following a review of the medical records, *'…that professional judgements relating to pain and distress were made on these occasions and that there is no evidence from either date that [the patient] was in pain or any other impact as a result of not receiving IV paracetamol.'*

63. *Overall, the N IPA concluded that the patient's '…care was not consistently tailored for a person with dementia and learning disabilities. Specifically there was a failure in care when he was provided with inappropriate diet on two occasions, and assessment of possible pain or distress was not appropriately supported.'*

64. The N IPA identified learning for the Trust *'…to ensure that staff have access to appropriate training and guidance on caring for people with learning disabilities and dementia, including assessment of pain and distress, and to ensure that all staff are appropriately trained and supervised to assist people who have swallowing difficulties. I recommend that use of food chart is good practice and should be*

[12] to administer a fluid (as of medication, blood, or nutrients) directly into a vein

routinely used for people with these needs. [The patient's] treatment and care overall is likely to have been enhanced by greater awareness of the needs of the person with learning disability and dementia in hospital, such as the GAIN Guidelines, and use of an appropriate tool to support assessment of pain and distress. A Learning Disability 'Passport' would probably also have supported staff in understanding his preferences, needs and communication.'

The Complainant's response to the draft report

65. In response to the draft report the complainant raised concerns in relation to the issues below. The complainant's full responses to the draft report are enclosed at Appendix eight to this report.

Diet

66. The complainant and her family were distressed to learn of the incidents when the patient was fed porridge as they previously believed this occurred only once on 3 and 4 December 2016. They stated that all the incidents were not disclosed in communications with the Trust through the complaints process or by Deputy Ward Manager who had, in face-to-face, contact promised a serious case incident report. The complainant also advised that the incident report never occurred. The complainant also believed that the porridge fed on 4 December 2016 was from the same bowl and not refreshed or reheated. The complainant holds the view that feeding of foodstuffs contrary to SLT advice accelerated the patient's decline since he became end of life on 6 December 2016.

End of life care

67. The complainant refuted the G IPA assumptions around *'family expectations'* and advised that the family expectations were clear with the patient's admission to hospital being for a palliative care procedure. The family wanted a dignified death and compassionate care.

Oral Suctioning

68. The complainant raised further concerns that the oral suctioning carried out on 9 December 2016 and, in particularly at 05:40, was not necessary as the patient was considered end of life and questioned the need for it. She also disagreed with the

IPA's advice that the oral suctioning carried out on the 9 December 2016 was to provide comfort and also to reduce the risk of developing pneumonia. She wished to clarify that the family were not upset by the rattling sound produced by secretions in the upper airways as suggested by the G IPA. The complainant highlighted that the family did not object to the patient being suctioned when it was for his benefit and stated that when it was carried out by physiotherapist, it was done so compassionately and following appropriate assessment. The complainant sought clarification in relation the clinical record on 7 December 2016 as to whether the *'…difficult oral suction…'* was difficult for staff or for the patient.

Pain Management – consent

69. The complainant affirmed that best practice, given GAIN guidelines, would have been to discuss the reduction in morphine with the patient's family and in the absence of consent any reduction should have been informed by recorded observations and assessment. She also raised concerns that the G IPA evidence that *'…family were unhappy with the reduced dose and protested…'* and the CT2 doctor's notes that *'…two sisters were very unhappy (about) changes to analgesia…'* lacked understanding of patient led care.

Vitamin drip

70. The complainant advised that that she and the family did understand the purpose of Pabrinex® but strongly object to it being administrated at all on the 9 December 2016. The complainant believed this provided evidence to the family that the clinical staff were driven by blood results rather than by observing the patient before them.

Pain Management – administration of paracetamol

71. The complainant commented that she appreciated that the investigation had identified the over prescribing of paracetamol however also highlighted that the G IPA had identified that the patient was given the incorrect dosage of Enoxaparin[13]. The complainant was concerned that the dosage of Enoxaparin was not reduced in a timely fashion. The complainant was also concerned that the G IPA had concluded and, I had accepted, there was *'…no evidence from blood results that*

[13] Used to prevent blood clots in people who are hospitalised or at home.

the patient came to harm as result of overdosing with paracetamol...' She further questioned how this conclusion could be reach based on a blood result alone and raised further queries in relation to reversal medication. The complainant further raised concerns as to whether the Trust should have raised a critical incident in relation to the overprescribing of paracetamol and queried the Trust's ability to follow their own 'Being Open Policy' as this information was not disclosed at any point to them.

Anaesthetics care

73. The complainant raised concerns that the family had been called urgently to the recovery suite following the patient's surgery on 10 November 2016 as he was very slow to regain consciousness. She went on to say she had been informed that the patient *'…may not waken up…and [she] was advised to prepare for [the patient] not recovering.*' The complainant queried whether this was also related to the use of the 'recalled weight' recorded on admission.

In general

74. The complainant was concerned about the G IPA's statement that ''*…Overall based on the available evidence/standards prevailing in 2016 the care provided to [the patient] cannot be greatly faulted.'* given that failings were identified in relation to incorrect feeding and the over prescribing of paracetamol she challenged that statement. The complainant also commented that this office did not seek advice from a learning disability independent advisor as part of the investigation.

Concerns about Trust's identified learning

75. The complainant raised concerns that the learning identified by the Trust was insufficient. In particular, in relation to the Learning Disability resource provided on the Trust's internal website and the use of the Hospital Passport for people with learning disabilities. She believed her concerns could be addressed by the appointment of an on-call specialist Learning Disability expert available to all hospital settings to advocate on behalf of learning-disabled individuals.

Trust's response to the draft report

76. The Palliative Care Team provided additional comments as further context to the patient's care and treatment as well as highlighting an existing operational policy, which outlines the Palliative Care Team's recognition of the importance of communication with clinical teams. '*As a general principle, if patients have significant and ongoing input from the Community Specialist Palliative Care Team, the Hospital Team should be able to provide continuity of input at the request of the Community Team. This approach has been agreed with the Oncology service, and it works well.'*

Coordination of end of life care

77. Clarification was provided on the parallel plan suggested by the Palliative care Team. This plan was '…*reflective of the uncertainty that can be involved during an acute deterioration, although recognising that this patient's health in the preceding weeks and months had been pursuing a downward trend…Recognising dying can be difficult…and can be best supported by a Multidisciplinary collaborative approach.'*

78. The Palliative Care Team believed *'There was evidence of good communication between the family and the Palliative Care Team and evidence of written communication between the Palliative Care and the Care of the Elderly Teams…*' However it highlighted there was a lack of coordination of the communication and *'…no evidence of direct face-to face communication between the Care of the Elderly and the Palliative Care Team…'* This also included the opportunity to have a multidisciplinary meeting following a request, made on 1 December 2016. It is the Palliative Care Team's belief that a multidisciplinary team meeting *'…might have facilitated better planning and a change in direction of care.*'

Pain Management - consent

79. The Palliative Care Team recognised that it is imperative for teams to change medication in the best interests of the patient but noted that on this occasion there should have been more communication between ward staff, family and the Palliative Care Team *'…which, perhaps, could have occurred in a more collaborative manner.'*

Pain Management – pain assessment tools

80. Clarification was provided on the provision of the Disdat tool with the Palliative Care Team advising that the tool was left by Palliative Care for the nursing team on Ward 3 South on 24 November 2016 on the recommendation of the Community Dementia Hospice Nurse. Although the Palliative Care Team recognised that the Disdat tool was not commonly in use in the hospital at this time. It was also raised that the team believed there was evidence that the Palliative Care Nurse carried out a holistic assessment of the patient on every occasion of attendance.

Oral Suctioning

81. The Trust provided further comment following the complainant's request for information of the oral suctioning carried out on 7 December 2016. They said '*Despite the time that has passed, the Physiotherapist has confirmed he recalled the intervention provided to [the patient] on 7 December 2016. He advised that he encountered technical difficulties when performing the suction due to the tongue position. This would be in keeping with what has been documented within the records as the terminology relates to the difficulty of performing the suction. There is no documentation or recollection concerning [the patient] experiencing any trauma during the procedure such as bleeding as this would be recorded as a consequence of a suction if difficulties were experienced by a patient.'*

Reporting of the over-prescribing of paracetamol

82. The Trust advised that *'IV Paracetamol medication issue was discovered on 7 North after the patient was transferred there. An incident was not completed on Datix. We are unable to confirm why an incident was not completed on Datix by either the Care of the Elderly team on 7 North or the Urology team on 3 South. We are also unsure what communication there was between the two teams when this was discovered….' '…This omission meant that the usual trigger that should have initiated a referral to the National Poison Information Service and/or the National Patient Safety Agency was not followed and therefore the referral did not happen...As these events happened more than 4 years ago, it is now not possible*

to determine why this error in the prescription of intravenous paracetamol was not recorded as an adverse incident on the Datix system. This was clearly an oversight and we wish to apologise for any additional upset or distress that this has caused.'

Anesthetics care

83. The Trust explained that the Consultant Anaesthetist, Dr C, who provided anaesthetic care to the patient during his surgery on 10 November 2016 reviewed the patient notes. The weight in the theatre checklist was listed as 56.9kg, which was completed by the ward nursing team before surgery. *'…There is nothing written beside this weight in the theatre checklist to prompt [Dr C] to question this weight. This is the weight…used to assist in determining the dose of anaesthetic drugs. This is acceptable practice.'*

84. The Trust explained that Dr C *'…has indicated that the anaesthetic management of this case was safe, effective, and patient centred. Generally, anaesthetic drugs are titrated to response and there are published theoretical drug doses, which are usually expressed as mass of drug per kg of body weight. It is not always safe or sensible to administer the dose of drug indicated by the published doses. A safe anaesthetic will involve careful selection and titration of the administered drugs and effective management of the resulting physiological changes. The direction of these physiological changes is predictable but there is inter-individual variation in the extent of the physiological compensation for drug-induced changes.'*

85. The Trust went on to explain that *'There were no intraoperative issues, and [the patient] was transferred from theatre to the recovery ward. On arrival to the recovery ward, there is a nursing note…'on arrival he was keeping his own airway, on 02 (SpO2 100%) SLM, BP 130/60, temperature 36.3". These parameters were clinically acceptable and are within normal limits. There is a further nursing note "not responding to voice, only rousable to painful stimuli. However comfortable and stable". The recovery room observations indicate that his respiratory rate, oxygen saturation, blood pressure and heart rate were always within normal limits. The level of consciousness recordings indicate that [the patient] was responsive to painful stimuli at 1730hr but was rousable to*

voice between 1730hr and 1900hr. After this, he was alert… There were no unusual issues or problems with [the patient's] perioperative care or recovery room care after surgery.' It also explained that '*It is normal practice for the recovery team to occasionally contact relatives of patients after surgery. If the patient is vulnerable, the relatives would be offered an opportunity to sit with and comfort their relative in the recovery room after surgery. This offer would be extended when the patient is stable.'*

Further Independent Professional Advice received.

86. Following receipt of the complainant's response to the draft report advice was sought from an A IPA and additional G IPA advice was sought. The additional clinical advice received is enclosed at Appendix five to this report.

Oral Suctioning

87. In relation to oral suctioning being carried out on the patient, who was end of life, on 9 December 2016 the G IPA advised *'The presence of secretions in the respiratory passages would produce difficulty in breathing and a choking sensation in the patient at the end of life. This is alleviated by suction. Suctioning during EOL would have therefore provided comfort…'* Given the specialist chest physiotherapist's recommendations *'… it was reasonable, appropriate and necessary to use suction of secretions to relieve distressing symptoms and provide comfort during EOL care on 9/12/16 by which time the patient was clearly terminal.'*

Pain Management – consent

88. The G IPA was asked to provide clarification on whether the decision to reduce morphine was based on clinical evidence and considering GAIN guidelines if consultation should have taken place with the family prior to any reduction. The G IPA advised *'...The decision to reduce the dose [of morphine] to 1 mg was made on clinical judgement. This decision was based also on the observations/ concerns of the consultant psychiatrist in learning disability and the palliative care team which have been recorded in the medical notes. Thus, it was not based on the observation of the consultant who reduced the dose alone but also on the observations of the learning disability consultant and the palliative care team…'*

89. He went on to advise *'…The treating doctor would be expected to discuss treatment modalities, diagnosis and prognosis with the patient (if he has capacity) or the next of kin. That is in keeping with Good Medical Practice laid down by GMC. BUT the clinician DOES NOT require to obtain prior consent to change/adjust doses of drugs given because to patients as it is not standard procedure and as such, is not mandated by GMC's Good Medical Practice. Thus, it cannot be claimed that the clinician was acting without consent…'* The G IPA further advised *'…GAIN Guidelines state… that "healthcare staff can apply doctrine of necessity for immediate decision making in the patient's best interests." This is standard practice concerning care of any patient in the hospital setting, including those with learning disability. This is what happened regarding the decision to reduce the dose of morphine in the syringe driver.*

90. *GAIN Guidelines…state that "expressions of concern must be addressed immediately". In the case of [the patient], the family's concerns were taken on board and the clinical decision was reversed promptly, in keeping with the family's wishes. It is thus NOT necessary to consult family before adjusting drug doses. It is not specified as mandatory under GAIN Guidelines. Neither is it a requirement of GMC under Good Medical Practice nor as part of Good Practice in Prescribing.'*

91. The G IPA also provided clarification regarding advice provided in his original report. He advised that *'… From further examination of the prescription record it is apparent that the dose of morphine was reduced to 1 mg for a period under 4.5 hours, rather than 6 hours as was mentioned…'. '…Morphine 1 mg was written up for the syringe driver to commence at 1300 hrs on 26/11/16 and this was revised with a fresh prescription that commenced at 1715 hours…The original dose was thus reinstated within less than 4.5 hours. There would have been no significant effect of the reduction in the dose via the CSCI on [the patient] because of the slow rate of infusion given through the syringe driver...'*

Pain Management – vitamin drip

92. The G IPA identified the times Pabrinex® was prescribed and administrated after the patient was deemed end of life. *'…Pabrinex® was prescribed and administered three times daily at 0600 hrs, 1400 hrs and 2200 hrs on 6/12/16,*

7/12/16 and 8/12/16 according to the Medicine Prescription and Administration Record….During this period, a single dose of Pabrinex® which was due at 1400 hrs on 7/12/18 was missed/ not administered.' He went on to advise that he could not find a prescription for Pabrinex® being given on 9/12/16…' The G IPA further advised *'…Pabrinex® was used to prevent electrolyte disturbances and resultant cardiac arrhythmias that may occur… As Pabrinex® had been started it was reasonable to continue with it even during EOL care because of its potential to prevent terminal cardiac distress. There could have been no adverse effect on the patient from a water-soluble vitamin and no toxicity from accumulation in the body would result as his renal function was normal.*

Pain Management – Overprescribing

93. The G IPA provided clarification about the patient's dosing of Enoxaparin. He advised *'Enoxaparin was being given for thromboprophylaxis (= to prevent deep venous thrombosis or clots forming from immobilisation in the hospitalised patient). Enoxaparin was commenced on 9/11/16 at a dose of 40 mg (p.33/62).The dose was reduced to 20 mg from 5/12/16.'* He further advised *that ' The dose of enoxaparin was halved because the medical team had been carefully monitoring the platelet levels as [the patient] had a previous history of thrombocytopaenia (= low platelet count) and they discovered that his platelet count had begun to decrease… Halving the dose on 5/12/16 was timely and it was the correct response to developing thrombocytopaenia*

94. The G IPA commented on the impact to the patient in relation to the dose of Enoxaparin received. He advised *'The original dose was the recommended prophylactic dose of enoxaparin to prevent deep venous thrombosis. The patient* was not adversely affected *by giving him the full dose because his kidney function was normal. Additionally, the medical team was closely monitoring his platelet levels and they opted to reduce the dose in good time…'* As to whether reversal medication should have been administered the G IPA advised that '*Paracetamol dose was reduced because patient's body weight was low. He did not suffer any toxicity from being given the full adult dose because liver function test and kidney tests were unaffected. Hence, there was no indication for any reversal medication. It has already*

been explained that enoxaparin dose was halved because patient developed thrombocytopaenia which is a known side effect of enoxaparin…'

95. In relation to the use of blood results to determine impact on the patient the G IPA advised '*Liver enzymes and clotting factors being tests of liver function remained normal throughout. [The patient's] blood urea, serum creatinine and eGFR, representing renal function, were perfectly normal. Thus, he had normal liver and kidney function and no ill effects were caused by paracetamol. No further tests were required as these are sensitive tests for evidence of paracetamol toxicity /poisoning.'*

96. The G IPA went on to advise on how clinicians should have reported the over prescribing both internally and to family members. He stated *'In Northern Ireland an adverse incident is defined as an event which causes, or has the potential to cause, unexpected or unwanted effects that will involve the safety of patients, staff, users and other people…The purpose of raising adverse incidents/ serious incidents is not to point the finger of blame but rather to obtain learning in order to prevent harm and /or recurrence. According to the Trust's own Adverse Incident Reporting and Management Policy[7] issued April 2013…the matter of overdosing with paracetamol should have been reported using the Trust's extant system for this purpose, even though the patient did not come to harm. This would have led to reinforcing the learning regarding dose adjustment for paracetamol depending on body weight (and other factors). One assumes this had not been done in this instance as documentation for this was not available.'* He went on to advise *'There was no learning to be had in citing having to reduce the dose of enoxaparin as a critical incident because it was a recognised side effect.*'

In general

97. The G IPA provided reasoning for his statement in relation to the overall care of the patient and remained satisfied that the *'…care provided cannot be greatly faulted.'*

Anaesthetic care

98. The A IPA advised that it would be considered acceptable and appropriate to ask the patient, or use scales to determine a patient's weight. He went onto advise it

would also be appropriate to ask a relative or carer if the patient was accompanied by them. The A IPA further advised that *'…anaesthetic drugs which could have their dose expressed on a mg/kg basis… were given at doses at the lower end of the range even if the patient's actual weight is taken into account…' and '…were titrated to physiological response.'* He went on to advise *'Based on the actual weight of the patient all drugs given in theatre were administered at the correct doses, with the exception of the paracetamol…There was no impact on the patient from this.'*

99. The A IPA also advised that the patient was at increased risk from the anaesthetic *'…due to his comorbidities. The increased risk was recognised by the anaesthetist treating [the patient]…and scored [the patient] as being in a high risk category "ASA 4*[14]*"…'* He went on to advise that within the records '*There is nothing that indicates particular concern on the part of the staff looking after the patient.'* The A IPA concluded that *'The anaesthetic care provided for this patient was of an appropriate standard, being tailored to the patient's comorbidities and physiological response.'*

Analysis and Findings

100. I wish to acknowledge the complainant's comments in relation to obtaining a learning disability independent advisor as part of the investigation. However on consideration it is my view that the use of an independent advisor is best addressed through my recommendations so to maximise learning for the Trust.

