



Northern Ireland

Public Services
Ombudsman

Investigation Report

Investigation of a complaint against the Northern Ireland Hospice

NIPSO Reference: 19330

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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 Northern Ireland Hospice (NIH) in respect of care and treatment provided to the complainant's late mother (the patient). The patient was receiving community palliative nursing care from the Hospice's nurse specialists (HNSs).

The complaint concerned care planning, the lack of advice on pain relief and the absence of effective communication with and support for the family in the months and days leading up to the patient's death. The complainant said that the failings in the NIH care left her mother '*unsettled, anxious and frightened*' and '*her end of life extremely difficult.*'

I did not find failures in relation to the provision of pain relief. However I identified deficiencies in the assessments completed by the HNS and subsequent care planning, including end of life management. There was support and assistance provided to the complainant and the patient, however this was based on urgent need rather than proactive assessment.

In particular, the HNS failed to communicate concerns about the patient's failing health to the complainant or to other Health Care Professionals on her final visit on 4 May 2018, despite knowing there was no planned visit by the Acute Care at Home Team until Tuesday 8 May 2018. This was the day that the patient sadly passed away. I identified little direct interaction with the patient despite her having mental capacity. As a result of the failures that I have identified the patient did not receive the end of life care she needed and the complainant felt unsupported and anxious.

I therefore partially upheld the complaint.

I made recommendations to the NIH to improve support and communication with families and to issue an apology to the complainant. I am glad to note that the Northern Ireland Hospice accepted my findings and recommendations.

THE COMPLAINT

1. The patient was receiving community palliative nursing care from the NIH from 6 October 2017 until her death on 8 May 2018. She received care from the NIH Nurse Specialists from 27 November 2017 until the time of her death.
2. The complaint made by her daughter centred around care planning, the care and treatment provided to her mother and the lack of effective communication with the family in the months and days leading up to her death. She complained that the failings in the NIH care left her mother '*unsettled, anxious and frightened*' and '*her end of life extremely difficult.*'
3. The complainant initially made a verbal complaint to the NIH on 14 May 2018. An investigation was carried out by the NIH. The NIH met with her and her sister on 20 August 2018. A final response letter was issued to her on 3 September 2018. She remained dissatisfied and she complained to this Office. Her complaint was accepted for investigation on 31 January 2019.

ISSUES OF COMPLAINT

4. The following issues of complaint were accepted for investigation :
Whether the NIH nurse acted in accordance with appropriate standards in relation to:
 - i. **End of life care planning for the patient?**
 - ii. **Provision of support and assistance to the complainant?**
 - iii. **Advice on pain medication?**

INVESTIGATION METHODOLOGY

5. In order to investigate the complaint about the actions of the NIH, the Investigating Officer obtained from the NIH all relevant documentation together with the NIH's comments on the issues raised by the complainant.
6. The complainant did not make a complaint to this Office concerning the patient's GP Practice or the Belfast Health and Social Care Trust (BHSCT), both of which were involved in providing care to the patient. In particular, the BHSCT operates the Acute Care at Home Team and District Nursing. The Investigating Officer asked the BHSCT to provide relevant information and policies relating to the roles of the District nurse/keyworker role and the Acute Care at Home Team in order to understand the interface with the NIH and the HNS.

Independent Professional Advice Sought

7. After further consideration of the issues, the Investigating Officer obtained independent professional advice from the following independent professional advisor (IPA):
 - A Nurse Consultant Palliative and Supportive care MSc Palliative Care, BSc Professional Practice
8. The information and advice which have informed my findings and conclusions are included within the body of my report. The IPA has provided me with 'advice'. However, how I weigh this advice, within the context of this particular complaint, is a matter for my discretion.
9. In accordance with the NIPSO process a draft report of the investigation was shared with the complainant and with the NIH for comment on its factual accuracy and the reasonableness of the findings and recommendations. My findings and recommendations were accepted by the NIH.

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.

11. The general standards are the Ombudsman's Principles¹:
 - The Principles of Good Administration
 - The Principles of Good Complaint's Handling
 - The Public Services Ombudsman's Principles for Remedy

12. The specific standards are those which applied at the time the events occurred and which governed the exercise of the professional judgement of the NIH and the individuals whose actions are the subject of this complaint.

The specific standards relevant to this complaint are:

- The Palliative Care in partnership Palliative Care Keyworker Role and Function (2017) (The Keyworker paper)
- The Community Operational Policy for the NI Hospice May 2016 (the Community Operational Policy)
- The Policy Framework for Nursing and Midwifery Workforce Planning in NI September 2017 (The Policy Framework)
- The Northern Ireland Regional Palliative care Programme Mandate 20 April 2016 [updated March 2018] (The Regional Mandate)
- National Institute for Health and Care Excellence (NICE) End of Life Care for Adults Quality standard (QS) 2011 (QS13)
- Nursing and midwifery Council (NMC) The Code : Professional Standards for Nurses and Midwives 2015 (the NMC Code)

¹ These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.

13. I have not included all of the information obtained in the course of the investigation in this report. I am satisfied, however, that everything that I consider to be relevant and important has been taken into account in reaching my findings.

THE INVESTIGATION

Background

14. The medical records show that the patient was diagnosed with Neuroendocrine Thymus² in 2007. She had retroperitoneal lymphadenopathy³ metastases⁴, right iliac bone⁵ sclerotic lesions⁶ and lung metastases. She also had a history of heart failure.
15. The patient had previously been a patient of the NIH but had been discharged in June 2017 as she was deemed to be symptom free at that time. However, she was admitted to hospital on 8 September 2017. On 5 October 2017 she was deemed medically fit for discharge.
16. After discharge from hospital, the patient attended the Supportive and Specialist Palliative Care Team at Belfast City Hospital (BCH) as an out-patient. She also continued to attend the Cancer Centre at BCH for reviews.
17. A new referral was made to the NIH by a Macmillan Palliative Care nurse on 6 October 2017. As a result, the patient received palliative nursing care from the NIH in the community from 6 October 2017 until just prior to her death on 8 May 2018.
18. The patient also received palliative care from the key worker who is the named District Nurse, from the Acute Care at Home Team and from her GP. As stated, no complaint has been made about the GP practice or BHSCT.

² A tumour in the lower respiratory tract

³ Enlarged lymph glands or nodes

⁴ The development of secondary malignant growths at a distance from a primary site of cancer.

⁵ Part of the hip structure

⁶ Thickening of the bone

19. As part of investigation enquiries, the BHSCT was asked to describe the role of the Acute Care at home Team and stated:

'Acute Care at Home is a Consultant led multidisciplinary team that provides treatment for older people in the patient's own home or care home. The care provided will be for a condition that would otherwise require hospital inpatient care and always for a limited time...The team will provide a comprehensive Geriatric Assessment and the necessary treatment at home and are involved at the acute phase of the patient's condition. The patient will have access to appropriate investigations and diagnostics.'

20. BHSCT was asked how the Acute Care at Home Team interfaces with the District Nurse and the HNS and provided the following explanation:

'When a patient is admitted to the Acute Care at Home Team with an acute illness and is known to District Nursing, the team will contact District Nursing staff to provide an initial update of the team's input. The District Nurse is normally the patient's key worker and the primary point of contact for patient information and clinical updates. However, there may be occasions when other professionals are identified as the keyworker. The Acute Care at Home Team will contact the keyworker and update them regarding the condition or status of the patient during the treatment plan and advise of discharge from the Acute Care at Home Team. On occasions, there may be joint home assessments / visits, case discussions and / or a shared care arrangement carried out with Acute Care at Home staff and District Nursing staff...The Consultant will also update the GP when necessary. Patients admitted to the Acute Care at Home Team frequently have multiple co-morbidities and can often progress to palliative stage during this acute phase. When clinically indicated, the team will actively engage with a range of services as required to meet the needs of the patient.'

21. In relation to the role of the HNS, I considered the NIH Community Operational Policy provided by the NIH which states:

'the service is delivered in the patient's home and our nurses will provide advice and guidance to support the management of complex symptoms, support the patient and their family and contribute to improved quality of life through the

promotion of assessing, planning (including advance care planning), implementing and evaluating care, using a patient centred approach...They [the HNSs] work in partnership and collaboration with the patient's general practitioner, the Primary Health Care Team, and other statutory and voluntary organisations.'

22. The objectives of the NIH Adult Community Specialist teams are outlined in the Community Operational Policy as follows:

- *'To provide specialist palliative care to patients with non-malignant and malignant disease in their own home.*
- *To provide advice and guidance on the management of unresolved complex symptoms.*
- *To work in partnership with general practitioners, the primary health care team and other statutory and voluntary organisations in providing a quality service to patients and their families.*
- *To act as a resource for health care professionals caring for patients with specialist palliative care needs.*
- *To provide specialist telephone advice to health care professionals 24/7*
- *To provide bereavement support.*
- *To discharge patients (with their knowledge) when they no longer have specialist palliative care needs.'*

23. The Community Operational Policy states that all referrals to the NIH will be allocated to a key NIH nurse and *'The nurse will carry out a first assessment and in collaboration with the patient, general practitioner and district nurse will determine the plan of care'*.

Issue (i) Whether the NIH nurse acted in accordance with appropriate standards in relation to end of life care planning for the patient?

Detail of Complaint

24. The complainant stated that a palliative care plan had been in place in 2016

and updated in 2017. She complained that the care plan was not further updated from October 2017 onwards and that no end of life care plan was in place. Consequently, when the patient's condition deteriorated over the weekend she had to ask her neighbour, who she knew to be a palliative care consultant, for help. The Out of hours' doctor was also contacted and carried out a home visit on the morning of 8 May 2018.

25. The complainant also said that the HNS's communication with her and her mother regarding end of life care was inadequate. She has questioned who has responsibility for overseeing the HNS with regard to the planning of the care, implementing the care plan and reviewing the care plan.

Evidence Considered

26. The NIH Community Operational Policy states:
'The service is delivered in the patient's home and our nurses will provide advice and guidance to support the management of complex symptoms, support the patient and their family and contribute to improved quality of life through the promotion of assessing, planning (including advance care planning), implementing and evaluating care, using a patient centred approach
27. The Policy Framework 2017 states *'the Regional Palliative Care programme recognises that the District Nurse will typically be the keyworker and key elements of this role include identification, co-ordination and contact, and delivering care and support'*.
28. The NIH provided me with a copy of the assessment form completed on 11 October 2017. I note the requirement that a 'Patient Assessment Methodology' is used *'to ensure a holistic assessment of individual patient and carer needs are considered to prioritise the services effectively'*. The methodology states *'the following criteria, scoring methodology and prioritisation definitions will be used to arrange patient visits in the community in line with service standards.'*

note that no scores have been allocated in the first section 'Patient Assessment'.

29. The assessment continues under the following headings:

- Medical history
- Social assessment
- Initial assessment
- Problem/management plan
- Ongoing Patient assessment (completed by the HNS).

