Association of Hospice and Palliative Care Chaplains NI and Donegal Regional Group
We are all chaplains for whom palliative care is either our primary focus or only focus. We are based in the following settings: hospice, acute and community. We are part of the multidisciplinary team(s) where we are based. As chaplains we are there to first and foremost provide spiritual support to patients; their loved ones, staff and volunteers whether or not people come from a faith perspective or not. We are there as a resource to support staff in their delivery of spiritual care and to signpost to other spiritual care providers where necessary. The Association of Hospice and Palliative Care Standards are what we follow.
For further insight - https://ahpcc.co.uk/pdf/ahpccstandards2006.pdf.

Current state of palliative care services

In your view what is the current state of palliative care services in Northern Ireland?
Poor.

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?

Our experience would suggest that there is a mixed understanding of what palliative care is. Some members of the public do understand what it is and are able to distinguish palliative care from end of life care. However, for a significant number there is a lot of misunderstanding and myths surrounding palliative and end of life care such as the use of syringe drivers, that palliative care is 'giving up', that embracing palliative care somehow accelerates death. These and other myths and misunderstandings greatly affect their willingness to engage with palliative care interventions. With regards to spiritual care among the general public there is even greater misunderstanding. Just as there are assumptions about palliative care so too the general public sometimes assume that chaplains only provide religious care. It is quite a revelation when they discover otherwise. Chaplains are there for patients, those who are important to them, staff and volunteers to provide spiritual, religious and pastoral support. (Seehttps://ahpcc.co.uk/pdf/ahpccstandards2006.pdf for further information).

Access to services

Are palliative care services equally accessible to all who need them?
No

From your experience where are the gaps in the provision of service?

Despite the emerging evidence and its status as a core dimension of palliative care spiritual care remains the least developed and most neglected dimension of palliative care Gijsberts, M 2019 Quinn, B 2023 Gaps include: LGBTQ+: People share how access to palliative care can be more difficult and opportunities for their spiritual, religious and pastoral support can be overlooked. Mental Health: People report late

diagnosis and during illness palliative interventions can be delayed. The mental health dynamics that are present affect their palliative care Post code lottery: where you live has a significant difference in the care that you receive both in terms of diagnosis and provision of palliative care Knowledge: workforce's knowledge of palliative care is not uniform. The health and social care curriculum contains little focus on palliative and end of life care and even less regarding spiritual care. Workforce: in some parts of the region there more staff than others including chaplains. Loved ones & carers: Carers and their loved ones report that while there can be some support for the patient there is little for those important to them Care in the community: Discharges delayed due to lack of resources. This can affect people's bereavement recovery pathways.

Do you believe barriers exist that prevent equitable access to these services? If yes, please provide examples in the box provided.

Yes.

The barriers include insufficient workforce, education and resources. Making access (please see answer to question 10) Having access to palliative care a legal right as in England and Wales would make a significant difference.

What additional services could/should be provided?

Workforce needs increased including chaplaincy. The introduction of Encompass is increasing general chaplaincy referrals and also the addition of further specialist palliative chaplaincy posts is greatly needed across the different areas; hospice, acute, community and primary care. The community is a particularly under resourced area and ideally research should be something that is factored into the chaplaincy hours. Hospice Community Services is an invaluable resource for patients, and their families with staff provision including Chaplains, Nurses, Physio, Reflexologist, Social Workers and Counsellors. Additional funding is needed for these services and the enhancement of them.

Integration of Services

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

While there is some integration there needs to be more done to make palliative care more of a 'go to' resource and less of a 'last resort'. This integration would be greatly helped by it being a regional service along with education among the health workforce and the general public and funding.

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

Yes

It is vital that palliative care is a regional service for many different reasons such as:

- Ensuring that good professional practice is shared and followed
- For economic reasons
- To ensure the embedding of holistic palliative care across all sectors, professions and post codes

What can be done to improve integration?

See previous answers.

Education both in the general populace and the health and social care workforce across ALL professions and role. Having a regional approach. See the Marie Curie standards https://ahpcc.co.uk/pdf/compauditttool.pdf

Best Practice

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?

There has been some pilot spiritual care training of care home staff that has had a positive impact on those who are resident and their loved ones Spiritual care training at undergrad and post grad level has been well received Chaplains being based in the community as part of a multi disciplinary team has proved to be very beneficial Chaplains have provided pauses and debriefs for staff and volunteers which have had a positive impact on morale and wellbeing Multidisciplinary spiritual care training via the NI Healthcare Chaplaincy Association Chaplains are among the professionals involved in contributing to the Advanced Cancer Toolkit developed by the Northern Trust In some of these examples it is not across N Ireland however the qualitative and quantitative evidence and feedback from participants would give the evidence that it would be very beneficial for the above to be rolled out providing there was the necessary policies and funding in place. The Marie Curie spiritual care competencies would be a good standard to aim for https://ahpcc.co.uk/pdf/compauditttool.pdf

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

No

As with previous answers we wish there was a ‘Yes & No’ box. Some families do report that they have received sufficient support however others tell a very different story where the lack of access has had an adverse effect on families and loved ones. These examples of lack of support not only impact on the wellbeing of the lives of individuals and families it creates a further demand on limited resources when people require more complex interventions because the support was not provided earlier.

Funding and Strategy

Do you think the current funding for palliative care is sufficient? Please outline your reasons in the box provided.

No

The answer is no given the improvements and changes that have been outlined in the other answers there will need to be further investment to action these recommendations. However, it should be highlighted that when palliative care is properly embedded in the delivery of health care so much money will be saved such as through reducing inappropriate ED admissions, when people witness ‘good deaths’ there is less demand on specialist bereavement support services, improved death literacy and when staff are fully trained to deliver palliative care there is better morale.

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

To stop the funding of hospices coming from charitable sources is vital. This model would seem to offer much more support never mind making it sustainable and sufficient. This would allow energies and resources currently being used to survive to be redirected to enable such delivery and places of care to flourish. This is providing that it is sufficient funding and a better level of funding currently being offered in other sectors.

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
YES! Such a strategy is essential if the need for holistic person centred care is to be met including the vital need for spiritual care to be delivered. This strategy needs a multi disciplinary team approach in order for people's physical, psychological, social and spiritual needs to be met. There needs investment across all the sectors both in the delivery of care to those who are ill and those important to them and also in training and research. Having long short, medium and long term goals along with matched funding would reap dividends.

Any other comments

As palliative care chaplains we wholeheartedly welcome this review of access to Palliative Care in N Ireland and chaplains being invited to contribute. Such a review will hopefully have a significant impact on the lives of our patients, their loved ones and the staff and the volunteers. Such a review will hopefully make a service that is

excellent in parts of the region will make it excellent across the region. Not only will this improve the palliative and end of life care experience of patients and those who are important to them it will have a ripple effect in other ways. Where there are sufficient staff and volunteers and they are fully equipped to deliver holistic person centred physical, psychological, social and spiritual care their own morale will improve as they deliver compassionate care at such a crucial time. Also bed flow pressures in ED, the demand for bereavement counselling support; care in the community; demand on GPs – all these areas and more will see a significant improvement.