FROM THE MINISTER OF HEALTH

Department of
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An Roinn Sláinte
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Dear Keith,

Thank you for your invitation for officials to provide oral briefing to the Health Committee on Thursday 3 July 2025 as part of its inquiry on access to palliative care. You have advised that the briefing session will cover the following: -

- Palliative care - strategy & funding
- Commissioning of palliative care services, including data led commissioning
- Update on adult palliative care scoping exercise

Attendees for this session will be:

Adult Palliative Care

Gearóid Cassidy	Director of Primary Care
Roger Kennedy	Programme Director Community Care Directorate (DOH Strategic Planning and Performance Group).

Children's Palliative Care

Ryan Wilson	Director of Secondary Care

You have requested that a briefing paper be provided for the Committee prior to the evidence session and this is attached at **Appendix A**. Officials will be happy to expand on this during the evidence session.

Yours sincerely,

Mike Nesbitt, MLA
Minister of Health

Appendix A

HEALTH COMMITTEE BRIEFING PAPER
IN ADVANCE OF ORAL BRIEFING SESSION ON 3 JULY 2025

Introduction

1. The purpose of this paper is to provide the Health Committee with a brief overview in relation to the areas that the Committee has indicated it wishes to address during the oral briefing session scheduled to be held on 3 July 2025.

2. The paper focuses on the following areas:
    - Palliative Care Strategy and Funding
    - Commissioning of palliative care services, including data led commissioning
    - Update on adult palliative care scoping exercise

3. Members are invited to note the content of this paper ahead of the oral briefing sessions. Officials will be happy to expand on the information provided and respond to questions from Members at the evidence session.

PALLIATIVE AND END OF LIFE CARE - BRIEFING PAPER FOR ORAL EVIDENCE SESSION 3 JULY 2025

STRATEGY AND FUNDING – ADULT PALLIATIVE CARE

1. '*Living Matters: Dying Matters'* (LMDM), the Department's palliative and end of life care strategy for adults, including a 5-year action plan, was published in March 2010. The overall aim of the Strategy was to improve the quality of palliative and end of life care for adults by providing a policy framework which enables public, independent, community and voluntary care providers to deliver high quality palliative and end of life that is focused on the person rather than the disease.

2. A LMDM Regional Implementation Board, comprising key stakeholders and chaired by the Director of Nursing, Midwifery and Allied Health Professionals at the Public Health Agency, was established to take forward the implementation of the Strategy's recommendations.

3. In 2015, the Regulation and Quality Improvement Authority (RQIA) undertook a commissioned review of progress on the implementation of the LMDM. The RQIA's subsequent report, published in January 2016, noted that despite a period of financial constraints, very significant progress had been made towards implementing the Strategy's recommendations.

4. It also concluded that although many initiatives had been developed to raise awareness of palliative and end of life care, there was a continuing need to raise public understanding of palliative care. The report also pointed to a need to standardise the availability of core services across the region. In addition, the report found that the increasing demand for palliative and end of life care was likely to continue with many patients having more complex needs.

5. The RQIA review did not identify the need for a new palliative and end of life care strategy, however it recommended that a new action plan should be developed, building on the work that had been completed to date.

6. It is acknowledged that *Living Matters; Dying Matters* was published 15 years ago and there have been changes in the context to palliative and end of life care over the years since. However, a strategy has not been a prerequisite for the improvement and development of palliative and end of life care services both regionally and at local level.

7. The regional Palliative Care in Partnership (PCiP) Programme, co-led by the Strategic Planning and Performance Group and the Public Health Agency, oversees the development and improvement of palliative and end of life care for adults across Northern Ireland. The Partnership brings together a wide range of stakeholders across the statutory, independent and voluntary and community sectors, including hospices, as well as service users.

8. The Palliative Care in Partnership Programme's remit includes providing regional direction for palliative and end of life care in Northern Ireland and ensuring the delivery of key priorities in palliative and end of life care both regionally and locally.

9. At the evidence session on 26 June, the Committee heard from SPPG and PHA colleagues in the PCiP about the work the Partnership has been taking forward and the difference it, and its member organisations, are making.

10. The regional Palliative Care in Partnership Programme's priorities for 2023-26 will continue to inform and support the Partnership in its work to ensure there continues to be a drive and focus on improving palliative and end of life care.

11. The NI Executive's Programme for Government 2024 - 2027 '*Our Plan: Doing What Matters Most*' recognised the importance of death, dying and bereavement and ensuring that people are supported at all stages of their lives. With the demographic trends which will see our population growing older, and with greater incidences of chronic illness and growing demand for palliative care, the PFG sets out a commitment to working across the Executive to identify opportunities to improve support to those coping with death, dying and bereavement.

12. As the Programme for Government has acknowledged, issues of death, dying and bereavement extend beyond the remit of the Department of Health and reflect the need for a public health approach to palliative care. This is one of the 4 priorities of the Palliative Care in Partnership programme.

13. The Committee is aware that the Department is commencing a scoping exercise for adult palliative care services. This is not a commitment to a new strategy, however, the scoping exercise will, we believe, provide a robust evidence base not only of current services, but also a population-based needs assessment as well as information on the qualitative lived experience of individuals.

14. The evidence and outcomes from the scoping exercise will help inform the planning and delivery of palliative care services, underpin progress on the PfG commitment and be a necessary precursor towards any future consideration of a new palliative care strategy for adults.

Funding – Adult Hospices

15. Current funding for adult hospice services is based on a 50:50 funding arrangement for inpatient services (in place since 2004/05) and also for community-based care (in place since 2005/06). This has been the basis of the funding arrangements between commissioners (both SPPG, formerly HSCB, and HSC Trusts) and the four local hospices. The funding arrangements are for agreed commissioned services costs and not actual hospice running costs.

16. The Department's Strategic Planning and Performance Group is responsible for the monitoring and performance management of the Service Level Agreements in place with hospice providers.

17. Annual funding provided by the Department to hospices for contracted adult services over the past 6 years is set out below:

Year	Funding *
2019/20	£7.502m**
2020/21	£7.916m**
2021/22	£9.300m**
2022/23	£9.142m** (includes £0.324million non-recurrent funding in recognition of financial pressures facing hospices)
2023/24	£9.334m** (includes £74,081 non-recurrent funding in recognition of non-pay inflationary pressures)
2024/25	£9.731m**

*These figures do not include funding provided by HSC Trusts for any contract arrangements they have with hospices.
**The above figures do not include:

- non-recurrent funding of £16million which was provided to hospices in NI in 2020/21 for COVID-19 in recognition of the impact on fundraising and the additional costs and impact on services due to the pandemic (largely in 2020/21).
- funding provided to hospices for the special Staff Recognition Payment for hospice staff (2021/22 and 2022/23).
- funding provided regarding Advanced Communication Skills training in respect of the Cancer Strategy Action 53 (2023/24).
- Core grant funding provided to the NI Hospice as part of the Department's Core Grant funding scheme (annually).

18. For 2025/26, an interim uplift of 2.98% has already been applied to hospice payments this year. This is an interim uplift and does not reflect the impact of any 2025/26 Agenda for Change (AfC) pay award, which if agreed, would normally increase and finalise the interim uplift for the year.

19. The interim contract uplifts for 2025/26, were formally advised to each hospice provider in February 2025 and payments made from April 2025 on this basis. The value of the interim uplift for each hospice is based on a weighted calculation covering increases in respect of National Living Wage, Employers National Insurance Contributions and a 2% non-pay uplift, all effective from 1 April 2025.

20. This resulted in an overall 2.98% interim uplift on all Hospice contract values, when uplifts were applied to each pay and non-pay proportion of the contract values.

21. The impact of applying the 2.98% uplift to SPPG held hospice contracts has provided additional funding of £342k to hospices. Of this, £285k was to provide support to hospices in response to the increases in National Living Wage and Employer National Insurance contributions.

22. Hospices will have a range of other funding streams, such as with HSC Trusts and other charitable donation income. Where HSC Trusts have contracts with hospices, further uplift funding may be provided directly from Trusts, based on individual contract arrangements between HSC Trusts and hospices.

23. In 2021, it was proposed that a comprehensive review of adult specialist palliative care services be undertaken to help inform future planning and delivery of services and funding arrangements, as well as providing greater clarity about what specialist adult palliative care services are needed and how these can best be commissioned, delivered and funded to meet the future needs of our population.

24. Given the ongoing and challenging financial and resource pressures facing the Department, it has not been possible to undertake the proposed review of specialist palliative care for adults.

STRATEGY AND FUNDING - PAEDIATRIC PALLIATIVE CARE

25. In 2016, the Department of Health published two paediatric strategies: *A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community 2016-2026* and *A Strategy for Children's Palliative and End of Life Care 2016-2026*.

26. The strategies were built upon the principles of "Health and Wellbeing 2026: Delivering Together", with the clear aim of delivering better health and wellbeing outcomes for children in Northern Ireland.

27. The *Strategy for Children's Palliative and End-of-Life Care*, published in November 2016 sets out 23 objectives across the spectrum of paediatric palliative care from diagnosis through to bereavement care.

28. Funding was made available as part of the Confidence and Supply agreement which allowed for work to be progressed against the Strategy's objectives.

29. The Regional Paediatric Palliative Care Network (RPPCN) was established in 2019. It is chaired by a Paediatric Palliative Clinical Care Lead. The network identifies the key priorities for delivery in line with the Strategy and puts in place measures to deliver these. It also acts as a vehicle to identify areas of best practice and share clinical opinion on specific cases.

30. Initiatives and action progressed by the Network include the development of ante-natal care pathways, rapid discharge plans, advanced care plans and agreed pathways regarding pain relief, amongst others. All Ireland clinical meetings now occur throughout the year. Two such meetings have occurred this year and it allows clinicians to share best practice on managing difficult clinical cases. It is hoped that this close working can be enhanced over coming months. Work has also commenced on agreeing advanced care plans that complement the plans that are used in GB and ROI. Scoping has now been done on the numbers of end of life cases that have happened and what lessons can be accrued from this.

31. The RPPCN has identified three key priorities:
    - the amendment and improvement to ante-natal care pathways
    - advanced care plans; and
    - assessment of the current provision on 24/7 end of life care.

32. The Network works closely together to ensure that irrespective of where a child lives in Northern Ireland, they can access high quality paediatric palliative care.

33. Locally, paediatric palliative care clinical leads in each HSCT Trust lead paediatric palliative care. They also ensure that best practice is shared with colleagues in other Trusts and regionally. A regional paediatric palliative care consultant was appointed to offer clinical leadership to the service across Northern Ireland. However, currently the regional paediatric palliative care consultant post is vacant. Despite efforts by the Belfast HSC Trust and the RPPCN a suitable replacement has not been found. The Trust has now begun the process of seeking to appoint a clinician with an interest in paediatric palliative care until times as a suitably qualified paediatric palliative care consultant is available.

34. In addition, there is a Paediatric Palliative and Life Limited Nurse employed by the Northern Ireland Children's Hospice at the Royal Belfast Hospital for Sick Children.

35. The RPPCN will continue to review and deliver improvements to paediatric palliative care to ensure children and young people in Northern Ireland receive optimal care.

Funding - Children's Hospice

36. Children's palliative care services are largely provided by the Health and Social Care Trusts in hospital and community settings. Alongside this, the Northern Ireland Children's Hospice provides specialist respite, palliative and end-of-life care to children and young people living with life limiting and life-threatening illnesses.

37. Funding for the NI Children's Hospice (NICH) is different to that for adult hospice services. The Department of Health has Service Level Agreements in place with the Northern Ireland Children's Hospice for the delivery of agreed commissioned services for bed nights and community support services. Relative to the total cost of commissioned services, funding has been previously assessed to be in the range of 30% for bed nights and up to 50% for community support services.

38. In May 2018, following the closure in 2017 of the four-bedded Horizon West hospice unit based in Fermanagh[1], the Department of Health provided funding for 50% of a bed in the NICH - £0.17million. This bed, the 'Horizon West/ One-hour bed' provided families who had to travel more than one hour to the NICH, the opportunity to avail of an additional night in the NICH facility. This funding was agreed for three years from 2018/19 to 2020/21. Due to COVID, the funding was extended for a further two years until end of March 2023. Following representations by the Northern Ireland Children's Hospice, this funding was further extended until the end of March 2024.

39. In 2024/25, the Department provided funding to the Northern Ireland Children's Hospice of £1.746 million to commission NICH to deliver:
    - Bed nights in Horizon House inpatient unit offering supported short breaks.
    - A specialist community team including a 24-hour on call service.
    - A family support service, including bereavement support.

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[1] Horizon West was a NI Children's Hospice service previously provided in Fermanagh but which was not commissioned by the then HSCB.

- The Palliative and Life Limited Service - the PALLS nurse facilitates the transfer of children from hospital to non-hospital settings, which could be back to home or to the Northern Ireland Children's Hospice, for step down or step up care, or where appropriate end of life care.
- The Hospice at Home Service providing practical nursing care, support and short breaks to children in their own home or community.

40. The 2025/26 funding for the Northern Ireland Children's Hospice included interim inflationary uplifts for non-pay, support for National Living Wage and changes to Employers National Insurance Contributions.

Annual NICH Funding

Year	Funding *
2021/22	£1.326m** (this includes £68,897 non-recurrent funding in relation to staffing)
2022/23	£1.830m** (this includes £64,756 non-recurrent funding in recognition of non-pay inflationary pressures)
2023/24	£1.857m** (this includes £14,738 non-recurrent funding in recognition of non-pay inflationary pressures)
2024/25	£1.746m**
2025/26	£1.798m**

*These figures do not include funding provided by HSC Trusts for any contract arrangements they have

**The above figures do not include:

- The NI Hospice, including the NI Children's Hospice, received £8.23m of additional non-recurrent COVID-19 funding which was made available to local hospices in 2020/21 to recognise the impact of the COVID-19 pandemic on both fundraising ability and the provision of services.
- funding provided for the special Staff Recognition Payment for hospice staff (2021/22 and 2022/23).
- Core grant funding provided to the NI Hospice as part of the Department's Core Grant funding scheme (annually).

COMMISSIONING OF PALLIATIVE CARE SERVICES

41. The provision of health and social care in Northern Ireland is currently provided under a range of legislation, the main provisions being the Health and Personal Social Services (Northern Ireland) Order 1972 and the Health and Social Care (Reform) Act (Northern Ireland) 2009 ("the Reform Act")

42. The Reform Act provides the legislative framework within which the health and social care structures operate. It sets out the high level functions of the various health and social care bodies. It also provides the parameters within which each body must operate and describes the necessary governance and accountability arrangements to support the effective delivery of health and social care in Northern Ireland.

43. Section 2 of the Reform Act sets out the Department's general duty in relation to the provision of health and social care in Northern Ireland, including the duty to

promote an integrated system of health and social care designed to secure improvement in the physical and mental health and social well-being of people in Northern Ireland and to develop policies for reducing health inequalities.

44. Section 3 sets out the Department's general power and provides that the Department may provide or secure the provision of such health and social care as it considers appropriate to the discharge of its duty.

45. The statutory basis for commissioning relates to all health and social care services, including commissioning of palliative and end of life care services.

46. The Health and Social Care Act (Northern Ireland) 2022, provided for the dissolution of the Health and Social Care Board (HSCB) with effect from 1 April 2022. In addition, the Act provided for the transfer of the HSCB's functions into the Department so that the duties and responsibilities previously held by the HSCB were placed, in the main, directly upon the Department, through the Strategic Planning and Performance Group (SPPG).

47. As a consequence of the closure of the HSCB, and the subsequent standing down of the Commissioning Plan Direction (CPD) and Commissioning Plan processes which had been in place, the Department has developed a new approach for setting the strategic direction to the system.

48. The Strategic Outcomes Framework (SOF) defines a set of statements that depict the longer-term condition of health and wellbeing of our population that we wish to achieve and associated key indicators that are reflective of the perceived needs and priorities of the population.

49. The Strategic Outcomes Framework consists of a suite of thematic outcomes and supporting key indicators representing the life course and life journey of an individual through their potential interactions (or non-interactions) with the system.

50. One of the thematic outcomes is that people approaching the end of their life live with dignity and their families or networks are supported during the illness and through bereavement. The key indicators supporting this thematic outcome are:

    - Decrease ED attendance in the last 90 days of life
    - Improve death literacy
    - Increase dignity
    - Improve experience in bereavement

51. In addition to the longer-term direction provided by the SOF, System Oversight Measures (SOMs) provide the short-term Departmental priorities to the HSC system and support system level performance accountability.

52. The work of the HSC system, including Trusts and the new Area Integrated Partnership Boards (AIPBs), will be guided by the Strategic Outcomes Framework.

53. The SOF and the SOMs are underpinned by the HSC Support and Intervention Framework (SIF) NI. The SIF sets out the Department's approach for gaining

assurance from HSC organisations, and the approach to support and intervention where there are matters of concern that need to be addressed.

DATA COLLECTION

54. The majority of adult palliative care is generalist, delivered by multi-disciplinary teams in primary and community care settings, hospital units and wards. This is the level of palliative care required by most people and is provided by GPs, District and Community nursing teams, Allied Health Professionals (AHPs), social workers, community pharmacy, care home staff and home care workers.

55. Specialist Palliative Care is provided by specialist personnel with expert knowledge, skills and competences. It is delivered by specialist multi-disciplinary teams dedicated to palliative and end of life care.

56. The Department's contractual arrangements with hospices provide data and information about contracted services. However, given the extent to which palliative care can be delivered across the primary, secondary and community sectors, data across the range of services is not readily available.

57. The ongoing roll out of Encompass to provide a single digital health and social care record for every citizen in Northern Ireland will improve communication and access to patient information across care providers and at crucial transition of care points.

58. Palliative care providers and clinicians are currently involved in ensuring the Encompass functionality meets the needs of patients and professionals. The regional Palliative Care Minimum Data Set (MDS), previously agreed in 2016, has been reviewed and updated. Data items to support regional population level palliative and end of life care data and local service level performance have been agreed.

59. The palliative care MDS has been submitted to the Digital Health and Care Northern Ireland (DHCNI) regional prioritisation process for implementation within the Encompass optimisation phase and for changes to the existing palliative care build to enhance the visibility and reporting of patients flagged as having palliative and end of life care needs.

60. Whilst hospice staff currently have read access to the Encompass system, a feasibility study is underway with Digital Health Care NI which will explore the opportunity for full system permissions for hospice services in the future.

61. Once fully implemented, Encompass will enable our understanding of the totality of health and social care services which our palliative care population access across HSCNI. This will support performance management and analysis of patient outcomes to inform future service planning and commissioning.

National Audit for Care at End of Life (NACEL)

62. In terms of other sources of information to support the planning and delivery of palliative care services, the National Audit for Care at the End of Life (NACEL), co-ordinated by NHS Benchmarking, is an annual national comparative audit of the quality and outcomes of care experienced by the dying person, and those important to them, in acute and community hospitals.

63. In Northern Ireland, the NACEL is commissioned by the Public Health Agency on behalf of the Regional Palliative Care in Partnership Programme.

64. Northern Ireland has participated in NACEL for four rounds. The most recent (Round 4) took place in 2022 with a report published in April 2023. All five HSC Trusts participated in the audit In Round 4, covering 20 hospital sites (12 acute and 8 community).

65. The audit comprised:
    - an Organisational Level Audit covering hospital/submission level questions
    - a Case Note Review which reviewed consecutive deaths in the first two weeks of April 2022 and two weeks of May 2022 (acute providers) or deaths in April and May 2022 (community providers) and
    - a Staff Reported Measure, completed online.

66. In 2024, NHS Benchmarking launched a new redesigned version of NACEL with a goal of providing more frequent and timely data aimed at driving organisational quality improvement. All 5 five HSC Trusts have participated in the audit. Results from Round 5 of NACEL are due to be made available in October.

67. All Trusts are currently progressing NACEL Action Plans to address recommendations made at individual Trust level. The recommendations from NACEL are also reviewed by the Palliative Care in Partnership Programme in line with the regional palliative care work plan and where applicable, a regional approach may be taken to consider the NACEL recommendations.

SCOPING EXERCISE – ADULT PALLIATIVE CARE

68. The Department recognises that as the population increases, with more people living longer and with more complex conditions, the demand and need for palliative care will continue to grow.

69. The Department will be undertaking a scoping exercise of adult services that will help inform future planning and design of adult services in the context of identified demand and need. The key aims of the exercise are.

    - **Baseline scoping existing palliative care service provision**: to baseline adult palliative care services (both generalist and specialist) which are currently available across all providers and understand the service activity, staffing, funding, contracting arrangements and performance of these services.

- **Palliative care population-based needs assessment**: to understand the palliative and end of life care needs of the NI population including a focus on people facing inequalities.

- **Quality of care & patient outcomes:** to understand the experience and quality of palliative and end of life services currently being delivered across care settings.

70. A Project Board will be responsible for overseeing the scoping exercise and Task and Finish Groups will be established to deliver each of the 3 key aims of the exercise. Project management will be provided by the existing Palliative Care in Partnership Programme team within the Department's Strategic Planning and Performance Group.

71. The Palliative Care in Partnership Programme provides an existing infrastructure of key palliative and end of life care providers and stakeholders from care settings across Northern Ireland, including hospices. Membership of the Project Board and the Task and Finish Groups will be drawn from the PCiP Programme Board and its member organisations to support the aims of the scoping exercise.

72. The scoping exercise will include adult services only. Children's palliative care is very different to adult with different arrangements in place for service delivery and funding, in terms of how and where services are delivered.

73. This will be a significant and extensive area of work across the three aims of the exercise to provide not only a baseline scoping of services, but also a population-based needs assessment to understand the palliative and end of life care needs of the population, as well as the experience and quality of palliative and end of life services currently being delivered across care settings.

74. The outcomes will inform the future planning and commissioning of adult palliative care services across the region, including specialist palliative care services provided by hospices.