

Submission to the Oireachtas Committee on the Future of Healthcare from All Ireland Institute of Hospice and Palliative Care

Executive Summary

With numbers of older people set to rise in Ireland, it is vital that models of care delivery adapt to enable people to live as well as possible until death. Continued change and innovation is required to future proof the health service in providing the best possible care for those living in Ireland, regardless of underlying diagnosis. This is especially true of the care provided to those living with serious and progressive life-threatening illnesses, such as advanced cancer, advanced dementia, degenerative neurological conditions, irreversible organ failure, or acquired immune deficiency syndrome (AIDS).

AllHPC is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. AllHPC advances education, research and practice to improve the palliative care experience of people with life limiting conditions and their families. As the palliative care sector's institute, AllHPC is:

- involving service users, carers and communities in palliative care delivery and development
- working to integrate palliative care across the health system so people are supported as early as possible,
- supporting the development of specialist palliative care services for everyone who needs them.

Overview

Now more than ever, society is facing many challenges when it comes to the provision of hospice and palliative care. With numbers of older people set to rise, along with rates of disability, dependence on carers and deaths set to increase over the next decade, it is vital that models of care delivery adapt to cope. Continued change and innovation is required to future proof models of care, enabling health services to provide the best possible care for those living in Ireland, regardless of underlying condition.

In 2014, Ministers of Health at the World Health Assembly¹ supported a ground-breaking resolution driving national action to reduce barriers to the accessibility and availability of palliative care. The Assembly urged Member States (inter alia):

- To develop, strengthen and implement palliative care policies to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care;
- To ensure adequate domestic funding and allocation of human resources for palliative care initiatives, including education and training, and quality improvement initiatives;
- To provide basic support, including through multi-sectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate;
- To aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities.

Since the publication of the 2001 NACPC Report², significant initiatives to enhance services have taken place across and between organisations within the palliative care sector in Ireland, as detailed in the report “Palliative Care - The Three Year Development Framework (2016 – 2018)” (produced by the HSE and submitted to the Department of Health for consideration). These include the creation of the HSE’s National Clinical Programme for Palliative Care³ to improve quality, facilitate equitable access and promote efficient use of resources, and the establishment of the All Ireland Institute for Hospice and Palliative Care (AIHPC)⁴ and The Palliative Hub⁵, with the potential to transform and promote palliative care education, research and practice across the island of Ireland.

Principles of rehabilitation are evident as central themes in the philosophy and vision for modern day hospice and palliative care espoused by its founder Dame Cicely Saunders: “All the work of the professional team ... [is] to enable the dying person to live until he dies, at his own maximal potential performing to the limit of his physical and mental capacity with control and independence whenever possible”⁶. Despite this, palliative care services are still considered by both professionals and the public as relevant only to last days of life and hospices are often seen as places of death, dying and bereavement with less of a focus on helping people to live well, and be the best they can be. A model of “total care” has grown up that can in practice disable the patient by taking over and “doing” for or to them⁷.

But is this what patients want? The evidence is that most people express a desire to remain as independent as possible for as long as possible in the face of advancing illness. It is paramount to people to be viewed as normal, rather than as an illness, and where possible to be able to do normal things such as wash, dress, shop, cook for themselves. The Let's Talk About Palliative Care Survey report⁸, commissioned by the AIHPC, revealed that of the 528 responses received:

- Over two thirds (68%) of respondents signified that planning for the future was their biggest practical worry.
- While 27% felt supported by care provided, 52% indicated that they felt frustrated, helpless or a combination of both.
- Forty-eight percent of respondents felt they were communicated to clearly or sensitively by those providing care, while 22% indicated that issues of relevance were avoided completely.
- Thirty-four percent of respondents experienced information being communicated in a timely or appropriate manner, yet 37% felt they received information too little, too late.
- Only 24% of respondents felt they were able to make choices they wanted whilst 34% felt control was in someone else's hands and 21% felt that choices were limited.
- Emotional or psychological needs were felt to be less well met than spiritual or physical needs in over half of respondents (51%). Notably psychologists and counsellors were rarely identified as being involved in the care of those reporting their experience.
- Forty-two percent of respondents indicated they would have preferred better coordination of care or treatment; 20% signified that better emotional support could have been provided.
- Half of respondents (50%) felt that family and friends were adequately involved in care plans, or that their views were respected, but 20% felt family and friends were forgotten about or excluded and 18% felt that carers were put under too much pressure.

In moving to new and improved models of care it is vital that patients and families are:

- approached with an ethos of what we enable you to do for yourself rather than what healthcare services do for you;
- asked what matters to you rather than asking what's the matter with you;
- asked what is your goal rather than what is your problem;
- rather than asked what is the pain stopping you or your loved one from doing, rather than just how bad is the pain,⁷

Sufficient consideration must be given to educating future practitioners in the art and philosophy of palliative care. In doing so we limit the dangers associated with prescriptive care planning which insufficiently considers the unique care needs associated with an individual's personal life preferences and goals⁷. The Palliative Care Competence Framework⁹ supports health care professionals in all Irish care settings to self-assess, develop and maintain skills, knowledge and attributes required for the provision of palliative

care and delivers a mandate to educators in the delivery of training which addresses these elements.

Research is a vital component of service development. In a systematic process which culminated in a prioritisation in 2015, the top 10 unanswered research questions, or evidence uncertainties, in palliative and end of life care in Ireland as identified by health care providers, patients and carers,¹⁰ were determined to be as follows:

1. What are the best ways of providing palliative care **outside of 'working hours'** to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families?
2. What are the benefits, and best ways, of **providing care in the patient's home** and how can home care be maintained as long as possible? Does good co-ordination of services affect this?
3. What are the best ways to make sure that palliative care patients receive adequate **pain and symptom relief** and which drugs for pain management are best in terms of side-effects, such as drowsiness?
4. What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also **explain the dying process compassionately and honestly**? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?
5. What are the benefits of **Advance Care Planning** and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?
6. What are the best ways to make sure there is **continuity for patients at the end of life**, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?
7. What are the best ways to **support children and young people** when someone close to them is dying or has died? This includes **communicating with them about the diagnosis and dying process**, enabling them to talk about their experience and providing bereavement support.
8. What **information and training do carers and families** need to provide the best care for their loved one who is dying?
9. What are the best ways to begin and deliver **palliative care for patients with non-cancer diseases** (such as COPD, heart failure, MND, AIDS, multiple sclerosis, Crohn's disease and stroke)?
10. Are hospices, hospitals and care homes providing adequate **staff training** to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered?

The National Clinical Care Programme (NCCP) for Palliative Care² aims to ensure that patients with life-limiting conditions and families can easily access a level of palliative care

service that is appropriate to their needs regardless of care setting or diagnosis. As a key collaborator of the NCCP, AIIHPC provide a platform for collaborative engagement with key stakeholders, including service users, carers and the wider community, care providers, educators and researchers.

Recommendations for action by Government

The AIIHPC recommend the following actions by Government:

- Continue to strive for a palliative care approach to be delivered equitably to all who need it, alongside provision of other forms of care, regardless of diagnosis or geographical location and as early in treatment planning as would support more positive health and well-being outcomes for patients and their families. A palliative care approach should be provided in any location or setting by all health care professionals and is not solely the remit of palliative care specialists.
- Ensure that the findings of the Let's Talk About Survey report and the voices of service users, carers and the wider community are adequately represented in decisions surrounding future palliative care developments.
- Support ongoing cross-organisational collaborative networks to ensure questions which matter most are answered in an efficient and effective manner and that research findings are translated into practical guidance for services and incorporated into curricula development for specialist training.
- Mandate that the Palliative Care Competency Framework informs the education and development of healthcare professionals across the health and social care sector and is considered within whole service CPD plans. These competencies are of relevance to all health care professionals and are not solely relevant to those working within specialist palliative care settings.

About the AIIHPC

All Ireland Institute of Hospice & Palliative Care (AIIHPC) is a leading organisation with national and international influence driving excellence in palliative care. We are a collaborative of hospices, health and social care organisations and universities on the island of Ireland, working to improve the palliative care experience of people with life limiting conditions and their families.

Major initiatives led by the AIIHPC include:

- **The Palliative Hub⁴** – an online gateway to information and resources about palliative care on the island of Ireland for the public, healthcare professionals, educators and researchers. The Hub offers a central repository for key reports, toolkits and guidance documents and an overview of the latest research and developments taking place in the Republic of Ireland as well as in Northern Ireland. It contains two public facing websites which aim to be portals to key information about palliative care. It also provides dedicated areas for palliative care professional online education and forums.

- **Voices4Care** - an initiative involving people receiving palliative care (service users), carers and the wider community to bring unique and fresh insights about care to those providing or making decisions about palliative care. Voices4Care members supported the Let's Talk About Palliative Care survey⁷ which provides a picture of what matters to people when they are living with a palliative condition, and co-produced the Top 10 Research Priorities for the island of Ireland¹⁰.
- **Palliative Care Research Network (PCRN)** – Launched in 2012 the PCRN aims to offer the all-Island palliative care research community opportunities to create and engage within a collaborative environment that supports the development of excellent, high quality, clinically-relevant and innovative research projects that reflect, inform and contribute to AllHPC's programmes of work and the wider palliative care community.
- **Education Network** - bringing the providers and consumers of education together to ensure that learning opportunities are available, accessible and of the highest quality and supporting the establishment of core competences for palliative care, this network of 50+ organisation promotes high quality palliative care education
- **Chief Executive Officers Network** - forum for the chief officers and Directors from voluntary hospices to meet to discuss issues of mutual interest and to share learning and experience both within and across the island of Ireland.

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