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# Pre-Budget Submission 2019

## **Dying is Everyone's Business**

Our Government can make a real difference to dying, death and bereavement in Ireland.

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**#YODOBudget19**

**#Budget2019**

*Submitted on Wednesday 20<sup>th</sup> June 2018*

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## Why dying, death and bereavement need investment

Death is an inevitable and universal experience – a fact of life.

Dying, death and bereavement present myriad challenges to the health service, to other state services and to wider society.

In 2016 as part of the challenge to “remember, reflect and reimagine” Ireland over the past 100 years, the Irish Hospice Foundation asked people to give their views on how dying, death and bereavement could be better addressed by the State and society in this context. Over 2,600 people responded to our “Have Your Say” (HYS) 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
- There is time to grieve and understanding of grief

This is important because in the next 10 years<sup>2</sup>:

- Over 300,000 people will die in Ireland
- Over 3,000 of those deaths will be of children
- Over 250,000 of those deaths will be of people over 65 years of age
- Almost 3 million people will be bereaved<sup>3</sup> and up to 150,000 of these will encounter significant difficulties or ‘complicated grief’<sup>4</sup>

If current trends continue:

- Each year 10% of the national healthcare budget will be spent on end-of-life care – over €13 billion over 10 years<sup>5</sup> - much of it unplanned
- Each year only 0.55% of the national healthcare budget will be spent on Specialist Palliative Care Services (SPC) - €765 million over 10 years<sup>6</sup>
- 74% of people will want to die at home<sup>7</sup> but only 26% will do so<sup>8</sup>

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

<sup>2</sup> Figures estimated from CSO statistics of 2017: Vital Statistics 2017 Yearly summary (30,484 deaths in 2017)

<sup>3</sup> Estimate based on 10 people directly affected by each death

<sup>4</sup> Kersting A, Brähler E, Glaesmer H, Wagner B. Prevalence of complicated grief in a representative population-based sample. *J Affect Disord* 2011;131:339-43 and [Newson RS<sup>1</sup>](#), [Boelen PA](#), [Hek K](#), [Hofman A](#), [Tiemeier H](#). The prevalence and characteristics of complicated grief in older adults. *J Affect Disord*. 2011 Jul;132(1-2):231-8. doi: 10.1016/j.jad.2011.02.021. Epub 2011 Mar 12.

<sup>5</sup> Research evidence (Gray 2004; Polder et al 2006; Ezekiel 2002 and Raitano 2006) summarised in *Access to Specialist Palliative Care services and Place of Death in Ireland: What the data tells us*, IHF Perspectives Series Number 2; Irish Hospice Foundation May 2013

<sup>6</sup> Calculation based on 2017 HSE SPC budget of €76.5m in 2017

<sup>7</sup> Weafer, J. (2014) Irish attitudes to death, dying and bereavement 2004-2014. Dublin: Irish Hospice Foundation

- 43% will die in hospital and 26% in long-stay care<sup>9</sup>
- 6% will die in a hospice<sup>10</sup>
- 5% of grieving people will require specialist mental health services/psychological intervention<sup>11</sup>

Given this evidence, it is essential that the healthcare system and all state services meet the needs of people facing dying, death and bereavement and ensure that everyone gets equal access to good care and support.

We are committed to making the aspirations reflected in the People’s Charter on Dying, Death and Bereavement in Ireland a reality. And we are asking the Government to join us in that commitment in Budget 2019.

By careful planning, we can make the best use of the substantial funds that we directly and indirectly invest in the care of the dying and the bereaved. It is crucial that this planning includes helping people to live well until they die.

There is no need to reinvent the wheel. The Government’s way forward is to be found in actually implementing current framework documents, reports and policy.

We very much welcome the “Palliative Care Services: Three Year Development Framework (2017-2019)” charting the future for this vital service throughout the country and in all care settings. The detailed recommendations in Senator Marie Louise O’Donnell’s comprehensive “Finite Lives” Reports of 2015 and 2017<sup>12</sup> provide a blueprint for better integration of State services outside of the health service and a more strategic approach to issues arising in dying, death, loss and care. They also very much reflect the views of those people who responded to the “Have Your Say” survey.

We urge the Government to respond to the concerns of people of Ireland and make a real effort to develop a more strategic approach to palliative care, end-of-life and bereavement issues as a priority. Many of the solutions are inexpensive and in many cases, cost saving.

In line with our policy and advocacy priorities our pre-budget submission is based on our belief that everyone deserves the best care at end of life and in bereavement – a belief shared by the people of Ireland.

We also believe that dying, death and bereavement are everyone’s business. This means that a population-wide, whole society response is required.

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<sup>8</sup> Irish Hospice Foundation: *Enabling More People to Die at Home* (supported by a research paper from Dr. Kieran McKeown) Irish Hospice Foundation Perspectives Series Number 3; December 2014

<sup>9</sup> Ibid

<sup>10</sup> Ibid

<sup>11</sup> Aoun SM et al. A public health approach to bereavement support services in palliative care. *Australian and New Zealand Journal of Public Health*. 2012; 36: 14–16. doi: 10.1111/j.1753-6405.2012.00825.x. pmid:22313700

<sup>12</sup> Finite Lives: Dying Death and Bereavement An Examination of State Services in Ireland: May 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) Senator ML O’Donnell

## We ask the Government to:

Take a more strategic approach to issues relating to end of life by supporting and implementing the recommendations of the strategy and policy frameworks already in existence namely:

- 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)

### A. GRIEVE WELL

Bereavement is a normal, if painful, life experience. We know that all bereaved people process their grief in their own unique way. Grief impacts us all to different degrees and in different ways. These 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.**

From our 2016, Have your Say<sup>1</sup>, nationwide survey:

*"We [should] have a public awareness campaign so that people know what is actually normal. That people allow time and space for people to grieve. Workplaces need better policies. That children and families with children have the support they need."*

*"I'm scared it's not something people like to talk about. I'm in my thirties and I've lost my baby, experienced suicide of someone very close to me ..... my dad died just after my baby was born..... and yet 8 years on from my last bereavement no one ever mentions what happened and do I need to talk? And yes I get scared about dealing with this type of silence and I'm worried for my children. Also grief is very hard."*

*"I worry most about those I leave behind that they will have support to deal with loss"*

When we look at how grief and bereavement are supported at a policy level, we see that 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.

*“Dying doesn't just happen when you are old. My son was stillborn in [10 years ago] & the treatment from some staff was terrible and the silence after was deafening.”*

Of great encouragement is the commitment shown to the implementation of the bereavement standards in maternity settings (Accepted national standards on bereavement care pregnancy loss and perinatal death). We are calling for continued investment in this area of policy and practice. **Bereavement matters – national policy should reflect that.**

Therefore we recommend:

### **Recommendation 1:**

**Full implementation of the recommendations of the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death, to include:**

- **Provision of adequate funding to develop quiet rooms (including mortuary facilities), family rooms and counselling rooms in Maternity units, following the model set in the IHF/HSE Design and Dignity programme**
- **Funding additional perinatal pathologists to ensure regional cover and access to services**
- **Funding Bereavement education and training based in maternity hospitals**
- **Meeting the IT and design costs associated with a repository and bereavement portal for families and for professionals- support for maternity bereavement care specific website**

**Estimated Cost €100,000**

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, and
- 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.<sup>1</sup>
- Low income and socioeconomic disadvantage are known<sup>13</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>14</sup>.

<sup>13</sup> Newsonme et al, 2017; Burke & Neimeyer, 2013; Garratt et al 2016; Santiago et al., 2013;

<sup>14</sup> Dutton et al 2014 cited in Patterson et al 2018

Concern about financial burden of death and loss was amply illustrated in responses to our “Have Your Say” survey. When asked what they worried most about in relation to serious illness, death and bereavement people said:

*“Financial costs & psychological impact on the bereaved”; “How will I pay for end-of-life care and possible death costs?”; “How I will hold up mentally and financially?”*

*“The future of my family emotionally and financially.”  
“Financial difficulties facing those left behind”*

These are not only concerns for individuals and families but they are important issues of concern for Irish society and for national policy.

We believe the time is right to address the ‘economics of bereavement’ in order to:

- Trace the dynamics of bereavement in Ireland
- Identify immediate and longer-term financial impacts for families
- Identify deficits or costs
- Explore ways of mitigating against 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.

We believe that this year there is an opportunity to focus on a number of key strategic areas which will have more impact. Two areas are particularly pertinent in 2019 – investment in research on the economics of bereavement, and an extension of the national patient experience survey to include a wave concerning bereaved relatives (building on IHF work in this area and that of the Mater/St. James’s Hospitals<sup>15</sup> (MaJam). **Bereavement matters – structured strategic research into the economics of bereavement, at this point, could provide us with a lasting lever of change.**

Therefore, for 2019 we recommend:

**Recommendation 2:**

**State 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**

**Recommendation 3:**

**Commitment to undertake a bereaved relative survey through the National Patient Experience Survey. The Irish Hospice Foundation is willing to partner on this research.**

**Estimated co-funding requirement of €60,000**

<sup>15</sup> Ó Coimín D., Korn B., Prizeman G., Donnelly S., Hynes G., Curran M., Codd M. Survey of Bereaved Relatives: VOICES MaJam. Dublin: Mater Misericordiae University Hospital and St. James’s Hospital; 2017.

## B. CHOICE & SERVICES

*“[What matters to me] is the availability of local hospice care”*

*“Are the facilities available locally for support?”*

*“Will I have an option to die where I wish or will it be the case no space (hospice)?”*

A 2013 report<sup>16</sup> found that because of regional inequity in resource allocation, an estimated 2,500 patients are denied admission to hospice beds every year. This is in spite of stated national policy since 2001 to secure equity of access to specialist palliative care by providing one hospice bed for every 10,000 people.

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 and again in 2015 a report by TCD and the ESRI<sup>17</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 centres 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.

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

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

As a first step in Budget 2019 we recommend:

### **Recommendation 4:**

**Resource a clear timeline and process for the implementation of the Palliative Care Services Three Year Development Framework (2017-2019) with a provision of capital funding for in-patient units in the Midlands and North East where there are currently critical gaps in services.**

**Estimated Cost: €5 million capital in year 1 to commence development**

<sup>16</sup> Access to Specialist Palliative Care Services and Place of Death in Ireland – what the Data Tells Us

<sup>17</sup> Economic Evaluation of Palliative Care Services in Ireland ESRI/TCD

### Recommendation 5:

Provide ongoing funding to expand and develop the children's palliative care service as outlined in the Evaluation of Children's Palliative Care Programme (CPCP) report. Priorities include additional children's outreach nurses, second consultant in Temple Street for Q4 2019 (IHF funded until then)

Estimated Cost: €230,000

In our "Have Your Say" survey, respondents associated being at home with comfort, being with loved ones, warmth, safety, familiarity, autonomy and control.

Both being at home while ill and dying at home were discussed in the responses. This may suggest that people value being at home whilst facing the end of life of most importance as opposed to necessarily dying there. However, for some both living and dying at home is clearly very important.

*"Having family close, being at home if possible but with access to medical care. Having support got for my loved ones. Being in control".*

Dying happens 24 hours a day, seven days a week. Many support services operate from 9.00 to 5.00, Monday to Friday. This means that despite the expressed wishes of people at end of life, and of their families and carers, gaps in services and supports can militate against people being able to die at home. Many experience unscheduled care at end of life in A&E departments because of crises which occur out of hours or weekends for regular service provision.

*"Where I will be? On my own in a nursing home, on a trolley...?"*

We believe that unscheduled care crises can be reduced by securing the future of supports that already exist as well as supporting primary care healthcare professionals to continue their end-of-life care in the community.

As a first step we recommend:

### Recommendation 6:

Commitment to providing 25% of the funding for Nurses for Nightcare (IHF funded) /Night Nursing (ICS funded). Estimated cost in 2019 would be €600,000.<sup>18</sup>

Introduce a national system for SPC advice outside routine working hours.

No cost

Seed fund ICGP backed GP Palliative Care Scheme for a demonstration project reducing admissions at end of life into hospital. Cost €120,000 – to include intervention by primary care, Community Intervention Teams, Out of Hours services and Nursing Home sites

## C. TIME TO PREPARE

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.

*"[I want] to continue to be able to make my own decisions. To be able to have good honest conversations about what is happening to help my family with their anguish and anxiety."*

*"Dying with dignity and respect. If I have a long term illness and reach a stage where I no longer had any quality of life I would like there to be an opportunity for me to have made a decision in advance for my own dignity and respect and for my family".*

*"Remaining in control of my life, making decisions about what happens to me and being allowed to keep my dignity"*

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 80,000 of such forms in circulation.

### **Dying matters – we need to help people 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). But health 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 recommend:

#### **Recommendation 7:**

**Funding for a National programme of training for healthcare and allied health and social care professionals to work under the provisions of the Assisted Decision Making (Capacity) Act 2015 as matter of urgency; to include**

- a. **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**
- b. **A programme to support patient interest groups to integrate advance care planning into chronic disease-management planning.**

**Estimated Cost €100,000**

#### Recommendation 8:

**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**

## D. DIGNITY AT END OF LIFE

More than 43% of people will die in hospital and over one quarter will die in long-stay care.<sup>18</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 to ensure that end-of-life, palliative and bereavement care are central to the everyday business in both these care settings.

**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.**

*“For the body of my loved one to be handled with care and dignity. For ‘someone’ to be there for those awful decisions. And a cup of tea...”*

*“Clear information, expert care, home comfort and close companionship.”*

*“To be treated like it matters. To be treated not just as a number but as a special person who is loved by family and respected by the health carers”.*

*“Adequate medical care provided with practical compassion.”*

*“Pain relief, care and their friends and family around them to help them through their journey.”*

*“Respect, comfort, family near, peace”.*

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<sup>18</sup> Ibid

We recommend:

**Recommendation 9:**

**Fund an additional 10 whole-time equivalent End-of-Life Care Coordinators across the 6 Hospital groups, as part of the Hospice Friendly Hospitals programme.**

**Estimated cost: €600,000 in a full year.  
10 coordinators @€60,000 each**

**Recommendation 10:**

**Fund 9 end-of-life care coordinators to build on the IHF CEOL Programme which introduces continuous quality improvement in residential care centres across CHO areas.**

**Estimated Cost: €540,000 in a full year based on 1 EOL End-of-Life coordinator (long-stay residential) for each of the 9 CHO @ €60,000 each**

## NOTES



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