

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-12-19 20:56:39

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:
Lynda Bell

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:

Palliative Care Education Facilitator (Nurse)

5 What is your organisation?

Organisation:
SET

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

Yes

1500 characters:

As a Palliative Care Education Facilitator, my role is to collaborate closely with generalist palliative care providers within the community. I support these professionals through education, skills training, and debriefing sessions. The aim is to enhance awareness of the respective roles of generalist / specialist palliative care services, improve staff confidence, and ensure the delivery of high-quality care.

The training is designed for staff at all levels and focuses on key areas such as:

- addressing common misconceptions in palliative care
- symptom management
- recognising the deteriorating patient, co-ordinating care and anticipatory medications
- Advance Care Planning
- SAGE & THYME / Advance Communication Skills Training
- etc

current state of palliative care services

7 In your view what is the current state of palliative care services in Northern Ireland?

Neither

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:

There is a varied understanding of palliative care among the general public. Common barriers to clarity include misconceptions, such as the use of syringe pumps, limited discussion about the distinction between palliative care and end-of-life care, and challenges associated with Advance Care Planning. Death and dying remain taboo subjects, with the public often reluctant to engage in these discussions or lacking opportunities to do so.

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:

Palliative care services are not equally accessible to all who require them.

Gaps in service provision include:

- Limited out-of-hours care, as 24/7 support is often unavailable.
- Accessing night sits in rural areas remain particularly challenging, resulting in what can feel like a postcode lottery.
- Individuals with non-malignant conditions are frequently referred to palliative care services much later, often during a crisis.
- Those residing in care homes / learning disability units / prisons are at risk of being overlooked.
- Regionally, the composition and availability of specialist multidisciplinary teams can vary significantly.
- Communication and coordination between primary and secondary care services can sometimes be disjointed, leading to fragmented care and inefficiencies in service delivery.

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:

As above

12 What additional services could/should be provided?

1500 Characters:

Additional services that could enhance palliative care provision include:

- Chaplain support.
- Increased carer support for personal care and assistance to help individuals remain in their own homes.
- Robust out-of-hours services to ensure consistent care availability.
- The use of patient passports for those with palliative care needs to facilitate bypassing emergency departments when appropriate.
- Mandatory palliative care training as part of staff induction processes and ongoing education / training for staff to improve competency and confidence.

Integration of Services

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

1500 characters:

In recent years, there have been improvements in the integration of palliative care services within the health system.

- As the Encompass system is rolled out regionally and staff become more familiar with its functions, it has the potential to enhance communication between primary and secondary care. To fully realise this benefit, it is essential that GPs and hospice services are included in the system.
- The Gold Standard Framework Palliative Care meetings in primary care - involving GPs, District Nurses, hospice teams - play a crucial role in the early identification of patients, adding them to the palliative care register, and ensuring coordinated care, as well as support and signposting to additional services. However, participation in these meetings varies, with some practices not fully engaging.
- To address these challenges, a focus on regional collaboration, shared learning and shared resources is essential to improve the consistency and quality of palliative care services.

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

Yes

1500 characters:

As above

15 What can be done to improve integration?

1500 characters:

As above

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:

Palliative care hubs play a vital role in facilitating hospital discharges with appropriate follow-up care, ensuring patients receive support from the multidisciplinary team. These hubs enable individuals to remain at home while receiving the necessary care.

Additionally, Hospital at Home services further support this goal by delivering care directly to patients in their homes.

I think there is a mixed understanding amongst the general public.

During Palliative Care Week (Sept 2024), a public-facing health and wellbeing event was held to address misconceptions about palliative care and provide an overview of available services in the SET. The event featured several stallholders, including charities, offering information and answering questions from the public. This initiative helped raise awareness and promote a better understanding of palliative care

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

No

1500 Characters:

Many families struggle with knowing where to access services or what resources are available to them. This can be due to lack of information, complexity in navigating systems, or not knowing where to turn for help.

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:

Further investment and funding are critical to improving palliative care services and ensuring that patients receive the compassionate, high-quality care they need.

- Growing demand: as populations age, the demand for palliative care will increase. More people are living with chronic and terminal illnesses, requiring specialised care to manage symptoms and provide emotional and spiritual support.

- Access to care: especially in rural / underserved areas. Increased funding can help expand services, ensuring more people benefit from palliative care, regardless of diagnosis / location.

- Training and workforce development: investment in education and training programs for staff, to build a skilled workforce that can deliver high-quality palliative care.

- Holistic approach: MD approach

- Family support: crucial support for caregivers, providing them with guidance, respite and counselling.

- End-of-life care: with more individuals choosing to spend their final days at home / hospice, funding is needed to improve these options (e.g. care packages / MDTs / etc)

- Research and innovation

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:

As above - investment needed

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

Not sure

1500 characters:

Any other comments

21 Any other comments

1500 characters:

Advocating for improved palliative care is incredibly important, as it can make a meaningful difference in the lives of patients and their families. Thank you for this opportunity, Lynda