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# Pre-Budget Submission 2020

**Dying is Everyone's Business**  
Why we must count the cost

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## OUR MANDATE

**In the next 10 years more than 300,000 people will die  
and 3 million of us will be bereaved**

### The People's Charter on Dying, Death and Bereavement in Ireland.

The Irish Hospice Foundation asked the people of Ireland what is needed  
for a good death and for healthy grieving.

**3,000 people say**

#### **I want to live and die in an Ireland where:**

- Death is talked about and not hidden away.
- I can prepare for what lies ahead.
- I can get relief from pain, no matter where I am being cared for or what condition I have.
- I am treated as an individual and my wishes, choices and beliefs are respected.
- I, and the people who care for me, can get the practical services and support that we need.
- I can get information to understand what is happening to me.
- There is the support to help me cope with worries or distress.
- I can die, surrounded by people I love, in a calm and comfortable place. In my home, if at all possible.
- I am supported to stay in control of my own decisions.
- My dignity is respected and maintained to the end of my life, and after my death.



#### **For the people who matter to me, I want an Ireland where:**

- People understand grief and do not avoid thinking or talking about it.
- Family and friends are supported during a loved one's illness and after their death.
- People get space and time to grieve, talk and remember.

Help us by rolling out the charter in your community, workplace, family or organisation.

**Learn more at [hospicefoundation.ie/haveyoursay](https://hospicefoundation.ie/haveyoursay)**

Your Life Your Death Your Say #haveyoursayirl



## WHY WE MUST COUNT THE COST OF DYING, DEATH AND BEREAVEMENT

In 2016 almost 3,000 people gave the Irish Hospice Foundation (IHF) their views on how dying, death and bereavement could be better addressed by the State and society as part of our “Have Your Say” survey. Their voices are reflected in the People’s Charter on Dying, Death and Bereavement in Ireland<sup>1</sup>.

People told us that they want to live and die in an Ireland where:

- There is more open conversation about death, dying and loss
- People have a chance to prepare for end of life
- Choice and dignity are upheld before and after death
- Services and information are available
- There is support for family and friends, time to grieve and understanding of grief

We are committed to making the aspirations reflected in the People’s Charter on Dying, Death and Bereavement in Ireland a reality. We are asking the Government to join us in that commitment in Budget 2020.

We ask the Government to implement the recommendations in existing policy and related reports to achieve an integrated approach to all issues relating to dying, death and bereavement. These reports include:

- Adult Palliative Care Services, Model of Care for Ireland
- National Palliative Care Services: Three Year Development Framework (2017-2019)
- The HSE National Bereavement Standards following Pregnancy Loss and Perinatal Death
- National Cancer Strategy 2017
- Sláintecare Report 2017
- Finite Lives: A study in how the State deals with issues relating to end of life: Part 1- A Report on how the Civil Service deals with dying, death and bereavement among its own members (2015)
- Finite Lives: Dying, Death and Bereavement in Ireland: An Examination of State Services (2017)

We urge the Government to take notice of the concerns and aspirations of the people of Ireland and make a real effort to respond to their needs – our needs – because dying is their business too.

As the only national organisation dedicated to all issues related to dying, death and bereavement, the Irish Hospice Foundation (IHF) has a long record of proactive intervention to try to make sure that no-one will face death or bereavement without the care and support they need. We are ready to continue in partnership with the Government and other agencies and groups to encourage, support and enable innovation and excellence in end-of-life and bereavement care.

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<sup>1</sup> <https://hospicefoundation.ie/haveyoursay/>

# SERVICES AND SUPPORTS

## PALLIATIVE CARE

The IHF has for many years advocated for the removal of disparities in the delivery of specialist palliative care (SPC). This work has been supported by numerous research reports. Again in 2015 a report by TCD and the ESRI<sup>2</sup> shows wide variations in access to SPC services for people with a terminal illness. It underlines the geographic inequity particularly in the availability of SPC inpatient units, specialist day care services and outpatient clinics. While all areas have access to specialist community palliative care/home care teams there are differences in service availability with some offered seven days a week, twenty four hours a day and others during office hours only. There are also variations in the availability of multi-disciplinary palliative care teams.

A 2013 report<sup>3</sup> found that because of regional inequity in resource allocation, an estimated 2,500 patients are denied admission to hospice beds every year. Whilst this situation would have improved with the opening of new inpatient beds in Kerry, Kildare and planned openings in Waterford, Mayo and Wicklow, there remain many areas of the country without access to inpatient hospice and palliative care beds. **This situation continues despite stated national policy since 2001 to secure equity of access to SPC by providing one hospice bed for every 10,000 people. The Midlands and North East have no SPC inpatient beds.**

There is compelling evidence that the provision of comprehensive SPC services across all care settings (hospital, home, inpatient hospice and daycare) is at least as cost effective as acute services. Where such services exist, people in those services use less acute hospital services and live longer in greater comfort and dignity.

The estimated minimal level of palliative care need in Ireland is considerable:

- At least 0.5% of the population have palliative care needs at any one time.
- Annually, 80% of deaths in Ireland are from conditions considered to have palliative care needs.

It has been noted that Ireland is one of the countries with the highest need for palliative care globally because of demographic changes.

Currently, every month in Ireland:

- 3370 patients are seen by community palliative care services
- 1340 patients are seen by hospital palliative care services
- 438 patients receive inpatient unit services
- 642 families receive bereavement services<sup>4</sup>

The provision of comprehensive palliative care services is proposed in “The Palliative Care Services: Three Year Development Framework (2017-2019)”, the “National Cancer Strategy” (2017) and the “Sláintecare Report” (2017).

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<sup>2</sup> Brick, A. et al. (2015) [Economic Evaluation of Palliative Care in Ireland: Final Report](#). Dublin: TCD

<sup>3</sup> Irish Hospice Foundation (2013) [Access to Specialist Palliative Care Services and Place of Death in Ireland – what the Data Tells Us: Irish Hospice Foundation](#).

<sup>4</sup> HSE National Clinical Care Programme (2019) [Adult Palliative Care Services, Model of Care](#)

**We ask the Government to:**

- **develop a new National Policy on Palliative Care to include all elements of current policy and address policy gaps**
- **fully resource a clear timeline and process for the implementation of the Palliative Care Services Three Year Development Framework (2017-2019) and the ring-fenced development funding outlined in the Sláintecare Report. This should include prioritisation of developments for inpatient hospice units in the Midlands and North East where there are currently critical gaps in services.**

## **NURSES FOR NIGHT CARE**

The 2016 Programme for Government cites the importance of delivering the right care in the right place and the inherent efficiency in health service delivery achieved through integrating care in all care settings. This is echoed in the Sláintecare Report.

About three-quarters of Irish people wish to die at home. About one-quarter of people achieve this. Whilst it is not possible that all can die at home, the difference between 74% and 26% is striking – **more can be done to enable quality care at end of life in the usual place of residence**<sup>5</sup>. There are gaps in services to support people to be cared for and to die at home.

Since 2006, the Irish Hospice Foundation (IHF) has been funding a service (delivered through the Irish Cancer Society's panel of nurses) that enables people who are dying at home with a non-malignant condition to access night nursing. This service responds to the nursing needs of persons who have an illness other than cancer, are in the final stage of their illness and are under the care of the local specialist palliative home care team, generally working together with the patient's GP and/or other health professionals.

The demand for this service and that of the Irish Cancer Society has increased year on year. In the case of the IHF Nurses for Night Care service, demand has increased from eight referrals in 2007 to 874 in 2018. At the same time the cost of the services to IHF increased from €64,000 in 2007 to €658,997 in 2018. Besides fulfilling an immediate need, this initiative has identified a demand for night nursing for this group and ultimately this should encourage local service providers to take account of this need when drawing up service plans.

**We acknowledge the recognition of the provision of night nursing/nurses for night care as a core component of homecare provision within the Three-Year Development Framework.**

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<sup>5</sup> McKeown, K. (2014) [Enabling More People to Die at Home: Making the Case for Quality Indicators as Drivers for Change on Place of Care and Place of Death in Ireland](#) Dublin: Irish Hospice Foundation.

Until 2017, this €3.3 million essential service was funded entirely from charitable sources. The recommendation in The Palliative Care Services Three Year Development Framework in relation to 50% statutory funding for this service must be implemented. To date, less than 10% of this state funding has been provided. This is NOT sustainable.

**We ask for:**

- **the Government to provide for the stated commitment to 50% statutory funding for this vital service.**

## **DIGNITY AT END OF LIFE ACUTE HOSPITALS AND RESIDENTIAL CARE SETTINGS**

Two-thirds of us will die in an acute hospital or in long-stay care<sup>6</sup>.

Continuity of care is paramount in delivering quality end-of-life care; yet we are aware of the variations that can exist and challenges that present to ensure that people dying in hospital and in residential care settings can have a good death. The IHF introduced the Compassionate End of Life Care Programme (CEOL) in residential care and the Hospice Friendly Hospital Programme (HFH) in acute care settings to ensure that excellence in the delivery of end-of-life, palliative and bereavement care are central to the everyday business in both these care settings. CEOL helps to reduce both unnecessary admissions to hospital and the burden on residents, their families and care-givers.

**These quality improvement and capacity-building programmes have successfully demonstrated how we can improve the experience of end-of-life care for people who are dying and their families, as well as supporting staff to deliver compassionate end-of-life care.**

**We ask for:**

- **continued support for end-of-life care initiatives through the Hospice Friendly Hospitals programme in acute hospitals and the CEOL programme in the residential care sector to ensure that continuous quality improvement is embedded across all care settings.**

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<sup>6</sup> Calculation based on HIPE data and CSO figures

## MORTUARY FACILITIES

Recent controversy about mortuary and post-mortem provision has brought into sharp focus the complexities which can arise in facilities providing services to the deceased and the bereaved.

We know that 43% of the average 30,000 people who die each year in Ireland die in the acute hospital sector. Many are brought to the mortuary before being transferred out of the hospital and in many regions in Ireland, people who die suddenly or from fatal injury are brought directly to the mortuary. Unfortunately, the majority of mortuaries in our public hospitals are in a state of disrepair and are far from being places which invoke feelings of respect and reverence for death and bereavement. Such environments can add additional stress and distress to those grieving the loss of a loved one and bring further pressure at a time when they are both most susceptible and most vulnerable. This can have a huge impact on the relatives' memories of the death and on their grieving experience. It also has potential to further undermine public confidence in the healthcare system.

Given the potential for similar distressing occurrences, we believe that a transformation project for all public hospital mortuaries should be undertaken as a matter of urgency.

Since 2010 the Irish Hospice Foundation's (IHF) Design & Dignity (D&D) programme has been working in partnership with the HSE to deliver a programme of excellence and evidence-based healthcare design to hospitals. Design & Dignity is part of the IHF's Hospice Friendly Hospitals (HFH) programme. The Tribal survey<sup>7</sup> of 2007 (funded by the IHF) showed the poor state of mortuaries throughout Ireland. We estimate that up to 21 public hospital mortuaries around Ireland require an upgrade. Since 2010 the four rounds of D&D grants scheme have approved and funded 41 projects in acute hospitals around the country, of which 13 projects were mortuaries. Eight of the mortuary projects thus funded are now substantially complete and the remaining six are ongoing.

In line with the IHF's proactive approach to overcoming difficulties, we believe that the D&D fund can offer a solution to this on-going problem. The programme – highly successful in its planned, high quality and partnership approach - could very effectively deliver on a specified ring-fenced capital fund for mortuaries. Real change for good is being effected in our public hospitals through HFH and D&D – though it is rarely brought to public – or indeed – political attention. We believe that an accelerated mortuary capital investment programme would be both timely and effective.

We know that there is general agreement about our goal that the dying, dead and bereaved should be afforded the best care in the most appropriate and dignified spaces and that those who care for and interact with them should have both optimum working conditions and on-going support. Accelerating progress on refurbishment of mortuary and post-mortem facilities would be a positive step to realising that goal in the short to medium term. This is a necessary investment which will help mitigate potential further distressing incidents in the future.

### **We ask for:**

- **ringfenced capital funding in 2020 to upgrade mortuary facilities across the acute hospital sectors through the IHF Design & Dignity Programme.**

<sup>7</sup> Tribal Consulting/Hospice Friendly Hospitals Programme (2007). [Design & Dignity Baseline Review](#). Dublin: Irish Hospice Foundation



## TIME TO PREPARE THINK AHEAD

In 2016, 3000 people answered the call to say what matters to them at end of life (Have Your Say 2016). There was overwhelming support for being able to prepare for what happens at end of life.

Citizens have told us that they wish to have a mechanism for discussing and recording issues relating to their end of life. The IHF's Think Ahead form is a popular method of facilitating such conversations and expressions with over 90,000 of such forms in circulation and a 75% increase in demand between 2018 and 2019. This form is widely accepted and can form the basis of public engagement activities envisaged under the Assisted Decision-Making (Capacity) Act 2015 provided there are resources to support this vital work. **Dying matters to Irish people – we need to allow them prepare for what lies ahead.**

The Assisted Decision-Making (Capacity) Act 2015 is not yet fully commenced. Its commencement will bring both choice and challenge to citizens and to the legal, health and social care professionals and service providers in advanced care planning (ACP) and in the recognition of advance healthcare directives (AHD).

Health and social care professionals will need support if they are to engage and fully implement advance health care planning, including advanced health care directives. This work needs to be supported by public engagement to help people understand issues concerning dying, death and bereavement and to help them think about, discuss and record their own wishes for end of life. The IHF has led this work through the Think Ahead Initiative.

### **We ask for:**

**funding for full commencement of the Assisted Decision-Making (Capacity) Act 2015 (ADMA), including Part 8 which provides for Advance Healthcare Directives to include:**

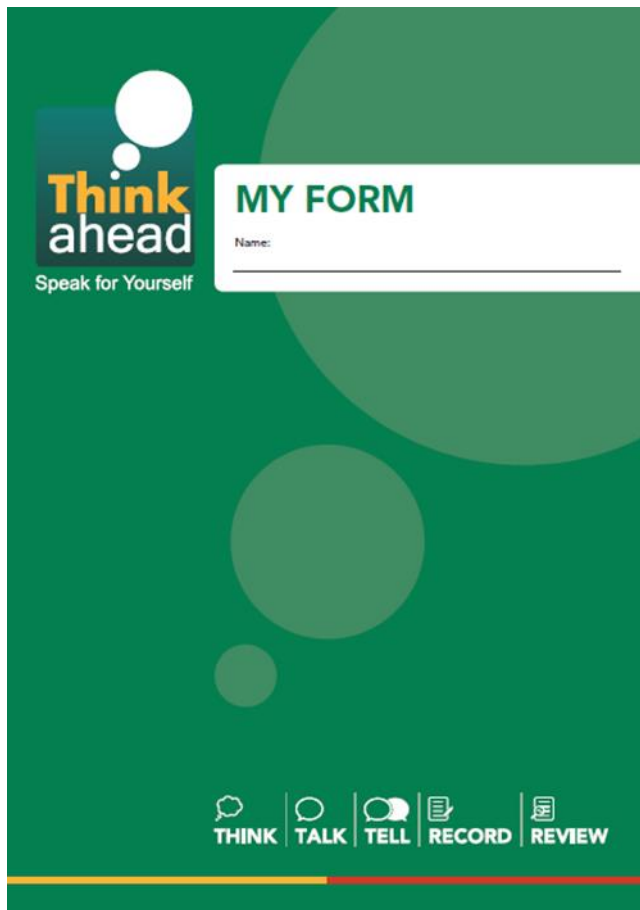
- **full funding for the Office of the Director of Decision Support Services, to include initiation of the following actions, outlined in legislation:**
  - **funding for a Register of Advance Healthcare Directives**
  - **national programme of training for healthcare and allied health and social care professionals to work under the provisions of the ADMA Communication, education and facilitation skills to support advance health care planning including advanced health care directives (AHD) in the implementation of HSE Codes of Practice on AHD**
  - **public engagement programmes to support patient interest groups to integrate advance care planning into chronic disease-management planning.**



**We ask for:**

- **funding for a National Programme to support public awareness of and citizen engagement in end- of-life issues, including planning for end of life, in line with commitments in the Programme for Government 2016. This should include:**
  - **adoption of and roll out by the Government of the IHF Think Ahead planning tool, in line with recommendations in the Finite Lives reports 2015 & 2017**

**Estimated Cost €150,000 per annum**



## UNDERSTANDING BEREAVEMENT

More than a quarter of a million of us are newly bereaved each year. Bereavement is a universal, normal – if painful - life experience. We know that grief impacts on bereaved people to different degrees and they process their grief in their own unique way. These impacts are influenced by the relationship we had to the person who has died, the support available from our family and friends, our life stage, beliefs and, of course the circumstance of the death. We know parental grief or sudden death can pose particular challenges. So too do financial problems, access to social support and the stress of carers' responsibilities. No matter what the grief or its cause, **we know bereavement matters and there is more we, as a society, can do to support the bereaved.**

Bereavement is largely invisible in formal policies. It does not feature as an issue in overarching health strategies/frameworks. It is given minimal consideration within mental health, suicide, cancer and palliative care policy frameworks. We believe that bereavement should be present in policies ranging from education to employment, from health to social protection. This is a view strongly endorsed in "Finite Lives" (2015 and 2017) and the HSE Palliative Care Services 3 Year Development Framework, as well as 'Enhancing Adult Bereavement Care across Ireland' (IHF, 2018).

Although bereavement is an individual experience, it is firmly set in a collective and societal context and that context is changing e.g. an ageing demographic, changing family structure and a more multicultural society. Most people rely heavily on social support during and after bereavement and sometimes we look outside our circle for additional support. We therefore need to support communities to respond better to grief and loss, and work with those who are directly involved with communities. The IHF actively raises awareness and encourages conversations about bereavement through hosting public events, many developed in collaboration with other bereavement support services in the community.

Our public opinion poll in 2016 showed that most Irish people have been bereaved at some point and 37% of these (over one million people) have a recent experience of the death of someone close. By no means had all received the support they would have liked, with over one third feeling they did not have enough support. Predictors of **loneliness** in older people include widowhood, financial pressure and health impairments. Older people are more vulnerable to developing problems or complications in grieving which reach a clinical level.

## IRISH CHILDHOOD BEREAVEMENT NETWORK

The Irish Hospice Foundation has taken the lead in actively encouraging organisations who provide bereavement support to work collaboratively, and to a common framework of care. The **Irish Childhood Bereavement Network (ICBN)**, hosted at the Irish Hospice Foundation with support from Tusla, works to promote the voice of bereaved children and young people in Ireland, acknowledging that theirs has traditionally been the silent voice of grieving. Longitudinal research on the long-term impacts of childhood bereavement is being planned and is vital to shape interventions which will support the bereaved children of the future.

**We ask:**

- **that the state continues the support of the highly successful ICBN through commitment to sustainable, multi-annual funding; and**
- **commits to fund a longitudinal research programme into childhood bereavement.**

**Estimated co-funding requirement €80,000 (€30,000 for co-funding of ICBN + €50,000 for research)**

## **PROLONGED GRIEF DISORDER**

There is growing consensus about when grief becomes a more serious problem. In 2018 ‘**Prolonged Grief Disorder**’ was noted in the International Classification of Diseases (ICD-11) and ‘**Persistent Complex Bereavement Disorder**’ in the Diagnostic and Statistical Manual of Mental Disorder (DSM-5). This affects 10% of bereaved people which equals 3% of the population. Of interest, there are now proven therapies for the minority (10%) that develop Prolonged Grief, one of which has been introduced in Ireland through the Complicated Grief programme at IHF. Dodd’s 2019<sup>8</sup> research with Irish mental health professionals showed that 83% of them welcome the new diagnosis for this more complex grief, believing it will result those in need being identified and in turn, accessing the appropriate help. However, it is not recognised in Irish mental health policy and the mental health services are currently not sufficiently trained or resourced to diagnose and support those with PCBD. **This means that many people remain unsupported in their deep grief and denied access to the specialist help they require.**

**We ask that:**

- **the explicit need to identify and treat Prolonged Grief Disorder is included in ‘Vision for Change’ in addition to preventive/public health concerns about bereavement; and**
- **resources are provided for training of general and specialist health professionals to recognise and treat prolonged grief/complicated grief.**

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<sup>8</sup> Dodd, A., Guerin, S., Delaney, S., Dodd, P. (2019) [Psychiatrists’, psychologists’ and counselors’ attitudes regarding complicated grief](#). *Journal of Affective Disorders* 256, 358-363

## THE COST OF BEREAVEMENT

Bereavement also has an **economic impact** on individuals and families in a number of ways. We know from experience and international research that the expenses families can face are:

- funeral costs
- living, medical and therapeutic expenses
- loss of benefit and household income.

Consider the following;

- A recent Irish Hospice Foundation survey found that one in five of bereaved people reported a deterioration in their financial situation after the death of someone close.
- Low income and socioeconomic disadvantage are known<sup>9</sup> indicators of higher levels of grief-related symptoms, psychological distress and increased likelihood of experiencing mental and physical health problems and can compound grief during an already difficult time.
- There is also an economic cost to society associated with bereavement. Studies reveal findings of deterioration in mental and physical health, reduced productivity, financial hardship and debt burden and potential reduced employability<sup>10</sup>.

Concern about financial burden of death and loss was amply illustrated in responses to our “Have Your Say” survey. Over 11% of respondents expressed concerns about financial costs and the impact on the bereaved. These are not only concerns for individuals and families but they are important issues for Irish society and for national policy. We believe the time is right to address the ‘economics of bereavement’ in order to:

- Explore the dynamics of bereavement in Ireland
- Identify immediate and longer-term financial impacts for families
- Explore ways of mitigating the economic impact
- Clarify the gaps in public policy and the potential for Government responses to improve the outcomes for bereaved people
- Identify and account for the contribution made by NGOs and volunteering peer-support groups in the provision of care to bereaved people in Ireland.

This year there is an opportunity to focus on a key strategic area – investment in research on the economics of bereavement. **Bereavement matters. Structured strategic research into the economics of bereavement, at this point, could provide us with a lasting lever of change.**

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<sup>9</sup> [Newson, R.S., Boelen, P.A., Hek K, Hofman, A., Tiemeier, H.](#) (2011) The prevalence and characteristics of complicated grief in older adults. [J Affect Disord.](#) 132(1-2),231-8

<sup>10</sup> Scottish Partnership for Palliative Care (2018) [A road less lonely. Moving forward with public health approaches to death, dying and bereavement in Scotland.](#)

**We ask for:**

- **State co-investment in an exploratory research project with a multi-agency approach to investigate the Economics of Bereavement.**

**The Irish Hospice Foundation is willing to partner on this research.**

**Estimated co-funding requirement €50,000**