

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-12-16 15:51:44

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 am interested as a learning disability nurse to advocate on behalf of people with a learning disability who do not always experience good palliative and end of life care

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?

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?

No

1500 Characters:

Public are Unable to differentiate between palliative and end of life care
There is no regional pathway - staff, patients and families do not know how to access support and at what point during a persons palliative care journey.
too many blurring of roles and responsibilities between palliative care services, acute care at home an district nursing

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:

People with learning disability continue to face inequalities when accessing palliative care. Diagnostic overshadowing due to someone's learning disability is still very much an issue. people with a learning disability should be able to access mainstream services through the implementation of person centered reasonable adjustments. there should be no separate pathway for people with a LD as this would contribute to the discrimination of people with a learning disability.

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:

Other professionals who do not work with people with a learning disability are too quick to consider DNRCPR - they need more education to see the person as a person first and foremost

12 What additional services could/should be provided?

1500 Characters:

more community support to prevent people with a learning disability having to leave their home and family and friends when their needs change

Integration of Services

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

1500 characters:

poorly integrated - roles and responsibilities and accessing services is not clear

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

No

1500 characters:

no but there should be regional consistency across all 5 HSC trusts. very unfair to expect someone with palliative needs to travel across the region if they are feeling so unwell.

15 What can be done to improve integration?

1500 characters:

regionally consistency in service provision across all 5 HSC trusts.

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:

Trainee Learning Disability Consultant Nurse working with Trainee Advanced Nurse Practitioner from local hospice to roll out palliative care awareness training to Trust staff and family carers

There is now a Regional Learning Disability and Palliative Care Meeting which is being led by Partnership Project Support Manager at DOH to look at palliative care needs of people with Learning disability - group only in infancy and includes representation from palliative care and learning disability services

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

No

1500 Characters:

Families do not know how access or who to go to for support

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:

not aware of funding details

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:

insufficient funding from DOH - too much reliance on fund raising for this valuable service

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:

needs to be considering in line with advanced care planning policy

Any other comments

21 Any other comments

1500 characters:

no