

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals

Submitted on 2025-01-09 12:15:54

Consent

1 The Committee for Health would like your permission to publish your response as part of the survey results. Please indicate your preference.

Consent:

Publish response.

Who are you?

2 What is your name?

Name:

Niall Gallagher

3 What is your email address?

Email:

4 Are you a healthcare professional? If yes, what is your role? If no, what is your interest in palliative care services:

Yes

1500 Characters:

I am a social worker working on the Community specialist palliative care team. My role primarily is to provide support to adults who have been given a palliative diagnosis. That support includes emotional, psychological, spiritual, practical and financial. I also provide bereavement support in certain cases. My work also includes working with families who have young children and providing support with difficult conversations. My role also includes advance care planning. I work as part of a multi-disciplinary team and cover the whole trust area.

5 What is your organisation?

Organisation:

SHSCT

6 Do you currently work in palliative care services? If Yes, in what capacity?

Yes

1500 characters:

current state of palliative care services

7 In your view what is the current state of palliative care services in Northern Ireland?

Poor

8 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?

Yes

1500 Characters:

Many families equate palliative care with end of life care.

Death and dying are not something that people like to talk about.

Religion had a part to play. The Irish wake for example - with decline in religion there is maybe less focus on this aspect of life. Break up of communities.

An over emphasis on treating people. Palliative care is very medicalized and medics are maybe not having those difficult conversations with families.

Lack of palliative care training for health care professionals.

Families try to protect a loved one by not wanting them to know.

Death literacy lacking - not promoted.

Over dependence on healthcare for support as opposed to family/community

Access to services

9 Are palliative care services equally accessible to all who need them?

No

10 From your experience where are the gaps in the provision of service?

1500 characters:

Many people from marginalised groups do not have the same knowledge to access healthcare services. These groups include ethnic minorities (language), travellers, people with severe mental illness, learning disability, homeless people, people with addiction, prisoners, people with dementia.

My experience is that the majority of people who are referred to our team have a cancer diagnosis. Palliative care includes many other conditions that are not referred e.g. dementia, heart failure, neurological conditions, respiratory conditions. There are many other conditions.

There is a clear lack of awareness among health care professionals about palliative care. Many medical professionals can over treat and not refer to palliative care.

There is only one social worker on our team covering the whole trust, and yet many symptoms that a person is experiencing are social / emotional. People struggle financially when they are no longer able to work.

People living in rural areas have great difficulty in accessing transport (someone in Kilkeel recently didn't go to a hospital appointment as they were being quoted £200 for a taxi.

Hospice provision is scarce and many people have to wait on a bed

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

Yes

1500 characters:

Transport
Language barriers
Financial
Hospice provision
Lack of public awareness about palliative care
Lack of health care professional awareness of what palliative care is.
Not enough staff working within palliative care
Palliative care provision is sporadic regionally with different models
Urban / rural split - postcode

12 What additional services could/should be provided?

1500 Characters:

More hospice provision
Greater emphasis on advance care planning
Development of community projects - eg Life and Time in Rostrevor, compassionate communities - Derry
Similar models of palliative care regionally and better linked up
More social workers/ support workers in this area are needed given the issues people face - loneliness and isolation
People in nursing homes need more GP involvement to prevent hospital admissions.
24/7 care - to try and keep people at home
Better education for people from ethnic minorities as they can really struggle financially (no critical illness, etc)
How can we sensitively educate our younger population about death and dying

Integration of Services

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

1500 characters:

From my own experience social workers working within palliative care services regionally do meet regularly and share information which has proved invaluable.

I don't think palliative services are very well integrated as there are different models and different charities providing different services. Hospitals also have palliative care provision which doesn't always link in effectively with the community.

There is a good link up between primary care and specialist palliative care in some cases but as I have already mentioned some palliative conditions are

not referred.

There appears to be lack of leadership in this area and many within palliative care may struggle to identify who is leading this area.

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

Yes

1500 characters:

I think it should because it would provide a better structure and a more streamlined/ service. At the end of the day it should be for the service user as currently it can be difficult to navigate all the different services. The same applies for health care staff.

15 What can be done to improve integration?

1500 characters:

I think that community and hospital staff should inter change their roles frequently to increase better understanding and better communication.

I believe that all healthcare professionals should have the opportunity to meet regionally more regularly.

Legislation needs to be introduced for palliative care in Northern Ireland to implement better integrated structures. The current policy needs updated.

Hopefully the new encompass system will help with communication.

Best Practice

16 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?

1500 Characters:

Joint working with primary care and palliative care services (families benefit from information and ease of access)

Early identification and diagnosis allowing people to plan for the future

Marie Curie rapid response service

Marie Curie Helper service, Marie Curie night and daysits.

Macmillan support services (eg - benefits, Support worker in Craigavon hospital)

Community specialist palliative care team providing specialist service and information (eg Southern PEARL)

Having a keyworker is very important from early on

Hospice community support in the Southern area hospice and bereavement support

Life and Time service

Voluntary transport schemes - eg Bolster in Newry for rural areas.

Compassionate communities / Foyle hospice

All Ireland Institute of Hospice and Palliative care - for education and awareness raising

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

Not sure

1500 Characters:

Accessing services can vary depending on where you live and also your ability to access the health care system.

Some areas have better provision than others. An example would be someone from Newry accessing counselling / bereavement services in the southern area hospice as opposed to someone who lives in Augher.

Transport is an issue

Families living in poverty struggle with heating and transport

Getting carer support depends on what is available at the time and also where you live. Many people have died in hospital because they cannot get a care package.

Some people report difficulty in accessing their GP

Macmillan benefits only help people with a cancer diagnosis. It would be good to see a specialized/ central service helping people financially for all palliative conditions.

Funding and Strategy

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

Not sure

1500 characters:

I believe that with an ageing population, funding for palliative care needs to be viewed as a priority.

19 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.

Not sure

1500 characters:

We hear that hospice funding is challenging and depends on a lot of fundraising. I believe that hospices should get increased funding for their community services as people I talk to prefer to remain at home.

Again with an ageing population, hospice services will become more and more used. They are much more preferable to people than a busy acute hospital.

20 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

1500 characters:

I believe that community development is an area that is neglected as many with a palliative care condition needs can be met from local communities. There was a scheme in the southern trust called Family Choices which ran out of funding. It was an excellent service to support people at home.

Strategy needs to be clear in its definition of palliative care.

Tackling isolation

Tackling inequality

Funding transport schemes

One regional team structure - ease of access

Raising awareness (schools included)

More training in medical schools

Any other comments

21 Any other comments

1500 characters:

It is important that palliative care is treated as a priority given the ageing population and their health needs. Good palliative care should decrease the pressure on our hospitals allowing people to remain in the place that they choose. GP's should be targeted to provide better care for nursing home residents at the end of their lives as many experience unnecessary and undignified admissions to hospital.

Palliative care is about focusing on quality of life. Many symptoms include anxiety , low mood and emotional distress. There is a lot of focus on physical symptoms and over medicalization. While it is important to meet a person's physical needs, it is the other needs that are often neglected.