30. Under the heading Problems/Management, the patient's complex specialist palliative care issues and the management plan associated with these were identified as follows:

'[The patient] has pleurex drain in situ for pleural effusions. DN draining 500mls twice weekly. Some pain during this event. SOB [shortness of breath]. Advised to reduce rate of drainage for last 100mls. Sevredol⁷ prescribed if required. Respiratory referral through by hospital - awaiting visit.'

31. There is a sub section called 'summary (include level of intervention)' which states *'[The patient] is currently relatively stable. She has no pain at rest. Energy low, appetite fair. Concerned about readmission to hospital.'*

32. The final subsection is titled 'Summary of carer's Needs and Management Plan' and states:

'Contact details left with [the complainant]. She is taking [the patient] to see DR [A] next Tuesday at clinic.'

The NIH response to the patient's complaint

33. The NIH provided this Office with its complaints file. This included a record of an interview with the HNS which took place on 22 May 2018. The HNS was

⁷ Morphine used to treat chronic severe cancer pain

asked to comment on the complaint that the complainant was not made aware that her mother was at the end of her life. The response is recorded as:

'HNS stated she called to see [the patient] late on Friday, she recognised that she was very unwell and enquired about the ongoing antibiotics and whether there was a plan for the acute care team to review this. [The patient] was in and out of sleep, she became aware that [the complainant] was becoming agitated/annoyed with us and said mum was very tired... She explained that she saw marked deterioration in patient, states tried to broach this conversation with [the complainant] but was quickly shut down, states she intended to advise re stat does of medication.'

34. The NIH also provided this Office with the record of an interview with a NIH nursing colleague, who had accompanied the HNS on the visit on 4 May 2018. She was asked to explain her understanding of the HNS's interaction with the complainant in relation to her mother's condition. She stated:

'HNS was trying to prompt conversations around the subject that mum was very poorly and appeared to be approaching the last days of her life and that the patient's daughter appeared to be somewhat hostile in terms of non-verbal communication. [She] was not engaging in this communication and was changing subject, there appeared to be avoidance and non-acceptance. HNS was professional at all times and [...] stated that she had previously observed a good rapport during the previous visit that she accompanied her on.'

35. The NIH was also asked whether the HNS had addressed the issue of the patient sleeping on a sofa/chair downstairs for up to two months. The HNS' response was:

'On 17th April 2018 HNS stated she had advised to try hospital bed as sleeping in chair-hospital bed upstairs, [it] was there on this date but unsure when this was provided. I asked HNS to clarify whether the patient could get upstairs to access the bed given her deteriorating condition; she was unsure about this and acknowledged the omission.'

36. I note from the notes and records provided by the NIH that the HNS was aware that the complainant was expecting a visit from the Acute Care at Home Team

on Tuesday 8 May 2018 to review the administration of intravenous antibiotic medication.

37. The NIH has provided me with the notes of a meeting on 20 August 2018 with the complainant and her sister organised to discuss the complaint. The notes of this meeting record that the complainant's sister referred to a conversation with the Acute Care at Home team '*the week before*' the HNS's visit on 4 May 2018. The note records that the complainant's sister states '*the week before Dr [...] had pulled me to one side and said things weren't good and we don't know how long we have and to just prepare yourself. The conversation that took place in the hall was that HNS asked was the acute care team coming and she would ring me on Tuesday.*'
38. The Investigating Officer asked the NIH to address the complainant's reference in the meeting to a palliative care plan that had been in place in 2016 but was not updated from October 2017. The NIH explained that the document produced by the complainant on 20 August 2018 during the meeting is not a NIH document. It was completed by a BHSCT Community Palliative care Nurse.
39. I note that the NIH had written to the complainant on 3 September 2018, after the meeting took place. In response to this aspect of the complaint, the NIH described the supervision and management processes in place in respect of the community teams. The NIH stated that :
- 'Supervision takes place in the form of:*
- *Daily team discussions*
 - *Weekly team meetings to review caseload*
 - *Weekly meetings with a consultant in Palliative Medicine*
 - *Fortnightly multi-disciplinary meetings*
 - *Clinical supervision'*
40. In relation to management processes, the NIH stated '*The assessment and planning of individual patient care remains within the individual Community*

Nurse's responsibility. The HNS had raised her concerns regarding this case in clinical supervision as she was uneasy about the anticipated outcome. This happened after the patient's death and before the complaint was made.

41. In response to investigation enquiries about the NHS 24/7 advice line, the NIH explained that this is a nurse-led telephone advice service. It provides advice to health care professionals, and is not an advice line for direct contact from patients and families.

Clinical records and IPA advice

42. The Investigating Officer referred the IPA to the NIH Community Operational Policy which states:

'nurses will provide advice and guidance...to support the patient and their family and contribute to improved quality of life through the promotion of assessing, planning (including advanced care planning) implementing and evaluating care, using a patient centred approach'.

43. The IPA was asked if this standard was upheld by the NIH. In response, the IPA referred to the initial assessment on 11 October 2017 undertaken by HNS 1 and advised:

'The focus appears mainly on acute oncology care and symptoms and not the holistic plan of care NICE QS13 recommends. Holistic care planning (advanced care planning) in the last 12 months of life should be integral to the first hospice assessment despite the role of the key worker as the referral is for a specialist assessment and plan of care to compliment the care being provided.

44. The IPA further advised:

'Consequently when [HNS 1] conducts her first visit to the patient on the 27/11/17 she does not repeat the original holistic documentation and bases her assessment on current symptoms only. Poor quality of the assessment documentation and limited written information against the scoring methodology does not provide enough information to justify symptom management as the main focus, therefore perhaps [she] should have taken the opportunity to

repeat and complete the assessment fully especially if she was now providing on-going care. Evidence following the initial assessment does show symptom control is adequately managed between the NIH Consultant, HNS, GP and Oncology but a clear over-arching plan of care including discussions around end of life management is lacking.'

45. The IPA advised that the fact that the initial assessment had been conducted by a different HNS (HNS 1) may have been a disadvantage to the initial relationship developing between the HNS, the complainant and the patient. The IPA also advised '*the initial assessment should be in partnership with the key worker so it's clear from the outset the plan of care as the patient deteriorates and the family are therefore fully informed with realistic expectations*'.
46. The IPA also advised that '*Minimal proof of clear implementation plans and robust evaluation exist however the correspondence between the professionals involved within the symptom management of the patient's care, mainly through telephone calls and Palliative/oncology clinic outcomes is reasonable*'.
47. The IPA advised '*Quality of the on-going patient assessments based on NICE QS13 and the documented evidence is less than adequate. I could not find discussions based on support services and sign posting to other agencies should the need arise. Communication at the point of assessment and forward planning with well-informed patients and families is best practice within the National Standards for end of life care.*'
48. The IPA further advised '*It's clear from the contact log provided that visits were based on urgent need rather than proactive planned assessments which are noted as less than adequate due to workforce issues.*'
49. It is the IPA's opinion that '*there is a lack of a patient centred approach and individual goal setting to include the identified needs of the patient and carer within the documentation. NICE QS13 Guidance states the importance of advanced care plans to ensure individual plans of care are created, updated with patient's preferences and discussed with and includes the needs of*

relevant family members. This would include access to information and coordinated care assessments in response to changing needs especially as end of life is approaching.'

50. The IPA also advised *'another area for consideration is the lack of direct communication between [HNS 2] and [the patient], and the fact that most conversations and telephone assessments are done via her daughter. Evidence in the notes does not suggest that [the patient] lacked capacity to hold conversations and therefore the opportunity to plan and support her on-going management is denied.'*
51. The IPA referred to the HNS's visit on Friday 4 May 2018, advising:
'It's clear from the episode on the 4/5/18 that HNS (HNS 2) attempted to have a discussion with the complainant because her mother was obviously rapidly deteriorating but this was dismissed. [The patient] was at this stage deemed too sleepy to be included in the conversations. The focus does appear to be on the acute care team's involvement rather than the HNS leading on the plan of care despite the recognition [the patient] is deteriorating and reaching the end of life.'
52. The Investigating Officer asked the IPA if she would expect the HNS to have liaised with the acute care team or other health care professionals to ensure that a plan of care was in place over the long bank holiday weekend. She advised *'Yes. It's not clear how the district nurse as key worker supported the situation but [HNS 2] would have a professional responsibility in transferring of information in regards to the patient's safety and risks as described in the Code for nursing (2015). It maybe however that HNS didn't anticipate the rapid decline over the weekend as this can be unpredictable but declaring the patient as very unwell should have resulted in some form of action whether internally at the hospice or via the community services in place through the acute care team'*.
53. The IPA also advised that *'[HNS 2] should have communicated the change in the patient's condition to the acute care team and established the plan of care for the weekend including the GP and district nurse so that everyone was made*

aware and the complainant supported. End of life care planning should have commenced at least 7 months earlier as the patient is re-referred to NIH with a poor prognosis and limited life expectancy however this should not be solely the responsibility of the HNS.'

54. The IPA also advised that end of life discussion could be initiated by any professional; *'However the specialist element of palliative care is the skills to initiate these conversations especially at the point of rapid deterioration... Early recognition, communication and planning of care with the patient and family is lacking in the documented evidence. This is evident from the quality of notes in the initial assessment which is the platform for difficult discussions, and the on-going case notes where both the patient and families anxieties and fears are lacking.'*
55. The IPA, in conclusion, advised that *'[HNS 2] is a highly skilled member of the community team and has identified areas of practice which could have been managed differently on reflection.'*
56. The IPA's advice was shared with the NIH on 24 April 2019. The investigating Officer asked if the NIH accepted the IPA's view that HNS 2 ought to have contacted other health care professionals on leaving the home on 4 May 2018, for example the keyworker/District Nurse, the GP or the Acute Care at Home Team. In response, the NIH informed the Investigating Officer that the HNS contacted the GP Surgery to order supplement drinks in response to the family's request. However *'Unfortunately the GP was reportedly unavailable and a message left with reception staff regarding the requested supplements and a request for a call back...Both [HNS 2] and Northern Ireland Hospice accept that HNS should have attempted contact with the District Nurse and Acute Care Team directly to communicate her understanding of the clinical picture.'*

Issue (i) Analysis and findings

57. I accept the advice of the IPA that end of life care planning was not solely the responsibility of the HNS, and that any of the professionals involved could have

initiated these difficult discussions with the patient and the complainant. However this investigation is only concerned with the actions of the NIH staff and not the roles and responsibilities of the other professionals involved in the patient's care.

58. The complainant said that a care plan initiated in 2016 was not updated following the patient's re-referral to the NIH in October 2017. I have established that this care plan, which the complainant referred to during the meeting of 20 August 2018, was a BHSCT document and not a NIH document. As this complaint deals solely with the actions of the NIH, I am unable to consider the merits of a care plan completed by the BHSCT.
59. The patient had been re-referred to the NIH with a poor prognosis and limited life expectancy. The IPA has identified the importance of a comprehensive initial NIH assessment as a platform to agree and share both the patient's initial holistic plan of care and forward plans of care. The first assessment had been carried out by the NIH on 11 October 2017, seven months prior to the patient's death. The IPA has identified deficiencies in this assessment. In particular the IPA did not get '*a sense of a collaborative approach with the Key worker*'. She also questioned the quality of the written specialist assessment and its focus on symptom management.
60. I accept the advice of the IPA that holistic care planning in the last 12 months of life should be integral to the first NIH assessment and that this was lacking. I also find it a failing that the HNS 2 did not fully complete the initial assessment. In particular, the scoring methodology (which was intended to prioritise services effectively and arrange patient visits in the community in line with service standards) was not utilised.
61. I consider that the HNS, given her level of skill and experience, ought to have taken the opportunity to review the initial assessment that had been completed by HNS 1 and to repeat those areas of the assessment that were of poor

quality or lacking in detail. I find that the inadequacies in planning in the initial assessment carried out by HNS 1 set the tone for future assessments.

62. I accept the advice of the IPA that the HNS complemented regular assessments from oncology and palliative care consultants throughout the period from October 17 to May 18 'albeit not to a satisfactory service standard'. I consider that the day to day assessment and management of the patient's symptoms by the HNS alongside the other professionals involved in the patient's care was adequate. However, I consider a clear overarching plan of care from the HNS to include end of life management should have been in place at an early stage in the referral process. It is a particular failing that the HNS failed to establish a specific plan of care for the weekend beginning 4 May 2018.
63. As a consequence of the absence of a specific plan of care over the bank holiday weekend, when the patient's condition deteriorated the complainant sought assistance from a neighbour who arranged for the Out of Hours' doctor to carry out a home visit in the early hours of the morning of 8 May 2018, shortly before her death. The complainant has described how these unforeseen events left the patient '*unsettled, anxious and frightened*' and caused embarrassment to her and her neighbour.
64. I consider that these failings caused the patient the loss of opportunity to plan for and experience a more dignified death and the complainant the injustice of uncertainty and upset and I uphold this issue of complaint about end of life care planning.

Issue (ii) Whether the NIH nurse acted in accordance with appropriate standards in relation to the Provision of support and assistance to the complainant and the patient?

Detail of complaint

65. The complainant said there was a lack of nursing visits, end of life care, support and assistance from the HNS in the months and days leading up to her

mother's death.

66. She complained that she was not made aware by the HNS on 4 May 2018 that her mother was approaching the end of her life.

Evidence considered

67. I considered the following provisions of the NMC code:

'Section 4 Act in the best interests of people at all times.

To achieve this you must:

4.1 balance the need to act in the best interests of people at all times with the requirement to respect a person's right to accept or refuse treatment

4.2 make sure that you get properly informed consent and document it before carrying out any action

Section 5 Respect people's right to privacy and confidentiality.

5.5 Share with people, their families and their carers, as far as the law allows, the information they want or need to know about their health, care and ongoing treatment sensitively and in a way they can understand.

Section 8 work cooperatively

8.3 keep colleagues informed when you are sharing the care of individuals with other healthcare professionals and staff

8.4 work with colleagues to evaluate the quality of your work and that of the team

8.5 work with colleagues to preserve the safety of those receiving care

8.6 share information to identify and reduce risk.'

68. I also considered the NIH Community Operational Policy which states:

They [the HNSs] work in partnership and collaboration with the patient's general practitioner, the Primary Health Care Team, and other statutory and voluntary organisations.'

69. In considering whether the NIH took sufficient account of the complainant's needs in determining what support she might need, I considered the

assessment form completed on 11 October 2017. I note the requirement that a 'Patient Assessment Methodology' is used *'to ensure a holistic assessment of individual patient and carer needs are considered to prioritise the services effectively'*.

70. I note that QS13, statement 7, states that *'families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences'*.
71. I also considered the Northern Ireland Single assessment tool (NISAT) form which was completed on 21 June 2017 by the BHSCT CPCN. There is a section which enquires if the need for a carer's assessment has been identified, requested or offered or declined and also whether a Carer's assessment has been previously completed. This section headed 'referral for Carer's Assessment' has not been completed.

The NIH response to the patient's complaint

72. As part of the NIH investigation, the HNS was asked whether family support or sign-posting to other services was offered to the complainant. Her response is recorded as follows:
- 'Her understanding is that [the complainant] wanted to manage everything herself, never said she wanted any extra help. HNS acknowledged that offering support or making people aware early on of what is available would help to avoid this. She explained that she would normally do this at first assessment but notes that she did not see this patient for first assessment and did not later address any such discussions.'*

Clinical Records and IPA advice

73. The Investigating Officer obtained the patient's medical notes and records, documenting her care and treatment. These were referred to the IPA. Referring to the Keyworker paper, the IPA advised:

'The rationale for the specialist palliative care professional not being best suited to the key worker role is access to 24/7 service provision and support as the hospice professionals only work 5 days a week mainly in an specialist advisory capacity to compliment the community services in place. The Specialist Palliative care team had been involved for many years with the patient and their operational policy 2016/18 states the initial holistic assessments will be in collaboration with the patient, GP and district nurse to determine the plan of care which is based on changing needs including end of life care.'

74. The IPA notes that *'The Hospice has acknowledged the HNS visits provided over the 7 month period before the patient's death are below the standard expected and policy has since been addressed accordingly stating one visit will take place every 10 working days'*.
75. The IPA advised *'The quality of the on-going patient assessments based on NICE QS13 and the documented evidence is less than adequate. I could not find discussions based on support services and sign posting to other agencies should the need arise.'*
76. The IPA referred to the Community Clinical Services Policy 2016 and advised: *'It's not clear from the records on the delineation of responsibilities between HNS and the other health care professionals which may be confusing, especially at the end of life'*. The IPA also advised *'this should not be solely the responsibility of the HNS.'*
77. The IPA was asked to comment on the quality of communication between the HNS and the complainant during the final visit on Friday 4 May 2018. The IPA advised *'HNS clearly identifies that the patient is very unwell during her visit on 4th May and does not succeed in opening the conversation with the patient or her daughter.'*
78. The Investigating Officer asked the IPA if she would expect the HNS to have liaised with the Acute Care at Home Team or any of the other health care

professionals at this stage. She advised:

'It's not clear from the case notes how these findings are communicated to the district nurse, acute care team or GP and as it's a Friday you would expect a plan of care to be in place to cover the fragile situation until services resume after the bank holiday. HNS acknowledges she could have put more services in place had the conversation been successful but also that the complainant was keen for them to exit abruptly. Communication and information in regards to contact out of hours is lacking and the role of the hospice to support the deteriorating situation over the weekend not evidenced.'

79. The IPA advised that HNS 2 should have communicated the change in the patient's condition to the acute care team the GP and district nurse, so that everyone was made aware and the complainant supported.
80. The Investigating Officer also asked the IPA if the HNS ought to have signposted the complainant to other organisations that may have been able to assist her following her mother's death. The IPA advised *'Most hospices provide a bereavement service which is beyond the quality of NHS services or voluntary sector provision generally so I would not suggest alternative support...it appears the right processes have been adopted and referral into the bereavement service would end HNS's on going contact with the family'*.
81. In response to the IPA's advice regarding the patient's mental competence, the NIH stated:

'There were no doubts about the patient's mental capacity. HNS has explained that the patient stated she would prefer [HNS2] to communicate with her daughter during telephone contact and that [HNS 2] duly honoured this request. However, this consent was not documented by [HNS 2] and she has fully acknowledged this. The importance of documenting such consent has been taken as a learning point from the original complaint process and action completed. [HNS 2] has explained that due to the patient's deteriorating condition, [the patient] was not able to communicate directly with [HNS 2] during her last visit on 4 May 2018.'

Issue (ii) Analysis and findings

82. I note that a referral was made on 6 October 2017 to the NIH from a Macmillan Palliative Care specialist nurse. This was prior to the patient's discharge from Belfast City Hospital where she had been admitted on 8 September 2017. She was discharged from hospital on 7 November 2017. The initial HNS assessment was carried out on 11 October 2017. I have noted in issue one the advice of the IPA that HNS 1's focus at this time was symptom management rather than the preferred holistic approach.
83. I note that the HNS's first contact with the complainant and the patient was a telephone call on 27 November 2017 followed by a home visit. The records indicate that there was regular contact thereafter between the HNS and the complainant. However most of the contact with the family was by telephone with the complainant and there was therefore little interaction directly between the HNS and the patient. It is not disputed that the patient had mental capacity. However, it is not documented that she had given consent for the HNS to communicate through her daughter. Section 4.2 of the NMC code states *'make sure that you get properly informed consent and document it before carrying out any action'*. Therefore, it is a failing that the patient's consent was not recorded. I consider that it is also a failing in care and treatment that the HNS did not initiate and establish a meaningful level of communication with the patient while she was well enough to participate.
84. The focus of the complaint is the end of life care provided by the HNS and, in particular, the lack of communication with her on 4 May 2018. QS13, statement 7, states that *'families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences'*.

85. The HNS states that she formed the impression on 4 May 2018 that the complainant did not want help or support. However this impression has not been informed by a comprehensive assessment of the complainant's needs or indeed a documented discussion as required by QS13.
86. A formal carer's assessment is primarily the responsibility of the BHSCT and could have been addressed by the BHSCT at the time of the referral or previously. However, this did not reduce HNS 1's responsibility to consider the complainant's needs at the time of referral and document these on the 'Summary of Carer's Needs and Management Plan' which she completed on 11 October. The HNS ought then to have reviewed this as the patient's and carer's needs changed. It is a failing that the assessment form failed to address the complainant's needs.
87. I considered section 5.5 of the NMC code *'Share with people, their families and their carers, as far as the law allows, the information they want or need to know about their health, care and ongoing treatment sensitively and in a way they can understand.* The HNS left the patient's home late on the afternoon of Friday 4 May 2018 on a bank holiday weekend, knowing that there would be no NIH cover in place until the following Tuesday should the patient's condition deteriorate. I consider that it is a failing that the HNS left the family on 4 May 2018 without using her skills and experience to effectively communicate to the complainant about how ill her mother was.
88. The NHS Community Operational Policy states that the HNSs *'work in partnership and collaboration with the patient's general practitioner, the Primary Health Care Team, and other statutory and voluntary organisations.'* I note it is also the role of the District Nurse to coordinate palliative care. The Keyworker paper states that a function of the Palliative Care Keyworker is *'Ensuring local arrangements are in place and that the person and those important to them know who to contact for advice and support 24/7.'* I consider that the HNS ought to have clearly signposted the complainant to the patient's keyworker on 4 May 2018, knowing that HNSs would not be available to provide support until 8 May 2018.

89. I refer to the NMC code which states:
Section 8 'work cooperatively
8.3 keep colleagues informed when you are sharing the care of individuals with other healthcare professionals and staff
8.5 work with colleagues to preserve the safety of those receiving care
8.6 share information to identify and reduce risk.'
90. I consider that the HNS did not act in accordance with the NMC Code when she failed to alert other health professionals involved in the patient's care to her concerns about the patient's condition. The patient was unprepared when her mother's condition deteriorated in the early hours of Tuesday 8 May 2018. HNS ought to have communicated with the Acute Care at Home Team, the GP and District Nurse so that the patient and the complainant were not left without support at a time when the patient was clearly very unwell. This is a failing in care and treatment.
91. I also consider in this regard that the HNS did not follow the QS13 statement 9 which states '*People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences*'
92. I consider that these failings caused the patient to experience the injustice of loss of opportunity to receive adequate support at the end of her life and the care she needed. I also consider that these failings caused the complainant the injustice of distress and anxiety. Therefore I uphold this issue of complaint.

Issue (iii) Whether the NIH nurse acted in accordance with appropriate standards in relation to advice on pain medication?

Detail of complaint

93. The complainant said that she should have been able to rely on the HNS for assistance and guidance with medication. She complained that the HNS lacked

knowledge with regard to pain relief dosages and that on occasions the HNS directed her to obtain advice directly from the GP. She referred specifically to a lack of response to her request for advice from the HNS regarding the required dose of a drug called Oramorph.

NIH response to the issue of complaint

94. In response to the complaint, the NIH stated that the case notes evidence *'prompt follow up communication with your mother's GP on any occasion that this formed part of the agreed plan. The review team did not find any evidence or reference to you being directed by [HNS 2] to obtain advice for yourself from the GP, District Nurse and out of hours' service'*.
95. The NIH referred to the entry in the HNS's notes on 1 May 2018. This is a record of a telephone call from the complainant. This record states: *'Phone call from [the complainant] to say [the patient] in pain in (r) posterior chest wall... Asking re oramorph dose. Advised 20mg/10mls 3-4 hourly, observe for signs of toxicity.'* The record also refers to a discussion about doses of Pregabalin⁸ and Fentanyl⁹ and the continuation of antibiotic medication administered by the Acute Care at Home team.

Clinical records and IPA advice

96. The IPA explained the role of the HNS in relation to advice about medication: *'It's clear that the HNS works in a specialist advisory role in regards to the medications and doses prescribed but does not actively prescribe. Advice given to both the GP, Patients daughter and other professionals in this case is based on specialist palliative care clinical practice and where complex the consultant in palliative care medicine is contacted for expert medical advice.'*
97. The IPA also advised *'[HNS 2] evidences her clinical expertise in advising and*

⁸ Pregabalin in palliative care patients is usually used for complex pain and is titrated accordingly under specialist guidance

⁹ An Opioid pain medication (see also Mezolar, sevredol and oramorph)

guiding other professionals as a valuable resource especially as the GP recognises the expertise required to manage complex pain issues.'

98. Referring to HNS 1's first assessment in November 2017 the IPA advised it *'states [the complainant] is managing her mother's pain well, but this does not establish the concerns holistically of a carer coping with a terminally ill mother'.*

99. In relation to the HNS's actions, the IPA advised:
'Pain management using the Mezolar patches, sevredol and oramorph is advised appropriately with the GP and titrated throughout the 7 month period to meet the patient's needs...Pregabalin in palliative care patients is usually used for complex pain and is titrated accordingly under specialist guidance and it's clear in the notes both the consultant in palliative medicine and the HNS are regulating the doses through various entries. Seeking approval from the Palliative care consultant before increasing doses may be required practice in some areas. Diazepam is organised by the HNS for the treatment of night time anxiety with the GPs agreement (14/4/18) due to breathlessness again appropriate. The Vitamin B12 prescribing would be the GPs Domain and not necessarily [a] HNS issue other than highlighting to [the complainant] to contact the GP to discuss.'

100. In her conclusion, the IPA advised *'Management of pain and symptoms is coordinated effectively with reasonable support and assistance offered, however establishing the needs of [the patient] and her daughter towards the end of her life is not evidenced in the documentation.'*

Issue (iii) Analysis and findings

101. I have carefully considered the IPA advice. I note that the role of the HNS is not to prescribe medication but to provide specialist advice to the GP, the family and other professionals.

102. The IPA identified from various entries in the patient's notes and records that the consultant in palliative medicine and the HNS were working together to

regulate the doses of pain medication over the seven month period. There is clear evidence of telephone calls with the complainant and with the GP regarding medication.

103. The complainant said specifically that she was not given advice about Oramorph. However the HNS's entry in the notes and records on 1 May 2019 clearly states that the complainant asked about Oramorph and was given advice about the recommended dose and warned to '*observe for signs of toxicity*'. I note also that the record of 4 May 2018 states '*Pain well controlled has not needed to take Oramorph.*' I have no reason to doubt the authenticity of these contemporaneous records. I am therefore satisfied that the HNS responded to the complainant's request about the recommended dose of Oramorph.
104. The complainant has stated that she requested Oramorph from the GP on 3 May 2018 but that he did not prescribe it. The actions of the GP practice are not the subject of this complaint therefore it is not for me to determine the reasons why this drug was not provided by the GP.
105. I accept the opinion of the IPA that the HNS's role in regulating pain medication was performed satisfactorily and I do not find any failings in care and treatment in relation to this matter. I do not uphold this issue of complaint.

CONCLUSION

106. The investigation of this complaint has considered the responsibilities of the NIH for end of life care and support. It is clear that these are not solely in the remit of the HNS. The Community Operational Policy states that the HNSs '*work in partnership and collaboration with the patient's general practitioner, the Primary Health Care Team, and other statutory and voluntary organisations.*'
107. The Clinical Service Policy also states that the NHS service is delivered five days per week, Monday to Friday, 9am to 5pm, excluding bank holidays. There is also a nurse led telephone advice service provided to health care

professionals '24/7'. The BHSCT has clarified that this service is not available to patients or their families.

108. The Policy Framework states '*The Regional palliative Care Programme recognises that the District Nurse will typically be the key worker and key elements of this role include identification, co-ordination and contact and delivering care and support.*'

109. The patient's condition deteriorated over the weekend when NIH services were not available. However the Keyworker paper makes it clear that it was the role of the keyworker/district nurse to provide services to Miss and the patient on a '24/7' basis. The BHSCT has explained that the Acute Care at Home Team liaises with the District Nurse and that there are often joint or shared care arrangements in place.

110. The complaint has been made solely against the NIH, therefore this investigation has not considered the actions of the key worker, the GP or other health care professionals such as the Acute Care at Home Team. It is not my role in this case to determine whether the care and treatment provided by any other health care profession met the relevant standards. Therefore, in making my findings I am making a determination only about the care, treatment and support provided to the patient and the complainant by the Hospice's Nursing Specialists.

111. The assessment of this complaint identified three issues to take forward for investigation to establish whether the NIH and in particular the Hospice's nurse specialists acted in accordance with appropriate standards in relation to:

- i. End of life care planning for the patient
- ii. Provision of support and assistance to Miss and the patient
- iii. Advice on pain medication.

112. I have investigated the complaint and have found failures in care and treatment in relation to issues one and two of the complaint as follows:

Issue (i) end of life care planning

- a) There were deficiencies in the initial assessment completed by HNS 1 and the subsequent assessment by HNS 2.
- b) There was no holistic plan of care to include end of life management.
- c) A plan of care for the weekend 4 to 8 May was not discussed or put in place.

Issue (ii) two, the provision of support and assistance to the complainant and the patient

- a) Support was delivered based on urgent need rather than proactive assessment.
- b) The HNS did not signpost the complainant to any other organisations who could offer her support.
- c) There was little direct interaction with the patient despite her having mental capacity. There is no record of her consent to the complainant acting on her behalf.
- d) Despite her training, experience and skill, the HNS failed to communicate her concerns about the patient's failing health to the complainant on 4 May 2018.
- e) The HNS failed to inform other Health Care Professionals about her concerns on 4 May 2018, despite knowing there was no planned visit by the Acute Care at Home Team until Tuesday 8 May 2018.

113. I have not found failures in care and treatment in relation to issue three, whether the NIH nurses acted in accordance with appropriate standards in relation to advice on pain medication. Therefore I do not uphold this issue of complaint.

114. The failures that I have identified in relation to issue one denied the patient the opportunity to plan for and experience a more dignified death and caused the complainant to experience the injustice of uncertainty and upset. I therefore uphold these issues of complaint.

Observations

115. The NIH has reflected on this case, acknowledged failings and identified areas of practice which could have been managed differently. I note that the NIH

apologised to the complainant for these failings in its letters of 12 June 2018 and 3 September 2018. The HNS has also personally reflected and identified areas for learning. I welcome this.

116. The complainant has questioned who has responsibility for overseeing the HNS with regard to care planning, implementation and review. The NIH has indicated that forms of supervision take place daily, weekly and fortnightly. However *'the assessment and planning of individual patient care remains within the individual Community Nurse's responsibility'*. The performance management of staff within the NIH is outside the scope of this investigation. However the NIH may wish to review its practices in the light of this case to ensure that care planning, although delegated to the employee, is appropriately supervised and managed.

Recommendations

117. QS13 statement seven states that *'Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences'*. The NIH has an important role in this. However the QS13 makes it clear that *'the proper management of these issues requires effective and collaborative, multidisciplinary working within and between generalist and specialist teams, whether the person is at home, in hospital or elsewhere'*.
118. The NIH should therefore review its role and responsibility for providing adequate support to families coping with a terminal diagnosis. This should include ensuring that the carer's needs are assessed at the time of the initial referral and as the patient's and carer's needs change. This requires collaboration with the other allied professionals in the multidisciplinary team who also have a duty to provide holistic care and support.
119. The IPA has commented on the learning points identified by the NIH. Taking into account the advice of the IPA, I recommend that the action plan is updated as

follows and a revised action plan provided to this Office within three months to include the following:

- 1) Demonstrate adherence to Section 4.2 of the NMC code which states *'make sure that you get properly informed consent and document it before carrying out any action'*
- 2) Provide details of when the Community Dietitian delivered the planned education session and the staff uptake.
- 3) Provide details of when the remaining eight staff received Advanced Communication Skills training.
- 4) Confirm that a framework for telephone contacts and home visits is in place and agreed with other members of the multidisciplinary team, particularly the BHSCT key worker.
- 5) Provide this Office with a copy of the Community Patient and Carer information pack including the introductory patient leaflet.
- 6) Provide evidence that the NIH has auditing processes in place to monitor the quality of the HNS assessments to ensure that they are being fully completed

120. I also recommend that the NIH apologise to the complainant for the injustice suffered as a result of its failings within one month.

121. The NIH has accepted my findings and recommendations.



Paul McFadden
Acting Ombudsman

5 March 2020

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.