

The Association for Palliative Medicine of Great Britain and Ireland

The Association for Palliative Medicine of Great Britain and Ireland (APM) is one of the world's largest representative bodies for professionals practising or interested in Palliative Medicine, with a growing membership of over 1,400. The APM represents its membership advocating for excellence in clinical palliative medicine. The Association for Palliative Medicine of Great Britain and Ireland.

Current state of palliative care services

In your view what is the current state of palliative care services in Northern Ireland?

Very Poor

Do you think there is an understanding by the public of what palliative care is? If no, what are the main barriers to the public understanding palliative care? No

There is generally a lack of understanding among the public and healthcare workers about what palliative care is and what it does. Misconceptions, such as viewing it as “there’s nothing more we can do to help” or “giving up” or only relevant in the final days of life create fear amongst the public and delays access to palliative care for many who urgently need it. It is common that palliative care inpatient units are misunderstood as places where lives are deliberately shortened. This is simply false, indeed evidence shows that early referral to palliative care not only improves peoples’ quality of life but can also extend life,. Once patients and their families experience that palliative care’s fundamental priority is to help people to 'live as well as they can until they die', they become our strongest advocates. Culturally, the communities of Ireland have long recognised the tradition of ‘the wake’ where families and friends would gather to support each other, pay respect to, and celebrate the life that the dead person lived. As wakes become less frequent, so do the opportunities for natural and open discussions of death and dying. The biggest challenge of this cultural shift is the medicalising of dying and thus separating dying from being a normal part of living. The more you separate dying from being part of a ‘normal life’ and make it a medical event to be feared, the more misconceptions grow.

Access to services

Are palliative care services equally accessible to all who need them?

No

From your experience where are the gaps in the provision of service?

There are two points to make:

1) General Palliative care – provided by predominantly GPs and district nurses is under-valued, under-resourced and has got expectations out-with capacity. Long gone are the days

when at end-of-life the GP visited you numerous times and increasing in frequency the closer to death you became.

2) Specialist Palliative care has been neglected for a long time. The APM believe specialist palliative care is an essential service and should be funded through Health and Social Care. The majority of funding of hospices/inpatient units in Northern Ireland is charitable, i.e. not statutory. The palliative care workforce within the hospitals has stagnated while parallel specialities (such as oncology) have increased exponentially. There are gaps in access to specialist palliative care in all settings. There is insufficient workforce to provide a comprehensive and responsive service. There is poor coordination between services, inequitable out-of-hours and no 7 day working. There should be single points of access for patients and their families as well as health professionals. There should be rapid access services to respond to urgent need in the community. There should be educational programmes to support all of this, with the workforce to deliver them.

Do you believe barriers exist that prevent equitable access to these services? If yes, please provide examples in the box provided.

Yes

These barriers include:

1. Funding Shortfalls: Palliative care services in Northern Ireland suffer from inconsistent and insufficient funding, which restricts their ability to provide equitable care, particularly in rural and deprived areas, and hampers long-term service development. How is less than 50% funding for hospices and palliative care in-patients a demonstration of value. Why isn't Cardiology less than 50% statutory funded? Why the difference?
2. No Legal Requirement for Palliative Care Commissioning: Unlike England and Wales, with Baroness Finlay's amendment in the Health and Social Care Act, there is no statutory requirement to commission palliative care services in NI. This leaves service provision vulnerable to funding cuts. The APM recommend legislation to be put forward outlining the statutory requirement to fund palliative care.
3. National insurance rises adversely and disproportionately affect General Practice, Hospice sector and nursing homes, all of which are keeping people out of hospitals and are the most involved in palliative care. This should be counterbalanced with appropriate increase in funding.
4. Lack of a Palliative Care Policy: NI remains the only region in the UK and Ireland without an up-to-date palliative care strategy. As such we recommend the development of a palliative care policy for NI. The palliative care leadership structure has not progressed a strategy, leaving services without a clear plan for improvement or future direction. This should be with measurable and real term action.
5. Poor effective leadership structures for palliative care, both general and specialist. The APM recommend a close look at the leadership structure of palliative care within NI to

understand why it has been so ineffective and moving forward how it can be made to be an effective advocate and implementer of much needed urgent change.

