

Response ID [REDACTED]

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

Submitted on 2024-11-19 01:23:44

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 response.

Who are you?

2 What is your name?

Name:

Ann-Louise Goligher

3 What is your email address?

Email:

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 healthcare assistant and clinical skills Assessor within a palliative and end of life organisation. I carry out hospice care at home within a 25mile radius of where i live covering at least 2 trusts, Belfast and South Eastern Trust mainly.

I carry out non invasive nursing care which also involves providing emotional support and guidance along the way as well as night time respite for those caring for their loved ones at home.

I also teach patient handling to all of our new and current staff across NI.

5 What is your organisation?

Organisation:

Marie Curie

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

Yes

1500 characters:

As above, I work as a clinical skills Assessor as a patient handling trainer but I also will do hospice care at home 3 nights a week as a health care assistant. Providing care and support to patients and families who are wishing to care for loved ones at home in their final months, weeks, days and hours.

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:

A lot of the public don't seem to really understand or know what palliative care is, those that do seem to think it means immediate end of life.

I think the public are unaware that people can be palliative long term and still live a decent quality of life.

Main barriers are perhaps a fear of educating themselves, it's a topic many don't wish to address until they are faced with it, perhaps religion/culture here in NI can affect us chatting openly about death and dying.

The information is out there but maybe not in the right areas.

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:

I think rural areas can be more difficult, there can be longer waits, less knowledge and difficult to access care packages

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:

I think we have the right services but just need more staffing and budget to perhaps meet demand.

Integration of Services

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

1500 characters:

I think it's still very much a work in progress, there are a lot of challenges, we are learning more especially with primary care, this is where the challenges do lie and it does depend on districts, demands on GP surgeries, how quick people can get appointments. Quite often I hear a lot of stories from families or patients saying they felt they had to push for second opinions, they gave up or didn't push themselves for appointments thus leading to late diagnosis which is a devastating experience for all involved as usually by this stage symptoms of the disease or cancer are at their worst and difficult to manage.

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

Not sure

1500 characters:

I can see the advantages of this as it would centralise our palliative services which would perhaps help create better quality care in one area rather than being spread out thinly in some areas and it would possibly help specialists share best practices under one area, the same standards of training and education for all staff working in palliative services. It might also reduce duplication or cross communication/miscommunication. It may bridge the gap between rural services if planned well.

However the challenges this faces are that it still might prove difficult for those in rural remote areas to gain access to a regional palliative service. Not all those living with palliative illness have access to travel, they may not be well enough, lack of technology or experience with technology. There are many who live alone with palliative illnesses and have little to no family support. This could also lead to delays in palliative care which could lead to prolonged suffering or traumatic deaths. If not well integrated there could be fragmentation with the regionalisation of palliative services.

15 What can be done to improve integration?

1500 characters:

Ensure that routine screening is implemented for palliative care needs in primary care and hospital settings especially those with cancer, dementia, heart failure etc.

I've read about palliative performance scales where patients can be individually assessed on whether palliative care be of benefit to them depending how quickly they are deteriorating. Also ensuring that there are clear protocols in place to ensure those living with life limiting diseases are referred to palliative care services sooner to allow for a better quality of life.

Ensure that ALL healthcare professionals are more educated and trained regularly in palliative care so that they understand what their aims are with patients.

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:

Hospice care at home is becoming, ore and more in demand, its a service that alot of the public are unaware exists from my experience. Everyone associates palliative and end of life with hospices.
Alot of our older generations especially want to be at home rather than a clinical setting so I think more funding and support for this aspect of palliative would be so beneficial.

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 it depends on their postcode, I think we have the right resources there but just need more of it and it needs to be more consistent across all of NI.

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 think with ever more people being diagnosed with diseases or cancers there needs to be more funding to ensure it isn't so hit and miss for some families or individual getting thr support and others not.

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:

Again as above I think we are under resourced and the demand seems to be growing and is predicted to grow so more funding will have to increase or if not perhaps better planning and reviewing.

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 as we have an aging population, rise of chronic diseases such as COPD, heart disease and failure which are increasing.
Issues with a significant population in rural parts who don't always have access to central services.
Lack of integrated services, referral delays and waiting lists. Workforce shortages, education and training and lack of public awareness and stigmas surrounding palliative care.

Any other comments

21 Any other comments

1500 characters:

No