Response ID ANON-PEFR-6RSU-W

Submitted to Review of access to palliative care services - Organisations/Health professionals Submitted on 2024-11-18 16:52:32

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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: Jackie WHYTE
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:
Healthcare Chaplain
5 What is your organisation?
Organisation: NI Hospice and NI Children's Hospice
6 Do you currently work in palliative care services?If Yes, in what capacity?
Yes
1500 characters:
I am a palliative care Chaplain with NI Hospice and NI Children's Hospice.
I work in Adult's IPU, and also visit Adults in the Community who have been referred by Hospice Nurse Specialists.
I also work one session per week at NI Children's Hospice.
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:
Generally the subject of death and dying is a difficult one for people to talk about.

There is also the misconception that everyone who is admitted to an IPU will remain there to die. This is not the case, they are admitted in order to

receive Specialist Palliative Care, and many are discharged again after 3 weeks on average.

Access to services

9 Are palliative care services equally accessible to all who need them?
Not sure
10 From your experience where are the gaps in the provision of service?
1500 characters:
I am not aware of gaps
11 Do you believe barriers exist that prevent equitable access to these services?If yes, please provide examples in the box provided.
Not sure
1500 characters:
12 What additional services could/should be provided?
1500 Characters:
Complimentary Therapy Music Therapy Art Therapy
Integration of Services
13 How well are palliative care services integrated across the health system, through primary, secondary and specialist care?
1500 characters:
My experience is limited to NI Hospice, and therefore I am unable to comment on this.
14 Should palliative care be a regional service?Please outline your reasons in the box provided.
Yes
1500 characters:
If 'regional service' means that it is fully funded by our executive, then I believe we should be fully funded. This is the case for Hospices in the South of Ireland.
15 What can be done to improve integration?
1500 characters:
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:
I am involved with Special Activities for patients at NI Hospice. Some examples of these are:
Helping a patient complete and publish a book Helping a patient visit his mother's grave for the final time helping a patient celebrate her 40th Birthday 6 months early
We have many examples of 'going the extra mile'.
17 Do you think that families receive sufficient support when accessing services?Please outline your reasons in the box provided.
Yes
1500 Characters:
Especially in the IPU
But we need to be fully funded by Stormont.
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:

It is quite shocking that NI hospice is promised 50% of the funding it needs by Stormont, in the South of Ireland the Hospices are funded to 100%. What is simply scandalous is that despite the promises, this is rarely met.

There is too heavy a burden placed on Society to raise the funds for Hospices.

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:

The current model relies far too heavily on fund raising. There needs to be a complete change of mindset from Government on this. This society needs to make people feel they are worth being cared for.

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:

It should include good access to MDT Specialist palliative care. This should also include provision for Spiritual care.

Any other comments

21 Any other comments

1500 characters:

Please take this opportunity to fix this really serious issue