Diet

101. The complainant raised concerns that the patient received foodstuffs contrary to SLT instructions. This included the feeding of porridge, on at least two occasions, as well as other staff leaving food for him or offering the family food for him when he was nil by mouth. I further note the complainant's concerns that the patient's porridge on 4 December 2016 may not have been refreshed or reheated.

102. I note the clinical records document that on 2 December 2016 at 11:45 SLT recommended *'Stage 2 custard thick fluid. Texture B thin puree diet. Little and*

[14] The ASA (American Society of Anaesthesiology) score is a measure of how fit or otherwise a patient is when coming for surgery. A patient washi s ASA 4 is someone who has been identified as having sever systemic disease that is a constant threat to life.

often. Stop if coughing regularly. This is a recommendation with acknowledged risk that aspiration is possible.'

103. I note the Daily Fluid Balance Charts document on 3 December 2016 at 08:00 the patient was given 30 ml of porridge and on 4 December 2016 at 08:00 4 tsp porridge (20 ml) which was repeated at 09:00.I note the SLT records document on 6 December 2016 at 11:40 a family member raised *'…some grievances regarding food and fluids offered to pt over the wkend…Over the weekend, pt was offered a minced meat dinner and porridge on Sat & Sun morning. These items are not within the recommendations…'* I am unable to determine from the clinical records if the patient's porridge on 4 December 2016 was refreshed or reheated. However, I would be concerned if this were the case, as, notwithstanding that porridge was not within the SLT recommendations, it would have additionally been very unpalatable if not refreshed or reheated and would show a lack of respect for the patient's human right to respect and autonomy.

104. I note the Trust's comments that *a review of [the patient's] medical records '…confirmed he was fed porridge on the 3 and 4 December 2016. There is no other documentation in the records that evidence [the patient] was fed other inappropriate food.'* The Trust also acknowledged the SLT records as detailed in paragraph 103 above. I also accept the N IPA's advice'…*that [the patient] received foodstuffs contrary to SALT advice on at least 3rd and 4th December 2016.'* I refer to the NMC Code which states staff must *'…deliver the fundamentals of care effectively…'* I am satisfied that feeding of the patient porridge contrary to SLT advice on 3 and 4 December 2016 and the offering other foods contrary to SLT advice as failures in the patient's care and treatment. I also accept the G IPA's advice in relation to the impact on the patient following receiving in appropriate foodstuffs *'…it is not easy to prove a clear cause and effect given the fact that he was already prone to aspiration.'* I acknowledge the complainant's view on this matter and I accept the clear distress caused to the patient and his family. However I do not consider that on the balance of probabilities a link can be drawn from these incidents and the subsequent deterioration of the patient though such action will have increased the risk.

105. I acknowledge the Trust accepted there was *'…clearly a breakdown in communication between the nursing staff involved in providing [the patient's] care that resulted in him being fed porridge, which was contrary to the Speech and Language Therapy recommendations...*' and that the Trust *'…unreservedly, apologise for the distress this caused to [the patient's] family.'* I further acknowledge the complainant's comments that the Trust failed to raise the feeding of porridge, against SLT advice, as serious incidents. I note the Trust's recognition of this. I have also noted the complainants comment that this has impacted on her confidence in the ability of the Trust to follow their internal policies and procedures.

106. I note the Trust's comments that it was *'…unable to identify who fed [the patient] porridge, as this is not recorded in nursing records and as a result there was no '…opportunity to discuss why this occurred.'* I note the Trust's comments that the Deputy Sister at the time *'…raised the issue with nursing staff and reinforced the specific SALT recommendations…* as well as liaising *'…directly with the Speech and Language Team to ensure that staff were aware of the correct consistencies as recommended by the team. '* I note within the clinical record dated 6 December 2016 there is recognition and reinforcement of the SLT recommendation by a Senior Nurse. I am concerned that the Trust were unable to identify who fed the patient porridge on the dates in question as well as failing to report and record the feeding of porridge as an adverse incident. I consider these two issues resulted in a missed opportunity to investigate these incidents and impacted on the ability to maximise the learning as detailed below.

107. I also accept the N IPA's advice that *'The failure to provide the recommended diet should have been picked up by the Registered Nurse, and recorded in the Daily Evaluation of Nursing Care…'* and the incident reviewed *'…with the person who incorrectly fed [the patient], advising them on the correct procedure, and identifying if additional training or other measures were required in order to prevent the situation recurring.* I refer to NMC Code, which states *'…you must…complete all records at the time or as soon as possible after an event…' and '…identify any risks or problems that have arisen and the steps taken to deal with them, so that colleagues who use the records have all the information they need…'* Although I accept the Trust comments that the issue was raised with nursing staff and the SLT

recommendation reinforced I am satisfied that, the failure to record who was responsible for feeding porridge to the patient, to identify that the recommended diet was not provided to the patient, and to report and record adverse incidents is a failing in care and treatment. This is a particularly concerning failing given the patient's learning disability and lack of verbal communication.

108. On consideration of the clinical records I was unable to determine if the patient was fed other foodstuffs contrary to SLT advice on any other occasions. I note the N IPA's comments that *'There are no specific food charts in the records. Entries are made ad hoc either in the nursing records or on the fluid chart.'* I accept the N IPA's view that '*an appropriate combination of written and verbal records and instructions...'* were used by SLT *'…to communicate with the nursing staff as well as the wider team.'* I am satisfied there was a failing to record foodstuffs given to the patient in a consistent manner. I consider the lack of detailed records regarding the patient's diet very concerning given the difficulties that he was experiencing and the SLT advice. I note the family's concerns that the patient was offered foods at other times that were not consistent with recommendations. Given the error in feeding the patient porridge, the account of the family and the lack of records I am satisfied that on the balance of probabilities the patient was offered food inconsistent with recommendations on other occasions.

109. Given the failures in the patient's care and treatment identified above **I uphold this element of the complaint.**

110. I note the Trust response that *'All wards within our service now have written advice available to staff detailing the correct food types for each consistency as a further reinforcement of best practice. The SALT Service facilitates training for all nursing staff on a rolling basis. Printed instructions regarding each SALT recommendation are displayed, for reference, on all Older Peoples Wards within Belfast City Hospital to include those foods, which must be avoided.'*

Coordination of end of life care

111. The complainant raised concerns about the lack of coordination between the Geriatric and Palliative Care teams. She believed this resulted in poor care of the patient. She also believed there was conflict between the two teams. I note the

clinical records document a referral to Palliative Care was made on 23 November at 15:15. I also note that on 28 November 2016 the Palliative Care Team document *'…Parallel plan for future care…'* and the Palliative Care team comments that this was reflective of the uncertainty involved.

112. I note that on 6 December at 12:00 that Palliative Care was to make a referral to a hospice *'…for symptom control, complex psycho and social support of [patient] and family and likely End of life Care…'* I also note that the Palliative Care record on 7 December 2016 documents *'…appears to me to be in final days of life…Would it be appropriate for managing team to agree/inform family members on ceiling of care? No hospice bed available... No suggested change to current medication but consider reviewing if medications are still appropriate…'*

113. I note the clinical records document that the Care of the Elderly team noted inputs from Palliative Care on 8 December 2016 at 09:30 and 9 December 2016. I also note on 9 December 2016 the patient's syringe driver was changed in line with Palliative Care recommendations.

114. I note the G IPA's advice that *'…The findings and recommendations of the Palliative Care team were '…properly recorded in the notes and have been acknowledged by the geriatric team.'* He also advised *'…There is no evidence in the medical records of any disagreement or discord.'* Therefore, based on the available evidence I do not consider there was any conflict between the Palliative Care and Care of the Elderly Teams. **Therefore I do not uphold this element of complaint.**

115. I note the G IPA's advice that *'Though it was probably recognised that [the patient] was nearing the end of his life, active treatment with fluids and antibiotics was still being administered on 3/12/16. It was only on 6/12/16 that the Palliative care team mentions for the very first time the phrase, "likely end of life care"…It can be argued that [the patient] should have been started on EoL care much earlier. That actual decision to launch into EoL care was however not made by the palliative care team…till 6/12/16.'* I also note the Palliative Care Team comments that '*Recognising dying can be difficult…and can be best supported by a Multidisciplinary collaborative approach.'*

116. I considered the relevant extracts of NICE QS13 relating to end of life Care as enclosed at Appendix four to this report. I note the G IPA's advice that *'… based on the available evidence/standards prevailing in 2016 the care provided to [the patient] cannot be greatly faulted.'* and his reasoning for this statement. I further note the complainant's disagreement with this statement. I also note the G IPA's advice that *'…Communication between the family and the two teams could have been better, especially as to their expectations for the patient and the aim of treatment…', '…Recognition that [the patient] was dying should have happened earlier…' and '…End of Life care should have been initiated sooner...*' I further note the complainant's comments that the family had clear expectations as to the care of the patient and it was geriatricians that had contrary expectations. I also note the Palliative Care Team comments in relation to their communication with the family and the Care of the Elderly team and their acceptance that there was a lack of coordination of the communication. I also accept there was a missed opportunity for a multidisciplinary meeting to ensure better co-ordination in the decision making.

117. Given the missed opportunity for a multidisciplinary meeting I am satisfied, there was an absence of a coordinated approach between the Palliative Care and Care of the Elderly teams. Communication between the family and the two teams could also have been more coordinated. I am also satisfied this lack of coordinated communication and approach meant that there was no clear decisions taken about end of life care and this would have ensured end of life care was initiated earlier. I consider the lack of coordinated communication and approach to be a failure in the patient's care and treatment. **Therefore I uphold this element of the complaint.**

118. I note the Trust's comments *'…that the ward fell short of the standards expected and there was an absence of a coordinated approach in the provision of [the patient's] care.' 'The medical records evidence extensive input for Care of older people and Palliative Care Teams. There is no record of a joined up review of [the patient's] care or evidence of direct discussion between the two teams however the records would indicate that both teams were aware of each other's inputs.'*

Oral Suctioning

119. The complainant raised concerns about suctioning being carried out on the patient on the night that he died. She believed this to be a painful procedure that was not required and caused the patient distress before he died. I further note the complainant's concerns that on 9 December 2019 that patient was considered end of life and oral suctioning was not to provide comfort or to reduce the risk of developing pneumonia and she believed it to be an unnecessary procedure.

120. I note the clinical records document that on 7 December 2016, the chest physiotherapist, states *'Happy to try oral suction but agreed NP suction is unlikely to benefit more than expected discomfort….No NP suction 2⁰ to discomfort of this…'*

121. I note the clinical records document that on 9 December 2016 at 05:50 the patient was *'…unsettled on and off, very chesty… and* oral suctioning was carried out on 3 occasions at 05:50, 08:00 and 16:00 and secretions were removed. I also note the clinical records document that at 19:30 the patient was '…*settled and comfortable*…'

122. I note the Trust's comments that the patient *'…had significant secretions that are known to cause distress. The rationale for completing [oral suctioning] was to optimise comfort…'* I further note the Trust's comments in relation to the oral suctioning carried out on 7 December 2016. I note the G IPA's view on the use of oral suctioning on the patient that *'…It is a safety decision to use suctioning and was being done in [the patient's] best interests to provide comfort...'* I further note and accept the additional G IPA's advice that *'…it was reasonable, appropriate and necessary to use suction of secretions to relieve distressing symptoms and provide comfort during EoL care on 9/12/16…'* I also accept the N IPA's advice that the carrying out of oral suctioning *'… was a reasonable action and is appropriate for a nurse to carry this out for upper respiratory secretions…'* I accept the N IPA's advice that the management of secretions on 9 December 2016, was *'…in line with good practice…',*the nursing team were monitoring the patient and *'There is no evidence that the suctioning specifically caused distress on this occasion.'*

123. Although I acknowledge the complainant's concerns in relation to oral suctioning being carried out on patient on 9 December 2016, based on the available evidence I

consider that the Trust acted appropriately in relation to the use of the oral suctioning **Therefore, I do not uphold this element of the complaint.** I hope the Trust's comments about the suctioning carried out on 7 December 2016 provided some reassurance to the complainant and her family.

Pain Management

124. The complainant raised concerns that the patient was not given appropriate pain relief. In particular, her concerns related to reducing pain relief without consent, given what is contained in the relevant Gain Guidelines. The complainant was also concerned about the purpose of the administering a vitamin drip after the patient was deemed end of life as well as being administered before pain relief on 9 December 2016. She believed as a result the patient suffered unnecessarily. The complainant also believed that no appropriate pain tool was being used to assess the patient. I further note the complainant's further concerns in relation to the dosage of Enoxaparin being reduced in a timely fashion and the overprescribing of paracetamol including concerns that clinicians did not report incidents internally or to the family.

Consent

125. I note from Palliative Care records that on 25 November 2016, at 12:15 the patient on examination *'…Indicates pain – moaning, holding lower abdomen /bladder area, reluctant to be examined. Had* hyoscine butylbromide 20 mg… - with good benefit…' and was prescribed '…*Trial CSCI - hyoscine butylbromide 20mg, Morphine Sulphate 2mg (Two) in H_20 over 24hrs…'* I also note the clinical records document on 25 November 2016 at 15:30 *'…Appears in discomfort ? abdomen. – facial grimacing – pulling @ sheets over abdo – not keen on examination…'*

126. I note from clinical records that at 09:00 on 26 November 2016 a reduction in the CSCI to '…*1mg Morphine…'* was suggested and this reduction in morphine started at 15:00. I also note that at 19:15 the clinical records document that, following a discussion with the patient's sisters and an examination, morphine levels were to be

restored to the original levels of 2mg. I note that morphine levels were restored to the original prescription at 21:05.

127. I note the Trust's comments in relation to consulting with the family and Palliative care about the reduction in morphine levels and that *'A clinical decision to reduce the morphine by 1mg was made on the assessment of [the patient's] condition. At the time of this dose change discussion with the Palliative Care Team was not felt necessary. The team did discuss this with the family later that evening and the dose was readjusted to the original dose and rate.'*

128. I accept the G IPA's advice that *'Reducing the dose was only a trial to ascertain if that would overcome [the patient's] delirium which may have been aggravated by morphine induced constipation…' '…The decision to reduce the dose of morphine was reversed within six hours due to the concerns expressed by [the patient's] sisters. It was not unreasonable to restore original dose of morphine as the family were so unhappy.'* I also note the G IPA's advice that ***'...****The decision to reduce the dose [of morphine] to 1 mg was made on clinical judgement.'*

129. I also note the G IPA's advice that the patient *'…receive the originally prescribed dose of 2 mg morphine sulphate via the syringe driver over 24 hours except for a 6 hour hiatus on 26/11/16.'* I further note the G IPA's further advice that '..*that the dose of morphine was reduced to 1 mg for a period under 4.5 hours, rather than 6 hours as was mentioned.'*

130. I accept the G IPA's advice that consultation with Palliative Care, prior to the reduction of morphine levels, *'… is not essential because the geriatrician is well versed in medical matters at the end of life. The clinician is therefore perfectly competent to prescribe and alter dose of morphine.'* I acknowledge the G IPA's comments about consulting with the family in relation to reducing the dose of morphine that *'…It is reasonable for the geriatrician [sic] make clinical decisions in the best interests of his patient…it was not a huge reduction in dose that was being proposed. 2 mg morphine over 24 hours is actually in itself a very small dose.'* I further note the G IPA's advice that *'…GAIN Guidelines state… that "healthcare staff can apply doctrine of necessity for immediate decision making in the patient's*

best interests." This is standard practice concerning care of any patient in the hospital setting, including those with learning disability. This is what happened regarding the decision to reduce the dose of morphine…' I also note the G IPA's advice that *'…There would have been no significant effect of the reduction in the dose via the CSCI on [the patient] because of the slow rate of infusion given through the syringe driver...'* However, given the patient's communication difficulties, I consider that it would have been considered reasonable for the rationale for reducing the morphine to have been discussed and explained to the family and the Palliative Care Team prior to the decision to implement the change.

131. I acknowledge the G IPA's advice that Gain Guidelines allow healthcare staff to *'…apply doctrine of necessity for immediate decision making in the patient's best interests."* I also accept that in line with the relevant GAIN Guidelines, *'Contribution of Carers'* that clinicians did listen to the concerns of the family following the reduction in morphine levels and as a result increased levels to the original dose prescribed. Based on the available evidence I consider it was not unreasonable for the Trust to reduce the level of morphine on 26 November 2016 without consent and its decision was based on clinical evidence. **Therefore I do not uphold this element of the complaint.** I hope the G IPA's comments that '…*There would have been no significant effect…on [the patient]…'* provides some reassurance to the complainant and her family. However, when the making this decision I acknowledge it would have been beneficial if clinicians had engaged with the family outlining their rational. I welcome the Trust's comments that The Palliative Care Team noted that perhaps on this occasion there should have been *'…more communication between ward staff, family and the Palliative Care Team..'* and would ask the Trust to reflect on this learning.

Vitamin drip

132. In relation to the administration of a vitamin drip to the patient I note that the clinical records document on 26 November 2016 at 09:00 *'…Not for NG at present r/v Monday…↓ CSCI to 1mg Morphine, Pabrinex.* The clinical records document pain relief was not discontinued as result of the administration of the Pabrinex. I also note the Trust comments that *'… this treatment was not related to pain relief…As [the patient] was nil by mouth and consideration was being given to the insertion of*

a nasogastric tube the intravenous Pabrinex (vitamin drip) was commenced in line with this.'

133. I accept the G IPA's advice that *'The vitamin infusion that the family mentions is probably referring to intravenous Pabrinrex® high potency solution for injection… Pabrinex® is often used when a patient who has not been eating but then starts feeding. This is standard practice and may be acceptable given the fact that [the patient] had not been made for end of life (EoL) care at that point.'* I further note the G IPA's advice that Pabrinex® was also used '…*to prevent electrolyte disturbances and resultant cardiac arrhythmias that may occur… As Pabrinex® had been started it was reasonable to continue with it even during EOL care because of its potential to prevent terminal cardiac distress.'*

134. Given the conflict of evidence between the complainant and the G IPA I am unable to determine if a vitamin drip was administrated on 9 December 2016 or indeed if it was given prior to any paracetamol. I acknowledge the G IPA's advice on why the vitamin drip was used and accept his advice that it was '…*reasonable to continue with it even during EOL care…'* Therefore, given the evidence I accept the Trust acted appropriately in the administration of the vitamin drip however, the reasoning for the administration of this drip could have been explained to family members when concerns were being discussed about the reduction to pain relief. **Therefore, I do not uphold this element of the complaint**. I hope the G IPA's comments that '…*There could have been no adverse effect on the patient…'* from the vitamin drip provides some reassurance to the complainant and her family. I remain concerned given the complainant's account that the Pabrinex may have been provided in advance of paracetamol and how this would cause distress to family members. Clinical staff should always be conscious of how their actions may be construed by patients and their families.

Administration of paracetamol and Enoxparin

135. I note the clinical records document that on 13 November 2016 the patient was prescribed paracetamol as 1g four -six times daily po. I also note that on 26 November 2016 at 19:15 the clinical records document*. '…Weight 44.8kg ∴ can have 500mg [unable to read] IV.*

136. I note the G IPA's advice that *'…the maximum dose of paracetamol that [the patient] could have safely had was only 2.7 g…This was because he was initially prescribed and administered full adult dose of paracetamol, usually 4 g/day. However since he was under 45 kg body weight, the usual dose of 4 g/day would have been excessive…'* I also note the G IPA's advice that on 25 November 2016 the prescription was *'…re-prescribed as 500 mg IV four times daily with a note to say that the dose reduction was being made because of low body weight. This was the correct step.'* Therefore I am satisfied the Trust acted appropriately in relation to the reduction in the dose of paracetamol. However, I also note the G IPA's comments about the use of a 'recalled' weight and *'…how unreliable "recall" is, and misleading when medical decisions are based on wrong values.'*

137. I further note the G IPA's comments in relation to the prescribing of Enoxaparin and the reasoning for initially administering 40 mg and then reducing the patient's dose. I also accept his advice that *'Halving the dose on 5/12/16 was timely and it was the correct response to developing thrombocytopaenia.'* and a result of the patient's platelet count decreasing.

138. I also note the G IPA's advice that the patient did not require any reversal medication and I hope this provide some reassurance to the complainant and her family.

139. I note the N IPA advice that the IV paracetamol *'…was given with exception of 2 and 7 December midday… No reason is given for the paracetamol not being given on the two occasions.* I also note her advice in relation to any impact on the patient *'…professional judgements relating to pain and distress were made on these occasions and that there is no evidence from either date that [the patient] was in pain or any other impact as a result of not receiving IV paracetamol.'*

140. This investigation considered the care and treatment of the patient in Ward 7 North, between 25 November 2016 until 10 December 2016. However, I am satisfied from the evidence available that the use of an inaccurate recalled weight on 9 November 2016 resulted in the incorrect prescribing of paracetamol on Ward 3 South and the

need to reduce the patient's paracetamol dose on relocating to Ward 7 North. This could explain why the complainant believed there was inappropriate pain management.

141. I accept the G IPA's advice that '…*there is no evidence from the blood test results that [the patient] came to harm as result of overdosing with paracetamol.'* and '*No further tests were required as these are sensitive tests for evidence of paracetamol toxicity /poisoning...'* Whilst the amount of paracetamol administered means the patient was unlikely to have been in pain and did not suffer unnecessarily the evidence is clear that the patient was administered an incorrect amount of pain relief. In relation to concerns that the patient was not given appropriate pain relief and suffered unnecessarily **I partially uphold this element complaint.**

Reporting of overprescribing

142. I also note the G IPA's advice and the policies provided by the Trust. I accept that the overprescribing of paracetamol should have been reported in line with the Trust's 'Adverse Incident Reporting and Management Policy', April 2014 and it's 'Guidelines for the administration of intravenous (IV) Paracetamol', December 2014. It is also my view that as well as reporting the adverse incident, clinicians should have discussed the issue with the family. Even though it was considered there was no adverse impact on the patient such an approach would be in line with the Trust's 'Being Open Policy' (February 2015) and is extremely important in building the trust of patients and their families. I consider these failings as maladministration. The failure to identify and report adverse incidents is a recurring theme in Ombudsman investigations. This is a matter of great concern as non-reporting reduces the potential for identifying the cause of the incident and taking steps to prevent any future occurrence. I note the Trust wish '…*to apologise for any additional upset or distress that this has caused.'*

Pain assessment tools

143. I note the N IPA's advice that '*Pain assessment tools are intended to support professional observation and judgement and do not replace this.'* I accept the N

IPA's advice that she *'…did not find any evidence of the Abbey Pain Tool being used by any of the multi-professional team or the visiting specialist palliative care team. There are a number of references to whether [the patient] appeared comfortable or in distress in the Daily Evaluation of Nursing Care, but these are not supported by use of a tool or scale.'* I consider that this was not accordance with GAIN Guidelines '*The Assessment and Management of Pain.'*

144. I note the N IPA's advice *'… that although pain assessment should have been supported by a pain score appropriate for the person with dementia and learning difficulties, professional judgements were made about [the patient's] level of comfort and appropriate follow up action was taken if pain or distress was detected.'* I also note the N IPA's advice that *'…In all cases where a score is given it is 0.'* The pain score *'…usually relies on the person being able to describe their level of pain and to report a score. It is unlikely that [the patient]…would have been able to cooperate with this effectively…'* I also accept the N IPA's advice that the patient's *'…care was not consistently tailored for a person with dementia and learning disabilities.'* I also note the Trust's comments that the Disdat tool was provided to nursing staff on Ward 3 South on 24 November 2016. However, I can find no evidence within the medical file that it was utilised by nursing staff when assessing the patient.

145. Given the available evidence, I am satisfied that the assessment of possible pain or distress was not appropriately supported or recorded by the use of an appropriate pain tool. I am also satisfied that the care of the patient was not consistently tailored for a person with dementia and learning disabilities in accordance with GAIN Guidelines. In 2010, the Guidelines & Audit Implementation Network (GAIN) published its original set of Guidelines on Caring for People with a Learning Disability in General Hospital Settings. Since then two significant reports (Confidential Inquiry into the Premature Death of People with learning Disabilities, Heslop et al., 2013 and Annual Report of the Learning Disability Mortality Review Programme, LeDeR, 2017) both reported that people with learning disabilities continue to die younger than people who do not have learning disabilities. The 2013 Inquiry also highlighted that staff failing to make reasonable adjustments, compounded by a lack of coordination within and between hospital services, '*were contributing factors in a number of deaths*' (Heslop et al, 2013, p4). In 2014, an

RQIA review of practice made 19 recommendations which were incorporated into the 2018 RQIA Guidelines on Caring for People with a Learning Disability in General Hospital Settings.

146. The failure to assess and record possible pain or distress using an appropriate pain tool and the failure to consistently tailor the care for a person with dementia and learning disabilities in accordance with GAIN Guidelines. This a significant failing in the patient's care and treatment. The anxiety and stress associated with being in hospital is particularly acute for people with a learning disability and is compounded by difficulties they may have in being understood and making their needs known, such as expressing levels of pain or discomfort.

147. I note some records indicate the patient's pain being assessed by professional judgement and being appropriately dealt with on these occasions, However, given the views of the family and, the failing to use an appropriate pain assessment tool to aid professional judgement I have concerns that, given his disability, the patient may have been in pain on occasions without it being adequately addressed.

148. I consider that an individual's human rights can be infringed as a result of poor care. The Patient and Client Experience Standards (DHSPSS) reflect human rights principles of fairness, respect, equality, dignity and autonomy (FREDA). Central to applying human rights in practical terms is the recognition of a patient as an individual and the delivery of care appropriate to their needs. I consider these human rights values when applying the Ombudsman's Principles of Good Administration. The first Principle of good administration "Getting it right" – acting in accordance with the law and with regard for the rights of those concerned – explicitly creates expectation that public authorities will have regard to published standards such as the Patient and Client Experience standards (DHSSPS) and failure to do so will attract criticism. It is my view that the Trust did not show regard for the patient's human rights in terms of dignity, equality and respect by failing to support or record the assessment of possible pain or distress appropriately and that the care of the patient was not consistently tailored for a person with dementia and learning disabilities. I therefore conclude that the failure of the Trust to appropriately support or record the assessment of the patient's possible pain or distress and that

the failure of the Trust to consistently tailor the care of the patient for a person with dementia and learning disabilities does not meet these principles. I consider this failing to constitute maladministration. I am also satisfied that as a result of this failure the patient, complainant and her family experienced injustice which I will consider later in this report.

149. I note the Trust's comments on learning from this complaint as detailed in paragraph 27 above. I also note the complainant's comments in relation to this learning. It is my opinion that the Trust should be given the opportunity to provide reassurance to both the complainant and this office on the comprehensiveness and accessibility to staff of internal resources provided both internal on the Trust internal web site and via resource packs on wards. In relation to the complainant's suggestion of the appointment of an on–call specialist Learning Disability expert, the Trust advised that training was being reviewed in *'…preparation for a proposed link nurse type role that will support best practice within each ward…'* I would ask the Trust to provide more information on this link nurse role, a timescale for a decision on whether they will be proceed with the role and a timescale for the proposed commencement. I further note the complainant's views that the Hospital Passport system is fractured and ineffective and her reference to the 2018 review[15] of this system. However I also note this review stated the Hospital passport *'…was considered by all stakeholders as an important tool that can be used to improve health care provided to [People with Learning Disabilities] when they attend hospital…'* I further note the review put forward learning improvements *'…to improve awareness and understanding…how it [the Hospital passport] can be used and how it can benefit stakeholders…'* I would ask the Trust to take account of this review when rolling out of the Hospital passport to service users.

Anaesthetics care

150. During the investigation, the complainant raised concerns about the use of the 'recalled' weight in relation to the anaesthetics care provided to the patient. I note the Trust's comments that the weight used to assist in determining the anaesthetic drugs was 56.9kg. I further note its comments that *'...Generally, anaesthetic drugs are titrated to response and there are published theoretical drug doses, which are*

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usually expressed as mass of drug per kg of body weight. It is not always safe or sensible to administer the dose of drug indicated by the published doses. A safe anaesthetic will involve careful selection and titration of the administered drugs and effective management of the resulting physiological changes...' I also note the Trust comments that *'There were no unusual issues or problems with [the patient's] perioperative care or recovery room care after surgery.'*

151. I note the A IPA's advice that asking a patient/relative/carer would be appropriate method of obtaining a person's weight. I also note his advice that *'…anaesthetic drugs which could have their dose express on a mg/kg basis… were given at doses at the lower end of the range even if the patient's actual weight is taken into account…' and '…were titrated to physiological response.'* I further note his advice that *'Based on the actual weight of the patient all drugs …were administered at the correct doses, with the exception of the paracetamol…There was no impact on the patient from this.'* I also note the A IPA's advice that the patient's risk from anaesthetic, due to his comorbidities, was recognised by the anaesthetist and *'The anaesthetic care provided for this patient was of an appropriate standard…'*

152. I accept that the patient's recalled weight was used to assist in determining the anaesthetic drugs. Whilst it is important for an anaesthetist to know a patient's weight in order to give an accurate drug dosage, I also accept the advice of the A IPA that these drugs were titrated to response and were administrated appropriately, even though the patient's actual weight, was not established until a number of weeks later. However I also note the A IPA's advice regarding the administration of paracetamol and accept that this did not impact the patient immediately post operatively. However I recognise that this may raise further concerns for the complainant given the failure already identified in paragraph 141. I acknowledge the differing accounts of the patient's immediate post survey recovery. Although I have no reason to disbelieve the complainant I acknowledge the risk the patient was at from existing comorbidities and it is my view that any issues arising in the recovery room, post surgery, were not as a result of the anesthetic drugs administered. Therefore in relation to the patient's anesthetics care **I do not consider there was a failure in the care and treatment provided.**

Injustice

153. There are a number of failures in relation to the patient's care and treatment, which led to the injustice of distress, frustration and uncertainty to the complainant and her family. I consider there were failures in the patient's care and treatment identified in relation to diet, end of life care and pain management. I also consider the Trust failed to appropriately support or record the assessment of the patient's possible pain or distress and that the care of the patient was not consistently tailored for a person with dementia and learning disabilities. The failure to make these reasonable adjustments lead to the injustice of distress to the patient and a failure to show regard to the patient's human rights.

154. I am satisfied that the maladministration identified in relation to the Trust not appropriately supporting or recording the assessment of the patient's possible pain or distress; and that the care of the patient was not consistently tailored for a person with dementia and learning disabilities caused the patient to experience the injustice of distress. I am also satisfied the identified maladministration caused the complainant and her family upset, frustration and uncertainty. The failure to report the over prescribing of paracetamol, in line with Trust policies, caused the complainant and her family to experience the loss of opportunity for an adverse incident investigation into the over prescribing of paracetamol.

Issue 2: Whether the complaint was investigated according to policy and procedure?

Detail of Complaint

155. The complainant raised concerns about the Trust's handling of her complaint. In particular, she believed the complaints process was not carried out within the relevant timeframes. She also believed the complaints process lacked compassion and was carried out in an insensitive manner. The complainant also said the Trust's response was not coordinated. A chronology detailing the complaint handling process is contained at Appendix seven to this report.

Evidence Considered

Legislation/Policies/Guidance

156. I considered the following guidance and standards:

- the Trust's Complaints policy; and
- the DHSSPS Complaints Procedure.

The relevant extracts of the guidance and standards referred to are enclosed at Appendix three to this report.

The Trust's Response to Investigation enquiries

157. In its responses to enquiries about complaints handling the Trust acknowledged, *'that this complaint was poorly managed and did not adhere to Trust procedures or recommended timelines. This undoubtedly led to increased distress for [the patient's] family and the Trust unreservedly apologies for this.'*

158. In relation to minutes produced following a meeting with the family on 21 September 2018 the Trust commented that it was *'…sorry that [the complainant] was not provided with an opportunity to provide the families comments in relation to the minutes and the Trust acknowledges that this was not in keeping with best practice..'* It explained that *'On the 16 November 2018, all senior managers within the service have received additional training on complaints management.'*

159. In relation to enquires about how the complaints process lacked sensitivity or compassion the Trust explained *'At the meeting on the 21 September 2018, Trust representatives apologised for the scheduling of the meeting in Level 7, Belfast City Hospital and agreed that whilst it was not intentional to cause distress there was a lack of thought in the impact this would have had on [the patient's] family.'*

160. The Trust further explained, '*The service are sorry that the family feel that there was no sensitivity or compassion around sending the final response. They were very much aware that [the patient's] birthday was in December and significant consideration was given to ensuring that the response did not arrive with the family at the time…..' 'It was not intentional to cause distress by sending the response in the days before Christmas. At this time the service were balancing their awareness of [the patient's] birthday, alongside processing the response, with the view that the*

family would prefer it sooner rather than later taking cognisance to the fact that it was already delayed. We are sorry this has caused additional upset to the family.'

The Trust's Complaint records

161. I considered the Trust's written response to the complainant dated 18 December 2018. The letter documented *'I also wish to convey my sincerest apologies for the distress caused by the delays you have experienced in addressing the issues you raised as a family in October 2017.'* The letter also documented '*The issues and the delays regarding how your complaint was managed have been raised as internal issue across the service directorate. We have acknowledged that a face-to-face meeting should have taken place from the outset and we are deeply sorry that the delay in the Trust's initial response and meeting with you both have added further to your distress. Further training in complaints management was provided to senior staff across our service area on 16 November 2018. This targeted the senior team and focused on ensuring that they have the skill and knowledge to manage complaints within process, within timeframes, and with compassion.'*

162. I also considered the Trust's response to the complainant dated 24 May 2018. This letter sought to clarify why the complainant had received letters providing differing information on the status of the investigation on 30 March and 15 May 2018.

Complainant's response to the Draft report

163. The complainant highlighted that the Trust response in paragraph 160 was factually incorrect as December is the anniversary of the patient's death and not his birthday. This has led her to have no confidence in the Trust's overall response when such facts were reported inaccurately.

Analysis and Findings

164. The complainant raised concerns about the Trust not handling her complaint within required timeframes. I note that the Trust received the complaint on 23 October 2017 and it received a completed consent form on 1 November 2017.

165. I note that the Trust Complaints Policy states that '*Where a complaint involves the death of a patient/service user complainants should be offered a meeting with the Service Area to discuss their concerns.*

166. I note that in its first letter to the complainant, dated 25 October 2017, the Trust stated '*it would welcome an opportunity to speak with you to seek clarity in how best you and your family would like the Trust to respond'*. On consideration of the complaints file, I note the Trust did not attempt to make further arrangements to speak to the complainant regarding her concerns until 30 March 2018, after the investigation was completed, 22 weeks later. I also note the Trust acknowledge that a face-to face meeting ought to have taken place at the outset of the complaint process and have apologised to the complainant for this separate to this investigation. I consider the Trust's failure to meet with the family prior to completing any investigation unsatisfactory and not in keeping with the Trust's Complaints Policy

167. I note the Trust's Complaints Policy states that '*complaints must be investigated and the complainant issued with a written response… within 20 working days where possible. If for any reason this is not possible the complainant must be advised of the delay and a time frame within which they are likely to receive a full reply.'* and the DHSSPS Complaints Procedures states '…*as soon as it becomes clear that it will not be possible to respond within the target timescales, the Complaints Manager should advise the complainant and provide an explanation with the anticipated timescales…'*

168. I considered the records contained within the complaints file. I note that the Trust did not issue the investigation report detailing the outcomes of the investigation until 14 June 2018. This was almost 11 weeks after the complainant was informed on 30 March 2018 that the Trust would like to meet with the family to discuss the outcome of the investigation. I note that in its first response to the complainant the Trust did state *'as your complaint crosses over a few specialities and given the passage of time, it is unlikely that we will be in positon to respond to you within the 20 working day timescale.'*

169. I further note that on 13 December 2017 and 21 February 2018 the Trust made contact with the complainant stating that the investigation remained ongoing. I note that only the letter of 13 December 2017 provided an explanation for the delay *'…a delay has occurred partly due to staff leave…'* and '*We will be in touch early in early [sic] 2018 with any further developments and a Trust response.'* On reviewing the complaints file I note the Assistant Service Manager (ASM) provided an internal update about the investigation on 5 December 2017 advising '*There has been a delay to some degree as the consultant involved was on leave…'* On 18 December 2017 the ASM requested an extension to providing a response as *'…the Consultant and Ward Sister were on leave and now due to significant staffing issues I have been unable to progress this as yet as far as I would have normally by this stage.'* I note from file records that this extension was granted however no date was given as the response was expected as soon as possible. The complainant was not provided with any information in line with the Trust's Complaints Policy or DHSPPS Complaints Procedures as detailed in Appendix 3.

170. On 21 September 2018 Trust representatives met with the complainant and her sister to discuss the investigation report. The minutes of the meeting and the investigation report, which was updated as a result of the meeting, were not issued to the complainant until 18 December 2018.

171. I note the Trust contacted the complainant on 23 October 2018 to advise of delays in issuing the minutes and amended report. However, due to no response having been received, the complainant wrote to the Trust, on 30 October 2018, expressing her concerns about how the complaint was being addressed. I also note a further update was provided to the complainant's sister on 5 November 2018 when the Service Manager (SM) provided assurances, over the phone that, the report and minutes would be with the family by the end of the week or at the very latest next week. I note that it took a further six weeks for the report and minutes to be issued on 18 December 2018. I note that the Trust did not contact the complainant apologising for the *'prolonged delay'* until 12 December 2018. In line with the DHSPPS Complaints Procedures I also note the minutes of the meeting were not *'…shared with the complainant for comment...'*

172. I accept that it may not always be possible for the Trust to fully respond to a complainant within the stated 20 working day timeframe. I consider that, even given the complexities of this complaint and issues around staff leave, the Trust's delay in providing a final response, including the issuing of meeting minutes, to this complaint was significant and unacceptable. When updated timeframes were provided, in writing or verbally, to the complainant or her sister, they were exceeded on a number of occasions. I consider that the delays in providing the complainant with regular and informative updates unsatisfactory. I also consider the failure to share minutes of the meeting, held with the complainant on 21 September 2018, unreasonable as it denied the complainant an opportunity to comment.

173. The complainant also said that the complaints process lacked compassion and was insensitive. On review of the complaints file I note that there were three occasions, 13 December 2017, 12 and 18 December 2018, when the Trust issued letters in and around the anniversary of the patient's death. I also note the Trust issued a letter on 4 July 2018 around the time of the patient's birthday. It is noted that prior to the letter being issued to the complainant on 13 December 2017 the Complaints Manager (CM), sought advice from the Trust Bereavement Coordinator (TBC). The CM was aware this would be the family's first Christmas without the patient and in light of this sought advice regarding the timing of any potential response before Christmas and whether the family should be asked for their preference as to when to receive the response. It is noted, in line with the advice received, as it was unlikely that the response would be finalised before Christmas this was not asked of the family. However, I note that despite awareness of the potential sensitivities of the date the letter of 13 December 2017 fails to acknowledge the difficult time the family may be experiencing as the TBC suggested.

174. With respect to the letters issued on 12 and 18 December 2018, on considering the complaints file and internal emails, I note that Trust staff were aware of the sensitivity of issuing letters on these dates. Its holding letter of 12 December 2018 stated *'I appreciate that this week is [the patient's] anniversary and do not wish to add to your distress any further, however, I felt it was important to provide you with an update on the current developments of this case.'* Whilst I accept the Trust had

identified and considered the anniversary of the patient's death I note in response to this office it incorrectly stated it had considered his date of birth.

175. On considering the complaints file I note that the Level 7 tutorial room in BCH was booked as a venue for the meeting with the complainant and her sister on 21 September 2018. I further note the ward on which the patient passed away was located on Level 7. The complainant's sister was verbally advised of the venue location on 20 September 2018 and she had to request a change of venue. On the same day the Trust arranged another venue and informed the complainant's sister. I note the Trust informed this office that '*there was a lack of thought in the impact'* of scheduling the meeting at this location.

176. At the meeting with the Trust on 21 September 2018 it was highlighted that the report referenced a complainant number and not the patient's name. I note prior to issuing the final report the Trust amended the front cover of the report removing the complaint number and replacing it with the patient's name.

177. In relation to the complaints process lacking compassion and being insensitive I accept Trust staff were aware of the issues around sending letters to the family on the dates detailed in paragraph 174 above. The Trust were balancing this *'alongside processing the response, with the view that the family would prefer it sooner rather than later taking cognisance to the fact that it was already delayed.* However, I do consider that the tone of the letter issued on 13 December 2017 ought to have been more compassionate. I further consider that as well as seeking advice from the TBC, when similar situations occur CMs should discuss the circumstances with the family and consider their views about receiving letters and be guided by this.

178. I also accept more thought should have been given by the Trust when arranging a venue for the meeting with the family. However I note that this was rearranged.

179. The complainant also believed the Trust did not provide a coordinated response. On reviewing the complainants file I note that on 30 March 2018 the SM wrote to the complainant stating that *'…we have investigated your concerns…'* and *'…would*

like to offer the opportunity to meet…to discuss your experience and the resulting outcome of the local investigation.' However, following a request by the complainant to see a written copy of the outcome of the local investigation prior to a meeting she received a further letter from the CM on 15 May 2018. This letter stated *'…the Trust's investigation into your complaint remains ongoing.' I would wish to advise that the Director was not happy with Trust response as it did [sic] fully answer all the questions posed in your initial complaint letter.'* I note these two letters required the complainant to express her concerns about how the complaint was being progressed and to seek further clarification from the Trust.

180. On consideration of the complaints file and internal emails I note, prior to the letter being sent to the complainant on 30 March 2018 a draft response to the complaint investigation had been drawn up. I note the SM requested a meeting with the family due to the sensitive nature of the complaint and timescale. This request was made before the final response could be issued.

181. I further note that the CM received the draft response on 30 April 2018 and was advised the Co-Director had reviewed and was satisfied with the response. In line with the Trust's Complaint Policy I note the CM, as the Co-Director had given approval, forwarded the draft response to the Director for signing. However, the CM raised concerns with the Service Director (SD) and the Governance Manager that the draft response did not answer all the questions raised in the initial response. On 10 May 2018 the SD returned the response to the Service area as it did not address the issues raised in the original complaint as well as recognising the complainant had requested a written copy of the response prior to any meeting. I also note that on the 15 May 2018 the CM updated the complainant informing her the Director was not happy with the Trust response.

182. I accept that the two letters sent to the complainant on 30 March and 15 May 2018 provided her with information that caused confusion. I am satisfied that this indicates a lack of coordination between the complaints team and the Service Area. I accept the investigation had been completed but the Trust response had not been signed off and approved by the SD.

183. I accept the Service Area wished to meet with the complainant. This is in line with the Trust's Complaint's Policy. However, I consider this should have been offered when the Trust's response was finalised as it would not be unreasonable for the complainant to want to view the response prior to any meeting.

184. The First Principle of Good Complaint Handling, 'getting it right', requires bodies to act in accordance with '*relevant guidance and with regard for the rights of those concerned'*. The Second Principle of Good Complaint Handling, 'being customer focused', requires bodies to deal with '*complainants promptly and sensitively, bearing in mind their individual circumstances*', '*Listening to complainants to understand the complaint and the outcome they are seeking'* and, '*Responding flexibly, including co-ordinating responses with any bodies involved in the same complaint, where appropriate.'* I consider that the Trust failed to act in accordance with these Principles in its handling of this complaint. I am satisfied that this constitutes maladministration. As a consequence, I am satisfied that the maladministration identified caused the complainant, and other family members, to experience the injustice of upset and frustration. Furthermore I am satisfied that it also caused the complainant the time and trouble of bringing her complaint to this office.

CONCLUSION

185. A complaint was submitted to this office about the actions of the Trust regarding the care and treatment provided to the patient, by the staff of BCH on Ward 7 North, from 25 November 2016 to 10 December 2016. The complainant also raised concerns about the Trust's handling of her complaint.

Issue One

186. The investigation of this complaint did not find failures in the patient's care and treatment in relation to the following matters:
    i. The decision to carry out the procedure of oral suctioning on the patient on the night before he died;
    ii. The vitamin drip was administered after the patient was deemed end of life on 6 December 2016 ;

iii. Reducing pain relief without consent; and
iv. Anaesthetics care of the patient.

187. The investigation was unable to make a determination as to whether the vitamin drip was administered prior paracetamol on 9 December 2016

188. However, the investigation established failures in the care and treatment in relation to the following matters:
i. The feeding of the patient porridge contrary to SLT advice on 3 and 4 December 2016 and offering other foods contrary to advice;
ii. The failure to record who fed the patient porridge;
iii. The failure to identify that the recommended diet was not provided to the patient and take appropriate action;
iv. The failure to record foodstuffs given to the patient in a consistent manner;
v. The failure to report adverse incidents in relation to the feeding of porridge on 3 and 4 December 2016;
vi. The failure to ensure a coordinated approach between the Palliative Care and Care of the Elderly teams;
vii. The lack of coordinated communication between the family, the Palliative Care and Care of the Elderly teams;
viii. The over prescribing of paracetamol to the patient on Ward 3 South;
ix. The failure to appropriately support or record the assessment of the patient's possible pain or distress using an appropriate pain tool and;
x. The failure ensure the care of the patient was consistently tailored for a person with dementia and learning disabilities in accordance with GAIN Guidelines.

189. The investigation found the following maladministration:
i. Failure of the Trust to show regard for the patient's human rights by failing to appropriately support or record the assessment of the patient's possible pain or distress; and to ensure the care of the patient was not consistently tailored for a person with dementia and learning disabilities;
ii. Failure to report overprescribing of paracetamol in line with the Trust's 'Adverse Incident Reporting and Management Policy', April 2014 and it's 'Guidelines for the administration of intravenous (IV) Paracetamol', December 2014; and

iii. Failure to inform the complainant and her family of the overprescribing of paracetamol in line with the Trust's 'Being Open Policy', February 2015.

190. I am satisfied that the maladministration and failures in care and treatment in relation to the Trust not appropriately supporting or recording the assessment of the patient's possible pain or distress; and that the care of the patient was not consistently tailored for a person with dementia and learning disabilities caused the patient to experience the injustice of distress. I am also satisfied that the maladministration and the failures care and treatment I identified caused the complainant and her family to experience upset, frustration and uncertainty as well as the loss of opportunity for an adverse incident investigation into the over prescribing of paracetamol.

Issue Two

191. The investigation established maladministration in relation to the Trust's handling of the complaints process namely:
    i. The failure to meet with the family prior to completing any investigation;
    ii. The failure to share minutes of the meeting, held on 21 September 2018, with the complainant for comment;
    iii. The delay in issuing minutes of the meeting, held on 21 September 2018, to the complainant;
    iv. The delay in providing a final response to the complainant;
    v. The failure to provide regular and informative updates to the complainant;
    vi. The failure to ensure coordination between the complaints team and the service area and;
    vii. The failure to recognise the sensitivities around arranging a venue for the meeting with the complainant on 21 September 2018.

192. I am satisfied that the maladministration identified caused the complainant, and other family members, the injustice of upset, frustration, and time and trouble by bringing a complaint to this office.

Recommendations

193. The Trust explained that *'All wards within our service now have written advice available to staff detailing the correct food types for each consistency as a further reinforcement of best practice. The SALT Service facilitates training for all nursing staff on a rolling basis. Printed instructions regarding each SALT recommendation are displayed, for reference, on all Older Peoples Wards within Belfast City Hospital to include those foods, which must be avoided.'* I welcome this learning already identified by the Trust.

194. The Trust explained *'As learning from the complaint GAIN Guidelines on Caring for People with Learning Disability in General Hospital Settings has been shared with all wards and have been discussed at team meetings. A Learning Disability resource is now available for all staff on the Belfast Trust Internal Web site and all wards have been provided with information regarding this. In addition, a resource pack is now available within all Older Peoples Wards to ensure staff are familiar with the appropriate assessment tools and guidance. The Learning Disability service was contacted to review current training available for staff within acute areas in preparation for a proposed link nurse type role that will support best practice within each ward. A formal request for training has been made through the Nursing Learning and Development Team for courses to be commissioned for Care of Elderly staff to access Learning Disability courses r*elating to Dementia to enable teams to ensure best practice…' I welcome this learning already identified by the Trust.

195. I also note that action plan for the RQIA[16] Review of Implementation of GAIN Guidelines on Caring for People with Learning Disability in General Hospital Setting was updated in March 2019. The action plan outlines that Hospital passport used in Adult Learning Disability services is now being rolled out to all known service users where possible. I welcome this rolling out of the Hospital passport to service users.

196. In relation to complaints handling the Trust also explained that *'On the 16 November 2018, all senior managers within the service have received additional training on complaints management.'* and that '*The Divisional Nurse, Governance*

[16] Regulation and Quality Improvement Authority

Manager and a Senior Manager from the Complaints department met on 21 February 2019 to review the management of the complaint.' I welcome this learning already identified by the Trust.

197. I recommend within **one** month of the date of this report:
    i. The Trust provides the complainant with a written apology in accordance with NIPSO 'Guidance on issuing an apology' (June 2016), for the distress caused to the patient and the, distress, upset, frustration, uncertainty, loss of opportunity and time and trouble caused to her and her family as a result of the maladministration and failures in care and treatment identified;
    ii. The Trust discusses the findings of this report with the clinicians involved in the patient's care on Ward 3 South, Ward 7 North and the Palliative Care Team; and
    iii. The Trust's Chief Executive reminds staff charged with the responsibility of investigating complaints of the need to provide a coordinated, sensitive response within a reasonable timeframe to enable the Trust to meet the target timeframe set out in relevant guidance.

198. I further recommend, for service improvement and to prevent future recurrence, the Trust:
    i. Carryout out a random sampling audit of patients' nursing records on Ward 7 North with a particular emphasis on records relating to the feeding of foodstuffs to patients' and nursing assessments of patients with learning disability relating to the use of pain assessment tools in conjunction with professional judgement. Take action to address any identified trends or shortcomings. The Trust ought to include any recommendations identified in its update to this office;
    ii. Provide evidence of the written advice now available to ward staff*,* within the Care of the Elderly service, detailing the correct food types for each consistency*;*
    iii. Engage an independent Learning Disability specialist:
        • To carry out a review of the issues raised within this complaint to identify any further opportunities for learning; and

- To conduct an audit of the implementation of the resources already developed.

Advise this office of the outcome of the review;

iv. Undertake a review of how the approach of the Palliative Care team and the Care of the Elderly are coordinated, including communication with each other, the patient and patient's family incorporating existing best practice between the Palliative Care team and the Oncology service. The Trust ought to include any recommendations identified in its update to this office;

v. Carry out a random sampling audit of admission records on Ward 3 South to establish how often 'recalled' weight is being used. Advise this office on the outcome of this audit including any recommendations or improvements in practices;

vi. Undertake a review of the Trust's approach to ward placement for patients with learning disabilities and/or dementia. The Trust ought to include any recommendations identified in its update to this office;

vii. The Trust advised the following training had been undertaken:

- Rolling training provided by the SLT service for all nursing staff on Ward 7 North.
- Learning Disability courses relating to Dementia for nursing staff on Ward 7 North.
- Senior service managers received training on complaints management

Provide evidence that the training detailed above has been completed;

viii. Provide evidence of The Learning Disability Service review of current training available for staff within acute areas in preparation for a proposed link nurse type role, including any update on the progress of the expected commencement of the link nurse and what their anticipation roles and responsibilities may be. The Trust ought to include any recommendations identified in this review in its update to this office; and

ix. Provide evidence that the roll out of the Hospital passport has taken account of any learning identified in the 'Evaluation of the Regional Hospital Passport for People with Learning Disabilities' review dated November 2018.

199. I further recommend that the Trust implements an action plan to incorporate recommendations and should provide me with an update within **six months** of the

date of my final report. That action plan should be supported by evidence to confirm that appropriate action has been taken (including, where appropriate, records of any relevant meetings, training records and/or self declaration forms which indicate that staff have read and understood any related policies).

200. The Trust accepted my findings and recommendations. I also wish to acknowledge the complainant's and her family's clear devotion to the patient and the advocacy provided on his behalf when in BCH.

MARGARET KELLY
Ombudsman **22 February 2022**

Appendix 1

PRINCIPLES OF GOOD ADMINISTRATION

Good administration by public service providers means:

1. Getting it right

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

2. Being customer focused

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to its commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

3. Being open and accountable

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.
- Stating its criteria for decision making and giving reasons for decisions
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for its actions.

4. Acting fairly and proportionately

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

5. Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

6. Seeking continuous improvement

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

Appendix Two

PRINCIPLES OF GOOD COMPLAINT HANDLING

Good complaint handling by public bodies means:

Getting it right

- Acting in accordance with the law and relevant guidance, and with regard for the rights of those concerned.
- Ensuring that those at the top of the public body provide leadership to support good complaint management and develop an organisational culture that values complaints.
- Having clear governance arrangements, which set out roles and responsibilities, and ensure lessons are learnt from complaints.
- Including complaint management as an integral part of service design.
- Ensuring that staff are equipped and empowered to act decisively to resolve complaints.
- Focusing on the outcomes for the complainant and the public body.
- Signposting to the next stage of the complaints procedure, in the right way and at the right time.

Being customer focused

- Having clear and simple procedures.
- Ensuring that complainants can easily access the service dealing with complaints, and informing them about advice and advocacy services where appropriate.
- Dealing with complainants promptly and sensitively, bearing in mind their individual circumstances.
- Listening to complainants to understand the complaint and the outcome they are seeking.
- Responding flexibly, including co-ordinating responses with any other bodies involved in the same complaint, where appropriate.

Being open and accountable

- Publishing clear, accurate and complete information about how to complain, and how and when to take complaints further.
- Publishing service standards for handling complaints.

- Providing honest, evidence-based explanations and giving reasons for decisions.
- Keeping full and accurate records.

Acting fairly and proportionately

- Treating the complainant impartially, and without unlawful discrimination or prejudice.
- Ensuring that complaints are investigated thoroughly and fairly to establish the facts of the case.
- Ensuring that decisions are proportionate, appropriate and fair.
- Ensuring that complaints are reviewed by someone not involved in the events leading to the complaint.
- Acting fairly towards staff complained about as well as towards complainants.

Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Providing prompt, appropriate and proportionate remedies.
- Considering all the relevant factors of the case when offering remedies.
- Taking account of any injustice or hardship that results from pursuing the complaint as well as from the original dispute.

Seeking continuous improvement

- Using all feedback and the lessons learnt from complaints to improve service design and delivery.
- Having systems in place to record, analyse and report on the learning from complaints.
- Regularly reviewing the lessons to be learnt from complaints.
- Where appropriate, telling the complainant about the lessons learnt and changes made to services, guidance or policy.