Response ID [redacted]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2025-01-09 12:35:04

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:

[redacted]

5 What is your organisation?

Organisation:
Private health care

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?

Very 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:

Yes, basic understanding of the meaning but not the detail of the service user needs and services

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:

2023- personal experience when caring for mum, perfectly healthy, who was diagnosed with a geoblastoma grade 4. She had ten months.
1. Acute services at SWAH were unable to prioritise the needs of this group. Physio focused on prioritising discharges, whilst mum slowly lost her mobility sitting for 8 weeks. The one thing she was adamant she wanted to hold onto for a long as possible. Her mobility.
2. Mum waited unnecessarily for 8 weeks in SWAH as community carers could not be sourced. Primary care needs to revisit specialist carers based at the hospital for this patient group to get them home for their final days.
3. Palliative care in the community for fermanagh patients are based in Derry. Over mums 5 final months at home, they visited 3-4 times. Outside of this week could contact a voicemail, or another nurse, who did not know mum. Their input, came too little and was extremely fractured. This added to mums distress.
4. The teams OT and physio input was also delayed and to infrequent for this patient group, resulting in mum not having the correct equipment to transfer her when home from hospital. Luckily as an OT, I knew and was able to purchase what she needed. This is disgraceful. Other families would be left lifting loved ones.
5. Gratefully, we had wonderful support from mums GP, District nurses and in her final days, Marie Curie. Without whom, mums final months would have been more devastating that necessary. Please do better for the people of fermanagh.

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:

[redacted] her only option of hospice was omagh, travelling from enniskillen daily. This is impractical and she felt isolated at the thought.

The community Palliative care team were based in Derry. Again, impractical. The neurological sequelae of mums disease was an evolving array of disabilities, changing weekly. Professional assessment and treatment of these issues was absent via the Palliative care team. They were unable, fractured.

12 What additional services could/should be provided?

1500 Characters:

1. Rapid response carers for palliative care patients home from hospital.
2. Top priority, for the community palliative care teams to have more availability, to give face to face support to their patients and family's. Or if there is an inability to provide the service they should, then to communicate with the patients GP to take over and offer reviews. In our case, we took control and regularly contacted the gp for guidance in relation to evolving symptoms and palliative management.
3. For the acute therapy services to better communicate with the community team in relation to patients ongoing rehabilitation needs.

Integration of Services

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

1500 characters:

Overall the integration exists. However, in my experience, services are under resourced and geographically fractured. This greatly impacts the patient experience.

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

No

1500 characters:

Palliative care needs to be provided at a local level. Our palliative care nurse was driving up to 5 hours a day. Attaining 2 patients. . How many could she have seen at a local level? It is not practical or achievable.

15 What can be done to improve integration?

1500 characters:

Local palliative care teams.

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:

I do not unfortunately.

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

No

1500 Characters:

Our support was given via mums local district nursing team. We will be forever grateful to them. However, they were unable to advice on specified palliative and neurological symptoms, adding to their and mums distress. Having palliative care speciality support was largely absent in our experience.

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:

I can only imagine that our negative experience in relation to this team specifically was due to their location and size of locality they had to cover. Which usually comes down to underfunding.

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:

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:

A review of the patients journey start to end.
Better communication between primary and secondary care.
A focus of maintaining quality of life /rehabilitation for those transitioning from primary care to home/hospice.
Care in the community availability to be optimised for those retuning home.
More options of hospice care local to the populations

Any other comments

21 Any other comments

1500 characters:

Thank you for taking time to read.