

Dr Grainne Crealey

## Introduction to palliative and end of life care in Northern Ireland

*NIAR-278-2024*

*21 February 2025*

*This briefing is the first of a series of papers on palliative and end of life care in Northern Ireland. It provides background, context and an overview of the policy landscape.*



Paper 23/25

This information is provided to Members of the Legislative Assembly (MLAs) in support of their duties, and is not intended to address the specific circumstances of any particular individual. It should not be relied upon as professional legal advice, or as a substitute for it.

# Contents

List of Abbreviations .....	3
Key Facts.....	4
Introduction .....	5
1. Background .....	7
1.1 Changing Patterns of Illness and Mortality in Adults .....	7
1.2 Changing Patterns of Life-Limiting Illness in Children .....	9
1.3 Impact of Assisted Dying Legislation.....	12
2. Understanding Palliative and End of Life Care .....	14
2.1 Defining Palliative and End of Life Care.....	14
2.2 Providers and Locations of Palliative and End of Life Care.....	14
2.3 Principles of Palliative and End of Life Care .....	16
2.4 Key Components of Palliative and End of Life Care .....	17
2.5 The Importance of Equitable and Accessible Palliative and End of Life Care .	19
2.6 Impact of COVID-19 on End-of-Life Services.....	20
2.7 Challenges in Provision of Palliative and End of Life Care.....	20
2.8 Challenges in Provision of Children's Palliative and End of Life Care.....	21
3. Policy Context in Northern Ireland .....	22
3.1 Adult Palliative Care Strategy .....	22
3.2 Children's Palliative Care Strategy.....	27
3.3 NICE Guidance and Quality Standards.....	28
3.4 Policy Context in Neighbouring Jurisdictions .....	29
3.4.1 England .....	29
3.4.2 Scotland.....	30
3.4.3 Wales.....	30
3.4.4 Republic of Ireland.....	31
References .....	32

## List of Abbreviations

ACP	Advanced Care Planning
BAS	Business as Usual
COPD	Chronic Obstructive Pulmonary Disease
GPC	Generalist Palliative Care
ICB	Integrated Care Boards
LLC	Life Limiting Condition
LMDM	Living Matters Dying Matters
NG	NICE Guidance
NICE	National Institute for Health and Care Excellence
PCLB	Palliative Care Locality Boards
PCiP	Palliative Care in Partnership
PEOLC	Palliative and End of Life Care
PfG	Programme for Government
PHA	Public Health Authority
PPCN	Paediatric Palliative Care Network
QI	Quality Improvement
QS	Quality Standard
RQIA	Regulation and Quality Improvement Authority
SPC	Specialist Palliative Care
SPPG	Strategic Planning and Performance Group
TYPEOLC	Transforming Your Palliative and End of Life Care
WHO	World Health Organization
UK	United Kingdom

## Key Facts

**50%**

The projected increase in the population aged 65+ in Northern Ireland (2022- 2047)

**90%**

Proportion of people who die that could benefit from palliative care (Marie Curie; UK-wide estimate)

**£18,020**

The cost (per person) spent on healthcare in the last year of life (UK-wide estimate)

**17,000**

Days and nights of palliative care provided by hospices in Northern Ireland

**16%**

The proportion of hospice services delivered in an inpatient setting

**112%**

The projected increase in people aged 85+ in Northern Ireland (2022 to 2048) (highest of UK Nations)

**47%**

The proportion of people who die in hospital in Northern Ireland

**11,000**

Number of visits made by generalist healthcare staff to hospice patients at home

**2,300**

Number of hospice provided appointments to patients' families, friends and carers (including counselling and bereavement support)

# Introduction

Palliative and end-of-life care (PEOLC) play a critical role in supporting individuals with life-limiting conditions, ensuring dignity, comfort, and quality of life in their final stages. Northern Ireland faces significant challenges in delivering these services due to evolving health trends, demographic shifts, and increasing demand for services. The Committee for Health is undertaking an inquiry into accessing palliative care services in Northern Ireland. This is the first in a series of papers on palliative care. This briefing outlines the current landscape, key principles, and policy context, both locally and in neighbouring jurisdictions.

The patterns of illness and mortality among adults are shifting and chronic conditions and ageing populations are increasing demand for palliative care. Advances in healthcare have extended life expectancy, yet this has also resulted in a greater prevalence of complex, long-term conditions requiring sustained support. Additionally, end-of-life trends highlight the need for integrated services that prioritise patient-centred care. For children, life-limiting illnesses present distinct challenges, requiring specialised paediatric palliative care models tailored to their needs.

The current evidence highlights the necessity of providing appropriate care to all individuals, irrespective of age, location, diagnosis, or socioeconomic status. An estimated 90% of those who could benefit from palliative care do not receive it. This unmet need results in lower quality of life for patients, increased avoidable hospital and emergency department admissions, and greater use of life-extending measures.

Access to PEOLC not only offers holistic support for patients and their families but also enables individuals to die in their preferred place. Additionally, it has the potential to alleviate pressure on the acute hospital sector. The COVID-19 pandemic further exposed vulnerabilities in end-of-life care provision, highlighting the need for resilient and adaptable health and social care services.

Policy frameworks in Northern Ireland provide a foundation for adult and children's palliative care strategies, aligning with NICE guidance and quality standards to promote best practice. However, there remain significant challenges, including resource constraints, workforce pressures, and inconsistencies in service delivery. The experiences of neighbouring jurisdictions offer valuable insights, with England, Scotland, Wales, and the Republic of Ireland implementing distinct approaches providing an evidence base that may complement policy developments in Northern Ireland.

To ensure high-quality PEOLC, a strategic and coordinated approach is essential. This includes accurately estimating future service demand, providing sustainable funding mechanisms based on patient need and service delivery costs, and strengthening workforce palliative care skills. Additionally, closer integration of palliative care across health and social care settings is crucial, complemented by strong public health messaging around death and dying.

These issues will be explored in more detail in papers 2-5 of this series. The overarching objective is to improve the experiences of individuals and families facing life-limiting conditions, fostering a compassionate and effective palliative care system for the future.

***Research briefing papers in this series:***

Paper 1: Introduction to palliative and end of life care

Paper 2: Palliative and end of life care provision in Northern Ireland

Paper 3: The economics of palliative and end of life care and sustainable funding mechanisms

Paper 4: Equity, access, coordination and integration of palliative and end of life care

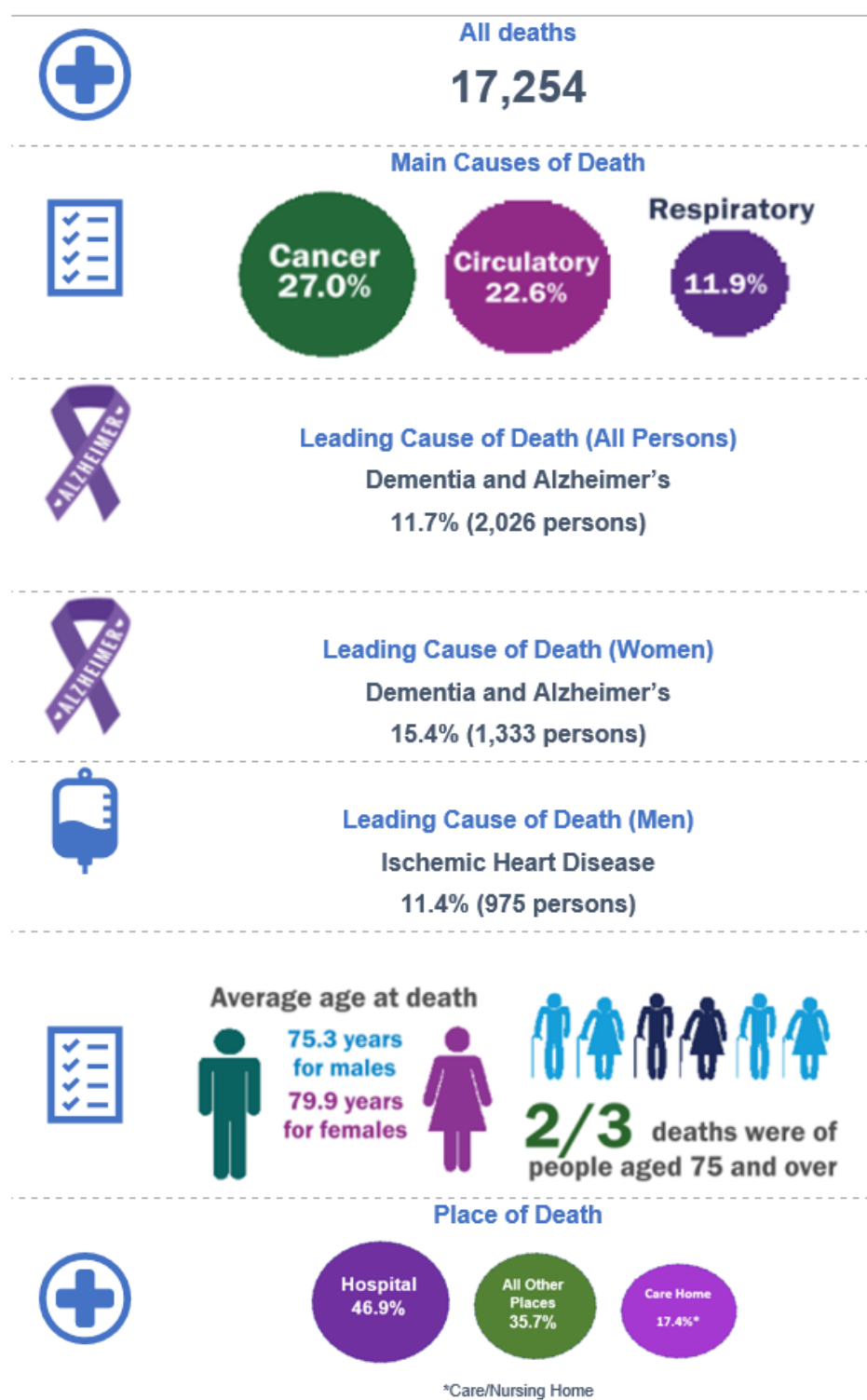
Paper 5: Future planning and need for palliative and end of life care services

# 1. Background

## 1.1 Changing Patterns of Illness and Mortality in Adults

The causes and nature of illness are changing; we are living longer and survival from diseases is prolonged. **In Northern Ireland there were 17,254 deaths in 2023**, with two thirds of deaths in people over the age of 75 years. The average age at death was 75.3 years for males and 79.9 years for females. Of these deaths, 27 per cent were attributable to cancer, and 23 per cent and 12 per cent to circulatory and respiratory diseases respectively (Figure 1).<sup>1</sup> The most frequent cause of death (for all persons) was dementia (12 per cent; 2,026 people) with the majority of deaths occurring in hospitals (47 per cent), followed by home (38 per cent), nursing homes (eight per cent), and hospices (four per cent).

Although life expectancy growth has slowed considerably in Northern Ireland, **the overall population is to rise to 1.93 million by mid-2047**. Over this period, the population of those aged 65 years+ will increase by 49.6 per cent (between mid-2022 and mid-2047), whilst those aged 85 years+ is estimated to increase by 122.2% over the same period.<sup>2</sup> This increase in the number of elderly people (Figure 3) will lead to an increase in the number of people living with chronic disease and multiple conditions. **This will result in an increase in demand for palliative and end of life services.**

Figure 1: Causes of Death and Mortality in Northern Ireland, 2023<sup>3</sup>



Increasing multimorbidity and degenerative conditions mean that end of life can be characterised by a prolonged period of decline rather than a sudden illness. Chronic diseases (such as asthma, diabetes, coronary heart disease, hypertension, stroke, cancer COPD and dementia) are a major cause of morbidity and mortality in Northern Ireland. The prevalence of most chronic conditions increases with age and is accelerated by deprivation,<sup>4</sup> which will mean an increase in the percentage of the population with one or more of these conditions. In addition, **10-year cancer survival is improving and obesity related morbidity is rising.**

Health policy makers have a strong interest in developing a better understanding of how they can improve end of life care. **Studies have found that in the months leading to death, the need and the costs of care increase substantially, with the bulk of these expenditures coming from high-cost individuals, such as those with persistent chronic conditions.**<sup>5</sup> In addition, there are serious concerns that the quality of care at the end of life falls short of expectations. As more people reach old age with chronic conditions, improving the quality and efficiency of care at the end of life will continue to grow as a priority policy area.<sup>6</sup>

According to the Nuffield Trust, other factors are key in determining demand for services such as geographical disparities in access to care, patient and family preferences, awareness of available services, healthcare professional training and timely identification of patients requiring palliative care.<sup>7</sup>

## 1.2 Changing Patterns of Life-Limiting Illness in Children

In addition to changing patterns in demography and mortality for our older population, gains in longevity are also being secured for children with life limiting conditions (LLCs). The *Make Every Child Count* study, estimated that the number of children had risen from 32,973 in 2001/02 to 86,625 in 2017/18 in England. At that time, the number of children with LLCs in Northern Ireland was estimated at 2,497. They conservatively estimated there would be between 52.5 and 56.4 children living with LLCs per 10,000 in Northern Ireland by 2030.<sup>8</sup>

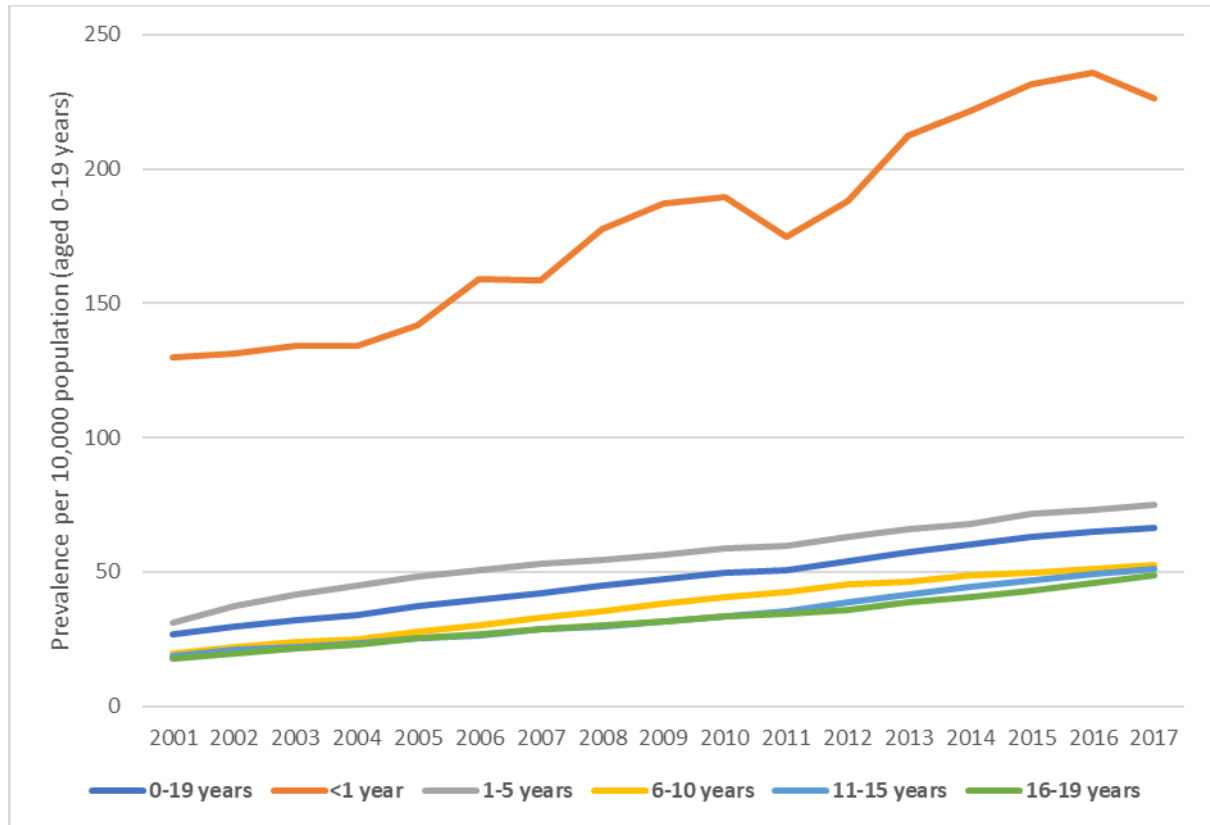
The prevalence of children and young adults with life-limiting conditions is increasing, leading to a significant rise in the number of hospital admissions for individuals aged 0-19 years (Figures 2 and 3). This trend can be attributed to improved early diagnosis and advancements in treatment, resulting in increased survival rates and longer life expectancy for these children. However, this extended lifespan necessitates a longer timeframe for caregiving, and requires more advanced medical technology to support ongoing health needs.

Compared to adult PEOLC services, treating children with life-limiting illnesses involves navigating more uncertain disease trajectories, managing issues related to parental consent and mental health capacity, and planning the transition to adult services.<sup>9</sup> The intensity and specificity of paediatric palliative and end-of-life care services often demand a more specialised workforce, which has cost implications.

Despite the similarity in the unmet needs between children and adult palliative care, the differences in service specifications and cost implications highlight the need for tailored approaches to effectively address the unique challenges in paediatric care. The total number of hospital admissions increased, driven largely the number of day cases.

**Across all age groups there was an increase in the prevalence of life limiting conditions over time**

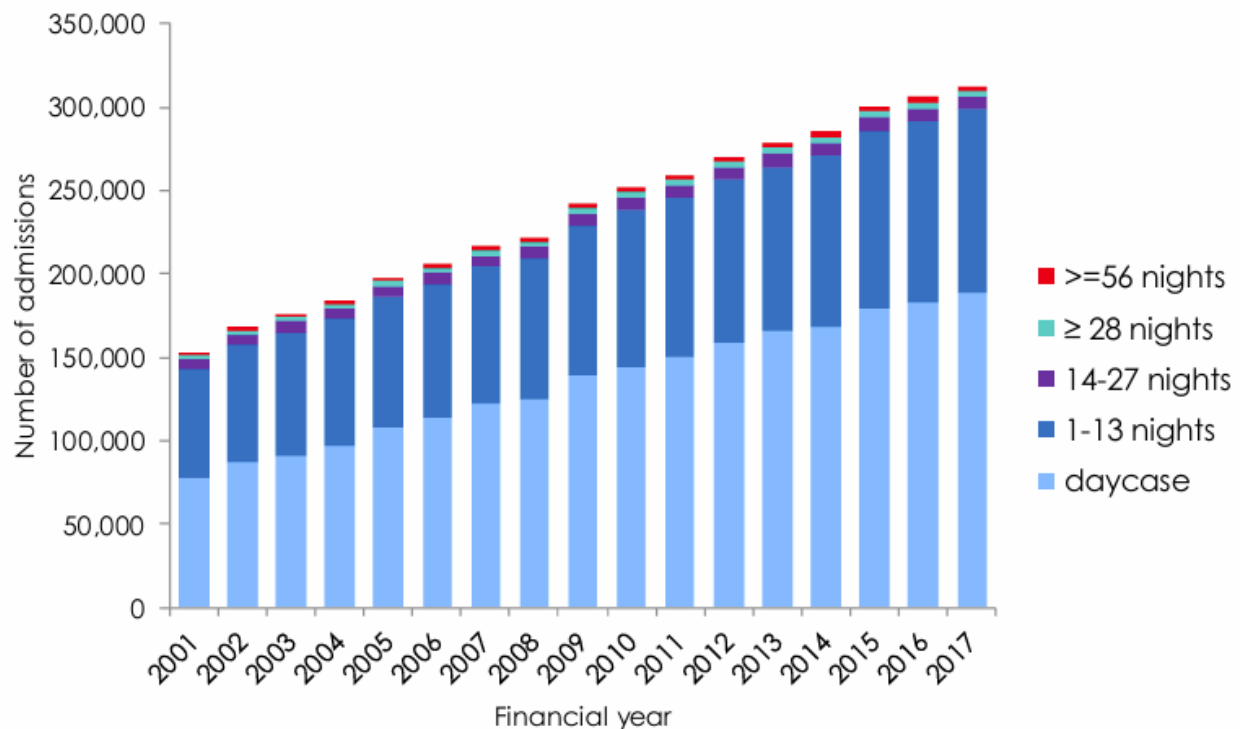
Figure 2: Prevalence of life limiting conditions in children by age group, UK, 2001-2017



Source: Fraser et al., 2020<sup>10</sup>

## Hospital admissions in children with life limiting conditions is rising

Figure 3: Number of hospital admissions for children (aged 0-19) with life limiting conditions, UK, 2001-2017



Source: Fraser et al., 2020<sup>11</sup>

## 1.3 Impact of Assisted Dying Legislation

The assisted dying legislation currently progressing through Parliament has reignited discussions around PEOLC provision.<sup>12</sup>

**“I worry about palliative care, end-of-life care, not being good enough to give people a real choice”**  
 —Wes Streeting (Secretary of State for Health and Social Care)<sup>13</sup>

The current Health Secretary, Wes Streeting, who voted against the Bill, highlighted the inadequacies in current palliative care services in his response to proposed

legislation. His sentiment underscores the broader debate on whether the current healthcare system can adequately support individuals nearing the end of their lives.

**In response to these concerns, the government has allocated an additional £100 million to enhance palliative care services in England.** Hospice UK has welcomed this funding, acknowledging it as a step towards ensuring that individuals receive the compassionate care they deserve.<sup>14</sup> However, the organisation continues to advocate for a more comprehensive approach, emphasising the need for systemic changes to address the root causes of the current shortcomings in palliative care.

## 2. Understanding Palliative and End of Life Care

### 2.1 Defining Palliative and End of Life Care

The World Health Organization (WHO) considers PEOLC a public health issue, focusing on reducing suffering, preserving dignity, and improving quality of life. Leading healthcare bodies recognise it as a basic human right.<sup>15</sup> It focuses on improving quality of life for individuals with life-limiting illnesses by managing symptoms, addressing psychosocial needs, and supporting families. End of life care is a component of palliative care provided when curative treatment is no longer an option.<sup>16</sup>

While commonly associated with cancer, palliative care now extends to conditions such as cardiovascular disease, respiratory disorders, neurological conditions, and dementia. Services are tailored to the patient's needs and delivered in various settings, including hospitals, hospices, care homes, and private residences.

### 2.2 Providers and Locations of Palliative and End of Life Care

PEOLC is multidisciplinary, involving generalist and specialist providers. Generalist care is delivered by GPs, hospital doctors, nurses, care home staff, and social workers. Specialist palliative care (SPC) is the management of unresolved symptoms and more demanding care needs including complex psychosocial, end of life and bereavement issues. SPC teams include palliative medicine consultants, clinical nurse specialists, and allied health professionals. Originally, this type of care was developed to provide support to people with cancer nearing the end of life. There is emphasis in policy on community-based SPC teams supporting people with more complex palliative care needs, with generalists providing wider care.<sup>17</sup>



## Generalist and Specialist PEOLC

**Generalist care:** Most palliative care is provided by health care professionals for whom care of the dying is not the major focus of their work. For example, General Practitioners (GPs), community nurses, hospital consultants, nurses and care home staff. It focuses on day-to-day care and support.

**Specialist Palliative Care (SPC):** This refers to services provided by multidisciplinary teams that include consultants in palliative medicine, clinical nurse specialists in palliative care and specialist allied health professionals. SPC teams provide care in hospital, hospice and community settings and have a role in co-ordinating services, supporting generalist providers and providing

Hospices play a key role in PEOLC, providing inpatient, outpatient, and community-based support,<sup>18, 19</sup> although it can also be provided in other settings such as prisons.<sup>20</sup> They offer medical care alongside psychological, social, and spiritual support for both patients and families.

In Northern Ireland in 2022-23:<sup>21</sup>

- **16%** of hospices' total service activity in Northern Ireland was delivered in an inpatient unit
- **74%** of hospices' total activity was delivered at the person's place of residence.
- **52,000** visits were made by specialist palliative care nurses and doctors to hospice patients at home.
- **11,000** visits were made by generalist healthcare staff to hospice patients at home (including nurses, healthcare assistants, social workers and carers).
- **12,000** outpatient appointments were made by hospices for physiotherapy, counselling and other support services.
- **17,000** days and nights of inpatient care were provided by hospices.
- **2,300** appointments were provided to patients' families, friends and carers, including counselling and bereavement support.

It is not uncommon that an individual will receive care from two or even three care settings during their end of life/palliative phase. PEOLC can also be provided alongside other forms of specialist care, such as geriatric care.<sup>22</sup>

## 2.3 Principles of Palliative and End of Life Care

Palliative care affirms life while recognising dying as a normal process. It prioritises pain and symptom management, psychological and spiritual well-being, and coordinated, person-centred care. **Advance Care Planning (ACP) is integral**, allowing individuals to express treatment preferences, ensuring care aligns with their values and reducing unnecessary interventions.<sup>23</sup>

**A defining feature of PEOLC is its multidisciplinary nature.** Care is delivered by teams that include doctors, nurses, social workers, physiotherapists, occupational therapists, and chaplains, among others. The integration of different disciplines enables a more managed transition between various stages of care, from diagnosis to end-of-life support.<sup>24</sup>

**Common misconceptions include the belief that palliative care signals imminent death or that it involves withdrawing active treatment.** In reality, palliative care is available alongside curative therapies and enhances overall patient well-being.<sup>25</sup>



## 2.4 Key Components of Palliative and End of Life Care

Key components of PEOLC include management of physical symptoms as well as social, psychological and spiritual care and provision for documentation of their values, goals, and preferences for future care in the form of advance care plans (ACPs).



### Management of physical symptoms

Palliative care reduces symptom burden. Common symptoms include pain, fatigue, anorexia, breathlessness, and anxiety.<sup>26</sup> Medical interventions should be tailored to individual needs, supplemented by non-drug therapies such as rehabilitation and physical activity. Obtaining prescription medications out-of-hours and adherence to medication schedules can be challenging.<sup>27</sup>



### Social, Psychological, and Spiritual Care

End-of-life care includes emotional, psychological, and spiritual support.<sup>28</sup> Many patients experience distress, depression, and anxiety, but mental health resources remain limited.<sup>29</sup> A 2021 review found dementia care often prioritised physical over spiritual and cultural aspects of care.<sup>30</sup> The expansion of mental health services has been identified as a key component of PEOLC.

The National Institute for Health and Care Excellence (NICE) has set a quality standard for palliative care for adults that includes social and practical support.<sup>31, 32</sup> NICE recommends that lower levels of need should be met by health professionals providing the person's day-to-day care, and higher levels of need met through intensive services provided by specialists. A range of quality standards exist for infants, children and young adults and for specific diseases.<sup>33</sup>



### Advance Care Planning (ACP)

ACP allows individuals to document their values, goals, and preferences for future care.<sup>34</sup> In 2022, 34 organisations, including the NHS, published six universal ACP principles.<sup>35</sup> ACP aims to minimise unnecessary hospitalisations, avoid futile treatments and enhance

---

comfort. Early ACP discussions have been deemed crucial, particularly for those diagnosed with dementia.<sup>36</sup>

Research suggests ACP can improve end-of-life care quality, reduce stress, anxiety, and depression in relatives, and lower hospitalisation rates and costs. However, other research suggests that ACP has limited impact on improving communication between healthcare professionals, patients and those close to them, or people dying in their place of choice.

A variety of challenges have been reported, including staff uncertainty on responsibility and documentation access, inconsistent recording and terminology, and low public awareness.

---



### What is Advanced Care Planning?

A person aged over 18, who has mental capacity, can make a(n):

**Advance statement.** This is a statement, usually written, of the person's general wishes and views. A copy can be held in the person's medical notes. It is not legally binding, but must be considered by anyone making decisions about the person's care.

**Advance Decision to Refuse Treatment.** This sets out the specific circumstances in which the person would not want certain treatments or would want a particular treatment to be stopped. It must be in writing if it is a decision to refuse life-sustaining treatment. It is legally binding if it is valid, acceptable and known.

**Lasting Power of Attorney for Personal Welfare.** This allows a family member or friend to make personal welfare decisions on the person's behalf and in their best interests, if they ever lose capacity to make those decisions themselves. This can include decisions about life-sustaining treatments.

## 2.5 The Importance of Equitable and Accessible Palliative and End of Life Care

### *Benefits to Individuals and Families*

Patients who receive PEOLC benefit from symptom management, including pain and respiratory distress, through the use of opioid analgesics and other treatments.<sup>37</sup>

Studies suggest that priorities for patients include access to pain relief, coordination of services, 24/7 support for people at home and good communication with, and help for, family and informal carers.<sup>38</sup> Clear communication that someone is going to die soon and provision of an ACP can provide people with the opportunity to express their preferences around treatment and care at the end of life.<sup>39</sup>

This form of care is especially crucial in the terminal phase of illness, where the burden of symptoms is most acute. It enables people to avoid acute hospitalisation and remain safely and adequately cared for in the community,<sup>40</sup> Increasing patient and family satisfaction with care<sup>41</sup> and reducing prolonged grief among bereaved loved ones.<sup>42</sup>

### *Impact on the Healthcare System*

Early integration of palliative care has been shown to reduce unnecessary hospital admissions and the use of intensive interventions, promoting home-based care that many patients prefer. This can result in lower costs by providing care that aligns with peoples' needs and preferences, reducing unnecessary hospitalisations, diagnostic and treatment interventions, and inappropriate intensive and emergency department care.<sup>43</sup>



### Findings from the Nuffield Trust and the Health Economics Unit (commissioned by Marie Curie)

Public expenditure for people in the last year of life across healthcare, social care and social security in the UK is in the region of **£22 billion**.

Over half of this public spending in the final year of life is on healthcare (£11.7 billion) – or **£18,020 per person who died**.

Hospital care represents the largest share of healthcare spending (**£9.6 billion**) with half going on emergency hospital care (**£6.6 billion**).

In contrast, spending on primary and community healthcare made up only 11% (**£1.3 billion**) of health expenditure for those in their last year of life, with less than 4% (**£414 million**) spent on hospice care.<sup>44</sup>

## 2.6 Impact of COVID-19 on End-of-Life Services

End of life services were disrupted during the COVID-19 pandemic, with a significant shift in the proportion of people dying at home. This shift accelerated a pre-existing trend, and is in line with existing policies that have identified scope to enable more people to die in their place of choice by improving access to care outside of hospital.<sup>45</sup> Care at home can be of high quality,<sup>46</sup> particularly when home services are available at all times, symptoms are well controlled, and communication is timely and skilful.<sup>47</sup> Furthermore, rapid innovations in anticipatory prescribing by general practitioners observed during the pandemic may have aided symptom management for patients at home.<sup>48</sup>

## 2.7 Challenges in Provision of Palliative and End of Life Care

PEOLC operates across multiple providers and funding streams, creating significant coordination challenges. Despite progress, service coordination, funding, and equitable access remain problematic. The fragmented commissioning and accountability landscape, with responsibilities split between healthcare providers, local authorities, and voluntary organisations, leads to gaps in service provision and

difficulties in assessing quality outcomes. Data sharing limitations between statutory and voluntary sectors further hamper continuity of care. The mixed funding model, reliant on NHS, local government, and charitable contributions, causes disparities in access and service availability. Additionally, workforce shortages, particularly in specialist staff and rural areas, impact the delivery of care. These topics will be explored in more detail in research briefing papers 2-5 of this series.

## **2.8 Challenges in Provision of Children's Palliative and End of Life Care**

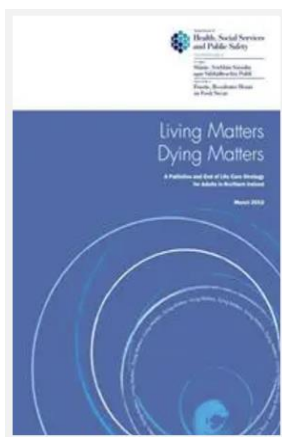
In addition to the aforementioned challenges, providing palliative and end-of-life care to infants, children, and young adults presents additional unique challenges, including navigating uncertain disease trajectories and managing complex, multi-system health needs. Palliative care may be introduced at any point throughout the child's life, with some requiring palliative care from birth, with others only requiring it as their condition deteriorates. Families may also vary as to whether they wish to pursue treatments aimed to cure or significantly prolong life. In practice, palliative care should be offered from diagnosis of a life-shortening condition or from recognition that curative treatment for a life-threatening condition is not an option.<sup>49</sup>

Children often require prolonged care, necessitating coordination across multiple providers and funding streams. Additionally, issues related to parental consent, mental health capacity, and the transition to adult services further complicate care delivery. There is a growing need for age-appropriate psychological and bereavement support for families to ensure they receive necessary emotional and mental health assistance.<sup>50</sup> Moreover, educational and social care systems must be integrated into the holistic support of the child and family to manage care needs effectively.

### 3. Policy Context in Northern Ireland

The responsibility for delivering and overseeing PEOLC services in Northern Ireland is shared across multiple stakeholders. The Department of Health, Health and Social Care Trusts, and partners from the voluntary and community sectors.<sup>51</sup>

#### 3.1 Adult Palliative Care Strategy



Good PEOLC is an important part of Health and Social Care. The most recent strategy **Living Matters Dying Matters (LMDM, 2010)**<sup>52</sup> defined PEOLC as "the active, holistic care of patients with advanced progressive illness". LMDM identified 25 recommendations to improve PEOLC through developing, commissioning and delivering a model for quality PEOLC. The strategy sought to improve public awareness of palliative care, enhance workforce capacity, and ensure equitable access to services, while promoting choice and dignity for individuals at the end of life.



**Transforming Your Care (2011)** further supported the work of LMDM and identified 7 key principles to inform future palliative care service design and implementation. From 2013 -2016 the **Transforming Your Palliative and End of Life Care (TYPEOLC) programme**, a partnership between Marie Curie, Strategic Planning and Performance Group (SPPG), Department of Health and the Public Health Agency (PHA) worked towards the enhancement of PEOLC through engagement with key stakeholders

including Health and Social Care, and independent providers and voluntary and community sector representatives.



Phase 1 and 2 of the TYPEOLC programme advanced the evidence base and set the direction for improving palliative care coordination and delivery in Northern Ireland. However, challenges remain in addressing service gaps, particularly out-of-hours care, ensuring consistency in service quality and access, and raising public awareness.



The 2016 **Regulation and Quality Improvement Authority (RQIA) Review** assessed the effectiveness of the strategy's implementation.

The review acknowledged that progress had been made in several key areas, including the integration of palliative care across care settings and improved collaboration between healthcare professionals.

However, it identified critical gaps, particularly in the consistent delivery of services and equitable access to care across Northern Ireland. The RQIA made several recommendations, including the need for enhanced data collection, greater workforce training, and improved public engagement to address ongoing stigma and misconceptions about palliative care



In September 2016, the previous LMDM and TYPEOLC structures were brought together to form the **Palliative Care in Partnership (PCIP) programme**. The PCIP programme management support has been sponsored by Macmillan from June 2018. The PCIP Programme mandate is to take forward the work initiated by the LMDM implementation board (from 2010 to 2016) and the TYPEOLC Regional Steering Group (from 2013 to 2016), and regional priorities and work plan for 2019 and beyond.

Progress has been made in areas such as the development of multidisciplinary teams, the introduction of advance care planning, and improved communication between service providers. However, challenges remain, particularly in ensuring uniform service provision across rural and urban areas and addressing the increasing demand for palliative care services due to population change. Despite these efforts, some of the RQIA's recommendations remain outstanding.

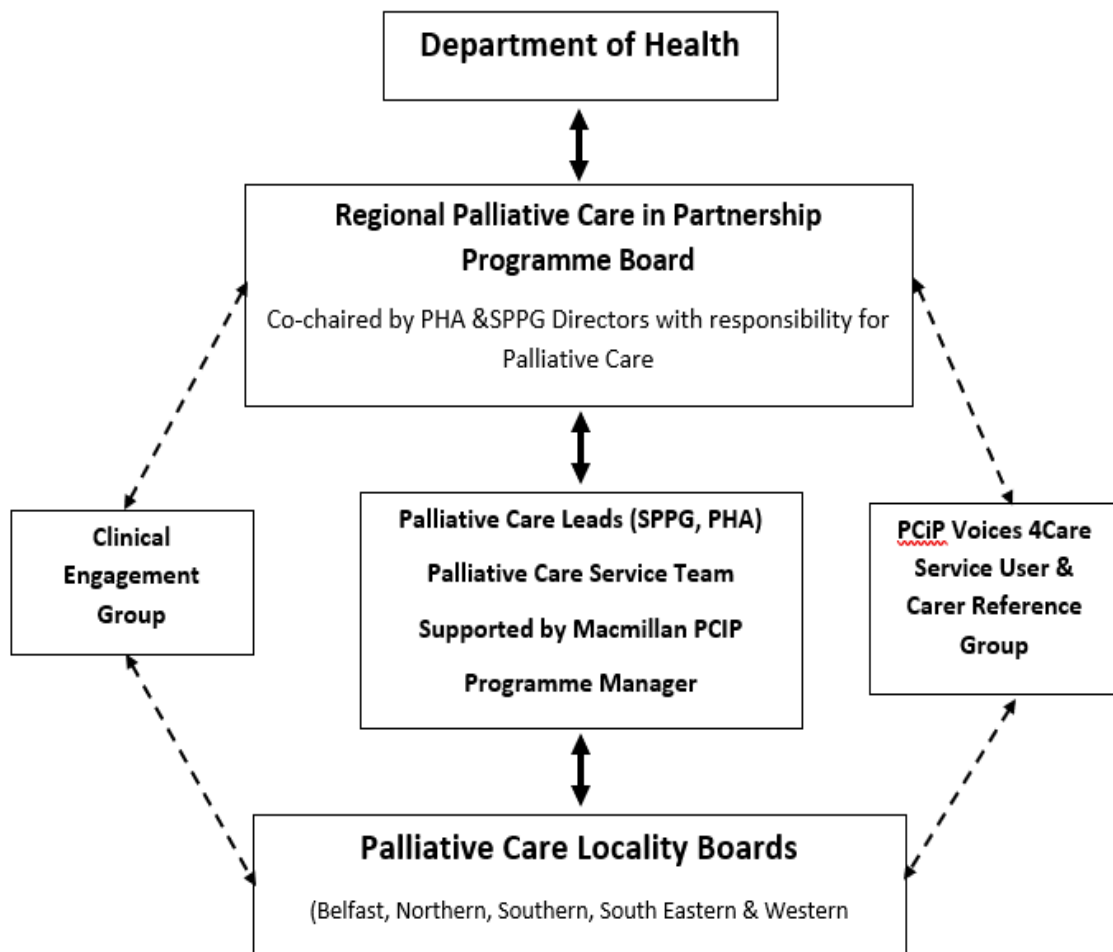
As of October 2024, the PCIP Board comprises: 35 members, supported by seven in the clinical engagement group, 12 professional representatives, and 13 co-opted members. Additionally, 21 Palliative Care Locality Board positions are yet to be filled. Figure 4 outlines the regional palliative care structures in Northern Ireland and the PciP programme mandate is presented below. It should be noted that before the collapse of the institutions in 2022, it was agreed that Death, Dying, and Bereavement should be included in the Programme for Government (PfG).



The aim of the PCiP programme is to provide regional direction so that everyone identified as likely to benefit from a palliative care approach (regardless of condition) is:

- Allocated a **palliative key worker**
- Has the opportunity to discuss and record their **Advanced Care Plan** decisions; and
- Is supported with appropriate **generalist and specialist palliative care services**

Figure 4: Regional Palliative Care Structures in Northern Ireland <sup>53</sup>





## PCiP Programme Mandate (October 2024)

**Priority 1: Early Identification and Timely Intervention:** To improve early identification of people who could benefit from a Palliative Care approach (regardless of condition) ensuring their information is captured, recorded and shared to co-ordinate supportive care for that person.

**Priority 2: Co-ordination and Quality Improvement:** Programme focus on Quality Improvement (QI) and supporting localities/providers to co-ordinate services. Including PC Keyworker QI Project.

**Priority 3: Palliative Care Education and Training:** Including communication skills. To ensure everyone is identified as being in their possible last year of life has an allocated keyworker who is appropriately trained and that operational processes and communication is in place 24/7 across settings.

**Priority 4: Public Health Approach to Palliative Care:** Upgraded to be a key PCIP programme priority. Activity will include promoting Advanced Care Planning Policy for adults.

The Regional Palliative Care Work Plan 2023-26, reported that of the 51 identified workstreams within the four aforementioned priority areas, 11 were 'complete', 34 were 'in progress' and 6 were 'not yet started'. Ten of the workstreams are classified as 'Business as usual' (BAS) and not expected to complete during the lifetime of the regional work plan.

## 3.2 Children's Palliative Care Strategy

The strategic direction for children's PEOLC services in Northern Ireland is set out in **A Strategy for Children's Palliative and End-of-Life Care 2016-2026**<sup>54</sup> and contains 23 objectives. These include:

- Families receiving planned and emergency short breaks
- Access to 24/7 multidisciplinary community services and direct access to a 24/7 crisis and specialist palliative care and end of life services, including access to medicines for symptom relief
- A regional protocol to facilitate discharge and transfer for chosen place of death
- Provision of bereavement services
- Development of a minimum dataset to support children's palliative care service

A progress report (June 2021)<sup>55</sup> noted that substantive work to progress the various objectives within the strategy did not commence until 2019, at which point a **Paediatric Palliative Care Network (PPCN)** was formally convened, and that the COVID-19 pandemic had impacted on many areas of work. The network includes clinical and nursing leads from all Health and Social Care Trusts and the Northern Ireland Children's Hospice.

The Network's current priorities are:<sup>56</sup>

- Improving and updating antenatal care pathways
- Enhancing advanced care plans to better meet the needs of children and families
- Strengthening 24/7 end-of-life care services
- Expanding collaboration with counterparts in the Republic of Ireland

This is complemented by **A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community (2016-2026)**<sup>57</sup> which focuses on acute hospital

services, the transition between child and adult services and the interface between hospital and community services. This document contains 7 key principles, 12 themes and 23 objectives, which aim to:

- Deliver seamless transitions between paediatric and adult care
- Strengthen coordination between hospital and community-based services
- Improve access to acute and specialised care for children

A September 2021 progress report <sup>58</sup> noted that formal implementation of this strategy also began in 2019, alongside efforts to support the palliative care strategy.

### 3.3 NICE Guidance and Quality Standards

The National Institute for Health and Care Excellence (NICE) provides comprehensive guidelines and quality standards for PEOLC in the UK. Key NICE guidance and quality standards are listed below. This list is not exhaustive as there are a wide range of condition specific guidance and quality standards in this area:

1. **End of Life Care for Adults: Service Delivery (NG142):** This guideline covers organising and delivering end of life care services for adults approaching the end of life <sup>59</sup>
2. **Care of Dying Adults in the Last Days of Life (NG31):** This guideline provides recommendations on the clinical care of adults who are dying <sup>60</sup>
3. **End of Life Care for Adults (QS13):** This quality standard outlines the priority areas for quality improvement in end-of-life care for adults (aged 18 and over) who are approaching the end of their life <sup>61</sup>
4. **End of Life Care for Infants, Children and Young People: Planning and Management (NG61):** This guideline outlines the care and support that children with life-limiting conditions and their families should expect from the point their needs are recognised until the end of their lives <sup>62</sup>
5. **End of Life Care for infants, children and young people (QS160):** This quality standard covers end of life care for infants, children and young people

(from birth to 18 years). It describes high quality care in priority areas for improvement<sup>63</sup>

NICE guidelines emphasise patient-centred care, the involvement of multidisciplinary teams, and the importance of providing care in the preferred setting of the patient. The implementation of these guidelines is supported by various tools and resources, ensuring that care providers can deliver high-quality, equitable care to those in need.

In Northern Ireland, the implementation of NICE guidance is supported by a structured process that involves endorsement, monitoring, and assurance by the Department of Health. This process ensures that NICE guidelines are adapted to the local context and are effectively integrated into the healthcare system.<sup>64</sup> The Department of Health has established a governance framework to oversee the implementation of NICE guidance, which includes regular reviews and updates to ensure alignment with current best practices.<sup>65</sup>

### 3.4 Policy Context in Neighbouring Jurisdictions

The policy landscape of PEOLC across the UK and the Republic of Ireland is characterised by a shared commitment to person-centred care, yet each jurisdiction has developed its own unique approach to addressing the complex needs of individuals facing life-limiting illnesses. All strategies recognise the importance of tailoring care to the individual needs and preferences of patients and their families.

#### 3.4.1 England

England's approach to palliative care has been significantly shaped by the **Health and Care Act of 2022**, which mandates that Integrated Care Boards (ICBs) commission palliative and end-of-life care (PEOLC) services.<sup>66</sup> This legislative change ensures that palliative care is embedded within the broader health and care system. The NHS England PEOLC team has produced statutory guidance for ICBs based on the National Palliative and End of Life Care Partnership's **Ambitions for Palliative and End of Life Care for Local Action 2021-2026**.<sup>67</sup> This guidance is further supported by a suite of technical documents on commissioning and funding

approaches, aimed at standardising and enhancing the quality of palliative care services nationwide.<sup>68, 69</sup>

Despite these efforts, England faces challenges in achieving consistent service provision across regions. Disparities in per capita spending on PEOLC services highlight the ongoing struggle to ensure equitable access to care. For instance, in 2023/24, the spending on children's hospices varied dramatically from £28 per child in South Yorkshire to £511 in Norfolk and Waveney,<sup>70</sup> with similar differences observed for adult services. However, pockets of excellence, such as the integrated models of care in the North East, demonstrate the potential for improved outcomes when statutory and voluntary sectors collaborate effectively.

### *3.4.2 Scotland*

Scotland's approach to PEOLC is characterised by its emphasis on early identification of care needs and the integration of services across sectors to ensure better outcomes for adults and children, as well as their families and carers. Scotland is currently in the process of refining its strategy with the **'Palliative Care Strategy: Palliative Care Matters for All' (2025-2030)**,<sup>71</sup> which builds upon the foundations laid by previous frameworks.<sup>72, 73</sup> Key objectives included improving early identification of care needs, integrating services across sectors, and enhancing workforce development. Scotland has also made notable progress in embedding palliative care within primary care settings and promoting the use of anticipatory care planning.

### *3.4.3 Wales*

Wales has adopted a nationally coordinated strategy through its **'Palliative and End of Life Care Delivery Plan (2017-2020)'**<sup>74</sup> and subsequent updates for children, young people and adults.<sup>75</sup> A distinctive feature of the Welsh approach is its commitment to co-designing services with patients and families, ensuring that the voices of those most affected by palliative care policies are heard and incorporated into service development. The establishment of regional palliative care networks has improved consistency in service delivery across health boards and local authorities,

although funding constraints and workforce pressures continue to pose significant challenges.

#### *3.4.4 Republic of Ireland*

The Republic of Ireland has recently launched its **National Adult Palliative Care Policy**,<sup>76</sup> which outlines four strategic objectives focused on delivering the right care, in the right place and time, by the right people, while ensuring good governance. This policy is notable for its emphasis on expanding specialist services and addressing the needs of non-cancer patients. The proposed use of comprehensive metrics to track progress, including hospital death rates and carers' views on the quality of end-of-life care, demonstrates a commitment to evidence-based policy implementation and continuous improvement.

# References

---

- <sup>1</sup> Northern Ireland Statistics Research Agency (NISRA) - Registrar General Northern Ireland Annual Report 2023
- <sup>2</sup> Statistical Bulletin - 2022-based Population Projections for Northern Ireland
- <sup>3</sup> Northern Ireland Statistics Research Agency (NISRA) - Registrar General Northern Ireland Annual Report 2023
- <sup>4</sup> Barnett et al., 2012 Epidemiology of multimorbidity and implications for healthcare, research and medical education: a cross sectional study
- <sup>5</sup> Blankart et al., 2021 International comparison of spending and utilization at the end of life for hip fracture patients
- <sup>6</sup> Virdun et al., 2018 National quality indicators and policies from 15 countries in adults end of life care: a systematic environmental scan
- <sup>7</sup> Nuffield Trust (2022) Evidence review for commissioners on the cost of providing specialist level palliative care in the community
- <sup>8</sup> <https://www.togetherforshortlives.org.uk/resource/make-every-child-count/>
- <sup>9</sup> Fraser et al., 2020 'Make Every Child Count Estimating current and future prevalence of children and young people with life limiting conditions in the United Kingdom
- <sup>10</sup> Fraser (2020) 'Make Every Child Count' Estimating current and future prevalence of children and young people with life limiting conditions in the UK
- <sup>11</sup> Fraser (2020) 'Make Every Child Count' Estimating current and future prevalence of children and young people with life limiting conditions in the UK
- <sup>12</sup> We ran England's first citizens' jury on assisted dying – here's what we learnt
- <sup>13</sup> Streeting says he changed mind on assisted dying over UK's poor palliative care
- <sup>14</sup> Streeting says he changed mind on assisted dying over UK's poor palliative care
- <sup>15</sup> World Health Organisation (WHO) - Palliative Care
- <sup>16</sup> What end of life care involves - NHS
- <sup>17</sup> The Regional and Quality Improvement Authority (2016) Review of the implementation of the palliative and end of life care strategy (March 2010)
- <sup>18</sup> Support at the end of life: The role of hospice services across the UK | Nuffield Trust
- <sup>19</sup> Innovation Hub | Hospice UK
- <sup>20</sup> Innovation Hub | Hospice UK
- <sup>21</sup> Statistics about hospice care in each UK nation | Hospice UK
- <sup>22</sup> Visser et al., 2021 - The Overlap Between Geriatric Medicine and Palliative Care: A Scoping Literature Review
- <sup>23</sup> Agarwal & Epstein 2018 Advance care planning and end of life decision making for patients with cancer
- <sup>24</sup> Borgstrom et al., 2021 Multidisciplinary team meetings in palliative care: an ethnographic study
- <sup>25</sup> National Institute of Health - Palliative Care Truths and Myths
- <sup>26</sup> Moens et al., 2014 Are There Differences in the Prevalence of Palliative Care-Related Problems in People Living With Advanced Cancer and Eight Non-Cancer Conditions? A Systematic Review
- <sup>27</sup> Mein et al., 2016 - Strength in numbers: patient experiences of group exercise within hospice palliative care
- <sup>28</sup> Mistry et al., 2015 - What matters most for end-of-life care? Perspectives from community-based palliative care providers and administrators
- <sup>29</sup> O'Mally et al., 2019 Mental healthcare and palliative care: barriers
- <sup>30</sup> Yorganci et al., 2021 - Quality indicators for dementia and older people nearing the end of life: A systematic review
- <sup>31</sup> NICE 2021 End of life care for adults - Quality standard [QS13]
- <sup>32</sup> NICE 2017 Care of dying adults in the last days of life- Quality standard [QS144]
- <sup>33</sup> NICE Quality Standards



- 
- <sup>34</sup> Sudore et al., 2017 - Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel
- <sup>35</sup> NHS England » Universal Principles for Advance Care Planning (ACP)
- <sup>36</sup> Care Quality Commission 2022 - 'A different ending': Our review looking at end of life care published
- <sup>37</sup> NICE Palliative care for adults: strong opioids for pain relief Clinical Guidance [CG 140]
- <sup>38</sup> NHS National Institute for Health research (NIHR) 2015 Better Endings: Right care, right place, right time
- <sup>39</sup> NHS England - Universal principals for advance care planning (ACP)
- <sup>40</sup> Gnomes et al., (2013) Effectiveness and cost-effectiveness of home palliative care
- <sup>41</sup> Aoun et al., 2018 - The Impact of supporting family caregivers before bereavement on outcomes after bereavement: Adequacy of end of life support and achievement of preferred place of death
- <sup>42</sup> Aoun et al., 2018 - The Impact of supporting family caregivers before bereavement on outcomes after bereavement: Adequacy of end of life support and achievement of preferred place of death
- <sup>43</sup> Smith et al., 2014 Evidence on the cost and cost-effectiveness of palliative care: a literature review
- <sup>44</sup> Nuffield Trust (2025) Over 80% of healthcare cost in the final year of life spent on hospitals
- <sup>45</sup> Higginson et al., 2021 Dying at home during the pandemic
- <sup>46</sup> Gomes et al., 2015 Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study
- <sup>47</sup> Sarmento et al., 2017 Home palliative care works: but how? A meta-ethnography of the experiences of patients and family care givers
- <sup>48</sup> Antunes et al., 2020 Anticipatory prescribing in community end of life care in the UK and Ireland during the COVID-19 pandemic: online survey
- <sup>49</sup> Together for Short Lives - Introduction to Children's Palliative Care
- <sup>50</sup> Together for short lives (2018) - A guide to children's palliative care
- <sup>51</sup> Health and Social Care (2023) Northern Ireland Palliative Care in Partnership Programme Mandate
- <sup>52</sup> DHSSPS (2010) Living Matters, Dying Matters
- <sup>53</sup> Health and Social Care - Northern Ireland Palliative Care in Partnership Programme Mandate
- <sup>54</sup> Department of Health NI - A Strategy for Children's Palliative and End-of-Life Care 2016-2026
- <sup>55</sup> Department of Health NI (2021) - Progress report on a Strategy for Children's Palliative and End-of-Life Care 2016-2026
- <sup>56</sup> Health and Social Care (NI) Regional Paediatric Palliative Care Network
- <sup>57</sup> Department of Health NI (2016) - A Strategy for Paediatric Health care Services Provided in Hospitals and in the Community
- <sup>58</sup> Department of Health NI (2021) - Progress report on A Strategy for Paediatric Healthcare Services Provided in Hospitals and the Community 2016-26
- <sup>59</sup> NICE guideline [NG142] End of life care for adults: service delivery
- <sup>60</sup> NICE guideline [NG31] Care of dying adults in the last days of life
- <sup>61</sup> NICE quality standard [QS13] End of life care for adults
- <sup>62</sup> NICE guideline [NG61] End of life care for infants, children and young people with life-limiting conditions: planning and management
- <sup>63</sup> NICE quality standard [QS160] End of life care for infants, children and young people
- <sup>64</sup> NICE Clinical Guidelines | Department of Health
- <sup>65</sup> NICE Guidelines - DOH/HSCNI Strategic Planning and Performance Group (SPPG)
- <sup>66</sup> NHS 2022 Palliative and End of Life Care - Statutory Guidance for Integrated Care Boards (ICBs)

- 
- <sup>67</sup> [NHS England Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-26](#)
- <sup>68</sup> [HOSPICE UK Palliative and end of life carer policy and guidance](#)
- <sup>69</sup> [HOSPICE UK Palliative and end of life carer policy and guidance](#)
- <sup>70</sup> [Together for short lives - Short lives can't wait: Children's hospice funding in 2024](#)
- <sup>71</sup> [Scottish Government 2024 Palliative Care Strategy: Palliative Care Matters for All](#)
- <sup>72</sup> [NHS Scotland 2008 Living and dying well - a national action plan for palliative and end of life care in Scotland](#)
- <sup>73</sup> [Scottish Government 2015 Palliative and end of life care: strategic framework for action](#)
- <sup>74</sup> [NHS Wales National Palliative and End of Life Care Programme \(2017-2020\)](#)
- <sup>75</sup> [Welsh Government 2022 - Quality statement for palliative and end of life care for Wales](#)
- <sup>76</sup> [HSE Department of Health \(2024\) - National Adult Palliative Care Policy](#)