

Trust Bereavement Co-ordinators Northern Ireland

Collectively we are Trust Bereavement coordinators from Northern Ireland with a wealth of knowledge and skills and caring for patients and families in specialist palliative care, oncology, haematology, ICU nursing, Organ donation, Chaplaincy and counselling.

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

We feel that the public perception of palliative care is that it only relates to the end of life. There is also a lack of knowledge between the difference in generalist and specialist palliative care. One of the miss conceptions is that palliative care is only for patients who have a diagnosis of cancer rather than understanding many illnesses are treated palliatively.

There is also a lack of understanding from the public and staff of the differing roles within specialist palliative care, Marie Curie, Macmillan and more.

Death is a taboo subject in Northern Ireland and the public avoid looking for further information perhaps due to a fear of what they might uncover.

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 appears to be a massive gap in the provision and accessibility of palliative care across Northern Ireland, this includes both acute and community settings. This is particularly visible at weekends, bank holidays and out of hours.

Within specialist palliative care there is a lack of multi disciplinary team professionals including, dietitian, physio, lymphoedema service and chaplaincy etc.

Limited bed capacity to access specialist palliative care units and therefore dying on waiting lists. Bereavement support across Northern Ireland is inequitable for adults and children due to funding in Trusts. Bereavement support for families who are grieving the death of a baby, child or young person is also a postcode lottery depending on the circumstances around the death and where they live.

There is NO core funding for bereavement services in Northern Ireland.

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

Yes

For people with a serious mental illness there is a lack of specialist palliative care support and expertise in this area. This is also witnessed in learning disability, ethnic minorities, homelessness, disadvantaged educational background and minority groups. These cohorts of people do not have the same access to palliative care services and many of these people do not know how to access this support.

Barriers also exist because of the lack of understanding of how to refer into the services that are available.

What additional services could/should be provided?

- Bereavement support for all families
- Lymphoedema services
- Talking therapy
- Move more
- Specialist palliative care hubs
- 24 hour, seven days per week access to palliative care services
- nutritional support
- Health and wellbeing clinics (for all palliative care patients)
- Emergency Departments should have a specialist palliative care designated health care professional
- Equitable access to specialist palliative care pharmacists

Integration of Services

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

Palliative care services are not integrated well across the health system through primary, secondary and specialist care. Gaps in practice are evident

mainly because of the IT systems that do not cross fire walls into hospices from hospital and community settings.

Lack of funding leaves all services under pressure with inadequate staffing levels.

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

Yes

A regional palliative care service across Northern Ireland would provide integration and understanding of palliative care services and hopefully improve equity.

What can be done to improve integration?

We need an IT system that will cross the fire walls that hinder other areas from accessing vital information to provide continuity of care.

The RESPECT document will also provide integration.

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?

"Care of the deceased adult and those important to them" regional guidance for registered nurses

Specialist Palliative Care hubs are available in SE Trust

DOVE project in stroke ward in RVH

PEARL resource in SHSCT

Comfort Trolleys/boxes available for families at end of life

CRADLE bag provided to mothers when they have a pregnancy loss

Bereavement outreach calls provided in Belfast Trust, SE Trust, Northern Trust and Western Trust

Bereaved NI website for Northern Ireland

Advanced communication skills training

Marianne Tinkler (PhD examining specialist palliative care for people with serious mental illness) QUB

Learning disability consultant nurses (pain tool)

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

No

No, families do not receive sufficient support in a timely manner. Health professionals often are unaware of the appropriate referral pathway and EOL support is often requested too late resulting in patients and families not receiving the care they should at end of life.

Funding and Strategy

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

No

Lack of funding for specialist palliative care services across acute, community and voluntary sectors. Hospices receive on average only 30% core funding.

There is no core funding for bereavement services who rely on charitable funds to pay their staff and in some areas this is not an option, resulting in the services being withdrawn and creating an inequitable service.

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

See above comments

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

A palliative care strategy would provide direction for the next ten years but only if it comes with appropriate funding to support palliative care over this time period.

It must also include bereavement support to those that are important to the deceased person.

Any other comments

Overall there is clear gaps in practice and lack of funding.

If you were planning a birth there would be extensive support provided yet the one sure thing we know is that we will all die and there is not enough specialist care and support to help people to die in a dignified and peaceful way.

It appears that we rely on charities and fund raising to fund specialists who provide care at end of life. If the public were asked to finance intensive care units there would be an outcry