

# Royal College of Nursing submission to the Commission on Palliative Care

#### About the Royal College of Nursing

With a membership of over half a million registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector. The RCN promotes patient and nursing interests on a wide range of issues by working with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

#### Introduction

This submission sets out the RCN's headline position on the improvements needed to ensure everyone nearing the end of life can access high-quality, person-centred care. It draws on a recent survey of nursing staff, insights from the RCN Pain and Palliative Care Forum Conference in March 2025, and our ongoing professional and policy work.

Palliative care is not an optional extra. It is a fundamental part of what a compassionate, effective health and care system must deliver. Nursing staff are on the frontline of this work — managing pain, providing comfort, and advocating for those at their most vulnerable. This submission aims to reflect the reality of what is happening now, and to help chart a better course for the future. While some of our reflections are specific to England, recognising that health and social care is devolved, the majority of our general recommendations are relevant across all four UK countries. Our member engagement has included nursing staff from across the UK.

#### Background

#### 1. The role of nursing staff in palliative and end-of-life care

Nursing staff are central to the provision of high-quality end-of-life care. They often form the longest and most consistent relationship with people approaching the end of life and their families, across a wide range of settings. Their contribution includes:

- Building therapeutic relationships that support sensitive, honest conversations about values, fears, goals and preferences.
- **Delivering holistic care**, including pain and symptom management as well as emotional, psychological and, where appropriate, spiritual support.



- Advocating for patients and families, particularly in complex or multi-agency environments, ensuring their voices are heard in care planning and decisionmaking.
- **Providing continuity and clinical oversight**, often coordinating care in hospitals, hospices, care homes and the community—responding to changes, ensuring care is aligned with patient wishes.
- Supporting families and carers with practical guidance, emotional support and clear communication during a time of significant stress and grief.

This work is deeply relational. Our members emphasise that good palliative care requires time, time to listen, to adapt, and to respond. Yet all too often, staffing shortages, high workloads and administrative burdens limit their ability to provide that time. The result is not just pressure on staff but missed opportunities to improve patient and family experiences at one of the most sensitive times in life.

Nursing staff also play a key role in educating and supporting their colleagues. They often act as mentors and informal leaders, equipping others to provide high-quality palliative care across settings and professions. Their input ensures that good practice is embedded not just in specialist teams, but throughout the wider health and care workforce.

#### 2. About the RCN Pain and Palliative Care Forum

The RCN Pain and Palliative Care Forum brings together nursing staff with direct experience of delivering palliative and end-of-life care across settings. The Forum plays a key role in shaping the RCN's policy in this area, ensuring that the voice of nursing staff informs national discussions.

Insights from Forum members have helped to inform this submission, drawing on their clinical experience to highlight the challenges facing the system.

#### 3. Insights from the RCN member engagement

The RCN recently conducted a member engagement exercise on palliative and end-oflife care. Responses were received from nursing staff working across a range of settings, including hospitals, hospices, community services, and care homes. Respondents shared reflections on what is working well and what urgently needs to change.

Topline findings from the engagement include:

• Strong consensus that current provision is inconsistent and under-resourced.



- Widespread concern about the impact of staffing shortages on the quality of end-of-life care.
- Calls for more joined-up, better funded services especially in the community.
- A clear desire for greater access to training and development in palliative care.
- Recognition that services for people with non-cancer diagnoses and for children are too often overlooked.<sup>1</sup>

Respondents consistently emphasised the emotional toll of not being able to deliver the level of care they aspire to. Many described situations where time constraints, lack of support, or system barriers had made it difficult to uphold the values of dignity, choice and compassion.

Respondents also shared clear priorities for improvement. The top themes emerging from both the engagement and the RCN Pain and Palliative Care Forum Conference were:

- **Greater integration between services**, especially between primary, secondary, hospice and social care, to reduce fragmentation and improve continuity.
- Increased staffing levels and protected time to care, with many members
  expressing frustration that they were unable to meet the needs of patients due
  to workload pressures.
- Access to training and skills development, particularly in communication, symptom management, and culturally competent care.

A number of RCN members have also highlighted the need for national leadership to reduce the postcode lottery in service provision and called for consistent commissioning standards. As one member put it, "there is outstanding care happening in places, but it should not depend on geography or charity." <sup>2</sup>

These perspectives provide a crucial insight into the challenges and priorities of frontline staff. They shape and reinforce the recommendations that follow and demonstrate the urgent need for action at national and local levels.

Policy issues and recommendations

4. National accountability and leadership

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<sup>&</sup>lt;sup>1</sup> Royal College of Nursing. (2025). *RCN Member Survey on Palliative and End-of-Life Care*. [Unpublished survey].

<sup>&</sup>lt;sup>2</sup> Ibid



Section 21 of the Health and Care Act 2022 amended Section 3 of the National Health Service Act 2006 to place a statutory duty on Integrated Care Boards (ICBs) in England to commission palliative care services.<sup>3</sup>

This inevitably limits central accountability for palliative care. ICBs now have a statutory duty to commission such services under the amended Section 3 of the National Health Service Act 2006; no equivalent responsibility is placed directly on the Secretary of State. This means national government has no formal specific duty to ensure universal access to palliative care or to address inequalities in provision, as it does for other aspects of health and social care, such as those set out in Section 1A of the 2006 Act and supported by the NHS Constitution.<sup>4</sup> There is a risk that an absence of national accountability leaves the public without assurance of consistent, high-quality services, and an increased risk of regional variation. This is amplified by a lack of data transparency.

The recent announcement that NHS England is to be abolished, with many of its functions returning to the Department of Health and Social Care, has been framed in part as a move to restore democratic accountability within the health system. Yet, without a corresponding statutory duty for palliative care placed on the Secretary of State, these reforms risk compounding an accountability gap in palliative care provision, compared to other services. If central government is to take more direct responsibility for health services, that responsibility ought to extend to palliative care, a core component of compassionate, person-centred care, underpinned by clear accountability.

The House of Commons Health and Social Care Committee also recognised this gap, stating in a 2023 report:

"We recommend the Government ensures universal coverage of palliative and end-of-life services, including hospice care at home, and more specialists in palliative care and end-of-life pain relief." <sup>6</sup>

https://www.legislation.gov.uk/ukpga/2022/31/section/21

<sup>&</sup>lt;sup>3</sup> Health and Care Act 2022, section 21. Available at:

<sup>&</sup>lt;sup>4</sup> National Health Service Act 2006, Section 1A. Available at: https://www.legislation.gov.uk/ukpga/2006/41/section/1A

<sup>&</sup>lt;sup>5</sup> European Observatory on Health Systems and Policies, *Abolition of NHS England announced*, Health Systems Monitor, 13 March 2025. Available at:

https://eurohealthobservatory.who.int/monitors/health-systems-monitor/updates/hspm/hspm-united-kingdom-2022/abolition-of-nhs-england-announced (accessed 2 April 2025).

<sup>&</sup>lt;sup>6</sup> House of Commons Health and Social Care Committee (2024) *Assisted Dying/Assisted Suicide:* Second Report of Session 2023–24 (HC 123), para. 278. Available at: <a href="https://committees.parliament.uk/publications/43582/documents/216484/default/">https://committees.parliament.uk/publications/43582/documents/216484/default/</a> (Accessed: 1 April 2025).



As such, the RCN believes consideration should be given to placing a statutory duty directly on the Secretary of State to ensure the provision and quality of palliative care services across England, alongside a clearly defined responsibility for workforce planning. These duties must be linked: high-quality palliative care cannot be delivered without the right number of appropriately skilled staff. Greater legislative clarity could support better integration across all health and care services, set clear expectations for minimum service standards, and help to reduce regional inequalities in access and outcomes.

#### 5. Sustainable hospice and community funding

Hospices are an essential part of the palliative care landscape, supporting hundreds of thousands of people each year. Yet most hospices receive only a third of their income from government sources and rely heavily on charitable donations to maintain services.<sup>7 8</sup>

RCN members working in hospices or in partnership with them report:

- Pay gaps between hospice and NHS-employed nursing staff.
- Cuts to community services, including home visits and out-of-hours support.
- Contracting arrangements that do not cover the true cost of care.
- Local disparities in service levels driven by inconsistent ICB commissioning, and other factors.<sup>9</sup>

This model leaves care provision exposed to market volatility and deepens existing health inequalities, especially in more deprived areas, where community fundraising is harder to sustain.<sup>10</sup> Staff morale is also at risk, with some hospice-employed nursing staff describing feeling undervalued and professionally isolated.

We support calls for a long-term, national funding model for hospice and community palliative care, grounded in statutory entitlement and aligned with NHS pay and workforce priorities. Funding must be adequate, predictable, and fairly distributed, with national oversight to prevent postcode lotteries and support innovation.

<sup>&</sup>lt;sup>7</sup> Hospice UK (2024) 'Urgent call to save end of life care as 20% of hospices threatened by cuts'. Available at: <a href="https://www.hospiceuk.org/latest-from-hospice-uk/urgent-call-save-end-life-care-20-hospices-threatened-cuts">https://www.hospiceuk.org/latest-from-hospice-uk/urgent-call-save-end-life-care-20-hospices-threatened-cuts</a> (Accessed: 1 April 2025).

<sup>&</sup>lt;sup>8</sup> Hospice UK (2024). *Hospice sector facing a collective deficit of £77m*. https://www.hospiceuk.org/latest-from-hospice-uk/hospice-sector-facing-collective-deficit-ps77m

<sup>&</sup>lt;sup>9</sup> Royal College of Nursing. (2025). *RCN Member Survey on Palliative and End-of-Life Care*. [Unpublished survey].

<sup>&</sup>lt;sup>10</sup> Newson, N. (2024). Hospices: State funding. *House of Lords Library*. Available at: https://lordslibrary.parliament.uk/hospices-state-funding/



## 6. Workforce planning, low pay, and support

The growing number of people living with complex and long-term conditions means demand for palliative care is rising rapidly. However, pay disparities between staff working in NHS settings and those delivering equivalent care in voluntary, hospice, or independent sectors pose a critical challenge to workforce stability. Palliative care nursing staff employed outside of NHS structures frequently report being paid significantly less for work that is at least equally complex, emotionally taxing, and professionally skilled.

This issue is especially pronounced in hospices, where reliance on charitable funding creates a persistent structural disadvantage in terms of recruitment, retention, and professional recognition. The RCN recognises the significant financial pressures hospices and other non-NHS providers face. However, we must be clear: nursing staff working outside the NHS are too often paid substantially below what the RCN deems an acceptable rate for the skill, complexity and emotional intensity of their work.<sup>11</sup> Terms and conditions, particularly around pension provision, also frequently fall short of those guaranteed under Agenda for Change.<sup>12</sup>

This situation is not only unjust, but it also has consequences for patient care. Chronic underpayment and diminished employment conditions undermine staff morale, hinder recruitment and retention, and contribute to service instability. These impacts are ultimately felt by patients and families, who may face reduced continuity, longer waits, or diminished access to skilled professionals at the end of life. It would be remiss of us not to raise this issue. A sustainable palliative care system requires not only adequate service funding but also parity of esteem and reward for the workforce who deliver it. Staffing pressures are already limiting capacity in many parts of the system, across the whole of health and social care. Action is needed now to avoid further strain in future.

#### The RCN recommends consideration of:

- A national workforce strategy, encompassing community, care home, hospice and hospital services.
- Fair pay and parity for hospice-employed nursing staff, supported by funding settlements that reflect NHS pay, terms and conditions.
- Better recognition of specialist roles, including alignment of Palliative Care Clinical Nurse Specialists with advanced practice frameworks.

