Western Health and Social Care Trust

Specialist Palliative care services include:

- Palliative care in patient ward Omagh Hospital
- specialist palliative care hospital liaison teams
- Macmillan AHP and Social Work team
- Foyle Hospice for Omagh and Fermanagh community team
- Marie Curie contract with Western Trust for palliative care community nursing services trust wide
- wider specialist palliative care team
- Supportive Care UK contract for the provision of consultant level out of hours medical advice for palliative care

Current state of palliative care services

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

Published evidence suggest that the public do not understand palliative care and the palliative care approach. There seems to be misconceptions that palliative care is only afforded to those with a cancer diagnosis or those nearing end of life.

Public perception would suggest that palliative care has negative implications rather than, improving quality of life and living well. The misconception seems to be that palliative care input, is the 'beginning of the end of life'.

One of the main barriers is lack of understanding and awareness of what palliative care services are and what it can provide. A wide public education campaign or awareness campaign could improve this.

There is confusion between generalist and specialist palliative care and the different roles and teams providing the services. It is also evident that health care professionals also have misconceptions about palliative care and palliative care services.

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?

- Inequitable provision across NI, post code lottery, not all Trusts are funded for palliative care services at the same level relevant to their palliative care population

- Lack of 24/7 services for palliative care, unlike many other medical specialties and within the community
- Recent Cancer strategy, provides clear recommendations which includes palliative care, but is limited to those with a cancer diagnosis, therefore omits many patients with palliative care needs
- Lack of a NI Palliative Care Strategy, unlike our neighbours in the Republic of Ireland, which is fully funded.
- there is no regional leadership within the NI Executive and or Department of Health for palliative care to advocate for and commission services for palliative care.
- there is clinical lead for palliative care services in NI
- access to services in rural areas
- lack of a single directory of all palliative care services in NI, which would identify where gaps are.
- major lack of investment in palliative care services,
- lack of fully funded Hospice services by the NI Executive.

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

Yes

- funding

- geographic/rurality

- religion, social and cultural

- lack of integration

- no clear public health data on palliative care

- no population health analysis of palliative care needs within NI.

- lack of a Pallaitive Care Strategy

- poverty

- accessing community pharmacy for pallaitive care drugs

What additional services could/should be provided?

- The failure of Northern Ireland to have electronic prescribing in place unlike the rest of the UK leaves families travelling across the country with loved ones very ill at home seeking medication that could be made readily available if electronic prescribing was in place. (Current estimate in 2030)
- Establish a Single Point of Contact for Palliative Care services to ensure patients and their families have seamless and consistent access to services and to avoid having to navigate a currently complicated system.
- A live directory of palliative care services

- Current services should be available in all areas to all palliative patients 24/7 365 days per year.
- rapid access to domiciliary cares services at end of life for those that require it and to enable patients who are in hospital and wish to go home, to do so.

Integration of Services

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

- very poorly integrated, there is lack of co-ordination and communication across the multiple services that can be providing care to a patient during their palliative and end of life phases.
- our systems are not designed to ensure effective communication and the exchange of information regarding the patient with palliative and end of life
- care needs, for e.g., there is no one central place to view advanced care planning documentation by all professionals involved. However this may improve with the introduction ENCOMPASS to our Trust
- for ENCOMAPSS to aid full integration it must be rolled to all service providing palliative care to that patient, e.g., the Hospices.

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

Not sure

- our experience has been that regional services are mainly located in Belfast and this becomes a challenge for all population west of the Bann and has proven to be particularly challenging for rural populations, e.g., Omagh and Fermanagh
- Need to be able to meet the population needs on a local level closer to home for this very vulnerable patient group
- However we are a population of 1.8 million with multiple organisations delivering different aspects of Palliative Care service in an ad hoc non joined-up way.
- There is need in all areas of NI and the inequity in recruitment for rural areas of senior clinicians is going to remain without a regional approach
- A regional service with one point of contact will also allow for the standardisation of service delivery, audit and quality improvement initiatives and ensure that trainees are exposed to Palliative Care services across all of NI.
- A regional approach may enable a consistent roll out of advance care planning policy and supporting Respect documentation. This is a priority.

What can be done to improve integration?

- A regional service with one point of contact will also allow for the standardisation of service delivery, audit and quality improvement initiatives and ensure that trainees are exposed to Palliative Care services across all of NI.

- A regional approach may enable a consistent roll out of advance care planning policy and supporting Respect documentation. This is a priority.
- All Hospices and Palliative Care services be integrated within the ENCOMPASS system ASAP so we can collectively share the same patient records together. Integration will not be possible without this.
- Commitment to produce a Palliative Care Policy by 2028
- Reintroduction of workforce planning for Palliative Care linking the growing need for services with the demographic changes that are coming
- Introduction of electronic prescribing in Northern Ireland as in other parts of the UK would allow medication issues at the end of life to be dealt with promptly and reduce family and patient distress.

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?

Integrated Care Fellowship Consultant Training Programme. This four year programme to train consultants able to work in both community geriatrics and palliative care was designed to meet the needs of the population in the Omagh and Fermanagh area. By creating a workforce trained locally in both Palliative and Care of the elderly medicine we are safeguarding a medical workforce for the future who can lead the sort of integrated service that we need.

Co-Creating Hope Project - Early phase of this programme to link up the Fermanagh and Omagh council, the Western Trust, voluntary sector and other community based assets to develop a population based approach to meeting the needs of the frail, elderly and dying across the Fermanagh and Omagh area.

Roll out of the Just in Case Boxes and supporting guidance and documentation – now V 14 – successfully implemented – await final draft of V14 documentation – showcased regionally / SPPG / DoH – need agreement regarding procurement of the documentation via BSO.

Development and implementation of Out of Hours and In hour pathway – guidance and contacts for staff – this has included implementation of a dedicated number for Out of Hours for community staff to access timely support and advice from Western Urgent Care out of hours GPs. Currently this is being piloted for Care Homes in partnership with WHSCT care home support team, WUC and Specialist Palliative Care Team.

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

Not sure

Can not confirm that sufficient support is given to all families all of the time.

Funding and Strategy

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

No

- as previous answers set out, there is gaps in service provision and inequity in service provision
- there is a growing aging population who are living longer with multi-comorbidities, who will require increasing pallaitive care support
- there has been no investment in pallaitive care for many years
- increasing family dynamics, who are living locally to support their loved ones
- we have gaps in our service provision and we are already over spending in our current budget.
- we have unmet need to support families with love ones at home, which is their preferred choice pf place, who then sometimes escalate into hospital
- inappropriately and spend long waits in ED.
- shortfall in hospice funding, often reliant on charitable funds, with approx. 33% of funding coming from the Department of Health

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

the current funding model for hospices needs reviewed. The decision that Hospices are no longer exempt from National Insurance increases will lead to reduced services.

palliative care services including hospice services, need to be fully funded and treated the same as any other specialty, that provides medical care to a patient.

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

- would be more helpful if this was a Palliative Care Policy that brings responsibility and accountability.

Including:

Integration of services
Workforce planning for the next 20 years
Data collection of services to demonstrate impact
Funding strategy for charitable services delivering Palliative Care
Single Point of Contact and access.
24/7 365 service including the Out of Hours services, with adequate multi- disciplinary team resources

Implementation and resourcing of the Advanced Care Planning Policy

Any other comments

Our Palliative Care service cannot be left in its current state as it is a service that more and more families are going to need, including our own.