

## Response ID ANON-PEFR-6REJ-4

Submitted to Review of access to palliative care services - Organisations/Health professionals  
Submitted on 2025-01-08 17:28:33

### 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:  
Primrose Coalter

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 a nurse but have also lost both my husband at 45 yrs and my father to cancer. Both were able to die in their own homes. My father had a lot of help from Marie Curie at night as my mother had to undergo two major operations while we were nursing my father at home. Thanks to Marie Curie covering the night's I was able to manage during the day. I had to take unpaid leave from work for over a month. I was working in a nursing home at that time.

5 What is your organisation?

Organisation:  
I now work for Marie Curie

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

Yes

1500 characters:

I'm a nurse working in both RR and doing house sits - PVs

### 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:

I find families do not fully understand and don't seem to have things explained to them in a timely manner. Sometimes it is hard for families to take all in. It can depend on the level of support and how soon they get the support. At present people are in their last days/ hours before families get help at night. Families are exhausted, every day is a rollercoaster of emotions and families can feel very much on their own.

### 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:

Rural areas can be really affected due to distance from communities, poor roads, poor transport links, lack of family nearby, their own friends and family being elderly and lack of carers in that community. Elderly people are being left to care for their loved ones when they themselves have medical needs.

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:

More day carers providing personal care. More help/ support for shopping etc. More help at night so families can get a good night's sleep. More finance to help with heating, washing bedding etc.

### Integration of Services

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

1500 characters:

I don't think they integrate very well. Each are doing their own thing and a lot overlap. Families want/ need more practical help.

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

Not sure

1500 characters:

This could cause some areas to lose out to others. What works in large towns/ cities doesn't always work in rural areas.

15 What can be done to improve integration?

1500 characters:

I do think organisation need to work more closely together and if one is already up and working well why does someone else need to start doing the same thing and leave gaps elsewhere in the service. Their needs to be someone overseeing all those working in Palliative care and linking them all together.

### 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 know people feel reassured when we come in to do a night sit. It's someone not related to the family who they can talk to and voice their concerns. Unfortunately due to budget cuts families aren't getting the input/ help they did. When my father was dying in his last days we had someone every night now that would not happen.

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

No

1500 Characters:

I know from what families have said that they are not getting enough practical help. Visits from Palliative teams giving advice on symptoms and treatment is not enough for them. Things take too long to get done/ changed i.e. if patient needs medication increased the Palliative nurse has to then liaise with the GP leaving the patient suffering for days - it should be able to be sorted straight away with no delays. It's hard for families to watch their loved ones suffering like this.

### 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:

People aren't getting the care and support they need. I can see it first hand with some of the patients I see. Everything is very last minute.

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:

It's not enough to meet the demands. No enough staff and there can be delays of hours before patients get the pain relief etc that they need.

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 overhauled and more centralised with the various groups/ charities working more closely together to give earlier and more timely the care the patient needs. More money needs to be provided so that it is not reliant on donations to provide a service which could be lost if the funding is not there.

Any other comments

21 Any other comments

1500 characters: