

# Pre-Budget Submission 2024

Investing in the Best End-of-Life and Bereavement Care for All



**Irish  
Hospice  
Foundation**

To die and grieve well wherever the place

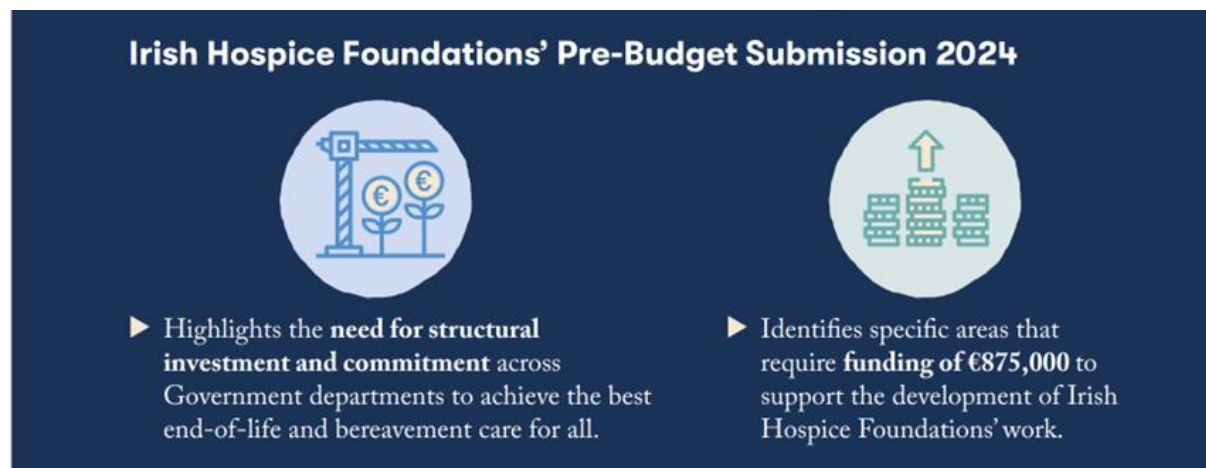
## Overview of Pre-Budget Submission 2024

Budget 2024 represents an opportunity to achieve an integrated approach to the issues related to dying, death and bereavement. However, investment is required to address the key needs at a structural level and to enhance and support the delivery of services.


The Programme for Government “Our Shared Future” (2020) states that *“the care and dignity of a dying person and their family must be our focus”* in developing end of life supports and services. IHF’s Pre-Budget Submission 2024 sets out the rationale and costings for the priorities that will help deliver this policy commitment.


## Priorities for Budget 2024

1. Resource a national approach to palliative, end-of-life and bereavement care
2. Increase the capacity to deliver quality end-of-life care in the community
3. Invest in and resource community bereavement supports
4. Support every person to plan for their end of life



**Irish Hospice Foundations' Pre-Budget Submission 2024**

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► Highlights the **need for structural investment and commitment** across Government departments to achieve the best end-of-life and bereavement care for all.
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► Identifies specific areas that require **funding of €875,000** to support the development of Irish Hospice Foundations' work.

## Budget 2024 - Priorities and Actions

Priority 1 - Resource a national approach to palliative, end-of-life and bereavement care

### Structural investment required

1. Implement and resource the forthcoming National Adult Palliative Care Policy

Priority 2 – Build on increased capacity for quality end-of-life care in the community

### Specific investment required for IHF - €300,000

2. Implement the recommendations from IHF's "Dying Well at Home" Report

Priority 3 - Invest in and resource community bereavement supports

### Structural investment required

3. Commitment to operationalising a public health model approach to bereavement
4. Multiannual funding and financial support for the regulatory compliance requirements of bereavement support organisations
5. Improve the provision of counselling supports

### Specific investment required for IHF - €475,000

6. Implement the recommendations from IHF's "Real Financial Impact of Bereavement" Report - €325,000
7. Deliver enhanced bereavement and grief training for mental health practitioners - €75,000
8. Co funded support from HSE to deliver IHF's Bereavement Support Line - €75,000

Priority 4 - Support every person to plan for their end of life

### Specific investment required for IHF - €100,000

9. Funding for our Think Ahead programme to encourage and enable Irish people to think, talk and plan ahead for their end of life - €100,000

# Priority 1 - A national approach to palliative, end-of-life and bereavement care

## Overview

Supporting improvements in palliative, end-of-life and bereavement care is Government policy. We welcome the commitment in the 2020 Programme for Government to publish a new Palliative Care Policy for Adults and the progress that has been made in this regard since 2021. The new policy will take account of the projected increase in Ireland's older population and an increase in the number of people with life limiting conditions which would benefit from palliative care.

The data from the report reviewing current Government policy on palliative care (National Advisory Committee on Palliative Care Report 2001) indicates that substantial progress has been achieved in developing Specialist Palliative Care (SPC) provision; however, deficits in workforce and infrastructure persist across most regions and services. Inequities also still exist in accessing SPC, in particular geographic areas. Palliative care is still mostly associated with cancer, resulting in delayed referral to specialist services for people with other life-limiting illnesses.<sup>1</sup>

The new policy must, in light of these changing demographics, address the increased demands that will be placed on the palliative care system and on SPC in the future. The policy will also need to consider how these demands can be met as the healthcare system in Ireland is remodeled. The application of new technologies and the increasing relevance of tele-health must also be considered.

When we speak of dying, death and bereavement together, bereavement has tended to be the most neglected. Likewise, when we look at how bereavement is supported at a policy level, we see that it is largely still invisible in formal policies. The upcoming National Adult Palliative Care Policy represents a real opportunity to fully integrate bereavement supports into palliative care in Ireland.

## Structural investment required

### Action 1 - Commitment to implement and resource the forthcoming National Adult Palliative Care Policy

The current Department of Health policy on palliative care for patients and families is contained in the 2001 Report of the National Advisory Committee on Palliative Care<sup>2</sup>. Notwithstanding its longevity, this policy on palliative care continues to be highly regarded internationally.

However, demand for every aspect of adult palliative care has greatly increased since 2001. Due to an ageing population, and as more people with life-limiting illnesses are living longer, Ireland faces the challenge of ensuring high-quality palliative care is available to increasing numbers of people with life-limiting conditions, in all settings.

With this context in mind, we welcome the 2020 Programme for Government commitment to publish a new Adult Palliative Care Policy. The development of a new policy on palliative

<sup>1</sup> <https://www.gov.ie/pdf/?file=https://assets.gov.ie/217581/9e55e788-0d93-4b74-9345-acbd33cdcda2.pdf#page=null>

<sup>2</sup> <https://www.gov.ie/en/publication/06aecd-report-of-the-national-advisory-committee-on-palliative-care/>

care, provides an opportunity to look at other aspects of dying, death and bereavement which may not have been focused on in 2001.

We have advocated for many years for the development of this updated policy. We welcome our representation on the national steering group and we will work hard to ensure these key needs are addressed, implemented and resourced in the policy.

The key needs to be addressed in the National Policy on Adult Palliative Care are:

1. Equity of access to palliative care that is not dependent on location, age, or diagnosis.
2. Commitment to investing in Generalist Palliative Care in the home, nursing homes and primary care settings, by ensuring that key health professional recognise and understand the need to deliver the core components of palliative care in their practice and they are upskilled and incentivised to do so.
3. Address the absence of a national approach to bereavement care, in particular a public health model for bereavement (see action 4 on page 10).
4. More clarity, commitment, and support for the delivery of enhanced community supports at end-of-life including out of hours care services (see action 2 on page 6).
5. Investment in night nursing and the current nurses for night care service (see action 3 on page 8) to reflect that this service is a core part of the care for people facing end of life.
6. Support for family carers particularly those supporting a loved one at home. Further consideration will be required in the policy to ensure that family carers have appropriate access to services and supports which avoids the burden of care and cost shifting on to them disproportionately.
7. The policy will need to **reflect and support broader policy developments** that are relevant to the work. These would include:
  - Statutory home care scheme as access to homecare hours is critical for people with palliative care needs in the community and their families.
  - Upcoming workforce policies that aim to address the difficulties recruiting and retaining staff as these are barriers to the delivery of quality palliative care.
  - The Assisted Decision Making (Capacity) Act legislation must be considered and incorporated into the new policy. End of life care planning is a critical aspect of the care trajectory and this legislation holds a key role for informing this work.
8. More public information and signposting of palliative care will be required.
9. Investment in health information management systems and infrastructure are needed to resource, grow capacity and ensure workforce planning. An information strategy that supports robust data collection, information sharing and service planning.

Budget 2024 must ensure that this new policy has an agreed implementation plan that is financed appropriately so that it can be delivered now and is also fit for purpose in the future.

## Priority 2 - Build on increased capacity for quality end-of-life care in the community

### Overview

Irish Hospice Foundation believes that with a more strategic approach, quality end-of-life care in the community can make a real difference to both the person and to the cost of health and social care provision. Continuity of care is paramount in delivering quality end-of-life care. However, there are challenges to enabling people to have a good death in hospital, at home, in hospice care and in nursing home settings.

Most adults in Ireland (74%) say that they want to die at home, however this a complex and nuanced wish when examined more closely. What we do know is that while not everyone can, nor should die at home, more must be done to enable greater choice in their place of care as death approaches. With the correct supports and interventions, people can experience a good end of life with quality care in their homes, if that is their wish and where it is possible.

### Specific investment required for Irish Hospice Foundation

#### Action 2 - Implement the recommendations from our “Dying Well at Home” Report - €300,000

In Ireland, it has been a policy goal for the past 20 years to make palliative care services available and easy to access for people in all care settings. The aim of the Palliative Care Model of Care (2019) for Ireland is that: *“Every person with a life-limiting condition can easily access a level of palliative care appropriate to their needs regardless of care setting or diagnosis in order to optimise quality of life.”*<sup>3</sup>

Primary Palliative Care is the term given to a holistic (whole person) approach to care for people who have advancing life-limiting conditions who are living at home. It includes improving quality of life through managing symptoms, and addressing psychological, social and spiritual issues.

This care is provided by a primary care team made up of General Practitioners (GPs), Public Health Nurses (PHNs), community physiotherapists, Occupational Therapists (OTs), psychologists, social workers and a range of other community-based staff. This team is supported by the community palliative care team.

In August 2023, IHF published our Dying Well at Home Report<sup>4</sup>. The report presents the findings of focus groups and interviews held with family and carer groups, healthcare professionals and patient advocacy groups, highlighting the challenges of ensuring a good death at home and the current gaps in provision of end-of-life care.

Irish Hospice Foundation is committed to implementing, leading and supporting the recommendations outlined in the report. Through investment in Budget 2024 we can increase capacity in end-of-life in the community to improve the care delivered for patients. We propose that this can be achieved in the following ways:

<sup>3</sup> <https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/moc/ncp-palliative-care-model-of-care-24-04-0219.pdf>

<sup>4</sup> <https://hospicefoundation.ie/wp-content/uploads/2023/09/Dying-Well-at-Home-Report-Irish-Hospice-Foundation.pdf>

### **1. Map social networks and services providing end-of-life care in the community - €60,000**

Conduct research to map social networks and services that support and provide end-of-life care in the community. Review good models of practise that could be adapted or tailored to enhance current systems and support good end of life care in our communities.

We will use the learnings out of this mapping process to identify areas in Ireland that show gaps in services and a need for more support and resources.

### **2. Identify best practice models of end-of-life care for underserved communities - €35,000**

The Dying Well at Home report identified health inequalities faced by underserved and low socioeconomic status groups that include migrants, Traveller communities, rural populations, people with disabilities and people who are homeless. These groups require culturally appropriate end-of-life care models to address the specific barriers they face to support dying well within their communities.

Irish Hospice Foundation would undertake research to identify best practice models of end-of-life to support the needs of these groups in the community.

### **3. Establish two End-of-life Community Co-ordinators posts - €140,000**

In the Dying Well at Home report it is evident that there are often gaps in services and inconsistencies in accessing appropriate timely support.

Irish Hospice Foundation would like to establish two end-of-life community co-ordinator posts in two identified Health Regions to act as the main point of contact for those needing information and support to enable them to remain in their own home, if it is possible and medically appropriate. The role of end-of-life community co-ordinators will serve as a conduit for bringing services together to ensure appropriate support and high-quality care is provided for the person and their family.

The two end-of-life community co-ordinator posts (costed at €70,000 each) would work as a point of contact for both healthcare professionals and people who need to access appropriate care. They would have local knowledge of the services in their area and ensure timely access to information and support for the dying person and their loved ones.

### **4. End-of-life care information line – €35,000**

Irish Hospice Foundation receive regular enquiries from the public seeking information about supports available to them or their loved ones who wish to die in their home. The Dying Well at Home Report identified that families and carers are often not sure how to access the care and support they need to support someone to die at home. By complementing the existing services in the community the establishment of a dedicated information line would act not only as an information and signposting service but also provide emotional support to people.

### **5. Education and Training - €30,000**

Appropriate skills and competencies are central to the provision of quality care, empowering home-based carers to have the confidence to care for a person at home. Enhancing and further developing their access to education and training will empower and further support both professionals and home-based carers to provide the best quality of care for the person throughout their illness journey.

Irish Hospice Foundation has a strong track record in developing educational programmes which focus on Quality Improvement at End-of Life. Themes include Communication at End-of Life, Self-Care, Palliative Care Levels and Advance Care Planning.

With investment in Budget 2024 we propose to develop training and resources for:

- Family carers
- Home support workers
- Healthcare professionals
- GP Practice Nurses\*

\*We currently support and input into the GP Palliative Care Certificate course led out by ICGP. We would propose that this is extended, to include GP Practice nurses on this course.



## Priority 3 - Invest in and resource community bereavement supports

### Overview

Grief can have a myriad of impacts on people who are bereaved as they process it in their own unique way. The ways in which people process their grief are influenced by many different things including the relationship they had with the person who has died, the support available from our family and friends, their life stage, beliefs and, of course the circumstance of the person's death. For example, 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.

Bereavement does not feature as an issue in many of the overarching health strategies or frameworks. Currently it is given minimal consideration within mental health, suicide, cancer and palliative care policy frameworks. There is a need for a recognition of the impact of bereavement and to take a public health approach to address these needs.

Not all bereavement needs are clinical in nature, they include the need for supportive communities and a range of responses - from education to employment, health to social protection. From an economic perspective we know that grief costs money, but unsupported grief costs even more. For example, there may be a loss of productivity for an employee experiencing grief. A report in 2023 by Eddy, Wolfson and Wagner in the USA highlighted that \$75 billion is lost annually from productivity reduction due to grief.<sup>5</sup>

There is huge potential and a need for the integration of grief and bereavement care into state policies to promote health and resilience, to ensure that supports and services are available for people when they need them and to plan specialist care provision for the minority that will require it.

### Structural investment required

#### Action 3 - Commitment to operationalising a public health model approach to bereavement

A 2022 report "The Real Financial Impact of Bereavement" by Irish Hospice Foundation<sup>6</sup> highlights the cross-cutting nature of the impact of bereavement. The adverse economic impacts are intertwined with the sometimes very intense adverse emotional effects of bereavement. The report is evidence that the impact of bereavement does not belong to any one department.

Irish Hospice Foundation has long advocated for a strategic and coordinated approach to bereavement care. Bereavement happens to people at any age, in different circumstances and with a wide range of consequences – psychological, physical, social and economic. These impacts cannot be the sole remit of health and social services.

The role that all Government departments play in relation to bereavement is noted in the 2018 report Finite Lives.<sup>7</sup> The report examined Departments' policies, services and procedures around dying, death and bereavement and how they could be improved or

<sup>5</sup> <https://journals.sagepub.com/doi/10.1177/08901171221145217e>

<sup>6</sup> <https://hospicefoundation.ie/our-supports-services/advocacy-research/research/the-real-financial-impact-of-bereavement/>

<sup>7</sup> <http://marielouiseodonnell.ie/wp-content/uploads/2017/05/Marie-Louise-ODonnell-Finite-Lives.pdf>

developed. While many Departments did not have a policy in relation to dying, death and bereavement, almost all were engaged in activities or had developed protocols and practices related to the issues.

Commitment and funding to operationalise a public health model approach to bereavement care is required. In Ireland a number of sector-specific policies and guidance reports build on a public health approach for bereavement care (e.g. Petrus report for suicide bereavement 2008<sup>8</sup>, Report of the National Advisory Committee on Palliative Care (2001)<sup>9</sup> and the Palliative Care Model of Care (2019)<sup>10</sup>).

A public health approach would identify bereavement needs and map out the appropriate informal, community, organised and professional responses which are needed. A public health model recognises that all bereaved people have needs; for compassion, for information and for the support of those around them. However, some factors can indicate a minority of bereaved people will require additional support.

In 2018 Irish Hospice Foundation published a consultation and research report on enhancing bereavement care in Ireland which concluded that agreement on levels of bereavement need and appropriate care were required.<sup>11</sup>

As a follow-up to this report and in the absence of a national cross-sectoral approach to adult bereavement care in Ireland, Irish Hospice Foundation facilitated a national collaborative process to develop a framework for adult bereavement care in Ireland. While in use since 2020 the Adult Bereavement Care Pyramid was formally launched in 2021 and provides a national framework for adult bereavement care in Ireland<sup>12</sup>.

The framework is based on a pyramid model which suggests that every person who experiences a bereavement will have some level of need. Support at all levels of the continuum of grief must be available so that people can access the support when and where they need it. The need may be for compassion and acknowledgement of the death (LEVEL 1). Some people may need additional support outside of their natural network, such as peer to peer support (LEVEL 2). Others will require more intensive support, such as counselling (LEVEL 3) and a few will require support from a specialist therapeutic service (LEVEL 4).

We fully endorse this 'pyramid' model and recommend that this approach shapes future bereavement care policy, planning and service delivery. Budget 2024 is an opportunity to begin to invest in funding in operationalising what is required for Ireland to have a robust and meaningful public health framework for bereavement.

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<sup>8</sup> Petrus Consulting, Bates, U., Jordan, N., Malone, K., Monaghan, E., O'Connor, S. & Tiernan, E. (2008). Review of General Bereavement Support and Specific Services Available Following Suicide Bereavement. Dublin: National Office for Suicide Prevention

<sup>9</sup> <https://www.gov.ie/en/publication/06aecd-report-of-the-national-advisory-committee-on-palliative-care/>

<sup>10</sup> <https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/moc/>

<sup>11</sup> [https://hospicefoundation.ie/wp-content/uploads/2020/12/Enhancing-Adult-Bereavement-Care-Across-Ireland\\_REPORT.pdf](https://hospicefoundation.ie/wp-content/uploads/2020/12/Enhancing-Adult-Bereavement-Care-Across-Ireland_REPORT.pdf)

<sup>12</sup> <https://hospicefoundation.ie/our-supports-services/bereavement-loss-hub/i-work-in-bereavement/adult-bereavement-care-pyramid/>

# Adult Bereavement Care Pyramid

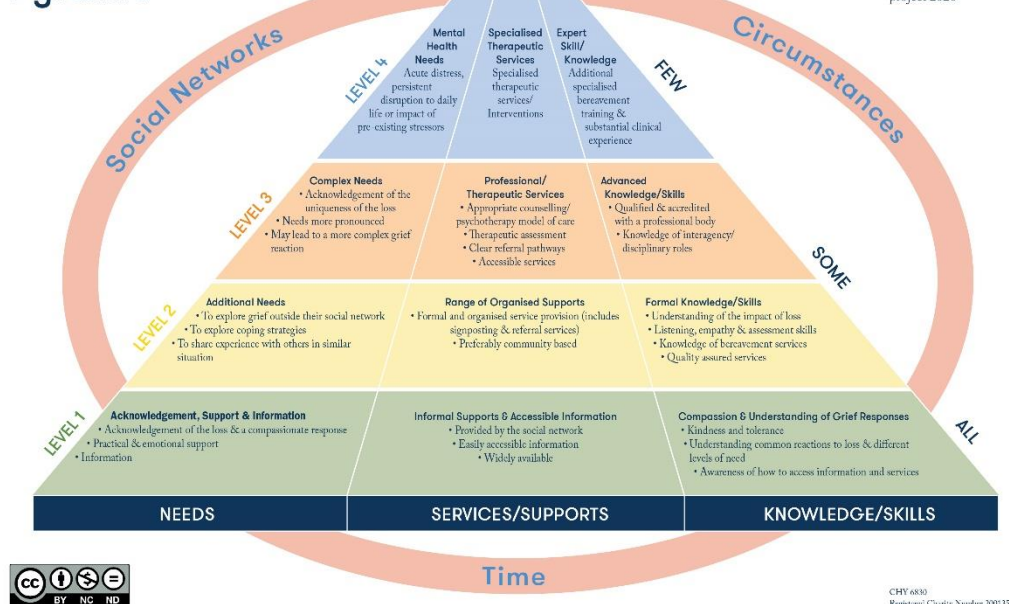


Figure 2: Adult Bereavement Care Pyramid, Irish Hospice Foundation; 2020.

We recognise that the operationalisation of this framework affects all areas of Government, yet no one department assumes overall responsibility. Therefore, the first step in operationalising this model will be a scoping exercise that reviews existing legislation, structures and brings together a variety of perspectives, knowledge and expertise. It also considers international models of good practice that could be helpful in the Irish context.

The scoping paper would identify:

- The benefits, costs, and risks of such a model
- The capacity and competence requirements for implementing the model across communities
- Who the target audience and key stakeholders would be
- The Government departments with responsibility for such a model
- Implementation issues that would need to be addressed

As the lead advocate for bereavement education, services and structures in Ireland we are fully committed to supporting, or if appropriate, co-funding and delivering this scoping exercise with the necessary funding that Budget 2024 has the opportunity to deliver and we would welcome dialogue on this.

## Action 4 - Multiannual funding and financial support for the regulatory compliance requirements of bereavement support organisations

Bereavement support organisations offer peer support and bereavement care at the community level. This care is often nationally coordinated but locally based and is generally not classed as counselling. Most of these bereavement supports come from the NGO sector, particularly parental and suicide bereavement, where community charities are set up by founders who have had personal experience of these types of loss.<sup>13</sup>

According to a recent survey by The Wheel, 60% of their charity members did not have sufficient funding as they began the year in 2023. In fact, a third of the respondents held no reserves.<sup>14</sup> These stark figures reflect the serious position many of the NGO bereavement support providers find themselves in as they face ongoing difficult and precarious financial situations. In a recent survey conducted by Irish Hospice Foundation it was noted that 50% of those overseeing the financial operations of bereavement services had concerns for the future of the organisation.<sup>15</sup>

We welcome and echo The Wheel's call for multi-annual funding models that would result in better outcomes for the bereavement support providers that are delivering an essential public service, in the absence of a state and policy response to bereavement. A reliable and consistent funding model will enable these organisations to plan and deliver better and more sustainable services.

Schemes such as Pobal's Support National Organisations (SSNO) 2022–25, which aims “to provide multi-annual funding towards the core costs of national, community and voluntary organisations in Ireland” should be expanded. Funding mechanisms such as this, fund services on a full-cost-recovery basis, providing for core costs, adequate salaries, training and development budgets, and pension contributions.

We would also call on state bodies such as Tusla to further invest in the needs of young people affected by bereavement and would echo the calls of the Irish Childhood Bereavement Network to increase the funding currently provided as this has not been reviewed for many years.

The state has rightly invested in developing regulations and compliance processes for the sector, including the Charities Regulator and the Charities (Amendment) Bill. However, there has been no equivalent investment made by the state to support the capacity of the NGO sector to comply with these processes. This is particularly problematic for the bereavement support providers, given their size and often limited capacity and time to comply with these processes. Therefore, we support the call of The Wheel to provide for the cost of compliance and streamline the regulatory and funding-related compliance requirements that apply to the charity sector.<sup>16</sup>

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<sup>13</sup> Roberts, A., Holme, I., Keating, M. and Keegan, O. (2021) The impact of COVID 19 on bereavement care in Ireland: A national survey of bereavement care providers

<sup>14</sup> <https://www.wheel.ie/sites/default/files/media/file-uploads/2023-07/Pre-Budget%20Submission%20-%20July%202023%20-%20Web%20Version.pdf>

<sup>15</sup> Roberts, A., Holme, I., Keating, M. and Keegan, O. (2021) The impact of COVID 19 on bereavement care in Ireland: A national survey of bereavement care providers

<sup>16</sup> <https://www.wheel.ie/sites/default/files/media/file-uploads/2023-07/Pre-Budget%20Submission%20-%20July%202023%20-%20Web%20Version.pdf>

## Action 5 – Improve the provision of counselling supports

As outlined above there is no national framework for bereavement and a public health model approach is needed (as outlined in Figure 2 on page 12). According to a public health model approach a proportion of people will be at risk for difficult outcomes and require extra support (up to 30% of bereaved people<sup>17</sup>).

However, for a small but significant proportion (nearly 10%)<sup>18</sup> grief is extremely debilitating over a longer period of time and will require more specialised support. The professional, therapeutic and specialised help needed must be available in a consistent and accessible way to those who require it.

Budget 2024 is an opportunity to extend the accessibility of primary care counselling which is currently only available to medical card holders. The Counselling in Primary Care (CIPC) service was established in 2013 to provide counselling for patients experiencing mild to moderate psychological difficulties in the community. The national budget for the CIPC service in 2021 was €7.4 million. This is used to provide up to 8 counselling sessions to adults with a medical card, although recommendations have been made through Sláintecare that the service be extended to all people.<sup>19</sup>

For this service to be extended to the whole population, a budget increase is needed over time. The rationale for this investment is that if people get the right intervention at the right time, they may not need to access other more acute/crisis mental health services. Extending counselling in primary care is a way of addressing mental health needs at a lower level of complexity, providing universal access to counselling sessions for those whom their GP determines needs the service<sup>20</sup>.

Almost one third (31%) of referrals to CIPC related to loss and bereavement issues at assessment.<sup>21</sup> Professional psychotherapy and psychology services should be readily available as part of a bereavement care pathway. Budget 2024 is a timely opportunity for the Government to respond to people's mental health needs related to bereavement.

The impact of bereavement is not limited to the first year, planning for access to counselling and therapy needs to incorporate some private provision of counselling and psychotherapy. People need to be able to access and choose mental health support, including people whose mental health needs are compounded by the impact of bereavement. Irish Hospice Foundation supports the Irish Association for Counselling and Psychotherapy Pre-Budget Submission 2024 which proposes that parity should be given to psychotherapy and counselling as a health expense open to tax relief.<sup>22</sup>

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<sup>17</sup> Aoun, SM., Breen, LJ., Howting, DA., Rumbold, B., McNamara, B. & Hegney, DA. (2015) Who needs bereavement support? A population based survey of bereavement risk and support need. PLoS ONE, 10, e0121101.

<sup>18</sup> Lunderoff, M., Holmgren, H., Zachariae, R., Farver-Vestergaard, I. & O'Connor, M. (2017) Prevalence of prolonged grief disorder in adult bereavement: a systematic review and metaanalysis. Journal of affective disorders, 212,138–149.

<sup>19</sup> <https://www.hse.ie/eng/services/list/4/mental-health-services/counsellingpc/cipc-national-evaluation/changing-lives-for-the-better-exec-summary-june-2022.pdf>

<sup>20</sup> [https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/committee\\_on\\_the\\_future\\_of\\_healthcare/reports/2017/2017-05-30\\_slaintecare-report\\_en.pdf](https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/committee_on_the_future_of_healthcare/reports/2017/2017-05-30_slaintecare-report_en.pdf)

<sup>21</sup> <https://www.hse.ie/eng/services/list/4/mental-health-services/counsellingpc/cipc-national-evaluation/changing-lives-for-the-better-exec-summary-june-2022.pdf>

<sup>22</sup> [https://iacp.agitate.ie/assets/files/pdf/pre-budget\\_submission\\_2024.pdf](https://iacp.agitate.ie/assets/files/pdf/pre-budget_submission_2024.pdf)

## Specific investment required for Irish Hospice Foundation

### Action 6 - Implement the recommendations from our “Real Financial Impact of Bereavement” Report - €325,000

The Real Financial Impact of Bereavement is the first study of its kind in Ireland that examined both the short and long-term impacts of bereavement on a person’s life from funeral costs to the impact on their employment and their wellbeing.<sup>23</sup>



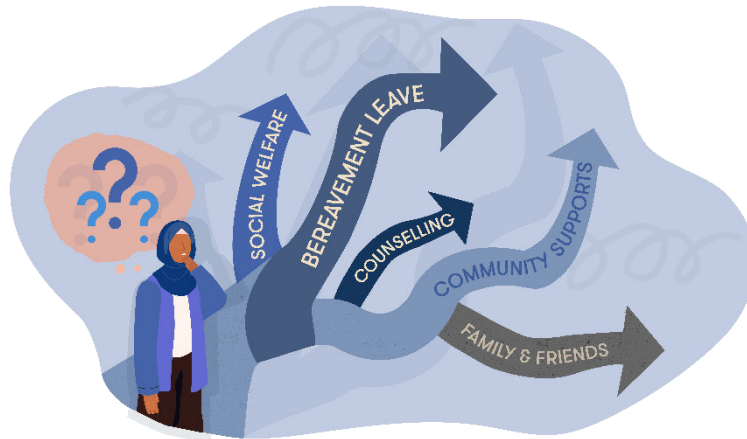
The recommendations in the report highlighted a number of areas for action:

#### a) **Develop a specific online bereavement information service - €125,000**

The findings identified a very clear need to signpost bereaved people more appropriately and effectively to the financial and emotional supports available to them. One of the report’s recommendations was to develop a specific online bereavement information service channelled through existing bereavement support specialists such as Irish Hospice Foundation and other bereavement support organisations and networks working with bereaved families. This work could be facilitated through an existing online portal [www.bereaved.ie](http://www.bereaved.ie).

The service would ensure that all the information people may need is in the one place and would be their first port of call. The information would expand upon what is already available and signpost people to the range of practical, wellbeing and financial supports currently available through mainstream sites such as the HSE, Department of Social Protection, MABS and Citizens Information.

<sup>23</sup> <https://hospicefoundation.ie/our-supports-services/advocacy-research/research/the-real-financial-impact-of-bereavement/>



**b) Annual bereavement campaign led by the HSE (similar to the campaign undertaken in 2022) - €200,000**

Approximately 350,000 people are newly bereaved in Ireland each year. The most basic type of support we can provide is to help people to understand how bereavement affects every aspect of life; and to help friends and communities to ‘be there’. Communities need to be supported to respond appropriately to those experiencing grief and loss. There is a need to engage in effective public health education and signposting of supports around coping with grief, to empower and encourage communities to play their role in supporting people who are grieving.

In 2022 in recognition of the need to acknowledge people’s experiences of grief the HSE ran a national bereavement awareness campaign to ensure that the public had access to effective public health education around grief and coping with grief. This must be an ongoing campaign and in Budget 2024 funding is required to continue to build on the work that was championed with our partners in the HSE.

**c) Review of the knowledge and communication about the Additional Needs Payment (ANP) - potentially cost neutral**

An Additional Needs Payment (ANP) is not a specific payment (or grant) for funerals, rather a payment that can be accessed by those who find themselves unable to provide financially for the funeral of a loved one. However, our study – The Real Financial Impact of Bereavement - found that awareness and understanding of the ANP in its current form is low among those affected, primarily recently bereaved people, and would warrant further review. This proposed review may result in a number of scenarios being explored:

- **Language describing the ANP includes the word bereavement**

We propose that when the ANP is being described and particularly when it references the instances that people can access it, the word bereavement is used, as opposed to just referring to the cost of funeral expenses. We recognise and acknowledge that the Community Welfare Services will take all the circumstances of an individual case into account and payments in these areas are not restricted to funerals but we would like this to be acknowledged in the language used.

- **The process of applying for the ANP is simplified**

More targeted publicity about the availability of the ANP to raise more awareness about it. Awareness is particularly needed among certain groups such as family carers or bereaved parents with young children that were identified in the study as being more vulnerable to the economic impacts of bereavement.

Irish Hospice Foundation would be willing to work with the Department of Social Protection to explore potential opportunities to work on these areas.

**d) Legislate for statutory bereavement leave (cost would be dependent on various factors that would need to be scoped out by Government)**

Currently in Ireland there is no statutory obligation to provide bereavement leave. It is considered good practice by an employer to allow an employee some paid time off following the death of a close family member.

Bereavement is a common experience in the workplace and it can have a significant impact on people's working lives. Employee grief costs businesses money, but unsupported grief cost even more.

Presenteeism occurs when the employee is physically present at work but mentally unable to concentrate, perform or engage meaningfully with their work tasks. In the UK, presenteeism as a result of employee grief costs the economy £16 billion per year with normal productivity rates reduced by 30% for the first 6 months following a bereavement. <sup>24</sup>

A study in 2018 by Irish Hospice Foundation identified that 46% of employees would take more sick days if not supported by their employer. The study also highlighted that almost a third of employees would consider leaving their jobs if not supported and a quarter would actually leave their job. <sup>25</sup> A Scottish study in 2015 identified that bereaved people were significantly more at risk of being unemployed in the two years following a bereavement. <sup>26</sup>

This impact should be formally recognised and supported accordingly through statutory bereavement leave, similar to the recent legislation which introduced statutory sick leave. Equally when grief is formally acknowledged in a workplace this in turn leads to improved morale and reduces the likelihood of sick leave and staff turnover.



<sup>24</sup> [https://www.mariecurie.org.uk/globalassets/media/documents/how-we-can-help/bereavement-hub/respecting-and-supporting-grief-at-work\\_sep-2021.pdf](https://www.mariecurie.org.uk/globalassets/media/documents/how-we-can-help/bereavement-hub/respecting-and-supporting-grief-at-work_sep-2021.pdf)

<sup>25</sup> <https://hospicefoundation.ie/bereavement-news/grief-in-the-workplace-research-preliminary-results-released/>

<sup>26</sup> <https://www.tandfonline.com/doi/abs/10.1080/07481187.2014.920435>



## Action 7 – Deliver enhanced bereavement and grief training for mental health practitioners - €75,000

In recent studies by Irish Hospice Foundation<sup>27</sup> and the Irish Childhood Bereavement Network<sup>28</sup> bereavement service providers have noted a significant lack of appropriate training to support them in their work. Investment is required to enhance their capacity to deliver existing services.

In these studies, organisations, both statutory and voluntary, were very positive about initiatives such as quality training interventions which are accessible and affordable and the development of core competences and/or bereavement care standards frameworks. It is important to note that while basic standards exist for the charity sector in Ireland (set by the Irish Charity Regulator), there are no bereavement-specific guidelines or standards for NGO bereavement organisations.

Similarly, professional psychotherapy and psychology services should be delivered by skilled and informed practitioners. In the recent past, Irish Hospice Foundation have been successful in gaining funding to provide grief training to the national Counselling in Primary Care (CIPC) service. Training similar to this would be beneficial for other mental health practitioners including the expanded Employee Assistance Counselling service used by the public service such as the HSE and therapists and counsellors providing care through Family Resource Centres.

Developments in this area may increase both public and referrer (e.g. GP) confidence and awareness in a bereavement care pathway. Recent advances in understanding grief and bereavement, and in particular therapeutic approaches to work with disrupted grief, termed Prolonged Grief Disorder (PGD), have been adopted by International Classification of Diseases (ICD-11) in 2018 and Diagnostic and Statistical Manual of Mental Disorder (DSM-5) in 2022.

There is a documented lag in research findings being translated to practice, internationally and in Ireland. The legacy of Covid-19 should provide an impetus to address this gap.<sup>29</sup> The recognition of the significant issues that PGD can present means that many professionals now require Continuing Professional Development training to work with more complex grief. To date, PGD is not recognised in Irish mental health policy and the practitioners in mental health services are not yet sufficiently trained or resourced to diagnose and support those with PGD.

