

Response [REDACTED]

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

Submitted on 2024-11-13 12:24:11

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] and we have 11 residential care schemes looking after people with dementia and 1 scheme that looks after people with complex learning difficulties. My interest is in allowing people to die with dignity in our homes and to support the family and staff to do this.

5 What is your organisation?

Organisation:

HOusing Association

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:

I think people view palliative care as only for people with Cancer or life limiting conditions, they don't see it as something that can be accessed for any end of life care. many of our families are shocked when it comes to end of life and the palliative care team become involved, they often think we are hiding a diagnosis of cancer from them.

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:

there are some excellent services provide by some Trusts but there is an inconsistency across the 5 trusts, referral pathways, criteria and information is different across all the trust and only adds to the confusion.

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

Not sure

1500 characters:

12 What additional services could/should be provided?

1500 Characters:

Services that support people without families, perhaps volunteers who could sit with people and support them on their journey.

Integration of Services

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

1500 characters:

there are some good examples of integration but in general it is very disjointed and one part of the system doesn't speak to the other

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

Yes

1500 characters:

to ensure a consistent and equitable service for all

15 What can be done to improve integration?

1500 characters:

more joined up working and including the voluntary and statutory services, not just the health care professionals

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:

SEHSCT and the SHSCT have good examples, but is inconsistent in other areas.

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

Not sure

1500 Characters:

again I think this can be mixed and inconsistent.

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:

The services are not always available due to funding issues or are time limited in duration which doesn't always meet the needs of the patient.

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:

the population is growing and more people are living longer so the need for palliative care will only increase so the current funding model is not fit for purpose. the fact that hospices rely heavily on their charity funding to fund nurses is not sustainable.

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

No

1500 characters:

I think we need action not strategies, there is a strategy that just needs to be reviewed and refreshed

Any other comments

21 Any other comments

1500 characters: