
Pre-Budget Submission 2018

Dying is Everyone's Business

Invest in the best care at end of life and bereavement

Submitted on Thursday 6 July 2017



PRE-BUDGET SUBMISSION: BUDGET 2018

Background and Context

Why dying, death and bereavement need investment

Death is an inevitable and universal experience – a fact of life. While most people will experience ‘death denial’, it is not appropriate that the State should adopt the same attitude. Dying, death and bereavement present myriad challenges to the health service and to other state services.

The facts:

In the next 10 years¹:

- Almost 300,000 people will die in Ireland
- Over 3,000 of those deaths will be of children
- Over 240,000 will be of people over 65 years of age
- Almost 3 million people will be bereaved² and up to 150,000 of these will encounter significant difficulties or ‘complicated grief’³

If current trends continue:

- Each year 10% of the national healthcare budget will be spent on end of life care - €13 billion over 10 years⁴ - much of it unplanned
- Each year only 0.55% of the national healthcare budget will be spent on Specialist Palliative Care Services (SPC) - €710.9 million over 10 years⁵
- 74% of people will want to die at home⁶ but only 26% will do so⁷
- 43% will die in hospital and 26% in long-stay care⁸
- 6% will die in a hospice⁹
- 5% of grieving people will require specialist mental health services/psychological intervention¹⁰

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 ensures that everyone gets equal access to

¹ Figures estimated from CSO statistics of 2015: Vital Statistics 2015 Yearly summary (29,952 deaths in 2015)

² Estimate based on 10 people directly affected by each death

³ 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 RS¹](#), [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.

⁴ 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

⁵ Calculation based on 2015 HSE SPC budget of €71.9m in 2015

⁶ Weafer, J. (2014) Irish attitudes to death, dying and bereavement 2004-2014. Dublin: Irish Hospice Foundation

⁷ 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

⁸ Ibid

⁹ Ibid

¹⁰ 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

good care. 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, crucially, that this planning includes helping people to live well until they die.

It has become widely accepted that dying, death and bereavement impacts all aspects of society and not just healthcare. Consequently, as in previous years, our submission calls for a population-wide response to these wider financial, legal, administrative, educational and cultural issues relating to end of life and bereavement. We very much welcome the initiative by the former Taoiseach Enda Kenny TD, to ask Senator Marie Louise O'Donnell to undertake a mapping exercise across all Government Departments to examine their interaction with and services to the public in relation to end-of-life issues. We particularly welcome the detailed recommendations in her comprehensive report¹¹ which covers all Government Departments.

Our recommendations advocate not only for the protection of the budget for specialist palliative care (SPC) but also for a more focused and strategic approach to the provision of end-of-life care in all care settings and enhanced response from relevant government departments, voluntary and commercial sectors. We would urge the Government to show that palliative care, end-of-life and bereavement issues are priority areas for policy development and investment.

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

We ask the Government to:

1. Ensure everyone has access to the best care at end of life and in bereavement through a political and public policy commitment to a strategic, responsive, population-wide approach to end of life issues;
2. Ensure the health care system delivers best palliative, end of life and bereavement care in all care settings.

The IHF strongly advocates for the development of a national strategy on palliative care, end of life and bereavement to include both health and non-health areas of public policy. This underpins all of our recommendations for budget 2018.

The IHF believes that with a more strategic approach, better end-of-life care can make a real difference to both the quality of healthcare provided to the patient and the cost of health and social care to the State – a view supported by an Oireachtas Committee in 2014.¹²

We believe that such a strategy can support

- Government policy set out in the 2016 Programme for a Partnership Government¹³ which seeks to ensure that we have an Ireland that looks after its people from the time they

¹¹ Finite Lives: Dying Death and Bereavement An Examination of State Services in Ireland: Senator ML O'Donnell May 2017

¹² Report on Palliative and End of Life Care in Ireland. Houses of the Oireachtas. Joint Committee on Health and Children July 2014

¹³ A Programme for a Partnership Government, Government of Ireland 2016

come into the world to the time they leave and promises investment in end-of-life care at all life stages. This proposed integrated approach echoes that set out in the National Positive Ageing Strategy¹⁴ and most recently by the Finite Lives Reports^{15 16}.

- Delivery of the targets set out in the Sláintecare Report¹⁷ of the Oireachtas Committee on the Future of Healthcare 2017 which builds on the 2001 National Strategy on Palliative Care (NACPC, 2001¹⁸) and the new framework for palliative care services, publication of which is expected.

Recommendations in our pre-budget submission relate in particular to the Departments of Health, Social Protection, Education and Skills, Finance, Public Expenditure and Reform, Children and Youth Affairs, Jobs, Enterprise and Innovation and An Taoiseach, but are relevant across the whole range of Government Departments and Agencies. They also make suggestions for future budget planning.

The recommendations in this submission are informed by the Irish Hospice Foundation's (IHF) work as a development and advocacy organisation. The IHF is committed to working to ensure that no-one faces death or bereavement without the care and support they need. The IHF currently contributes an average of €3 million annually supporting such development and programmes in the health and social services sector.

Our recommendations are detailed overleaf.

¹⁴ Positive Ageing – Starts Now! The National Positive Ageing Strategy, Department of Health, April 2013

¹⁵ 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. Senator ML O'Donnell. December 2015

¹⁶ Finite Lives: Dying Death and Bereavement An Examination of State Services in Ireland: Senator ML O'Donnell May 2017;

¹⁷ Houses of the Oireachtas Committee on the Future of Healthcare: Sláintecare Report, May 2017

¹⁸ Department of Health (2001) Report of the National Advisory Committee on Palliative Care; Available online.

Recommendations

OVERARCHING RECOMMENDATION

Invest in the development of a national strategy on palliative care, end of life and bereavement; support this strategy through an overarching, interdepartmental framework encompassing wider financial, legal, cultural, social, educational and administrative issues relating to end of life building on the recommendations of recent reports¹⁹.

To achieve this we recommend:

1. A WHOLE SOCIETY APPROACH

Bereavement

- Commit to resourcing outputs of the **‘Enhancing Bereavement Care in Ireland’ feasibility study** commissioned by IHF on behalf of bereavement care stakeholders in Ireland, commencing July 2017.
- Provide funding of €35,000 per annum to financially support the **Irish Childhood Bereavement Network** in its work through TUSLA. [COST: €35,000]
- **Undertake research on the personal and family costs at end of life**, including funeral costs, to inform government policy and foster a cross-departmental strategic approach to issues arising at end of life. In particular policy on supports available for bereavement and funeral costs should be reviewed by the Department of Social Protection to ensure that they are appropriate and easily accessible to those in most need.
- **Reintroduce the Bereavement Grant on an interim basis** and reframe in future budgets as required by the re-evaluation of the supports described above. [ESTIMATED MAXIMUM COST per annum €25.5m based on 30,000 eligible people at €850 per person]

Advance Care Planning and Advance Healthcare Directives

- **Commence the Assisted Decision Making (Capacity) Act 2015 in full** as matter of urgency; providing adequate funding in 2018 to allow the Director of Decision Support Services to establish the Office and essential supports, drawing up of Codes of Practice and training for healthcare professionals arising from this; and support healthcare staff and patient interest groups to integrate advance care planning into chronic disease-management planning.
- **Adopt Think Ahead planning tool** nationally and encourage people to plan ahead [ESTIMATED COST €150,000 per annum]
- **Commit Government to join with the wider voluntary and commercial sectors** to foster a culture of discussing end-of-life issues and support planning for end of life (to include legal, financial and health matters) in line with commitments in the Programme for a Partnership Government 2016²⁰.

¹⁹ Finite Lives: Dying Death and Bereavement: An Examination of State Services in Ireland: Senator ML O’Donnell 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. Senator ML O’Donnell. December 2015

²⁰ A Programme for a Partnership Government, Government of Ireland 2016

Information on essential supports

- **Give prominence to and make accessible on the HSE website and in other appropriate publications the special application process for medical cards** without means test to people who are approaching the end of life.

2. INVESTMENT IN HEALTHCARE

Specialist Palliative Care Framework and Infrastructure

- **Publish the new framework for specialist palliative care services** and outline and resource clear timeline and process for implementation.
- **Address critical gaps and inequities in the provision of palliative care and hospice services in Ireland**, particularly in the Midland and North East regions, so adults and children with all life limiting conditions have access to the care they need, in line with the provisions of the Programme for a Partnership Government 2016²¹ and commitments given to progress the developments of specialist in-patient units in Cavan, Drogheda and Tullamore in liaison with local hospice groups. [ESTIMATED COST: €5 million capital in year 1 to commence development]
- **Accelerate implementation of workforce planning document** to address shortages in specialist palliative care nursing, medical consultant/non-consultant and allied healthcare professionals in acute and community settings allowing full multi-disciplinary team availability. In particular this should address the ratio of 1 hospice homecare nurse per 25,000 of the population²² or other contemporary workforce planning.

Children's palliative care

- **Re-evaluate the national priorities for this service** in light of the publication of the Evaluation of the Children's Palliative Care Programme (CPCP) published in September 2016, and the on-going budget to realise these priorities²³.

Dying at home – 24/7

- **Increase investment in the Nurses for NightCare/Night Nursing service** of €500,000 to €2,000,000 by 2021 to allow this service to be provided on a statutory basis and to address gaps in service provision in the "twilight" hours. [COST €500,000 in year 1]
- **Provide funding to extend Community Intervention teams nationally** and ensure all are equipped to deliver end-of-life care for those dying at home.
- **Introduce a national system for SPC advice outside routine working hours.**

²¹ A Programme for a Partnership Government, Government of Ireland 2016

²² NACPC report: Department of Health 2001

²³ Evaluation of the Children's Palliative Care Programme (CPCP) - A National Policy; DOH, HSE and Irish Hospice Foundation, September 2016

GPs

- **Include GP Palliative Care Scheme as part of the new GP contract** to improve quality of end-of-life care in primary care settings.

Quality end-of-life, palliative and bereavement care in acute and residential settings

- **Fund 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]
- **Fund 9 end-of-life care coordinators to build on the IHF Journey of Change 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 (long-stay residential) coordinator for each of the 9 CHO @ €60,000 each]

Maternity Hospitals and Units

- **Fully implement the recommendations from the National Standards²⁴ for Bereavement Care following Pregnancy Loss and Perinatal Death;**
- **Provide adequate funding to develop full staff cohorts for bereavement support** including medical social workers attached to maternity units.
- **Fund additional perinatal pathologists** to ensure regional cover and access to services
- **Meet the IT and design costs associated with a repository and bereavement portal** for families and for professionals.

²⁴National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death, HSE, August 2016



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