

# **Northern Ireland Public Services Ombudsman (NIPSO) Response to Committee for Health Inquiry – Access to Palliative Care Services**

**January 2025**

## **1. Background to the Northern Ireland Public Services Ombudsman (NIPSO)**

The Northern Ireland Public Services Ombudsman (the Ombudsman) was established by the Public Services Ombudsman Act (NI) 2016 (the 2016 Act). The role of the Ombudsman is to independently and impartially investigate complaints brought by members of the public about public services in Northern Ireland. The Ombudsman also has the power to conduct investigations without a complaint (often referred to as ‘own initiative investigation’) under section 8 of the 2016 Act. The Ombudsman’s investigation service is free to members of the public and plays an important role in both providing access to justice and redress for individuals as well as supporting improvement and learning in public services.

Where maladministration is found, the Ombudsman makes recommendations to address the injustice sustained by complainants, to improve public services and to prevent future occurrence of similar failings. The Principles of Good Administration, appropriate legislation, policy, procedures, and standards are the benchmarks against which the actions of public bodies are measured. The Office also identifies and shares learning to help improve public service delivery.

## **2. NIPSO’s role and Health & Social Care Complaints**

NIPSO consistently receives more complaints about Health and Social Care than any other sector. The jurisdiction of our Office in this sector is wide, including all six Health and Social Care Trusts (Trusts), the Department of Health (DOH), the Regulation & Quality Improvement Authority, the Northern Ireland Medical & Dental Training Agency, the Patient Client Council, the Public Health Agency, the Business Services Organisation, general health care providers such as General Practitioners (GPs) and independent providers when the service is provided on behalf of the Trusts. In the context of health care services, NIPSO can look at both alleged maladministration, and professional judgement.

In 2023-2024, 43% of our total complaints related to Health and Social Care, of which 377 were about Health and Social Care Trusts and 126 about other healthcare providers. Health and Social Care (HSC) complaints continue to also be the largest proportion of complaints reaching further investigation stage, reflecting not only the large numbers of people accessing health care but also indicating the complexity and severity of the concerns raised.

NIPSO is very aware of the significant pressure on our public services but is concerned that despite a number of reviews and inquiries, our health system continues to operate in crisis. Evidence points to a high level of dissatisfaction and stress among HSC staff and practitioners and a decrease in public trust in our health service. We accept that in health care, as in any area of service delivery on some occasions there will be human error or system failings. However, when something goes wrong, we strongly believe this is an opportunity for the public body to be open and honest, to involve patients and families, and seek to rebuild trust. However, it remains the case that too often we see a defensiveness within the system. Patients and families who approach NIPSO have often experienced a lack of candour or support and report a lack of compassion or empathy – often compounding their trauma.

### **3. Inquiry Response**

In preparing this response we identified a number of complaints about palliative care which had progressed to further investigation and had a final report issued by the Ombudsman. Each investigation is independent and impartial; where we find failings, these are clearly documented with recommendations for improvement. We did not find failings in every palliative care complaint brought to the office but in the interests of sharing learning with the Committee we have focused on the areas our investigations have highlighted as needing improvement. A summary of some of these cases can be found in Appendix 1.

### **4. Summary of key failings found**

It is NIPSO's experience of health care complaints that, sadly these failings are not unique to palliative care. Whilst it is important to stress that not all palliative care is end of life and not all palliative care is provided under distressing circumstances – it

is the case that in many of the complaints brought to the office, these were distressing and often unexpected situations for patients and families. Many of the cases identified involved poor communication and / or poor recording keeping and planning which resulted in lost opportunities to improve quality of life when receiving end of life care. We have grouped the key findings of failures into the below themes.

#### **4.1 Care and treatment**

Failings found included poor clinical assessments by staff, failing to escalate concerns or make appropriate referrals and failing to facilitate palliative care team review for patients. In one case the Trust failed to provide access to a clinical nurse specialist or keyworker to facilitate the patient's care management, denying her and her family additional specialist support provided which could have alleviated some of their concerns around her pain management and symptoms. In some cases, there was a failure to have appropriate pain management or pain advice in place leading to patients suffering unnecessarily.

#### **4.2 Communication**

Given the potentially distressing nature of palliative care and that in many cases a patient may be receiving end of life care, communication is of the utmost importance. It is also a time when effective, compassionate communication is needed to support patients and families to make decisions about their care. Failings found in communication included poor communication with patients and their relatives on their options for palliative care optimisation, poor communication about the commencement of palliative care and failure to signpost to support services. There were also communication failings between medical staff and teams leading to delays in palliative care being provided and a loss of opportunity to optimise palliative care. In some cases, this led to patients suffering unnecessarily.

#### **4.3 Staffing issues**

Staffing issues included failures to provide patients with a key worker and clinical nurse specialists to help them during their treatment journey. There were also failings in relation to handovers and to ensure coverage during out of hours periods. In one case, the clinical nurse specialist (CNS) highlighted they were working with staff to patient ratios three times greater than the recommended ratio of one CNS to

seventy-six patients. The CNS Independent Professional Advisor consulted on this case suggested that a review of resourcing of cancer clinical nurse specialists should be undertaken to ensure that the appropriate quality care is given to patients and that CNS staff are better able to meet their patients' needs.

#### **4.4 Record keeping**

The need for improved record keeping was noted in several cases. Good documentation is essential for high quality patient care, helping ensure continuity of care and that the patients' wishes are respected. This included a failure to properly document a patient's consent to communicate with her family.

#### **4.5 Transitions and Children's Palliative Care**

In November 2016, the Department of Health estimated that around 1300 children were living with life limiting conditions in Northern Ireland, a figure which is likely to be much higher now. As early as 2009, the Integrated Care Pathway, introduced by DOH, acknowledged the number of service users transitioning between Children and Adult services would rise as life expectancy increased.

Two recent NIPSO investigations highlighted concerns around the transition from children to adult care and whilst not focused on palliative care it is relevant to this Inquiry. For young people with complex and life-limiting conditions, transition can be a challenging time for both them and their families / carers. They may already be accessing or may soon need palliative care and delays or poor practice in relation to transition could have an impact on palliative care for this particularly vulnerable group. Poor transition can lead to disruption in continuity of care, disengagement from services, and poorer clinical outcomes.

Two investigation reports (see Appendix 1 for a summary of the case most relevant to the Inquiry) highlighted issues in transition planning including:

- Lack of Trust transition policies
- Failure to apply policy where one was in place
- Delays in commencing transition planning
- Delays in transition referral

- Lost opportunity for earlier assessment, planning and intervention
- Ineffective transition planning contributing to disruption of services to service user
- Lack of understanding of the process due to lack of information/transition meetings/planning
- Lack of effective communication between Children and Adult services
- Lack of effective communication with service user and their family

<sup>1</sup>A study in 2020 found that the prevalence of children with a life limiting condition in the UK had increased markedly over the 17-year study period. It also found that the number of young people surviving paediatric services is increasing and as there are a large number of deaths amongst those in their twenties, these young people will require access to appropriate services. This further emphasises the need to get transitions and palliative care right for this very vulnerable group whose healthcare is complex, sometimes unique and will highly likely be new or unfamiliar to adult services. This is particularly pressing as best interest decision making when the young person lacks capacity post 18 years, becomes the responsibility of the Trust. Up until this stage, parents (who have considerable expertise and knowledge about their child's needs) have authority over how their child is cared for. If trust, confidence, and effective communication is not maintained there can be risks for all involved.

## **5. Summary of recommendations**

When an investigation finds failings, the Ombudsman makes recommendations to provide redress for the complainant to improve the service or care and implement learning from the complaint. In each case shared in Appendix 1, NIPSO recommended an apology for the complainant. The recommendations made in relation to service improvement for palliative care are highlighted below.

### **5.1 Staff training and development – NIPSO recommended end of life care training for out of hours district nursing staff and recommended that staff receive**

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<sup>1</sup> 'Make Every Child Count' Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom February 2020, Fraser I.K. et al

advanced training in communication skills. Recommendations also included Trusts sharing the investigation outcome with relevant staff to enable reflective practice.

**5.2 Review of processes to enable improvement** – For example, recommendations were made to conduct a review of the process of moving patients from one cancer pathway to another. One Trust was asked to conduct a review of “pain management” in identified wards in two hospitals to ensure an appropriate standard of care provided to patients, with a particular focus on appropriate pain scoring, assessment, incorporation into nurse care planning and recording. The Trust was also asked to conduct a review of the documentation, communication and recording in respect of community specialist palliative care options for Regional Cancer clinic patients.

**5.3 Sample audits or sharing results of audits** – For example, audits relating to delayed or omitted medications, timelines of referral to assessment by hospital palliative care teams, auditing medical records to ensure appropriate assessments and referrals are occurring and to confirm that an audit process for Hospice Nurse Specialist assessments is in place. One Trust was asked to conduct a random sampling audit of patients’ discharges from an identified Ward to ensure clinicians have provided (and documented) information to a patients/family members to enable informed decisions to be made regarding discharges for those patients with complex needs.

**5.4 Policy development** – One Trust was asked to develop a policy to cover the transition between Children and Adult Services, which it did not have in place despite the vulnerability of this group.

## **6. Conclusion**

Research indicates that palliative care is poorly understood by the general public, with a University of Ulster study finding that only 1 in 5 survey respondents could describe it accurately. It concluded that for many people, palliative care is a taboo subject and called for greater awareness to facilitate better understanding and

prepare people to have conversations and make decisions about their and their loved one's care<sup>2</sup>.

Other research published by Marie Curie<sup>3</sup> estimated that (at the time) 11,300 of the 15,000 people who die each year in Northern Ireland need palliative care. However, their research, suggested that 1 in 4 people who need palliative care in Northern Ireland each year are not accessing it. This highlights that for many people, when the time comes to access or make decisions.

Discussions around prognosis, longevity and palliative care are often dealt with in the most trying of circumstances and the ill patient (particularly so if the illness is terminal) may have little understanding of what lies ahead, and the impact this will have on their lives and that of their families.

In light of this, the instances of poor communication and poor planning found in some of our investigations are concerning and, in some cases, had significant impact on patients and their loved ones. This means that empathy, clarity of information and excellent communication with both the patient and their loved ones is essential.

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<sup>2</sup> <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-northern-ireland-summary.pdf>

<sup>3</sup> <https://professionalpalliativehub.com/what-do-the-general-public-know-about-palliative-care-and-advance-care-planning-in-northern-ireland/>

## **Appendix 1**

The following summaries are some of the palliative care complaints which reached further investigation by the Ombudsman. They highlight some of the key issues arising from complaints relating to Palliative Care.

### ***Poor discharge planning meant that woman was discharged from hospital and passed away without appropriate end of life medications (Belfast Health and Social Care Trust)***

A woman diagnosed with lung cancer was being treated with chemotherapy and radiotherapy. However, she unfortunately suffered a stroke, was admitted to hospital and was subsequently discharged from hospital. Although her family reached out to district nursing and Out-Of-Hours care they felt they had not been adequately supported with palliative care in the last weeks of their mother's life. This investigation found failures of delays in pain management advice and antiemetic<sup>4</sup> drug administration and delays in assessment by the hospital palliative care team. It found that the hospital palliative care service did not adequately proactively plan for the patient's discharge regarding end-of-life care and that there was poor multidisciplinary communication between district nursing and general practice doctors regarding ongoing symptom management and optimising end of life medications. Because anticipatory medications were not prescribed, and the patient was not adequately prioritised for review, this patient very sadly died in distressing circumstances.

Read the Investigation Report here<sup>5</sup>

### ***Poor communication prevented family receiving support and certainty from a palliative care referral (South Eastern Health and Social Care Trust)***

A woman deteriorated in hospital post-operatively and a decision was made to place a Do Not Attempt Cardiopulmonary Resuscitation Order and refer her to the

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<sup>4</sup> Antiemetic drugs are medicines that treat nausea and vomiting and work by blocking neurotransmitters, which are chemical messengers that send information about nausea to the brain

<sup>5</sup> <https://www.nipso.org.uk/our-findings/search-our-findings/failures-end-life-care-had-significant-impact-cancer-patient-and>

palliative care team (PCT). However, she sadly died before PCT could review her. Her family raised concerns with the Trust relating to her care and treatment and also about the communication with them. The complaint was partially upheld and NIPSO found that communication with the family could have been documented more clearly, and that better communication with the family regarding referral to palliative care would have provided the comfort of greater certainty regarding their mother's care.

Read the Investigation Report here<sup>6</sup>.

***Support from a clinical nurse specialist could have helped family co-ordinate care for woman with terminal cancer (Belfast Health and Social Care Trust)***

During treatment for cancer a woman's scans showed spinal and abdominal metastases<sup>7</sup>. She was referred to palliative care and for palliative radiotherapy for poorly controlled pain but sadly she died before she could be reviewed for palliative radiotherapy. NIPSO did not find failings in the management of her pain or her referral to palliative care. However, the investigation did find that the patient should have been assigned a clinical nurse specialist or keyworker. This professional would have co-ordinated the care and management of her symptoms between oncology and her GP and provided specific support for the patient and her husband during the last months of her life.

Read the Investigation Report here<sup>8</sup>.

***NI Hospice failed to co-ordinate out of hours care and additional resources for a woman when she was reaching the end of her life***

The health of a woman with several conditions including heart failure sadly deteriorated and she required palliative care towards the end of her life. This involved being cared for in the Northern Ireland Hospice (the Hospice), in hospital

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<sup>6</sup> <https://www.nipso.org.uk/our-findings/search-our-findings/poor-communication-trust-left-man-unprepared-mothers-death>

<sup>7</sup> Metastases is the spread of cancer cells from the original tumour to other parts of the body

<sup>8</sup> <https://www.nipso.org.uk/our-findings/search-our-findings/patient-should-have-received-additional-support-overall-care-was>

and in the community. Her family made a complaint about the Hospice as they felt that the care planning and advice received on pain relief was inadequate and that they should have been better supported by community hospice nurse specialists. NIPSO found that the Hospice failed to carry out a full holistic assessment, poorly documented the patient's consent to communicate with her family and there was ineffective handover to support the patient and her family during the bank holiday weekend (when there would be a lapse in Hospice coverage). Despite some aspects of her care being the responsibility of the BHSCT, the Hospice Nurse Specialist, as the person responsible for co-ordinating end of life care for this patient could have flagged any omissions or gaps in care with the Trust, but failed to do so. The Hospice Nurse Specialist also failed to raise concerns appropriately to colleagues about the patient's deterioration, meaning that no additional resources were allocated to this family during the last days of their mother's life.

Read the Investigation Report [here](#)<sup>9</sup>.

***Delays in providing diagnosis for a woman with metastatic cancer prevented early palliative care input (Belfast Health and Social Care Trust (BHSCT))***

The care of a woman who died with extensive metastatic cancer and an unknown primary tumour was managed by gynae-oncology, with some input from urology and gastroenterology in the Belfast Trust. Delays in arranging a biopsy and an ultrasound scan led to uncertainty for the family regarding a diagnosis and impacted on them being able to prepare for distressing news and to both consider and access palliative care options. The investigation found a number of issues of concern. The nursing assessment completed in hospital did not include details about the patient's spiritual and religious care needs, pain management was not consistent, meaning the patient suffered unnecessarily and added to her family's distress. The BHSCT failed to facilitate appropriate palliative care input for the patient, and the Clinical Nurse Specialist (CNS) did not do a hand over to the medical team so that they could seek

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<sup>9</sup> <https://www.nipso.org.uk/our-findings/search-our-findings/investigation-upholds-complaint-about-patients-end-life-care>

palliative care input for this patient. The investigation also noted concerns from the CNS regarding nurse-to-patient ratios. The Independent Professional Advice received by NIPSO suggested that the BHSCT review resourcing of CNS staffing levels in order to provide high quality care to all cancer patients.

Read the Case Summary here<sup>10</sup>.

***Poor documentation led to a loss of opportunity to advise woman on access to palliative care services (Belfast Health and Social Care Trust)***

This complaint was made about the care and treatment of the complainant's wife, who passed away from a terminal brain tumour. The patient had recurrent issues with pain management, and although she was referred to community palliative care, she declined their input. The investigation found that the medical records did not document the decision to refer to palliative care nor the refusal from the patient regarding this referral. This failure in record keeping meant that no further discussion was had with the patient and the family about the refusal and the opportunity was lost to explain the benefits of palliative care, holistic care, and symptom management of her cancer at the end life. There was also a failure to have in place an appropriate pain management, assessment, scoring and recording system. The investigation also established failures by the Trust in how they handled the complaint, including inordinate delay of 425 working days beyond target for response.

Read the investigation report here<sup>11</sup>.

***Delays in review appointments during COVID-19 pandemic meant that man could not plan palliative care options (Southern Health and Social Care Trust)***

This complaint was about the treatment a man received for rectal cancer. Due to the COVID-19 pandemic, his 6 month follow up appointment and CT scan were

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<sup>10</sup> <https://www.nipso.org.uk/our-findings/search-our-findings/trust-failed-give-cancer-patient-adequate-level-care>

<sup>11</sup> <https://www.nipso.org.uk/our-findings/search-our-findings/trust-implements-action-plan-following-ombudsman-investigation>

cancelled. This was rescheduled; however, the patient was not given a higher priority for review. Due to delays from the backlog of appointments during the pandemic, the patient's CT scan was not undertaken until 18 months after his initial surgery. The CT scan showed that the patient experienced a recurrence of their cancer, however he sadly passed away following further treatment.

Although the investigation found that an earlier CT scan would, on balance, not have changed the outcome, it did find failings in a loss of opportunity to optimise palliative care for the patient. The communication relating to palliative care with this family was not of an acceptable standard and prevented them having appropriate expectations and making an informed decision regarding the discharge to an assisted living facility.

Read the Investigation Report here<sup>12</sup>.

***Inadequate transition planning and failures in care and treatment for a young woman with life-limiting and complex medical needs (Belfast Health and Social Care Trust)***

This investigation found that the community care provided to a young woman with learning difficulties and a severe physical life-limiting condition failed when she transitioned between the Trust's Children and Adult Community Services. When the young woman transitioned to adult care, the Trust dismantled the existing package in favour of a new contract with a nursing provider. The investigation also found a gap in the Trust's policy and procedures for governing the process as the Trust accepted that 'unfortunately there do not appear to be any policies and procedures in Children or Adult Services in relation to Transitioning to Adult Services.' Additionally, the Trust failed to engage in the process of transition as early as it should have done.

Opportunities were lost to build relationships with the service user and her family, and to observe how care was being delivered. Care plans were incomplete and insufficient at the commencement of the new care package and there were many

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<sup>12</sup> <https://www.nipso.org.uk/our-findings/search-our-findings/trust-failed-provide-appropriate-follow-care-cancer-patient>

gaps in documentation. Sadly, due to the subsequent death of the service user, those disruptive and anxious months were among the last that the family had with their precious daughter and sister.

Read the Investigation Report here<sup>13</sup>.

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<sup>13</sup> <https://www.nipso.org.uk/our-findings/search-our-findings/failures-care-and-treatment-young-person-life-limiting-condition>