

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals  
Submitted on 2024-11-18 11:42:00

## 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 my response but keep it anonymous.

## Who are you?

2 What is your name?

Name:

[REDACTED]

3 What is your email address?

Email:

[REDACTED]

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 worked in specialist palliative care in [REDACTED]

5 What is your organisation?

Organisation:

[REDACTED]

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

No

1500 characters:

current state of palliative care services

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

Good

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?

No

1500 Characters:

The public often believe that Palliative Care is just about the end of life, giving medications and ensuring a comfortable death. They are often unaware about the difference between palliative care and specialist palliative care and that someone can have a palliative diagnosis and live for years.

## 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:

In-patients in the Downe Hospital receive a visit from the Palliative Care Consultant once weekly, as far as I know. There is no specialist PC CNS on site. However, my understanding is that Lagan Valley Hospital In-patients have a full time Specialist Palliative Care CNS and Palliative Medicine sessions for their patients.

There is a lack of specialist palliative care dietitians, OTs, Physios in the community.

In hospital, it is difficult to refer to a Physio who specialises in lymphoedema management and this would be a service that is needed by many patients with palliative care needs.

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:

Lack of funding.

Traditionally in Northern Ireland, Charities like Macmillan, NI Hospice and Marie Curie provided the services or pump primed posts in hospital. We rely on coffee mornings to fund specialist palliative care services and that would never be the case for an ICU or Maternity Services, so why is Palliative Care so poorly considered and valued?

We attach so much emphasis on planning to bring a baby into this world, so why do we not prioritise the planning and services as we leave this world?

12 What additional services could/should be provided?

1500 Characters:

Specialist Palliative Care Teams in hospital and community should include a dietitian, OT, Physio, Chaplain and Social Worker.

The care of a person and their family at the time of death should continue with the appropriate family bereavement support after their loved one dies. Tragically, Bereavement Teams in Hospital are also unfunded and the bereavement services that remain are relying on Charitable Funds to pay the staff to outreach to bereaved families. This cannot be sustained unfortunately.

## Integration of Services

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

1500 characters:

I have not been working in this speciality for a number of years, so I cannot comment. Sorry.

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

Not sure

1500 characters:

I see challenges with Palliative Care being a regional service as it is funded and delivered through Trusts, GP surgeries, NI Hospice, Marie Curie and Macmillan. For an IT perspective, that would be difficult with Encompass and firewalls to Hospices.

If it is possible, it would be a huge benefit to have a single point of access and this would alleviate the confusion about who to refer to, what referral form to complete etc.

15 What can be done to improve integration?

1500 characters:

A single point of access for services.

IT systems that are shared.

## 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:

The skills and knowledge among specialist palliative care teams is excellent and if there was investment in these teams, it would enable them to provide more education to generalists.

In the Mater Hospital, a specific comfort trolley is provided for families who are staying in hospital with their loved one who is approaching the end of their lives.

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

Not sure

1500 Characters:

I think the public are unsure what a Marie Curie nurse does and how they are different to a Macmillan Nurse?

In hospitals, referrals to specialist palliative care are often left too late. It is a crisis often by the time the team arrive and symptoms, emotional and spiritual support could be offered in the days before so that it wasn't a crisis at the end of life.

I'm not sure if it is widely known about the district nurse and their role as keyworker. The key worker is invaluable and if the patient is referred in a timely way, they can provide invaluable support and assistance with accessing other services.

## Funding and Strategy

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

No

1500 characters:

Not at all.

It has never been.

We rely on coffee mornings and fundraising to fund our services and this is shocking. We would not expect the community to bake buns so that we can have Maternity Services or an ICU.

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.

No

1500 characters:

Just this year, the Children's Hospice had to publicise that they were about to close beds, until the public came to their rescue.

Charities are struggling to fund their services and it is a shame that we are relying on the public to fundraise for palliative care.

The current model is not working.

There is no funding for bereavement services either.

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:

Yes, because if there is no new strategy then I doubt funding will be prioritised.

It should include:

A plan for the next 10 years - including workforce

Succession Planning

Integration between generalist and specialist palliative care

Education

Bereavement

Holistic Care at the end of life

Information Technology

## Any other comments

21 Any other comments

1500 characters:

Please consider the importance of Bereavement Services and the support that they offer to families. These services identify bereaved people who are experiencing complex grief and some who have active plans to end their lives. Early access to appropriate bereavement support should be a core component of the care of the family when their loved one dies.