<sup>11</sup> Royal College of Nursing (2024) *RCN Employment Standards for Independent Health and Social Care Sectors*. Available at: <a href="https://www.rcn.org.uk/Professional-Development/publications/rcn-employment-standards-for-independent-sectors-uk-pub-011-603">https://www.rcn.org.uk/Professional-Development/publications/rcn-employment-standards-for-independent-sectors-uk-pub-011-603</a> (Accessed: 1 April 2025).

<sup>12</sup> Grainger, A. (2024). Differences between state and independent sector provision. *British Journal of Nursing*, 33(10). <a href="https://www.britishjournalofnursing.com/content/regulars/differences-between-state-and-independent-sector-provision/">https://www.britishjournalofnursing.com/content/regulars/differences-between-state-and-independent-sector-provision/</a>



- Expanded access to funded post-registration education, particularly in symptom control, communication and bereavement support.
- Support for internationally recruited staff, and additional protections from exploitation.

These actions must be backed by a long-term workforce investment plan, including clear targets and transparent monitoring. Employers must also ensure that staff have protected time for supervision, reflection, and emotional support, especially given the complex and often emotionally intense nature of palliative care work.

#### 7. Consistency in commissioning

Despite the statutory commissioning duty on ICBs, there remains significant variation in access to services. Some ICBs fund only limited services. Others rely on short-term contracts or fail to keep pace with inflation. This creates instability for providers and inequity for patients.

RCN members describe a clear postcode lottery, in what is commissioned, how services are paid for, and what patients can expect. Inconsistent local commissioning undermines national standards and planning. It also places unnecessary administrative burdens on providers, who must navigate different processes and frameworks depending on geography. The All-Party Parliamentary Group on Hospice and End of Life Care also echoed this sentiment explicitly in their report published in January 2024.<sup>13</sup>

Furthermore, efforts to reduce inequalities in palliative care must include attention to communities that are traditionally underserved in our health and social care system, including people from minoritised ethnic backgrounds, those with learning disabilities, and those experiencing homelessness.

We also note that many patients with non-cancer diagnoses, including those with dementia, frailty or neurological conditions, continue to face barriers to accessing specialist palliative care. <sup>14</sup> The same is true for children and young people with life-limiting conditions. <sup>15</sup> A more inclusive, needs-led approach is essential.

<sup>&</sup>lt;sup>13</sup> All-Party Parliamentary Group on Hospice and End of Life Care (2024) *Government Funding for Hospices*. Available at: <a href="https://www.hospiceuk.org/our-campaigns/policy-and-influencing/influencing-parliamentarians/appg-hospice-end-life-care">https://www.hospiceuk.org/our-campaigns/policy-and-influencing-parliamentarians/appg-hospice-end-life-care</a> (Accessed: 1 April 2025).

<sup>&</sup>lt;sup>14</sup> Marie Curie. (2023). No Place Like Home: Delivering Palliative Care for People with Dementia. Available at: <a href="https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/dementia">https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/dementia</a>

<sup>&</sup>lt;sup>15</sup> Together for Short Lives. (2024). Short Lives Can't Wait: Children's Hospice Funding in 2024. Available at: <a href="https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-hospice-funding-in-uk/">https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-hospice-funding-in-uk/</a>



These steps would reduce bureaucracy, improve efficiency, and give patients and families greater confidence in the care they will receive, regardless of where they live.

### 8. Integration, coordination and timely care

Patients nearing the end of life often interact with multiple services — primary care, hospitals, social care, and voluntary providers. Poor communication between these services can lead to distress, duplication, and missed opportunities for good care. RCN members identify frequent problems with:

- Delays to discharge (where applicable).
- Poorly coordinated care between health and social care.
- Lack of standardised advance care planning documentation.

# We recommend:

- Integrated care pathways across all settings, where possible, co-produced with patients and families. The nursing profession is the key to this.
- Shared care records, accessible across providers and updated in real time.
- Faster discharge planning, supported by anticipatory packages of care and community equipment.

Better coordination means better care. It also means less stress for patients and families, fewer unnecessary admissions, and more efficient use of limited resources. Nursing staff are already doing extraordinary work to hold fragmented systems together. It is time the system worked for them, and their patients.

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