Belfast Health and Social Care Trust

The Belfast Health and Social Care Trust provides Palliative and End of Life Care Services across many specialties.

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

Public awareness of palliative care as an essential service for people with life limiting disease or close to the end of life is limited and could be vastly improved. The standard of death literacy in Northern Ireland is poor.

A lack of a co-ordinated public awareness campaign around palliative and end of life care (PEOLC).

Many professionals are reluctant to engage with Specialist Palliative Care (SPC) teams- and this is compounded by professionals failing to recognise when a patient is dying. Late engagement of the palliative care team reinforces the myth that palliative care is just for the last days of life and it denies the patient and their family support and improved quality of life.

Regional initiatives (e.g. ACP and RESPECT) have not been implemented, leaving NI behind the UK in terms of legislation, public engagement and public awareness. A regional end of life care template has not been developed, which leaves patients at risk of variable care, rather than a minimum standard of care for staff to follow and deliver.

Recent coverage around the Assisted Dying Bill in England has diverted attention to assisted dying without promoting palliative care as a necessary and viable alternative. There are concerns that funding will be diverted from PEOLC)to the assisted dying movement.

Generalist and SPC roles are misunderstood by professionals and the public.

Complex systems and regional variation can lead to confusion for professionals and patients/carers.

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?

Inequities with Hospice's being partially funded while all other medical and nursing services are considered "core business". Limited capacity in Hospices.

Roles such as Advanced Nurse Practitioner, should be consistently developed for specialist palliative care across the region 7 days a week.

Limited access to GPs both in hours and Out Of Hours (OOH).

District Nursing (DN) services have experienced an increase in EOLC workload.

OOH medications are not easily accessible.

Palliative care services are underfunded, within hospital and community.

Lack of 7 day a week SPC services within the community and hospitals.

In-hours specialist services in Belfast are extremely pressured.

In Belfast, there has been no new commissioning monies for SPC teams in recent years.

OOH medical remote advice is provided by a private company. The majority of calls happen over the weekend, indicating that a 7-day service/hospital presence would be well used.

A lack of standardisation of care has resulted in variations in care, depending on the site where a person dies.

Regional variation on services and OOH access to care, support and advice.

Very limited Palliative Care Out-patient services.

Poor integration and coordination of services for this population.

Specialist AHPs resource: insufficient to meet demand.

Some Trust bereavement staff are funded non-recurrently via charitable funds.

Lack of funding for PEOLC training for all staff working in palliative care.

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

Yes

Barriers exist both regionally and locally.

Poor planning and a lack of a standardised regional approach. For example, the lack of a regional End of Life individualised plan of care template has resulted in unacceptable variations in care.

Regional variation and limited availability of: OPD services, social care and OOH access to care, support and advice.

Increase in complexity, longevity and expectations of patients that has not been matched with clinical resources.

Poor provision of PEOLC for non-malignant conditions.

Very limited access to GP services (both in hours and OOH) causes a downstream pressure. This has resulted in some patients inappropriately accessing unscheduled care.

Reluctance to refer to palliative care by some healthcare professionals e.g. considering palliative care to be the last days of life or not recognising dying.

DN and keyworker role: lack of resource in relation to training and awareness.

Lack of funding/training e.g. Advance communication skills.

AHPs under resourced.

OOH medications are not easily accessible.

SPC services (hospital and community) are grossly underfunded and undervalued.

Lack of 7 day a week SPC services. In-hours services run for 40 hours per week, leaving 128 hours per week uncovered.

In-hours SPC services in Belfast are extremely pressurised.

Hospices are financially stretched and struggling, particularly with the increases in National Insurance contributions.

What additional services could/should be provided?

- Rapid access for palliative care patients for assessment or imaging or direct admission if required, to avoid using unscheduled care routes for general patients.
- Regional approach to clinical services and systems. Regional approach to planning, coordination, developing pathways, policies,etc.
- Adequately funded hospice services.
- Adequately funded specialist services in hospitals and in the community.
- Mandatory palliative care training for all healthcare professionals at induction and regular ongoing mandatory training in general palliative care for all HCPs, including the private sector.
- Advanced communication skills training for all staff involved in palliative care.
- Update in regional guidelines e.g. Breaking Bad News (2003)
- Single point of access for all palliative referrals including care homes.
- A responsive, timely MDT rapid response in times of crisis.
- Fully funded bereavement teams within trusts.
- Ensure equity of access to all palliative care patients with non-malignant diseases.
- Ensure equity of access for marginalised groups e.g. ethnic minorities, prison population and travelling community.
- Develop supportive care clinics in line with UK models e.g. the Christie Hospital.
- Raising awareness of palliative care in the wider community across all age groups including schools.
- If there is an increase in end of life palliative care at home, there will need additional nursing workforce for District Nursing at night.

Integration of Services

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

Services are integrated to an extent but continuity of care is lacking across all sectors due to an under-resourced workforce and poor integration of IT systems.

Encompass will go some way to linking hospitals and community services, but hospices are not currently linked in and many GPs will not have direct access to the system. This creates a barrier and a risk.

Communication of clinical information between organisations and trusts requires further development to ensure a seamless and safe transfer of care.

The Belfast Trust is creating a single point of access for co-ordination of community PEOLC services and care. If this project is successful it could provide a template for regional co-ordination and integration of services.

There are examples of palliative care pathways that have improved patient care e.g. the antenatal palliative care pathway.

Variation of MDT availability across Belfast impacts on service integration e.g. time to organise and attend MDMs and GP MDT meetings.

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

Yes

A regional service approach would remove inequities and ensure that there is no post-code lottery. For this to happen, there needs to be a political will and leadership to ensure that patients and families are entitled to good palliative care, with adequate safety nets to ensure that safe care can be delivered, regardless of one's area of residence.

A regional approach to getting basics such as a public awareness campaign on normalising dying, Advance Care Planning, RESPECT, DNA CPR should enhance the safety and effectiveness of end of life care across the region and promote the benefits of palliative care to all healthcare professionals.

Commissioning should be considered regionally to ensure equity and transparency.

A guaranteed equity of access to services and standards of care across the region, supported with adequate funding.

What can be done to improve integration?

- Fast-track IT integration across all services, in particular to include the hospices
- Commitment to delivering palliative care to all people as a basic right in healthcare.
- Raising awareness of what palliative care is, who can access it, where it can be accessed (for both public and professionals).

- Increase the profile of palliative care in all governance structures within the Trusts, to ensure that palliative care need is appropriately identified, addressed and accounted for in each service.
- Investment in workforce and MDT working

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?

Ward 5F in the Royal Victoria Hospital- comfort checklist.

DOVE project in the Stoke Ward.

Marie Curie Night sits service which is invaluable for patients to remain at home at the end of their lives.

The piloting of Just in Case boxes in Belfast with the district nursing teams.

24-hour District Nursing service available to deliver PEOLC.

Horizon House hospice: Families appreciate a more home from home environment in which to spend time with their babies and extended families.

Belfast Trust Community Palliative Care hub (without dedicated funding) is in development in collaboration with BHSCT, Marie Curie and Northern Ireland Hospice (due to start in early 2025), and will promote co-ordination of community palliative care, with direct access for patients to self-refer.

There are many examples of excellence in services, evidenced by the returned compliments and thanks from service users.

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

No

Patients and families are not aware of all of the services and supports available. There is a lack of publicly available resources to help this.

Patients and families struggle to access services due to the significant barriers previously mentioned and due to stretched services that struggle to meet growing demand.

Access to OOH medications and practical help is a significant hindrance.

Healthcare professionals not always up to date on the availability of current services.

Earlier integration of palliative/supportive care could increase awareness and access to this support.

Carer distress: need for rapid access to services. i.e. access to hospice, social care, etc.

Funding and Strategy

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

No

The lack of multi-year budgeting and commissioning impacts on service planning and developing.

Succession planning and career development are impacted by inadequate and non-recurrent funding.

Community general palliative care is not adequately funded—GPs no longer have QOFs or dedicated funding to enhance their palliative care services.

District nursing teams are under resourced when benchmarked against DOH recommendations. Therefore impacting end of life care provision.

Hospital and community specialist palliative care teams are underfunded to meet demand. There has been no workforce investment in recent years.

Hospices are struggling to maintain services as workforce costs and treatment intervention costs rise, with little expansion of statutory budgets. This puts services at risk.

Cost neutral initiatives rarely get implemented and negatively impacting existing service provision. E.g. ACP policy implementation and advanced

communication skills training.

Inadequate resource to provide reactive palliative care for the large population of older people who are in care homes

Specialist Palliative Care Workforce Planning Report Northern Ireland 2017 – 2024 recommendations have not been implemented.

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

There is a predicted significant increase in the number people requiring palliative care in the future due to an increase in elderly population with increasingly complex needs.

Hospices financial modelling is out of date and unsustainable. The hospices in Republic of Ireland receive 100% statutory funding, to include staffing costs, in-patient and out-patient services and to allow for planning.

All Hospices appear to be in some financial difficulties with increase in general utility costs and with the recent rise in Employers National Insurance contributions, this is bound to have an impact on services.

There is a significant dependence in charitable contributions to fund hospices.

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

The Living Matters/Dying Matters strategy (2010) had no funding stream and therefore it was not fully implemented. A new 10-year strategy with realistic aims, objectives and funding, would provide clear direction, coordination and accountability for delivery of services. This will require political commitment and leadership to prioritise palliative care.

The new strategy should include all healthcare settings: statutory, charitable and private e.g. care homes and hospice. It should encompass all life limiting conditions addressing the holistic needs including mental health.

The new strategy should address deficits in MDT service provision and promote the public health agenda.

A review of current commissioning is needed, to provide a responsive solution to the new and expanded problems that the sector faces.

There is a need for a robust palliative care workforce plan.

The impact of grief and bereavement is felt through generations and impacts on the general wellbeing of society. The new strategy must address care during pregnancy through to care of the elderly.

Any other comments

The population of NI deserves excellent palliative care services, but even “good enough” services would be acceptable.

There is a need for support/ profile / funding and leadership to achieve this.

Political and public awareness campaign is essential to enable the public to make informed decisions about place of death and advance care planning.

The modelling predicts a large increase in the number of people dying in NI in the next 25 years. This will require an increase in the workforce across all disciplines in acute hospitals and community.

Poverty related to bereavement and grief needs to be recognised e.g. loss of income, prolonged grief reactions and mental health consequences.

The Social care model to support people to remain at home will need to be reviewed and resourced.