

Response ID ANON-PEFR-6REB-V

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2025-01-06 13:58:26

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:
David J Johnston

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 one of the Clinical Director of Dalriada Urgent Care, the Out of Hours primary health care provider that covers the Northern Trust area of Northern Ireland.

5 What is your organisation?

Organisation:
Dalriada Urgent Care.

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

Yes

1500 characters:

Yes we provide out of hours palliative care in association with the MArie Curie nurses who are co-located with us.

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?

Yes

1500 Characters:

It is only relevant to most people when they are in the position of having a friend or relative with palliative care needs. It is probably something that should be discussed more widely so people can make informed decisions about their care and future wishes.

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 are 168 hours in the week. Of these roughly 123 hours are "Out of Hours" or after hours when there is less resource to support patients in the community. This might include access to medical, nursing or carers support. It can also include access to medicines vital to maintain the patient in their home. Sometimes these needs could not have been reasonable predicted and obtaining medication is difficult. This can be particularly the case in more rural areas.

Sometimes legislation can also be a barrier. For example some innovative and helpful solutions were initiated during the pandemic but subsequently stood down.

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:

See above.

12 What additional services could/should be provided?

1500 Characters:

Access to support services including medical, nursing and carers.

Timely access to medication especially in the Out of Hours period.

Integration of Services

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

1500 characters:

There are gaps between in hours and out of hours services.

In hours services are relatively good but services become much less accessible in the Out Of Hours period and sometimes information is more limited in Out of Hours. However hopefully Encompass will improve this situation.

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

Not sure

1500 characters:

The secret is NATIONAL PROFILE BUT LOCAL DELIVERY.

If patients and their relatives are to have confidence in a service that they will utilise when they are most vulnerable and in their greatest need they need to know what to expect (NATIONAL STANDARDS) and then actually have that service delivered on the ground in their locality (LOCAL DELIVERY). The model and process is much less important than the Outcome.

15 What can be done to improve integration?

1500 characters:

There has been a fragmentation of care in recent years. Often everyone thinks someone else in the team is doing something and in fact no-one is doing it or several team members are doing the same thing.

There should be a named person responsible for each patient identified and on a palliative care list.

In my view this should sit with the patients GP and should be a real and meaningful process.

When done well palliative care ensures patient centered, flexible and intelligent care for individual patients and a positive experience and memory for their family.

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 Dalriada the Marie Curie Nurses are co-located with the medical staff out of hours and this facilitates good communication and a focus on the needs of the patient.

In Dalriada, when possible, Marie Curie nurses proactively contact families at 10 pm each night using a list of known patients or patients that have been highlighted by their GP. This helps reassure patients and also ensures they know who to contact if required during the night.

At times small preprinted cards have also been given to families with details of who to contact should help be required.

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

Not sure

1500 Characters:

Sometimes there is sufficient support but often this could be improved.

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:

Marie Curie is a charity and is not fully publicly funded yet it is the cornerstone of much out of hours nursing care and in our area is the only nursing service available between 11 pm and 7am.

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:

Not my area of expertise.

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:

The model to care for and support people with palliative care needs in the community 24/7 needs to be urgently reviewed.

Any other comments

21 Any other comments

1500 characters:

The aspiration of most people appears to be to stay at home during their final illness. If we are to achieve this both in terms of quality of care and public confidence in the service much more needs to be done to provide the patient centered, flexible and intelligent care that we would all want for our own families.