

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2025-01-17 16:46:13

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:
Dympna Browne

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 Deputy Head of Adult Psychological Services for Dr Sarah Meekin in Belfast Trust.

5 What is your organisation?

Organisation:
Belfast Trust

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

Yes

1500 characters:

Indirectly via management of psychologists who provide services to patients who are in palliative care pathways due to a range of health conditions eg cancer, respiratory, diabetes, renal, progressive neurological conditions.

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 think there is minimal understanding about the breadth and nature of palliative care services as it is often confused with end of life care only. This misconception may be due to limited public education, stigma and the complexity of the health care system and referral pathways. Due to these issues and the sensitive nature of the topic, raising public awareness as well as specialist training for healthcare staff is essential to ensure that opportunities are not missed to inform about palliative care options and promote Advanced Care Planning.

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 is currently no dedicated psychology service for palliative care patients in NI. This is despite the clear need for such support as it is estimated that approximately 30-40 percent of patients with a life-limiting cancer diagnosis will experience clinically diagnosable mental health difficulties such as depression and anxiety. Similar rates of mental health disorders have been found in other life-limiting diseases such as End-stage Renal Disease and COPD (Kozlov et al 2018). In addition to the need for psychological input for mental health difficulties, it is also important to note the potential for psychologists to support the patient's 'total pain' experience. 'Total pain' is a term used in palliative care in acknowledgement of the psychological factors that influence the pain experience.

Psychological support is not only necessary for patients but also for family members who are at increased risk of psychological burden and distress (Davis et al 2020).

The UK National Council for Hospice and Specialist Palliative Care and The Cancer Strategy for NI (2022) recommend that psychological assessment and treatment should be prioritised for palliative care patients.

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:

Lack of integrated care across settings reduce early identification of palliative needs and hinder Advanced Care Planning (ACP) conversations. Timely ACP conversations have the potential to reduce psychological distress for patients and their families at the end of life.

Cancer Research UK report that patients from deprived populations have higher risk, worse experiences and poorer outcomes at every step of the cancer pathway.

Cultural and linguistic barriers for ethnically diverse populations, those with communication difficulties, and those for whom English is not their first language.

12 What additional services could/should be provided?

1500 Characters:

Psychological Services:

As recommended by the UK National Council for Hospice and Specialist Palliative Care, patients should be prioritised for psychological assessment and treatment to reduce psychological symptoms and enable patients to engage more meaningfully in their lives and care decisions.

Access to psychological support integrated into palliative care teams would provide individual and family psychological assessment, treatment and counselling.

Palliative Care staff would also benefit from the presence of psychology services given the emotional demands of the job. It is well established that when staff members are supported in processing the emotional demands of their work, they are better able to deliver quality care for longer.

Integration of Services

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

1500 characters:

There is a lack of continuity of psychological care and mental health support across primary, secondary and specialist settings for patients in palliative care. For example, within current service models, psychological input might not be continued if the patient moves from a hospital setting to hospice setting. This leads to a fragmented and variable experience for patients and families.

Whilst there are specialist palliative care medical professionals, there are currently no specialist palliative care psychologists in NI and psychologists are not integrated into palliative care teams. This is remiss given that death and dying is a psychological process as well as a medical process.

Integration across care settings would ensure that patients have access to psychological therapy early, before they become too fatigued or unwell to be able to engage in psychological treatment and support for Advanced Care Planning.

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

Not sure

1500 characters:

There is a strong argument for palliative care to be organised regionally to enable equitable access, standardisation of care, efficient resource utilisation, workforce planning and staff support. However, particularly depending on the patient's geographical location and the stage of disease, aspects of palliative care should be delivered in patient's preferred setting such as in their own home and community.

15 What can be done to improve integration?

1500 characters:

Integrating a psychology service into palliative care teams would enable the creation of a pathway for psychological care to continue as patients transition across the different care settings. Psychology services can also act as a bridge between healthcare teams and can help integrate the psychological needs of the patient with the medical and social aspects of care. This collaboration would lead to a more holistic and person- centred understanding of a patient's needs and a more co-ordinated approach to 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:

Belfast Trust partnered with Marie Curie NI to pilot the provision of psychological services for palliative cancer patients from March 2023 – March 2024. In total 86 patients and 57 family members were referred and there were 838 patient and family contacts with the psychology service.

Feedback from Marie Curie Staff :

[Having Psychological Services] allows other professionals to focus on other aspects of their specialism whereas we were previously possibly providing inexperienced or untrained counselling support; I mean from a doctor – we are not trained in CBT!"

"[Having Psychological Services] adds an extra dimension to comprehending a patient's 'total pain' and offers strategies to cope with that".

[The multidisciplinary team is] now able to be more informed by the psychological approach. This has been particularly important regarding complex cases which can often trigger challenging emotions in staff members."

"The introduction of psychological services has meant that patients are supported holistically as they navigate the close of their lives."

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

No

1500 Characters:

As there is no dedicated psychology service for palliative care patients in Northern Ireland, family members and carers are often without this crucial resource to help them process feelings of distress, grief, remorse and guilt. Lack of psychological support during this sensitive stage heightens the risk of prolonged complex grief reactions.

Staff feedback from pilot study of psychological services in Marie Curie:

"[Psychological Services has] allowed patients a safe place to talk. Someone outside the family, to talk to about what they are going through and how they are feeling. The service has also been hugely beneficial to family members pre- and post-bereavement."

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:

Currently no funding exists for dedicated psychological services in palliative care settings despite the heightened distress and mental health needs for palliative care patients and their families.

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.

Not sure

1500 characters:

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:

There is a clear need for a new strategy as demand for palliative care is increasing due to people living longer with complex medical conditions, an aging population and challenges in service capacity and workforce. The integration of psychological services within palliative care teams should be included in a strategy to ensure that the psychological needs of patients are addressed in addition to the medical and social needs. The strategy should include a funding plan to sustain better integration and collaboration across primary, secondary and specialist care.

Any other comments

21 Any other comments

1500 characters: