Response ID [redacted]

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2025-01-09 11:31:54

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:
Dorothy Thompson

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 Band 7 Advanced Practioner Occupational Therapist and work in the Community Specialist Pall Care Team in the Belfast Trust.
The main aim of Occupational Therapy is to maintain, restore or create a match, beneficial to the individual, between the abilities of the person, the demands of his/her occupations and the demands of the environment, in order to maintain or improve the client's functional status and access to opportunities for participation. (Creek, J. 2006)
The Specialist Occupational Therapist will be involved in
• Expert Clinical Practice, particularly in complex cases.
• Professional Mentorship
• Practice and service development, research and evaluation
• Education and professional development
Key areas for specialist intervention are:
• One or more complex symptoms that are difficult to control and impact on occupational performance eg. Breathlessness, fatigue, pain, lymphoedema, anxiety
• Sensory and motor impairment
• Metastatic Spinal Cord Compression
• Brain Tumours/ cerebral metastases.
• Perceptual and cognitive impairment
• Pathological fractures/ bone metastases.
• Emotional, psychological, spiritual problems, which impact on occupational performance.
• Issues relating to complex equipment and/or housing adaptation.
• Difficulties experienced by carers or family in the management of the person with palliative care needs.

5 What is your organisation?

Organisation:
BHSCT

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

Yes

1500 characters:

As above

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:

I responded 'Neither' above, because the services vary greatly across NI.
The Belfast Trust Community team has been in place for 20 years, with no further investment, yet the population of palliative patients has increased greatly, meaning that the resources are insufficient to meet the needs of the population

In my 20 years experience in this post, I do not think that the public understand the breadth of the term, Palliative Care.
It is still perceived as the dying process, where it is now much more inclusive of long term, incurable conditions, such as organ failure, neurological conditions, dementias as well as cancers.
Every year on Palliative Care week, the team aims to provide information and opportunity for the public to become better informed regarding the term.
Also with every intervention in the community, we are educating patients and families.
As an MDT and as individual professions we also provide education for other professionals and aim to support them in their management of their own palliative patients.

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:

Each Trust has different levels of service to patients with Pall Care Needs. Some have a Specialist team with no waiting list, other trusts have no Specialist Teams at all.
BHSCT Specialist Community Occupational Therapists 1.4 WTE
Palliative patients are categorised as complex and non-complex.
- Non-complex patients will be referred Core Community OT Teams and will generally be prioritised as urgent and seen within 2 weeks of referral, dependent on available resources.
- In most cases the patient will be discharged after the intervention is complete, requiring re-referral if deterioration occurs and further input required.
- Complex patients are generally referred to the Specialist Team and are triaged as routine or urgent based on the referral information.
- Due to the limited OT resource in the Specialist Team, waiting times can vary greatly.
- Even urgent cases may wait several weeks to be seen, as there is no cover provided when there is Annual Leave or short term sick leave. In cases of long term sick leave, some cases will be transferred to the Core Teams.
It is also known for patients to sadly pass away before being seen.
Specialist Palliative Care Workforce Planning Report Northern Ireland 2017 – 2024 made the following recommendations -
Projected number of WTE required to meet SPC need in 2024* - 22.99 WTE OTs based on 2.9 per 250000 population.
Provision in 2017 (which has not changed) - 7.49 WTE OTs
GAP - 15.5 WTE

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 human resources are the barrier.
As medical advances continue and survival increases, patients are living longer with the consequences and side effects of the treatments, causing long term and severe disabilities. The complexity of cases continues to rise, with greater need in relation to face-to-face contacts, increased prescription of specialised equipment and treatment planning and more regular reviews as disease progresses and health deteriorates. This combined with the same staffing levels are 20 years ago is a huge barrier.
In 2024 our referral rates for SPC OT in BHSCT were as follows :-
Total referrals received - 342
Rejected / referred on - 117
Total seen 225

12 What additional services could/should be provided?

1500 Characters:

Team Lead to facilitate co-ordination, development, forward planning and bring together the Team eg to respond to requests such as this.
-Band 4 rehab assistants / therapy assistants.

With advances in treatments, many Palliative patients have much longer prognoses than in previous years and evidence exists to show that rehabilitation can improve functional ability, independence and Quality of Life. At present, rehabilitation potential is identified and some attempt is made to support the patient in this but time constraints do not allow. These tasks, if carried out by appropriately trained Rehab assistants would allow the Band 7 to carry out initial assessments and interventions and keep the waiting list to a minimum, giving all patients access to services
There is a lack of skill mix within the Team.
As all Band 7s, we have become very knowledgeable and highly skilled and feel that having Band 6 staff would allow for knowledge and skill sharing and succession planning for up-coming retirements. New referrals would be triaged and les complex allocated to Band 6 with direct supervision support.

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 good liaison between Hospital services, ourselves and Community Hospice staff.
MDT meetings are held between S&E Belfast Hospice and ourselves. These are used to discuss and co-ordinate patient care.
The same is not available for N&W Belfast due to limited resources.
As a team, we co-ordinate the best care possible for the patients referred to us, to provide a holistic approach and address all needs.
As a community team, community can be limited from Management and working groups at senior level.
Eg a new Palliative referral hub for the Belfast Trust has been proposed and is being developed, without consultation with ourselves, who are the staff 'on the ground'.
Progress of this development is found out by chance and cascaded to the other team members for information.

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

Yes

1500 characters:

A regional service would be useful to lead Policy and Procedures and to ensure that services are equitable across NI.
It would also be able to monitor and measure interventions and restrictions of service and this would serve to allow changes in resources to better meet the needs of the patients.
A Regional AHP Group exists currently who meet bi-annually.
This is used to discuss developments, chare ideas, carry out audit/ research.
It allows staff from other Trusts to liaise and discuss commons issues, problems or positive changes

15 What can be done to improve integration?

1500 characters:

Communication from management to clinical staff of new workstreams and invitation to be on these workstreams to enable our voices to be heard.
The problem with this is the time that is required when there is already insufficient staffing as already outlined. This is why a Team Lead for the team would be invaluable

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:

In the South Eastern Trust in recent years the Spec Comm Pall care Team has been expanded and developed with additional funding to create a Team Lead Post, which lead to an increase in WTE staffing in AHPs and employment of rehabilitation assistants .
A Pall out patient Hub has been established at Ards Hospital, for those patients able to attend, where it is a 'one stop shop' for patients to see which ever professional they require.
I am not aware of this level of provision any where else in the Province.

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 that the support received will differ across NI.
Once a patient is open to our service, the family are well supported and educated as appropriate. In most cases, the case remains open to the team until they pass away, allowing the families to have a point of contact . Families are also supported through bereavement if required.
However Social Work resources are also stretched to be able to provide Specialist input for bereavement care.
But this will be different to those who are open to the Core OT services, who once the initial intervention is complete, the patient is discharged from the service.

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:

For the reasons already given

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:

This is not within my knowledge base

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:

Living Matters, Dying Matters 2010, is a comprehensive document which made 25 recommendations for the provision of Palliative Care Services.
When it was launched, we were positive about the changes that were proposed.
Certainly some changes were made and new services brought into effect as a result of this which has definitely improved the services to these patients.
It may be more productive to review the recommendations made in 2010, then look at those that have not been implemented, why they have not and whether they are still appropriate, before embarking on a whole new document.
I suppose this consultation process will provide much of the info from across NI, that will help you to do this .

Any other comments

21 Any other comments

1500 characters: