## Response ID

Submitted to Review of access to palliative care services - Organisations/Health professionals
Submitted on 2024-12-31 12:46:06

### 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 my response but keep it anonymous.

### Who are you?

2 What is your name?

Name:

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 work as a GP for a 8500 patient practice. I work along with district nurses as a generalist delivering palliative care.
It is estimated that 80% of PEOLC is undertaken in community/ care home. The District Nursing Framework defines the Key worker role as the DN in palliative care, however this is seldom highlighted. The most important part of the role of the DN and GP is the therapeutic relationship with the patient and family within the home. The DN is most likely to be the person who sees the patient most often in the home and is the person with the most up to date information about health and social needs. They liaise with the GP and work together to manage their palliative patients. GPs and district nurses also can refer and sign post to other agencies for help with more complex palliative cases.
. I act as a liaison between primary and secondary care. I feedback into regional and trust palliative care groups. The groups focus on advance care planning, symptoms management , identification, services, carer and patient support, communication skills bereavement etc I work along with palliative care education facilitators to improve palliative care and cancer education.

5 What is your organisation?

Organisation:

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

Yes

1500 characters:

I work 1 day per week as a Macmillan GP. Taking part in regional and trust groups from a primary care perspective
I work in alliance with primary and secondary care
Practice based learning in primary care. Advance care planning course. Regional ACP group- looking at review of resources, programme of learning.
Palliative and Cancer regional masterclasses planning and facilitating
Palliative pain group. Lunch and learns.
Health and well being event for the general public.
Key information summary promotion
SAGE and THYME training
Mentoring non-medical prescribers
Implementation of just in case boxes and education around this
Cancer strategy input
NIMDTA ST3 training
review of guidelines

### 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:

There is a misunderstanding of the public thinking palliative care is end of life., some fear being referred as they see it meaning end of life.
There is a lack of understanding of who delivers palliative care. The majority is delivered by the GP and the District nurses.
Some think when referred to palliative care that a team of nurses are going to come in and deliver 24 hr care. misconception that palliative care is only for cancer patients however it is also for non cancer conditions.
Lack of knowledge of when to refer some people are referred to late.
People can fear death and dying.
lack of understanding of roles of healthcare professionals and this is not made any easier by different organisations being involved.

## 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 some inequity within trusts. Some trusts do not have full complement of multidisciplinary teams.
There is no regional strategy.
Lack of Out of Hours cover in all of the trusts some have no cover from specialist palliative care consultants, some have no cover after 12 midnight. lack of 24 /7 palliative care support within hospitals.
Majority of palliative care is by GP District nurses but demand versus capacity is very difficult to manage. It is hard to be proactive visiting palliative patients on a regular basis.
Some GP practices have had to hand back their GP contract so difficulty with continuity of care.
Some primary care staff are unaware of all the services available.
lack of a single point of access to service. Sign posting and referral to services is complex.
Rural versus urban provision.
Difficulty with social care support in rural areas to support patients to stay at home.
Public can have misconception that hospital care is always best.
Lack of advance care planning documents e.g. ReSPECT, IT system for sharing of information, ACP regional communication training, DNACPR policy and lack of being able to applicable in primary and secondary care. Anticipatory prescribing and emergency medication boxes for EOL care not available in all regions, or settings

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:

Barriers is lack of knowledges of all the services.
Services need more inclusion of learning disabilities, Homelessness, prisons, LGBTQ etc
Workforce barriers-
Concerns over the current specialist palliative care workforce numbers and projected numbers over the next 5 years.
No 24/7 service (specialists), good provision, current model is crisis management
Palliative Care Consultants posts across the region are difficult to fill . GP posts not all filled.

Support for the workforce e.g. burnout and career pathways

Misconception of who is delivering palliative care. Family not fully understanding that the DN and GP are providing this care

With the ever growing and aging population, to stop the system being a victim of its own success the palliative care that is available out there is going to become more and more strained unless it is funded and made robust enough to cope. We need a new model to not only sustain the good practice but to progress at the population needs level with best outcomes.

Regional inequity
Not all trusts have multidisciplinary Community Specialist Palliative Care teams, or HUBS
Regionally much inequity there can be waiting times overnight in rural areas
There is also a rural v urban issue with access too

Difficulty with palliative care identification there are tools available like anticipal but not fully implemented.

Difficulty transitioning from child services to adult services.

Lack of implementation of advance care planning resuscitation policy ReSPECT

12 What additional services could/should be provided?

1500 Characters:

Better transition from child to adult services
more hospital at home models to support care in the community
More domiciliary care workers to support care in the persons home
More 24/7 access to palliative care advice
implementation of Advance care planning policy
Implementation of ReSPECT and DNACPR policy
Regional palliative care strategy on a power with that of Southern Ireland
Funding of services so that funding does not rely on cake sales
Single point of access /contact to make referral easier so that the correct service is matched with the patient/carer
Better partnership working clients do not care which charity partner delivers the service but more that there is a service that is easy to negotiate
More joint MDT working, more hubs with MDT support
Better funding to allow GP and District nurses to meet and formulate care plans and be more proactive in care
Better IT systems to aid communication between primary secondary care and partner organisations
Regional education to promote good practice
Communication training

## Integration of Services

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

1500 characters:

Services are not integrated
There continues to be silo working
ENCOMPASS instead of helping has proved a barrier for partner organisations
Commissioning of palliative care services needs to improve with the aging population
There is lack of consistency regionally

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

Yes

1500 characters:

Northern Ireland is a small enough area to have a regional service instead of each trust having different services.

15 What can be done to improve integration?

1500 characters:

no more silos working
Sharing best practice instead of reinventing the wheel

Specialist palliative care HUB e.g. SET/ non malignancy focus

SET are a joint heart failure and specialist palliative care rapid access hub and MDM working in partnership with the respective professionals

Belfast specialist HUB

Marie Curie overnight sits to continue and expand

Marie Curie and CRUISE project bereavement awareness in schools

Bereavement/comfort-coordinators bereavement calls, funding unsure

GP anticipatory care ACP in care homes and with palliative patients

Marie Curie Rapid Response is a wonderful service out of hours

## 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:

Care home facilitators linking with care homes to help prevent admissions or to help with early discharges. Helping with care home education to up skill staff.

Specialist palliative care HUB e.g. SET/ non malignancy focus to help prevent admissions or to help with early discharges.

SET are a joint heart failure and specialist palliative care rapid access hub and MDM working in partnership with the respective professionals

Belfast specialist HUB for a single referral point.

Marie Curie overnight sits

Marie Curie and CRUSE project bereavement awareness in schools

Bereavement/comfort-coordinators bereavement calls, funding unsure

GP anticipatory care ACP in care homes

Marie Curie Rapid Response is a wonderful service out of hours
Regional education for primary care on cancer and palliative care done via zoom monthly to upskill primary care
Advance communications skills training

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

No

1500 Characters:

Hard to know what to ask for.

Once in the system there is better support but can be difficult knowing when to ask for support as well as being able to access support.

## 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:

Charity partners have to fund raise to run their service needs to more like the funding in Southern Ireland.

Aging population more funding to provide a regional gold standard service

More domiciliary support required to keep people at home
More training positions required for staff

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:

Charity partners have to fund raise to run their service needs to more like the funding in Southern Ireland.

Aging population more funding to provide a regional gold standard service

The aim to care for people in their preferred place of care and this need the support of hospice at home/community care/rapid response support

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 needs to be a strategy and a policy with funded implementation

## Any other comments

21 Any other comments

1500 characters: