

Irish Hospice Foundation Opening Statement to Joint Committee on Assisted Dying

Thank you Cathaoirleach, Committee members and clerk for the invitation to Irish Hospice Foundation (IHF) to speak with you today on the topic of “accessing palliative care and social supports.”

We are a national organisation with over 37 years’ experience in the field of dying, death and bereavement. Our vision is an Ireland where people facing end of life or bereavement, are provided with the care and support that they need. We understand how difficult the conversation on dying, death and bereavement is. We also understand that Assisted Dying adds a further complexity to this discussion. We have advocated that any exploration of this issue is robust, respectful, inclusive and informed.

Current experiences of dying and death in Ireland

35,477 deaths were registered last year in Ireland. ¹ This equates to nearly 100 people dying every day. 83% of these deaths are people aged over 65. ² CSO projections suggest the number of deaths will increase to just under 46,000 by 2040.

74% of Irish adults would prefer to die at home³, but only 23% will do so. Hospitals remain the most common place where 44% of people will die, 23% of people will die in a nursing home and 8% will die in a hospice. ⁴ Cancer (31%) and heart-related disease (29%) are the leading causes of death. ⁵

Public perceptions of death

In 2016 we conducted a survey (‘Have your Say’) to find out what is most important to Irish citizens as they think about living with illness, death, and bereavement. ⁶ Over 2,500 people responded and the findings suggest that most people want to be pain free, be treated with and die with dignity, feel comfortable and cared for, ideally at home. The survey also found that people had worries about being a burden on their family as they approached end of life.

In 2022, we carried out our Time to Reflect survey, which was completed by over 2,200 people. The aim was to establish the impact of COVID-19 on attitudes towards dying, death and bereavement in Ireland. The findings revealed the importance people place on the rituals related to dying and the need to prioritise supports for end-of-life and bereavement care. ⁷

¹ [Vital Statistics Yearly Summary 2022 - CSO - Central Statistics Office](#)

² Ibid

³ [Weafer, J \(2014\) Irish attitudes to death, dying & bereavement 2004-2014.pdf;sequence=1 \(lenus.ie\)](#)

⁴ [Dying-and-Death-in-Ireland-what-do-we-routinely-measure-how-can-we-improve-2021.pdf \(hospicefoundation.ie\)](#)

⁵ Ibid

⁶ [Have-Your-Say-Report.pdf \(hospicefoundation.ie\)](#)

⁷ [Time to Reflect](#)

In our recent consultation report *Dying Well at Home* - a good death was described by focus group participants as comfortable, free from pain and suffering, honouring the end-of-life wishes of the patient, allowing them to die with dignity in the place of their choosing, with those they wanted present.⁸

Obstacles to a good death

There are enablers to a good death, but conversely there are also obstacles that people face in realising a good death in Ireland today.

Access to palliative care at all levels

Access to timely palliative care is associated with improved quality of life. The percentage of people dying in Ireland that will require palliative care is projected to increase by up to 84% by the year 2046.⁹ However, these figures only account for people in their last year of life and many people will be living longer with complex needs, therefore are likely to need longer term palliative care.

While availability and access to palliative care services has been increasing, access is uneven and there are still some regions without an inpatient Specialist Palliative Care unit. The vast majority of those admitted to inpatient Specialist Palliative Care beds have a primary diagnosis of cancer. However, there has been a small but steady increase in the proportion of new patients with a non-cancer primary diagnosis being admitted to inpatient beds.

There is a need to focus on strengthening access to Primary Palliative Care and Generalist Palliative Care. Access to care can be improved through expanding the knowledge on end-of-life care across different professionals and care settings.

Community and home supports

The services delivering primary care and home supports are facing ever increasing challenges. Waiting lists continue to grow for accessing community supports and there is an alarming number of people who have been assessed and approved but remain without adequate or indeed any home supports.

Essential conversations

Conversations are key to enabling a good death. They are dependent on the person and their family being supported and having good relationships in place with their healthcare professionals, particularly in terms of Advance Care Planning.

Lack of bereavement supports.

Bereavement is relatively invisible in formal policies, yet it impacts so many people each year. For every one death, up to 10 people are bereaved and significantly impacted.¹⁰ That means over 350,000 people are grieving the death of a loved one each year.

A lack of preparedness can lead to poor bereavement outcomes for people. The factors that can influence this include:

⁸ [Dying-Well-at-Home-Report-Irish-Hospice-Foundation.pdf \(hospicefoundation.ie\)](#)

⁹ [Population-based palliative care planning in Ireland: how many people will live and die with serious illness to 2046? - PubMed \(nih.gov\)](#)

¹⁰ [Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States | PNAS](#)

- Inadequate levels of understanding and information about the **caring** responsibilities involved when looking after a loved one at end of life;
- Practical considerations such as **planning** for a funeral;
- **Emotional** preparedness or having “unfinished business” with the person;
- Medical preparedness such as **knowing what to expect** at the time of death. ¹¹

Recommendations

The recommendations we present offer opportunities for the Committee to highlight in their final report areas that require investment and improvements in end-of-life and bereavement care. These are recommendations that apply regardless of how a person is supported to die or whether the Committee recommends to legislate for change in this area.

1. Publish the new National Adult Palliative Care Policy alongside agreed multi-annual investment and action plan with timeline of implementation
2. Strategic planning to support an expansion of community-based primary palliative care and home care services to support people at end of life to die at home
3. Provision of education and training to improve death literacy, understanding of palliative care and promote conversations about end-of-life care among healthcare professionals to support patients and families
4. Cross departmental commitment to an agreed public health model approach to bereavement
5. Development of standards for bereavement care to provide a framework for services with the associated staff competencies and training needs
6. Initiation of a Register of Advance Healthcare Directives, by the Decision Support Service, as outlined in legislation

¹¹ [Preparedness for the death of an elderly family member: A possible protective factor for pre-loss grief in informal caregivers - ScienceDirect](#)