6. Opaque Commissioning by the Department of Health (DoH): A lack of transparency in how the DoH commissions palliative care services creates uncertainty around funding allocation, priorities, and accountability. The APM would strongly recommend the structure within all other areas of the UK and Ireland in having a named National Clinical Lead for Palliative and End-of-life care.

7. Absence of a Regional DNACPR Document: Unlike all other parts of the UK, NI lacks a standardised DNACPR or ideally ReSPECT document, leading to inconsistent decision-making and distress. ReSPECT has been ready for at least 5 years.

8. No Individualised End-of-Life Care Document: The absence of a unified, EoLC document results in fragmented delivery of care and risks failing to honour patients' preferences. The NACEL (National Audit of Care of End of Life) we have done each year in NI does not advocate a statutory national document per se but a care plan : this can align with clinical documentation within the individual organisation. Wales does have the same documentation for the care plan across the country, NI has no document.. This has been ready for over 15 years.

9. Lack of Impetus for Advance Care Planning, developed in 2019, there has been no urgency in its implementation.

10. Absence of Power of Attorney for Health and Welfare: Northern Ireland lacks a formal PoA process similar to everywhere else in the Western World. This makes it difficult for families and healthcare providers to navigate decisions about treatment, particularly when patients lose capacity to express their wishes.

11. Regional Palliative Care referral form: Since 2019 a regional referral form has been developed and had RPMG agreement yet not progressed. Now with the implementation of regional Encompass, why delay?

12. Demand for Charitable sector hospices to be urgently incorporated in Encompass for seamless transition of care.

13. Fragmentation and Overlapping Services: Multiple organisations often provide overlapping services, each operating with its own agenda. This leads to duplication, inefficiency, and confusion for patients and families navigating the system and is a failure of coordinated leadership and lack of funding.

14. Limited Integration and Collaboration: Poor coordination between health and social care providers creates gaps in service delivery and disrupts continuity of care, particularly for patients with complex palliative care needs.

15. Each primary care GP practice should have a mandatory palliative care list. This can be the Gold Standard Framework (GSF) or other. Needless-to-say if you are on the required palliative care list this should be regularly discussed, appropriately funded, and be

benchmarked to be seen within 28 days of death. All of this should be benchmarked, monitored, recorded.

16. Inequality of access across demographics, geography, ethnicity, homelessness and prisons, should be made fair and equitable

17. Out-of-hours access for palliative care should be equitable.

What additional services could/should be provided?

The current leadership structure of Palliative Care in NI has proven to be ineffective, with no accountability or authority to drive meaningful change as evidenced by the lack of progress on multiple metrics. The structure has ringfenced clinical engagement as a subcommittee with limited influence and no authority.

The APM recommends a fresh start is needed with a new regional leadership structure that includes a clear accountable commissioning process, a transparent processes for both a regional generalist palliative care approach and the specialist services. A governmental commitment to develop a Palliative Care strategy with the governmental commitment to fund the implementation are the essential requirements.

NI should also look at models used in Wales, England, Scotland, and Ireland. We suggest this would involve appointing a 'National Palliative Care Clinical Lead' with a direct reporting line to the Minister of Health. This role would carry responsibility, accountability, and the authority to commission palliative care services across NI with permission and direction from the minister of health. This role acts as an advocate of these services to the minister. There should be a service specification for palliative care with clear outcomes. As seen elsewhere in the UK and Ireland, this funded post should be a clinician and supported by dedicated civil servants tasked with overseeing palliative care policy in Northern Ireland.

Integration of Services

How well are palliative care services integrated across the health system, through primary, secondary and specialist care?

The regional 'Encompass' electronic notes needs to be urgently commissioned for all hospices and palliative care in-patient units, facilitating the effective integration and coordination of services across the region. Encompass will also allow better integration with secondary care.

Regarding primary care, palliative care is unique in that it straddles across all settings and primary care and nursing homes also need special attention. A reactive timely service is vital for our population and therefore there is a wider question of funding to primary care, district nurses and the provision of packages of care. There is also further need for integration of nursing homes.

This requires strong clear leadership working throughout the sectors coordinating for best interest of patient care rather than organisational imperatives. QoF points have been

disbanded since covid and GP's receive a lump sum. Additional funding of QoF points for palliative care and effective trust funded district nurses are vital incentives.

The APM would also recommend a model in which GP's have a voice in commissioning of services on par with and similar to CCG's in the rest of the UK with palliative care provision being a statutory requirement. Regarding Specialist services the APM recommend single points of access to support patients and their families, and health professionals access the help and support they need with simplicity, usability, equity and fairness and transparency.

Should palliative care be a regional service? Please outline your reasons.

Yes

NI health service would benefit from a regional structure, reducing bureaucracy by consolidating the current five trusts into two. A regional approach to generalist palliative care is essential, addressing ACP, PoA, ReSPECT, GP funding for home visits, district nurses, and NIAS with palliative care training and workforce for palliative care. Clear leadership, such as a national clinical lead for palliative and end-of-life care, is crucial, as these issues have been raised for 20 years without resolution.

A 24/7 single point of contact for specialist palliative care advice should be regionally funded and clinician-led. SCUK provides out-of-hours phone support, but the funding source is inconsistent. A 7 day specialist palliative care service, in-line with NICE guidance (2004) and NI's outdated 2010 strategy, remains unfunded despite its importance.

The specialist palliative care workforce has seen limited growth compared to oncology, despite increasing demand. Regional benchmarks, such as district nurses delivering anticipatory medications within an hour, must be established. All GP Integration of Services.

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What can be done to improve integration?

To improve the integration of palliative care services both generalist and specialist, charitable and trust, with existing healthcare systems we recommend several key actions:

- 1) make timely access to palliative care a legal right, as implemented in England and Wales, to ensure equitable access for all and make an essential service the health service is responsible for, the same as any other specialty.
- 2) provide appropriate resourcing through strategic workforce planning and fair, transparent commissioning processes
- 3) strengthen regional palliative care leadership to foster collaboration and guide integration efforts with a restructure of the system with a responsible national palliative care lead to coordinate fair and appropriate services
- 4) develop and implement a regional palliative care policy with funding (APM recommend 100%) to drive cohesive and integrated care delivery.

Best Practice

Do you have any examples of good practice or pilots in palliative care that are meeting the needs of patients and families/carers? If so, is this best practice happening widely across Northern Ireland?

Examples of changes in Republic of Ireland have turned around coordination and delivery of palliative care through clinical leadership, governmental commitment to develop and fund national policy and appropriate commissioning. Examples of single points of access, projects to increase advance care planning and recording of decision making, 24/7 working and educational programmes all exist elsewhere and have demonstrated significant positive

change. Measurement of specialist palliative care impact should be through patient related outcomes (PROMS).

Do you think that families receive sufficient support when accessing services? Please outline your reasons in the box provided.

No

They do not. Considering all the points raised above, how can it be said that the current system and services are adequate? Families deserve appropriate support, yet they are not receiving it, and failing to address this need causes real harm. This is not a criticism of the services themselves, as each is doing its utmost with the limited funding provided. The issue lies in failed direction and leadership.

Funding and Strategy

No

The current funding is grossly insufficient. Indeed, the gap is getting greater with the National insurance rise which is shrinking funding further in hospices, general practice and nursing homes which together all contribute to the vast majority of palliative care services as a whole. There is a disproportionate hit to this sector.

Although not linked to the National Insurance rise there is a realisation that leaving palliative care to charity and shrinking the sector further is politically poor.

The consequences of not funding palliative and end of life care for both generalist services and specialist is the situation of poor outcomes we see today.

Palliative care services in the Republic of Ireland are now 100% funded by the state. The APM calls for the government of Northern Ireland to properly fund palliative care.

Is the current model for the funding of hospices, including hospice at home/community care/rapid response support, sustainable and sufficient to meet needs now and in the future? Please outline your reasons in the box provided.

The NHS, was founded on the principle of providing care "from cradle to grave," yet we fall short, offering care only to the very old, not to the grave.

Essential palliative and end-of-life care relies heavily on charitable services rather than the NHS. Funding through cake stalls and sponsored runs is unsustainable, insufficient and inequitable.

This financial instability prevents hospices from maintaining services, retaining skilled staff, and fostering innovation. It also forces unnecessary competition for limited funds, fragmenting care and hindering collaboration. Without multi-year budgets, long-term planning and meaningful service development are impossible, leaving clinical needs unmet and communities underserved.

In contrast, the Republic of Ireland provides 100% statutory funding for hospices. Northern Ireland must commit more to funding palliative care to ensure sustainable, equitable, and comprehensive palliative care. Increased funding is not just necessary but a moral imperative to uphold the NHS's founding vision.

Specialist palliative care within trusts has stagnated, lacking investment and growth compared to specialties like oncology. This service must be expanded and properly funded.

In primary care, GPs should reclaim their role as local practitioners, visiting patients at home before death. District nurses require similar support, with appropriate funding and incentives to ensure equity with the UK and Ireland.

Is there a need for a new Palliative Care Strategy for Northern Ireland? If yes, what should it include? If no, why not? Please outline your reasons in the box provided.

There is an urgent need for a palliative care strategy which should cover leadership, commissioning, cooperation and coordination of services, workforce, delivery and evaluation of services. We strongly suggest a palliative care policy.

It should include all the points mentioned previously:

- Funding Gaps: Less than 50% funding for hospices limits equitable care & development
- No Legal Mandate: Unlike England, NI lacks legislation to guarantee palliative care funding
- Financial Strain: Rising costs disproportionately affect GPs, hospices, & nursing homes
- Policy Void: NI lacks a current palliative care policy or measurable action plan
- Ineffective Leadership: Bureaucracy hinders accountability, innovation, & change
- Opaque Commissioning: No transparency in DoH funding; a National Clinical Lead is needed
- No Standardized DNACPR/ReSPECT: Absence causes inconsistent decisions & distress
- Lack of End-of-Life Plans: No unified documents for individual care preferences
- Delayed Advance Care Planning: Existing framework remains unimplemented
- No Health PoA: Families struggle with decisions for incapacitated patients
- Unutilized Tools: Regional referral forms & Encompass integration remain stalled
- Fragmentation: Overlapping services create inefficiency & confusion
- Primary Care Issues: GPs need funded palliative care lists with benchmarks for patient reviews
- Specialist working: 6-7day working, 24/7 regional advice
- District nurse benchmarks for palliative care

Any other comments

The largest existential challenge to palliative care is the proposal of an assisted dying law in Westminster and the Dail affecting the NI population. It is incorrectly often assumed palliative care can function alongside a state-assisted suicide service and, indeed, be intricately involved in it. Assisted dying/suicide does not allow effective palliative care to

both exist and function. It is a relatively common occurrence for a palliative care patient to ask for their life to end. As soon as a palliative care physician attempts to address a wish to die in a jurisdiction in which assisted dying/suicide is legal, they are seen as blocking access to a service and imposing their own beliefs upon the patient and family. There is a further complication that in the previous proposals by Gino Kenny (2024) in the Dail are for the 'Island of Ireland', which would include direct access for the NI population.