

Northern Ireland Hospice and Northern Ireland Children's Hospice

A local charitable hospice providing inpatient and community specialist palliative care services to adults, children and babies.

Current state of palliative care services

In your view what is the current state of palliative care services in Northern Ireland? 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. We believe there has been an increase in public awareness over recent years, particularly through the COVID pandemic and with the increased media attention given to the Assisted Dying debate. However, further resources allocated to improving public awareness and death literacy would be important. Increased awareness will support early access to services, advance care planning and support the practice of realistic medicine. Additionally, improved public understanding would help alleviate unnecessary anxieties some patients experience when considering hospice care, which often stem from misconceptions and misunderstandings about its purpose and benefits. There is no legal right to Palliative Care services in Northern Ireland.

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?

Currently across Northern Ireland there is significant geographical variation in the provision of services.

There is no regional workforce plan to facilitate recruitment, training and career progression and this may be contributing to current workforce shortages.

One of the most pressing challenges is the extent of funding deficiencies. The absence of a multi-year budget hinders service development and growth. Limited resources particularly affects access to services during unsociable hours where

there is increased need, such as evenings, during the night and weekends, increasing the pressure experienced by Primary and Secondary care emergency services.

England and Wales have changed legislation to make access to palliative care a legal right. Northern Ireland should also do this to ensure patients can access the care they require and deserve.

In most areas, there has been no investment in building sustainable capacity in palliative and Specialist Palliative Care (SPC) workforce in the community. Against a backdrop of finite SPC in-patient bed capacity and with increasing proportions of people wanting to be cared for, and die, at home investment in the community specialist multi-disciplinary workforce is vital. This includes training, education and the establishment of clear regional career development pathways, in preparation for meeting the needs of people with palliative care needs. Without proper investment and funding, the growing demands will place unsustainable pressure on the current workforce, increasing the risk of burnout and turnover, adversely impacting individual's health and wellbeing and recruitment and retention in the specialty.

Crucially, the absence of an up-to-date palliative care strategy and/or policy has caused a vacuum in strategic planning with limited service development. With a robust strategy, there would be opportunity for clearer accountable regional leadership empowered to make impactful decisions.

From the children's perspective the current strategy is not funded and progress achieved in the Regional Paediatric Palliative Care network has relied on the goodwill of professionals. Research demonstrates that the number of children with a palliative care need will continue to grow. We need to be building for this growth. Currently we have no paediatric palliative care consultant and medical leads only have one PA per week dedicated to this important area. Benchmarking the palliative care provision for Children in NI against other regions would demonstrate the significant development required. As with Adult Services, there is little or no community-based out of hours cover for end-of-life care. Care often relies on the goodwill of staff or a ramping up of independent services to plug the gap.

In addition, supported short breaks – a key element of paediatric palliative care, and distinct from adult palliative care are underprovided in NI, compared to other regions.

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

Yes. Currently across Northern Ireland there is significant geographical variation in the provision of services. The wider system can be very difficult to navigate and has often been perceived as fractured, overly complicated and bureaucratic.

A common example in Hospice care is the late referral of patients, particularly those with terminal non-cancer diagnoses. These delays are often due to the lack of recognition of specialist palliative care needs.

As a charitable organisation, hospices often face challenges in being fully included in strategic healthcare planning. For example charitable hospices were excluded from the regional 'Encompass' programme.

Making palliative care a legal right as it is in England and Wales could address barriers related to commissioning and service provision.

However, funding limitations drive unnecessary competition between charitable hospices.

Delays in implementing important regional initiatives add to complexity and creates barriers e.g., Advance Care Planning, regional DNACPR and Power of Attorney for Health and Welfare.

From the children's hospice perspective the challenge is ensuring clarity about what children's palliative care is and how it differs from services for children with disabilities or learning disabilities Children's palliative care is holistic support tailored to the most medically complex children who are unlikely to live beyond their 18th birthday.

What additional services could/should be provided?

Regional leadership should develop a regional palliative care strategy and/or policy which addresses commissioning, workforce planning and service provision.

The introduction of electronic prescribing would minimise unnecessary delays in medications for patients in the community.

Establish a clear governance framework for community prescribing inclusive of independent sector organisations.

Provide regional out of hours advice and support for service users as well as health care professionals.

Ensure dedicated, reliable wraparound social care services during final days to enable people to die in a place of their choosing.

Fund in-reach of palliative care/ specialist palliative care services to emergency departments to best support patients with palliative needs and maximise patient flow.

Allocate funding for comprehensive palliative care/ specialist palliative care services to the care home sector across the region.

Appoint a regional lead for palliative care with sufficient accountability, authority and influence to drive meaningful change.

From the children's perspective palliative care service should include a medical lead at level 4, out of hours services, and adequately resourced supported short breaks to properly support families.

Integration of Services

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

Charitable hospices struggle to fully integrate as they operate outside of the NHS. Notably, they have not been included in the Encompass programme.

The involvement of multiple provider organisations, and variation across regions, complicates integration and increases the chance of duplication and unnecessary variation.

In addition, the continued under-funding and financial uncertainty faced by local hospices prohibit progression of opportunities for improvement as associated costs pose organisational risks.

Should palliative care be a regional service? Please outline your reasons in the box provided.

Yes. Palliative care should work to a regional policy and strategy. However, it is essential to maintain the flexibility needed to deliver services across

Northern Ireland, as a one size fits all approach is not feasible.

With specialist palliative care being a relatively small workforce, greater regional working would provide more resilience.

To support commissioning, clear service specifications for specialist palliative and end of life care services (as per NHS England Publication reference: PR1674) should be developed. These would ensure clear provider responsibilities and service provision against specification, aligned to appropriate remuneration dependent on levels of care provided.

What can be done to improve integration?

Develop a regional palliative care strategy and/or policy with an appropriate budget and leadership to drive meaningful change.

The Republic of Ireland has recently published their palliative care policy which includes 100% funding of hospices and better integration into the HSE. This is a strong model to emulate.

Change legislation to make access to palliative care a legal right.

Strengthen regional palliative care leadership and empower it with the authority to implement effective change.

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?

NI Hospice successfully piloted a community rapid assessment and intervention service for people with increased complex needs in the Belfast area. This was very well evaluated, demonstrating significant improvements in patient outcomes and reducing avoidable hospital admissions.

Unfortunately, due to a lack of funding, the service could not be sustained or expanded to provide the much needed 7 days per week service, and it had to be discontinued. We could provide more details of this pilot upon request.

NIH continued to advance its work to enhance holistic and specialist multi-disciplinary palliative care at home through funding from the Cancer Charities Support Fund up to March 2024. During this project they provided more

encompassing care through a multi-disciplinary approach, at home, to improve the quality of life of people with cancer. This increased Specialist Nursing and Medical care in addition to newly providing Complementary Therapy and Social Work, supporting families, carers including children and young people, to navigate the journey of dealing with death, dying and bereavement. Overall, this service enhancement delivered an additional 5,635 interventions from the team and provided valuable learning and service-user feedback to inform future care provision.

In 2023-24 NIH Specialist Community Nursing Teams supported 1695 patients to die in the place they call home, representing an indicative HSC Trust saving of 5085 acute bed days (>£2.8m indicative cost saving based on a typical end of life admission to hospital lasting approx. 3 days). During the same period, through supporting 230 admissions for complex symptom management and end of life care, the adult in-patient unit represented an HSC Trust saving of 5634 acute bed days for patients presenting with complex physical, psychological, social and spiritual needs. The antenatal pathway for families who receive a palliative diagnosis at the 20 week pregnancy scan and work with fetal medicine in Belfast has led to increased and earlier referrals for palliative care. This achievement aligns with one of the objectives of the current paediatric palliative and end of life care strategy.

Collaborative efforts to develop the Palliative and Life limited Nurse role employed by NICH but based in the RBHSC has brought benefits. This role has improved advance care planning, choice of location of care, and support for professional in the acute environment for difficult conversations. This role is the main support for the Palliative Consultant Role.

Horizons Project is a collaboration with NICH and Trusts to provide bereavement support for families who experience the unexpected death of a child. This project is based on charitable funding. Details on all projects are available.

Do you think that families receive sufficient support when accessing services?

Please outline your reasons in the box provided.

No. Accessing palliative care can be a challenge for patients in a chronically under-funded, under-resourced and under-valued services. The unnecessarily complicated and bureaucratic system is a challenge for patients to navigate.

Funding and Strategy

Do you think the current funding for palliative care is sufficient? Please outline your reasons in the box provided.

No. The current funding of local charitable hospices is inadequate.

Contributing factors include the absence of accountable commissioning, the lack of a multi-year budget and the absence of a regional palliative care policy.

Charitable hospices face significant challenges in attracting healthcare professionals with an appropriate wage, in operating safe services and providing robust clinical governance equal to, if not better than, large NHS Trusts with a fraction of the resource.

A letter from the Director of Secondary Care Dean Sullivan, dated 3rd March 2004 instructed all Chief Executives of Health and Social Services Boards to implement 50:50 funding arrangements for agreed inpatient and community hospice services from 2004-05 & 2005-06 respectively, and to tighten up service delivery agreements with hospices. Based on current statutory funding levels and expected costs for FY24-25, NI Hospice forecasts that it will be funded to approximately 41% across all of its charitable activities, equating to a £1.201m shortfall in the agreed 50:50 statutory funding commitment of 2004. (see below for details across the services).

	Total Expected Cost FY24-25 £000s	Current Stat. Funding £000s	Stat. Funding %age	Funding Gap £000s
Adults IPU	£ 5,487	£ 2,361	43%	£ 382
Adults Community (Inc. HaH)	£ 4,231	£ 1,910	45%	£ 206
Adults Total	£ 9,718	£ 4,271	44%	£ 588
Childrens IPU & PALLS	£ 4,297	£ 1,497	35%	£ 528
Childrens Bereave. & Fam. Supp. & HaH	£ 765	£ 297	39%	£ 85
Childrens Total	£ 5,062	£ 1,795	35%	£ 613
Total Care Costs / Funding / Funding Gap	£ 14,780	£ 6,066	41%	£ 1,201

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.

No. Research undertaken by Marie Curie projects a 32% increase in demand for palliative care in Northern Ireland by 2048, compared to 2023.

The Hospice sector in Northern Ireland provides a substantial proportion of all palliative care services delivered regionally. In addition, Northern Ireland is estimated to have the highest number of people accessing hospices per 100,000 of population across the UK. Despite this, the funding position is insufficient to meet existing needs, and therefore entirely unsustainable for future demands.

Funding pressures are putting current services at risk of being scaled back.

Constant financial instability and risk diverts attention away from providing clinical care and prevents meaningful development and growth. (see above for detail) For many years there has been an awareness of the increasing aging

population and their increasing palliative care needs. However, there has been no planning or investment to meet this future demand.

A multi-year budget would greatly help all hospices with planning and development.

Improved service delivery agreements should be implemented, with standardised contract templates across all Trusts, to include: -

- 1) Multi-year contracts. Allows hospices to plan ahead financially across multiple periods, eliminating the current 'hand to mouth' existence. This would result in hospices being sustainable and reliable partners to the NHS, enabling hospices to offer their workforces the benefits of working within stable organisations.
- 2) Agenda for Change uplift applied to full contract value. Pay awards are the biggest risk to hospices' cost base. Providing NHS grade service requires NHS grade remuneration in order to attract and retain the highest quality of staff. This would remove the need for hospices to ask for 'pressures monies' during end of year monitoring rounds.
- 3) Service Specific KPIS & volume based remuneration. Establish Agreed service levels in line with NHS metrics, with agreed per service unit reimbursement levels. Current 50% reimbursement of an NHS General Medical Bed is insufficient to cover the true cost of care

Improved clarity around commissioning goals and decisions would be important to ensure effective service provision.

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.

Yes.

Baseline data of projected population need across the age span to include antenatal data.

Baseline data of current service provision.

Include generalist and specialist palliative care.

Detail commissioning arrangements.

Workforce planning strategy.

Review leadership arrangements to facilitate change.
Development of a national clinical lead role.
Adequate funding to deliver any strategy objectives.
Proposal to make access to palliative care a legal right.

Any other comments

We would like to acknowledge the contribution of our local volunteers, without whom charitable hospices would be currently unable to provide services.
We would also like to acknowledge the people of Northern Ireland whose continuous fundraising efforts sustain services and fill the significant gaps left by inadequate statutory funding.
We would lastly like to acknowledge that despite all the chronic problems and challenges listed above, high quality care is delivered through the compassion, care and dedication of our staff.