Northern Health and Social Care Trust

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

No there is not an understanding by the public of what palliative care is. Unless you are directly affected by palliative care, then there is limited understanding. Palliative care is normally associated with patients with cancer at end of life. If people understood what palliative care is, then this would help with managing patient expectations of ongoing medical management.

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?

Gaps:
Geographical differences eg. post code lottery
High areas of social deprivation
Difference in acute and community services
Difference between MDT access
A lot of services for patients with cancer and not for others
Marginalized groups eg. homeless, travelling community groups etc
Workforce gaps eg. CNS, AHPs, Chaplains etc
Need a regional workforce review
Funding - less flexibility with funding opportunities. This should be standardized across the region
Gaps in social support at home eg. more packages of care
Rapid access to specialist palliative care support
Rapid access to equipment
Structured support for parents with cancer who have children - talking to children
Complementary services End of Life Facilitators - to support staff caring for those patients who are end of life care.
Do you believe barriers exist that prevent equitable access to these services?
If yes, please provide examples in the box provided.

Yes

We don't have robust data to develop services eg. workforce planning
Accurate data per Trust on the number of patients who have palliative care needs
Work with a lot of service providers who maybe have more autonomy to develop services, potentially not in line with Trust. There should be more integration with all service providers.
Workforce - not a pull of specialist staff that we can access
Encourage development posts, where staff can gain experience, knowledge and skills Specialist Practice Course is not available to AHPs
Commissioning not always available - don't always have the staff able to attend
Palliative Medicine - changes to medical training for palliative care, may impact on workforce
No Succession Planning - aging workforce, not having the staff to replace
Changing to retirement options - partial retirement.

What additional services could/should be provided?

Increased workforce with a pool of staff to recruit into service
Need for permanent funding for chaplaincy
Introduction to Advance Nurse Practitioner in Palliative Care
Investment in community services eg. Specialist services
Access to specialist pharmacy service also enhancing local services
Need to enhance the OOHs service eg. timely admin of medicines
Investment in hospital specialist services
End of Life Facilitator
Keeping people at home - more packages of care, rapid response, equipment, easy direct advice line.

Integration of Services

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

Not very well - still working in silos
Communication between providers/ professionals - there is poor transfer of info eg. DNACPR can't get this transferred between care settings
Palliative care not integrated in other services eg. HF clinics, frailty etc
The specialist providers are working in silos too ie. Hospices.

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

No

Local services should be delivered - however regional co-ordination would be helpful
Revised palliative care strategy - nearly 15 years out of date
Palliative Care Services should be standardized however some flexibility to meet the need of the local geographical context
More accountability for pall care.

What can be done to improve integration?

Looking at regional oversight - consider a regional network, which is different from the PCiP
Senior oversight in every organization eg. AD or director level
Better improved communication
Improved relationships.

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?

Medical education - simulation communication training to final year medical students.
RCN - Specialist Palliative Care Award (2025) - first award that was introduced this year. Hospital staff recognized for all their great work.
AHP - The Advancing Healthcare Awards recognize and celebrate the work of AHPs, healthcare scientists and those who work alongside them in support roles, leading innovative health care practice across the UK.
Macmillan Awards- national award which the specialist community team were highly commended on their work. The toolkit was an exemplary model of co-production and co-design with service users, who themselves had identified a gap in available information for patients with advanced cancer.
Front Door Palliative Care through rapid response in ED/ DAU from Palliative Medicine Consultant input. Helping to avoid admissions to acute hospitals.
Development of a palliative care training directory - this was shared regionally with PHA and SPPG as an exemplar of best practice.
Health and Wellbeing Toolkit - online toolkit for patients with advanced cancer. The DoH are very interested in this work in making it regional. Engagement ongoing.

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

No

They need a single point of contact as often they don't know who to contact.
Can be difficult getting GP appointments.

Funding and Strategy

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

No

People are living longer with more complex needs who are ultimately palliative.

Funding has not been matched with the growth in the demographic.
Increase in cancer CNSs - this will impact on SPC, not the workforce to match this.
More younger people are being diagnosed late, and not fit for treatment, thus referral to SPC SPC has been underinvested for many years - government not seeing the added value the service provides.

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

Very fragmented funding - different services in different areas. Some areas have no rapid response.

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

Workforce
Predictive figures on caseload
Acuity of patients
What are the clear standards for access to palliative care - benchmarking eg. All patients with cancer have a CNS, what would this look like to palliative care
More accountability for targets and standards.