

Response ID ANON-PEFR-6RQK-H

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-12-16 14:57:26

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:
Gerard Leddy

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:

Specialist Palliative Care Service Lead.
Physiotherapist by background

5 What is your organisation?

Organisation:
Southern Health & Social Care Trust

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

Yes

1500 characters:

Specialist Palliative Care Service Lead

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:

People's general understanding that palliative care isn't only about end of life.

Barriers with people's perceptions and not wanting to talk about palliative care. Still feels taboo in areas.

Not enough resource to share information widely in relation to what palliative care really is, how to access and what is available.

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:

Large gaps in the out of hours period. Decreased resources available, especially in specialist palliative care in the evenings, overnight, weekends and at bank holidays.

Inequitable Out of Hours access generally across the region.

Difficulties in access to palliative medications in the out of hours periods.

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:

Not enough resources and funding to ensure standardised, adequate access for all.

12 What additional services could/should be provided?

1500 Characters:

Specialist Palliative Care supports in the out of hours period to support staff providing general palliative care.

Additional personal care support is needed to help ensure dignity and comfort at home as people approach end of life.

Integration of Services

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

1500 characters:

Not well.

Too many gaps and not enough regular communication. More regular meetings and joined up communication is needed.

All areas are seeing the same patients but not always discussing these patients and also documenting outcomes/plans/assessments etc in different places or on different systems.

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

No

1500 characters:

I feel local provision is still very important as local, personal knowledge is important to understand the problems with the patient and also the locality they live in which may impact how they are and what they have access to.

By moving it regional you may lose some of the personal and individualised approach which is required for true patient centred care.

Building relationships is extremely important when treating patients and families when they are at their most vulnerable

15 What can be done to improve integration?

1500 characters:

Better communication - might need larger resource to allow this to not dilute down time needing to be spent on clinical intervention.

More regular meetings across all interfaces if a number of interfaces or organisations are required to meet the demand.

All documentation on the same system or accessible to all involved in care.

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:

Life & Time Charity providing Out of Hours support to patients approaching end of life in the South Down & Mourne area.

Southern Area Hospice providing Out of Hours support to patients approaching end of life in the Newry area.

Local Specialist Palliative Medicine Consultant support, providing Out of Hours support to medics in Southern Health & Social care Trust. Helps ensure

timely support with access to the patient's information when providing specialist advice.

Compassionate Communities working across NI

Just-in-Case boxes being rolled out in Southern Health & Social Care Trust, South Eastern Trust, Western Health & Social Care Trust to increase access to medications required in the Out of Hours Period.

Single Point of Access pilot in Belfast Trust

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

No

1500 Characters:

I think this varies not only across trust areas but also across service delivery areas.

From looking at feedback at various times a lot of comments are returned in relation to patients/families not knowing where to reach out to, when to reach out or even how to reach out at times.

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 enough funding per head per locality. Patients are having to wait for services when they are vulnerable and in need.

A lot of palliative care service is being funded by the Charity Sector which doesn't feel like a sustainable model.

If babies were being delivered by staff in charities and relying on charitable donations to survive, I don't believe this would be accepted therefore why are people allowed to die while needing to rely on organisations that survive off charitable donations as their main source of income...

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 Funding model for the funding of hospices doesn't feel sustainable or sufficient as it is mainly reliant on charitable donations which can not be guaranteed.

This is going to have negative implications on paying growing wages and meeting the increasing need/demand that is predicted.

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, new strategy required.

It should include: identification, access to palliative care services, Support from Specialist Palliative Care, coordination of care, a patient centred/individualised approach and education for both professionals and patients.

A new strategy should tie in with the strategy released in the Republic of Ireland to show and demonstrate an All Ireland Approach which would be beneficial moving forward to maximise support, resource and sharing of knowledge.

Any other comments

21 Any other comments

1500 characters:

I think it is great to see this review/inquiry happening

Thank you