

Foyle Hospice

Based in the North West, Registered Provider for a ten bed Inpatient Unit, alongside Day Hospice, Community Specialist Palliative Care services, an Integrative Care Clinic and other support mechanisms for patients and families. We provide hospice and palliative care for patients across the Western Health and Social Care Trust, as well as offering support for families and carers through offering a wide range of services. As an organisation, Foyle Hospice is a key player in the delivery of palliative care services in the North West region and therefore, we welcome this inquiry to ensure that a comprehensive review will look to the development and implementation of a holistic palliative care strategy in order to fully meet the needs with an increasing and in a much more complex environment. We support this inquiry with a view to a sustainable service model, which ensures equitable and fair access to a consistent and highest standard of care for every patient who needs it.

Current state of palliative care services

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

Good

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

There is a slow increase in awareness and understanding of palliative care across the general public, which is generally driven by their personal experience of engagement with palliative care services as a patient or through a family member receiving support. The perception of palliative care as a last resort and misconception of it as simply being end of life, needs to be addressed. This would be best served through the development and implementation of a comprehensive palliative care strategy, with a focus on educational interventions. Additional investment in short term projects, such as Compassionate Communities and Hospice Out Patient Services would enable earlier engagement and offer improved pathways to holistic palliative care services for those who need it, accessing it as early as possible without fear that it signifies end of life. A proactive approach to supporting activities such as Palliative Care Week and Hospice Week through community groups and elected representatives would strengthen the message that palliative care is everyone's responsibility to facilitate appropriate intervention in the right place at the right time for those people with a life limiting illness.

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?

Independent hospices and health trusts are currently contributing to the provision of excellent palliative care in Northern Ireland, but this is not considered consistent or equitable. The key areas that require attention are support for young adults who are transitioning from children to adult

services; lack of capacity in non-specialist settings to care for people with ongoing care needs but who no longer require a bed in a hospice; late diagnosis meaning that there has been a delay in patients accessing the services that might have been more suitable and better supported them through their journey; and gaps in services for people who live in more remote rural and isolated areas because of poor access to public transport and/or infrastructure. Hospice UK has been undertaking a policy research project on palliative care in remote and rural areas across the UK over the last year, with a report expected to be published shortly. This work has included speaking directly to palliative care professionals and people with lived experience in Northern Ireland and the results would certainly assist with this inquiry.

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

Yes

It is not always clear about what services are available to patients and their families across the palliative care spectrum, when they are required to make choices about their care. There has been an increase in the promotion of Advance Care Planning and whilst this is helpful, there is still an education piece amongst health care professionals so that they are fully informed about options available in terms of care provision. There is still work to be done in order to dispel the myth that hospice and palliative care is only for cancer patients, but is also available to those with neurological diagnoses or complex multi-morbidity combined with frailty. There are also barriers to specific groups of individuals, such as those who share protected characteristics or who face wider issues such as financial hardship. With an increasingly diverse population in Northern Ireland, it is important that adequate resources are made available to ensure that palliative care services providers reach out and engage with ethnic minorities and socially marginalised groups, addressing socio-economic issues and other barriers so that palliative care is available to everyone and anyone who needs it. Palliative care service providers need greater access to training and/or resources such as interpretation and sign language, as well as increased confidence in understanding and dealing with neuro-diverse patients. There needs to be a framework whereby we have a system that is inclusive for all, in particular we need to better support and address the needs of those who are isolated, living in rural areas, homeless, identify as members of the LGBTQIA+ community and those who may find themselves in prisons at the end of life.

What additional services could/should be provided?

We believe that although the delivery of palliative care is good, services are well established and can be built upon to ensure a comprehensive, consistent and cohesive delivery across

all of Northern Ireland. Foyle Hospice operate a 24/7 advice line, and we see merit in this being operated on a regional basis as a service to support health and social care staff as well as patients and families. Increased support for non-medical prescribing, alongside electronic prescribing and a regional, standardised approach to the roll out of Just In Case medication would address many issues patients and families face, particularly out of hours and for those who live in remote and rural areas. We would also encourage a focus on seven day service and/or hospice at home models outside of hospice and hospital buildings. We are well aware that patients do not deteriorate or become more ill during weekdays 9am - 5pm and this really needs to be taken into account when allocating resources to support people at end of life. We should be more ably equipped to support people at home, in familiar surroundings with those most important to them.

Integration of Services

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

Integration of services across the whole health system is different across the region and varies. Hospices and HSC palliative care units have a good approach and reach outwards, but sometimes referrals arrive too late from other specialists to achieve maximum impact for patients. Hospices need to be more adequately supported to maximise our effectiveness. For example: difficulties with non-medical prescribing – where processes were not adequately put in place to support qualified nurses to prescribe as part of the hospice services in the community; full access to a suitable IT system for hospices has been significantly delayed and needs to be treated as an urgent priority to ensure patient safety and effective working; seven day community services. In addition, there are at times wider issues sharing data between hospices and Trust organisations as the hospices are viewed as “external” and therefore less trusted. Although we are fortunate to benefit from Allied Health Care Professionals and a wide range of volunteers, but these are not dedicated resources and may not be always immediately available for patients. We work closely with Health Trusts and other community and voluntary sector organisations, but we are fragmented. Sometimes there is no single point of contact, which results in frustration and confusion among the hospitals, community and hospices in terms of where patients, families and carers can seek support.

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

Yes

Without doubt we believe it would be helpful to see palliative care become a regional service. However, any work to develop this would need to recognise the substantial scale of palliative care that is delivered out with specialist palliative care services. GPs, District Nursing teams and care homes all provide crucial support to many who need care. Specialist palliative care is primarily delivered by independent hospices across Northern Ireland and a

regional approach could help to deliver greater visibility of any gaps in service and address existing inequities. That said, it is important that local needs are recognised given the inequities that have been previously outlined and it would be crucial for those respective communities are able to be part of providing practical and innovative solutions. It would be extremely important that local delivery be accountable at a regional level, with the overall aim of a comprehensive, cohesive and consistent experience for patients and families. I am aware that Hospice UK has submitted a response to this consultation and the advantages of a regional service are well made in their submission.

What can be done to improve integration?

We would like to see a commitment to the development and implementation of a new palliative care strategy for adults and children in Northern Ireland. This is fundamental to address ongoing issues and enable improvement, including greater integration of services. We need a single point of access for all those needing palliative care support out of hours. All hospices should have appropriate training and full access to the encompass IT system as soon as possible. The roll out of the ReSPECT form to provide a regional approach for end of life care planning should be accelerated - this has been raised several times at the Palliative Care in Partnership Programme Board, without resolution. The appointment of a clinical lead for palliative care could support greater integration of services across all areas - incidentally Northern Ireland is the only region in the UK that does not have such a resource. Workforce planning for palliative care is needed to consider the growing need for services (due to demographic change), and should include the needs of hospices. Significant collaboration on the streamlining of systems and processes to enable better communication, access to information and data sharing is essential, so that patients can be referred to the most appropriate service in the right place and at the right time.

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?

Foyle Hospice has been delivering a Seven Day Community Specialist Palliative Care service in the northern sector of the Western Health and Social Care Trust since January 2022 and in the southern sector of WHSCT since August 2024. This service has enabled patients to remain in their home, prevent a weekend admission to hospital and avoid undue pressures on emergency services. In addition, we currently have a Specialty Doctor available three days per week to support the community team with more complex patients, supporting them to stay in their own homes where reasonable and possible. We have also been operating an Integrative Care Clinic since 2015 where patients can attend once a week and have an assessment by one of our medical team and/or nursing assessment. This three day per week service has resulted in reduced need for appointments with GPs and/or consultants thereby lessening waiting times. Our adult and children bereavement support, complementary therapies and carer health services have all positively contributed to the

wellbeing of our patient and families. We recognise the public health approach as a key driver moving forward and to this end, our Compassionate Communities project has proven to deliver numerous outcomes towards a better understanding of palliative care, earlier intervention and a proactive response to death, dying and bereavement.

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

No

We pride ourselves on holistic care, treating the person and not just the symptom, including support to families and those carers who have been caring for patients during their illness. UK Commission on Bereavement estimate at least five people are affected by each death. As a compassionate organisation, staff provide support to a large number of people, other than the patients at an extremely difficult, emotional and sensitive time. They follow up with relatives after the death of their loved one and our volunteer chaplains will assist as appropriate. Staff will advise families about the condition of their loved one receiving palliative care and as they approach end of life. This is emotionally challenging and a significant expectation in addition to responsibility for providing care and support for patients. Staff contribution in this regard is positively reflected in the feedback received. Given the magnitude of impact and the complexities associated with health care provision in Northern Ireland, families can find it frustrating and confusing to navigate, further compounded by the fact that they are grieving for their loved one. A resource to engage with relatives and carers directly, offering advice and support would be beneficial. This would allow for our medical and clinical team to focus on the delivery of direct care to the patient, knowing that the needs of family members are being met through a network of internal and external support services.

Funding and Strategy

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

No

Hospices in Northern Ireland provide care to around two thirds of the people who die each year in the region and that is substantially higher than the UK average. The current funding model is not sustainable given that we rely heavily on the kindness and generosity of the local community to contribute approximately 60% of our running costs each year and volunteers to support our services.

Palliative care services face the same pressures as other health and social care services, including the impact of social care shortages, workforce issues and capacity to deliver our services on an already stretched landscape. Since the pandemic, our Inpatient Unit has been supporting more complex patients and a higher number of patients at end of life, as opposed to symptom management or respite care. For those who may be discharged, this is

difficult because of a lack of suitable care packages. We are witnessing a higher number of younger adults referred to our services - many with aggressive disease and symptoms that are more difficult to manage at home. In part, this is a result of later terminal diagnoses and this is to some degree attributable to the current pressures on the wider health care system.

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

Hospice Alliance NI collectively met with the Health Minister in December 2024, to highlight the strategic challenges facing our respective organisations. The current funding model for hospices is out of date and not fit for purpose. We are reliant on approximately 60% of voluntary income through fundraising activities to deliver what is ultimately the responsibility of the government - to ensure the health and wellbeing of the people of Northern Ireland. A well-supported hospice sector is a key enabler of moving more palliative and end of life care into the community. Dependency on the generosity of local communities is unsustainable, particularly when considering the long-term impact of the cost of living crisis and the substantially increasing needs of the population. The Committee should look to the Republic of Ireland where full funding for hospices has been delivered, with a view to transparency and meaningful engagement for hospices as equitable partners when decisions are being made that have a direct impact. We are delivering more services in the community and whilst commissioners have indicated this is the approach they wish to see, that message is then undermined by the fact that it seems a majority of funding is calculated on the basis of IPU beds. We appreciate the potential for cost pressures to be addressed, and recognise that some additional funding has been made available. However, this has not met the financial impact of cost pressures.

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

Northern Ireland will have an increasingly ageing population. The number of people aged 65 and over has already increased by approximately 25% in the last decade. People are living longer - many with multiple conditions and/or severe frailty and the care needs of individuals have become increasingly complex. The need for palliative care is increasing, and reflects that the care needed is becoming more complex and challenging. The Living Matters Dying Matters strategy published in 2010 is well outdated and without the development of a new strategy and no forward planning, it is difficult for services to meet the current and future levels of demand. It is clear that an overarching vision for palliative care is urgently needed. There is no doubt that some people receive outstanding care right to the end but that is not always guaranteed, because of the pressures on an increasingly stretched sector. Any new strategy should consider policy changes to ensure services meet population need across the region. The Republic of Ireland has recently launched their new palliative care

policy and again we would urge those undertaking this review to include that as a reference point for this Inquiry.

Any other comments

We warmly welcome the Review of Access to Palliative Care Services through this Health Committee Inquiry. We consider it as a positive opportunity for the Committee to engage with various organisations delivering services with a view to improving access and delivery of appropriate and high quality services, without exception to those who need them the most. We trust that those responsible for final conclusions and any recommendations will consider the needs of the population now, and well into the future, so that planning for a palliative care model will be sufficiently resourced and supported by highly trained and skilled staff. The increasing complexity of patients and comorbidities, growing ageing population, and change in both cultural and family dynamics cannot be emphasised enough. We are hopeful that the outcome will result in a new palliative care strategy for Northern Ireland, taking account of both adult and children's services, which is consistent and equitable across the whole region. We would also highlight the need for a commitment to sustainable funding so that it can be delivered accordingly and help support people's choice in their preferred place of care at end of life.