Marie Curie
NORTHERN IRELAND

Unscheduled care in the last year of life

Summary of research commissioned by Marie Curie

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Executive summary

THIS briefing provides an overview of unscheduled care use by people in the last year of life, based on two studies commissioned by Marie Curie in Northern Ireland.

The first study, by Queen's University Belfast (QUB) and the NI Ambulance Service Health and Social Care Trust (NIAS), analysed official hospital and ambulance service data from 2014 to 2023 to quantify inpatient hospital and emergency department (ED) attendances among people in their last year of life. This research linked system-level datasets for the first time, offering a unique perspective on end of life patient interactions with acute care services.

The second study, led by the University of Ulster, explored paramedics' perceptions of their role in end of life care within the Northern Ireland Ambulance Service. It identified factors affecting their contribution and highlighted how equipped paramedics feel when responding to patients nearing the end of life. Together, these studies deepen our understanding of how dying patients engage with emergency services, while revealing areas for future policy consideration.

The briefing emphasises the importance of using these evidence-based findings to inform policy, planning, and practice. The next steps will involve stakeholder engagement to further discuss the implications and support improvements in end of life care provision.

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Photo: Karen Dunlop- Research Paramedic- NIAS

> **“We were having to call for an ambulance nearly once a week. They were fantastic, but awareness of our situation was limited. We had to repeat ourselves.**
>
> – Tasha, who had to repeat her dad's diagnosis, treatment and symptoms each time they interacted with the ambulance service

1.0 Introduction

IN 2024, Marie Curie commissioned two research projects that focused on end of life patient interactions with hospital, emergency department (ED) and ambulance services in the last year of life in Northern Ireland. This is the first time official data has been analysed in this way. As a result, it provides a unique insight into parts of the acute care system where dying patients are seen, and the prevalence of these interactions.

This policy brief draws out a summary of some of the key findings from across these two studies.[a] Together, they enhance our understanding of the interactions patients have with unscheduled/emergency services.

The study by Queen's University Belfast (QUB) and the NI Ambulance Service Health and Social Care Trust (NIAS) quantifies these interactions, and the University of Ulster (UU) survey gives a sense of how well-equipped paramedics believe they are in responding to patients at end of life.

The next phase of this work will involve engagement with key stakeholders to further explore the findings and implications for policy and practice. We also want to support the system to use this evidence to inform all relevant policy and planning activities.

1.1 Health Service Use by People in their Final Year of Life (2026)

The aim of the study, led by QUB and NIAS, was to quantify overall inpatient hospital and ED attendance of people in their last year of life, as a proportion of overall hospital use. It also aimed to explore trends of use over the 10-year period from 2014 to 2023.

The study involved linking a number of different system-level datasets, namely inpatient and emergency hospital episodes with mortality information. To our knowledge, this was the first time that data has been linked and analysed to track and quantify end of life patient interactions with unscheduled and emergency services in Northern Ireland.

1.2 Paramedic Perspectives on End of Life Care in Northern Ireland (2025)

Led by UU, this study sought to identify Northern Ireland Ambulance Service (NIAS) paramedic workforce perceptions of current practice and factors influencing their contribution to end of life care.

Registered paramedics from NIAS were invited to complete an online questionnaire adapted from the England ParAid study.[b] To our knowledge, this is the first Northern Ireland-wide survey seeking views of paramedic interactions with patients at end of life.

The survey was completed by 182 paramedics, representing a 34% response rate. The vast majority were in frontline operational (80%) and/or leadership roles (27%).

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a. The views presented in this briefing are those of Marie Curie. The QUB/NIAS and UU studies are standalone pieces of research and links to the original source documents are available here.

b. The questionnaire used was adopted with minor adaptations to fit NI context from an existing University of Southampton led study programme in England called ParAid.

2.0 Context

2.1 Increasing demand and place of death projections

Northern Ireland has the fastest growing ageing population in the UK. By 2048, it's estimated that approximately 20,500 people will be dying with palliative care needs each year.[1] It's also projected that co-morbidities will have increased by 80% and that the greatest increase in palliative care need will be in the over 85s.

The most recent population-need modelling also estimates that 1 in 3 people in Northern Ireland are missing out on at least some of the palliative care they could benefit from.[2] With the projected growth in our ageing population, this gap will only increase without urgent investment in palliative care services.

There has been a decline in the number of people dying in hospital over the last 20 years, however hospital still accounts for nearly half (46%) of deaths in Northern Ireland.[3] While hospital can be the most appropriate place of care some people at the end of life, a lack of capacity and other barriers to accessing community services is driving some dying patients into hospital unnecessarily. In short, more suitable alternative care is not always available.[4]

2.2 Public health spending in the last year of life

A 2024 Nuffield Report on public expenditure in the last year of life found that, across the UK, approximately 80% of the health budget in the last year of life is spent in acute care – with less than 10% spent on primary or community services.[5] It is also estimated that 12% of overall public spending in the last year of life goes on social care, with the largest element of that spend on residential and nursing homes. The latest data presented in the research below broadly corroborates Nuffield's spending estimates.

The need to transform how health and social care services are delivered, and therefore where public money is spent, has been recognised at political and policy level for well over a decade.

Unfortunately, the much-needed reconfiguration of services hasn't happened at the pace or scale needed. The pressures faced by all parts of the health and social care system has become an ingrained problem, the most obvious consequence of which is dealt with by our ambulance and ED services.

Ambulance use and emergency attendance for those at end of life can be necessary and appropriate. But medical professionals are also raising concerns that emergency care has become the default service where other more appropriate services are not accessible.[6]

In a recent Royal College of Nursing report, nurses from across the UK including Northern Ireland, reflected on the pressures they face with what they describe as 'corridor care' – nursing care being given in inappropriate, undignified and in some cases unsafe spaces.[7]

The Royal College of Emergency Medicine has also made repeated warnings of unsafe practices in emergency departments and the need to address blockages to patient flow through the system. They highlight the lack of social care to safely discharge patients home from hospital as a significant contributor to this problem.[8]

2.3 Policy drivers for system transformation

Supporting the health and wellbeing of an ageing population with increasingly complex needs is a resource challenge faced by many health and social care systems across the western world.

This is a particular challenge for Northern Ireland as the fastest growing ageing population in the UK, a palliative care system in need of urgent investment and reform, and a Health Minister grappling with a sizable health and social care budget deficit of circa £800 million

The challenge has been exacerbated by transformation constraints and a lack of Executive agreement on a multi-year budget. Northern Ireland also has more people living in rural areas than any other UK nation,[9] which makes equity of access to all public services, including palliative care more difficult.[10]

The current Department of Health-led policy drive to shift more care into the community and out of acute care settings, through a ‘neighbourhood model of care approach’, is laudable. However, such a change cannot be achieved without a significant shift in investment from acute to community. It’s not possible to deliver this change for end of life patients if we continue to spend five times more on acute hospital care in the final year of life than on primary/community care.[11]

It is critically important that a holistic community care approach for palliative and end of life patients ensures everyone has the financial and practical means to be cared for safely and comfortably at home.

Access to social care packages is a major issue and a significant cause of delayed discharge and emergency admission to hospital.[12]

An expansion of care in the community must consider practical issues such as the suitability of being cared for at home, the need for home adaptations, and the ability to pay living costs for heating and electricity, including the running costs of medical devices.

It’s estimated that 1 in 5 people **(20%)** are spending their final year of life in poverty in Northern Ireland. This figure is estimated to be closer to 1 in 3 **(27%)** for fuel poverty specifically.[13]

3.0 Key themes from research findings

THE QUB/NIAS and UU studies are standalone pieces of research, which you can access here. Viewed together, however, they provide a fuller picture of end of life patients' interactions with acute and emergency services. This policy brief draws out key themes from the overarching findings set out by both research studies.

They key themes discussed below are:

- emergency attendance and hospital admissions for those in the last year of life
- ambulance service use by those in the last year of life
- actions taken by paramedics and primary drivers of conveyance to ED
- challenges with referral pathways, and
- hospital costs in the last year of life.

3.1 Emergency department attendance and emergency hospital admissions for people in the last year of life

- 8 in 10 people had at least one ED attendance in the last year of life **(81.6%).**
- Of all ED attendances, **59.3%** were in the out of hours period.
- **67.8%** (2 in 3) of all ED attendances resulted in an emergency admission to a hospital ward.
- 1 in 2 **(49.9%)** emergency admissions to a hospital ward (via ED or direct admission) were in people aged 80+.

67.8%

of all ED attendances resulted in an emergency admission to a hospital ward

The data linkage analysis that the QUB/NIAS study undertook reports that during the 10 year period 2014 to 2023, 8 in 10 people had at least one ED attendance **(81.6%)**. Of all ED attendances, **67.8%** resulted in an emergency admission to hospital and almost **60%** of ED attendances were in the out of hours period.

Furthermore, half **(49.9%)** of all the emergency admissions to hospital whether via ED or direct admission to a ward occurred in people aged 80+.

The most common reasons for emergency hospital admission or ED attendance were generally the same: infection, respiratory, cardiac and gastrointestinal problems. Cancer was also one of the most common reasons for emergency hospital admission, but not for attendance at ED.

A review of patient level data is needed to understand if alternative pathways could have been pursued. However, it's very likely that a proportion of these crisis situations could have been avoided with a strengthened community infrastructure, which includes better integration between key support services eg GPs, district and community nurses, palliative key workers, hospices and pharmacies.

3.2 Ambulance service use by those in last year of life

- On average **1 in 5** of all calls received by NIAS relate to people in their last year of life.
- **2 in 3** people who had an ED attendance in their last year of life arrived by ambulance.
- **ED attendance by ambulance conveyance** increased strongly with age (78% amongst 80+ age group).
- **48%** of paramedics reported that at least half of end of life calls were from care/nursing homes.

The system-level data from the QUB and NIAS study estimates that on average 20% or 1 in 5 of all calls received by NIAS relate to people in their last year of life. This is a significant proportion of calls and much higher than NIAS 999 call logs would capture. This is primarily due to call handlers not always being made aware that the call is related to a person in receipt of end of life care.

The system-level data also indicates that the ambulance service conveys a large proportion of end of life patients to hospital. It is estimated that 2 in 3 attendances at ED of people in their last year of life arrived by ambulance. ED attendance by ambulance increased strongly with age, for attendances of people aged 0 to 49, **47%** arrived by ambulance compared to **78%** by those aged 80+.

On average

1 in 5

of all calls received by NIAS relate to people in their last year of life

The paramedic survey also showed that almost half **(48%)** of the paramedics reported that at least half of the patients they attended in their last year of life were living in a care/nursing home.

3.3 Actions taken by paramedics and primary drivers of conveyance to ED

- Only **34%** of paramedics had access to an existing advance care plan (ACP) document.
- GP recommendation was the primary driver for conveyance to ED **(80%)**, followed by a family request **(64%).**
- Paramedics reported that symptom control **(60%)** or a palliative emergency **(44%)** were the two main clinical reasons for ambulance conveyance to ED.
- **58%** of paramedics rarely or never knew in advance that they were attending an end of life call.

Paramedics have complex and challenging real-time decisions to make when they are presented with end of life patients. The paramedics surveyed reported that they often work with limited or piecemeal access to any advanced care planning documentation, with only **34%**

58%

of paramedics rarely or never knew in advance that they were attending an end of life call

encountering an ACP document and **58%** rarely or never knowing in advance they were attending an end of life patient. Just over half of paramedics reported themselves to be 'somewhat' confident and competent in end of life care support- which means that nearly half did not.

Paramedics reported that a GP recommendation **(80%)** was the primary driver for conveyance to ED, followed by a family request **(64%)** or other health professional advice or request **(49%).** Furthermore, paramedics reported that symptom control **(60%)** was the most common clinical reason for conveyance to ED followed by a palliative emergency **(44%).**

Half **(46%)** of the paramedics surveyed indicated that when they were made aware that a patient had palliative needs or end of life, they would 'sometimes' convey patients to the ED. They also expressed that they would 'rarely' or 'never' convey the patient to a hospice **(93%)**, indicating a potential gap in referral pathways and/or a lack of awareness of the referring professionals where services do exist.

> **"As paramedics, we're often caring for patients at the end of life without knowing in advance that they're receiving or should be receiving palliative care.**
>
> – Jade Hunter, Trainee Advanced Paramedic in Urgent Care, NIAS

3.4 Challenges with referral pathways

- **54%** of the paramedics 'always' or 'often' had **no access to specific medicines** needed.
- **47%** of paramedics 'often or always' **feared doing the wrong** thing when providing end of life care.
- **30%** of paramedics **lacked confidence** in **administering end of life medication.**
- Almost **60%** of the attendances to ED occurred **out of hours**, with **40%** occurring Monday–Friday **9am-5pm.**

The paramedic survey carried out by UU provides some insight into the referral pathways NIAS use Monday to Friday 9am-5pm (normal working hours) and out of hours.

During normal working hours, paramedics stated that they most commonly contact GPs and community nursing teams for patient referrals.

Paramedics described challenges with accessing further support and advice for end of life patients, during normal hours and out of hours. For example, **54%** reported that they 'always' or 'often' had no access to specific medicines needed. They also said that access to specific medicines and health professionals were particularly limited during the out of hours period.

Paramedics also indicated a lack of confidence and/or competence in responding to palliative and/or end of life patients.

Nearly half **(47%)** of the paramedics surveyed said that they 'often or always' feared doing the wrong thing when providing end of life care and **30%** reported a lack of confidence in administering end of life medication. Self-reported concerns raised by paramedics regarding their confidence and competence, points to a need for full consideration to be given to gaps in end of life training and education for paramedics.

The additional challenges they face with a lack of easily accessible information and onward referral services runs the risk of further complication and delay in patients' care and highlights an urgent need to review referral pathways and protocols.

Ambulance and hospital activity data provided in the QUB and NIAS study estimates that almost **60%** of the attendances to ED occurred in the out of hours period, with **40%** occurring Monday to Friday 9am-5pm. It's reasonable to assume that at least some of the ED conveyances during the out of hours period could have been avoided if alternative referral routes were operating effectively.

Unfortunately, data is not available to corroborate this. However, we do know that the operationalisation of NIAS protocols such as the alternative referral pathway protocols for end of life patients has been problematic.[14]

Almost

60%

of the attendances to ED occurred out of hours

> **“We went to the emergency department with a letter to go straight through but even with that we had to wait. There were people screaming and fighting, hitting on the windows, and it was a very scary experience.**
>
> – Kim, whose mum attended the emergency department shortly before she died

3.5 Hospital costs in the last year of life

- Hospital admissions dominated expenditure **(85%)**, with ambulance **(9%)** and ED **(6%)** costs comprising smaller shares.
- The majority **(90%)** of emergency admissions led to hospital stays averaging at **14 days.**
- Hospital costs for those in the last year of life appear to be driven more by **length of stay** once admitted than by frequency of admissions.

The QUB and NIAS study provides system-level cost estimates for hospital, ED and ambulance service use by people in their last year of life in Northern Ireland. These estimates are based on official HSC hospital activity data and therefore offer the best available approximation of health spend in Northern Ireland for those in the last year of life.

Basing system costs on hospital activity data spanning a 10-year period, the study found that hospital admissions dominated expenditure **(85%)**, with ambulance **(9%)** and ED **(6%**) costs comprising smaller shares. It also found that the biggest cost to the health system comes not from the frequency of admissions to hospital but from the length of time that people spend in hospital when they are admitted. The data shows an average length of stay of **14 days** following admission to ED.

Overall, the QUB and NIAS study reports that these patterns demonstrate that system pressure and hospital costs attributed to those in the last year of life are driven more by length of stay than by number of admissions or ED activity.

While it's impossible to quantify which ED presentations could have been avoided without detailed patient-level data analysis, it's reasonable to assume that some people could have been cared for in the community if alternative care pathways were working effectively.

It's also the case that some end of life patients may have had their discharge delayed following emergency admission because of a lack of available community support required for their safe discharge home, such as care packages or nursing home beds. Previous research has highlighted the considerable problem of delayed discharge for palliative and end of life patients.[15]

Hospital admissions dominated expenditure (85%), with ambulance (9%) and ED (6%) costs comprising smaller shares

The majority (90%) of emergency admissions led to hospital stays averaging at 14 days

4.0 Policy considerations

NORTHERN Ireland has an integrated health and social care system delivered through HSC Trusts. This should be seen as a strength when considering the HSC transformation process and the changes needed to palliative care services to better meet the need of palliative and end of life patients.

The challenges with the current way palliative care services are delivered is clearly documented by the Northern Ireland Assembly Health Committee in its Inquiry report on Access to Palliative Care.[16] Fragmentation and lack of coordination between services are making the delivery of services more difficult for healthcare professionals and leading to unnecessarily complex pathways for patients to navigate.

The various HSC Transformation programmes such as Neighbourhood Health Approaches to care and Committees in Common offer the opportunity to make a real shift in how we deliver end of life care. But without addressing this, the problem will only get worse.

The findings from both studies provide robust evidence to support policy and decision makers tasked with leading health and social care system reform, addressing ED pressures, and strengthening community support. Below, we set out some of the most pressing policy and practice issues related to community services, referral pathways, identification and system coding, workforce and ways of working.

4.1 Investment in community services and the workforce

There is an urgent need to invest in both the physical infrastructure and workforce needed to bolster community services for palliative and end of life patients.

Service mapping exercises and population needs assessments should inform this process and be aligned to optimal care and referrals pathways for palliative patients. A fully resourced community service model would better meet patients' needs and wishes, and prevent crises that too often lead to unnecessary ED attendances and emergency hospitalisation by palliative patients.

4.2 Referral pathways

Clear referral pathways for palliative and end of life patients are critical. They help to manage the flow of patients through the healthcare system in the most efficient and effective way.

Most importantly, they help ensure patients get access to appropriate care in a timely way. As new service configurations are developed, we must consider the strengths, weaknesses and gaps of existing referral pathways for palliative patients and use this learning to inform new approaches.

4.3 Identification and system coding

Timely access to palliative care services avoids crisis situations which cost more to the health service and lead to poorer quality of care and patient outcomes. Healthcare system data must be used to support identification of patients and the information sharing needed for their care.

4.4 Upskilling the workforce

A workforce trained to support the needs of palliative and end of life patients, wherever they are in the system on a 7 days a week, 24/7 basis, is a central pillar to the successful delivery of care. Focus must be given to the training needs of generalist and specialist staffing disciplines across statutory and voluntary or independent providers. This should address knowledge and competency gaps for paramedics, primary care and social or domiciliary workforces.

The contribution, training and support for unpaid carers must also be considered.

4.5 Integrated working

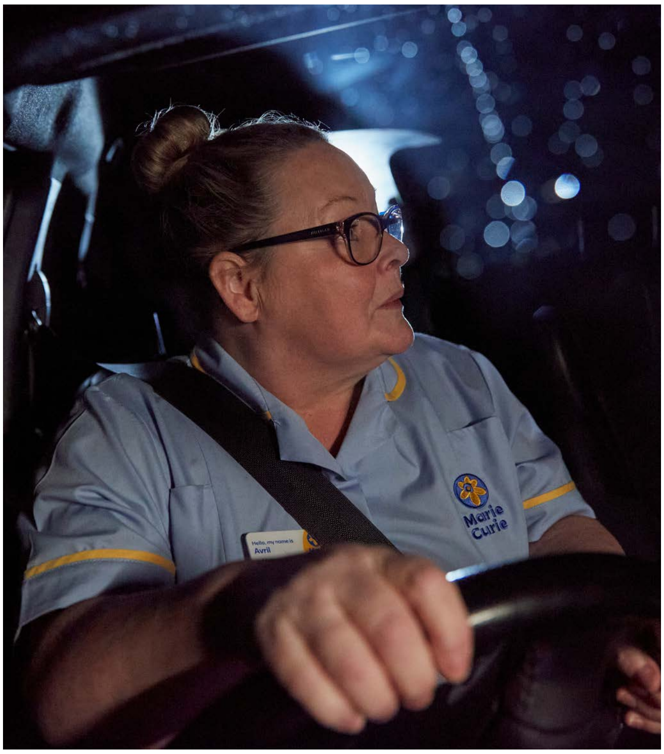
When working at its best, the palliative care sector involves all care providers at primary, secondary and tertiary level working together seamlessly and in tune with patient needs.

Unfortunately, too many people fall through service gaps and experience unnecessarily complicated processes and delays. Improving co-ordination and multi-disciplinary working across the system must be a priority when considering the actions needed to meet the needs of palliative and end of life patients.

5. Conclusion

THESE research findings are concerning. They reflect the issues that we hear about all too frequently from patients and carers and those that work in services.

The evidence presented in these two studies should encourage us all to collaborate and play our part to address the urgent and necessary changes needed to improve care pathways and the quality of care for palliative patients and those approaching the end of life.



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