In Budget 2024, Irish Hospice Foundation calls for an initial commitment of €75,000 to commence a national training programme on PGD for clinicians. A key component of this will be the provision of training for general and specialist health and social care professionals to recognise and treat PGD. The funding being called for in Budget 2024 for the national training programme for clinicians would target HSE specialist mental health services in community settings e.g. through General Adult Community Mental Health services, CAMHS and other specialist mental health services.

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<sup>27</sup> Ibid

<sup>28</sup> <https://www.childhoodbereavement.ie/childhood-bereavement-services-national-survey-2023/>

<sup>29</sup> Dodd, A., Guerin, S., Delaney, S., & Dodd, P. (2022). Complicated grief knowledge, attitudes, skills, and training among mental health professionals: A qualitative exploration. *Death studies*, 46(2), 473–484. <https://doi.org/10.1080/07481187.2020.1741048>

## **Action 8 - Co-funded support from HSE to deliver Irish Hospice Foundations' Bereavement Support Line - €75,000**

In response to the COVID-19 pandemic Irish Hospice Foundation established their Bereavement Support Line (BSL) in 2020, in partnership with the HSE, to help address some of the additional bereavement needs people were facing in the community.

The BSL continues to meet a very real and continuing need for those who are bereaved. To date the BSL has taken nearly 4,800 calls. The calls are from people who have been recently bereaved, bereaved during COVID-19 but also from those who were bereaved before the pandemic. The service continues to provides connection, comfort and support to those who are struggling. The service also signposts people to supports and services that relate to their needs.

We are currently cofunded by the HSE to deliver this service. In 2022 we received €50,000 in funding from the HSE to meet the annual costs of €156,000 of running the service. In Budget 2024 we are seeking an additional €25,000, bringing the total to €75,000 in co-funded support from the HSE to deliver this service. The costs of running this service continue to increase as we invest in our staff and volunteers to build our capacity to respond effectively and ensure that the needs of the callers are being met.

Most importantly we want to grow public awareness of this vital service to ensure that people know that they can access it at a time when they may need it most. This funding would enable us to raise further public awareness about the BSL.

## Priority 4 - Support every person to plan for their end of life

### Overview

It is not possible to predict or know what will happen in the future, but most people will have an idea of what they want, especially in terms of their care at end of life. Planning ahead can help ensure that a person receives the care they want and can also help to make things easier for families and health care professionals when the person is nearing their end of life.

The importance of planning ahead is reinforced by the recent commencement of the Assisted Decision-Making (Capacity) Act 2015<sup>30</sup> and the operationalisation of the Decision Support Service. The Act is about supporting decision-making and maximising a person's capacity to make healthcare (or end of life) decisions.



From our work we know that these are not easy topics to think or talk about. Enabling people to have discussions about their future end of life wishes with families and clinicians' can often avoid difficult decisions later on or when the person may lack capacity. Families and clinicians are reassured that they have direction about what the person would want for their care.

By supporting people through these discussions and decisions before they are needed, we ensure that people receive the care and treatment that they choose throughout their entire lives. For many years our Think Ahead programme has been guiding people through these discussions and processes.

### Specific investment required for Irish Hospice Foundation

#### Action 9 - Funding for our Think Ahead programme to encourage and enable Irish people to think, talk and plan ahead for their end of life - €100,000

Irish Hospice Foundation has been to the forefront in the development of a citizen-led tool for advance care planning, called Think Ahead<sup>31</sup>. To date in 2023, over 10,000 Think Ahead planning packs have been distributed to the public. We know from our work on the Think Ahead programme that many people are unprepared for end of life. They have not thought about or actively planned for a time when they may not be able to communicate or make decisions for themselves about their future care or end of life preferences.

More support is required to bring the concept of planning ahead to communities across Ireland – to encourage and enable them to open up conversations and plan for end of life. State investment is essential to support people to plan for their end of life.

Funding of €100,000 in Budget 2024 would enable Irish Hospice Foundation to deliver a nationwide public awareness campaign. Information workshops and resources would be developed and delivered to cover a range of topics including AHDs, making a will, the

<sup>30</sup> <https://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>

<sup>31</sup> <https://hospicefoundation.ie/i-need-help/i-want-to-think-ahead/>

Decision Support Service, financial affairs and what happens after you die e.g. funeral and burial arrangements. The awareness campaign would serve two purposes:

1. Provide the Irish public with good quality information about planning ahead and signpost them to resources that enables them to discuss and plan what would be important to them in case they are unable to make these decisions in the future.
2. Promote awareness and signpost people to the establishment of the Decision Support Service, a critical service with far-reaching implications for the Irish public, but that many are currently unaware of.

## About Irish Hospice Foundation (IHF)

IHF is a national charity that addresses dying, death and bereavement in Ireland. Our vision is an Ireland where people facing end of life or bereavement, and those who care for them, are provided with the care and support that they need.

Through advocacy and education, and the provision of services such as Nurses for Night Care and the Bereavement Support Line, IHF works to ensure that every person in Ireland can die and grieve well, whatever their age and wherever the place.

Our mission is to work towards the best end-of-life and bereavement care for all. To deliver on this mission a population-wide, whole society response is required to the issues highlighted in this submission. We remain committed and ready to work in partnership with Government and other state bodies to encourage, support and enable innovation and excellence in end-of-life and bereavement care.

## Facts and Figures about Dying, Death and Bereavement in Ireland

Current figures for dying, death and bereavement in Ireland show that:

- 35,477 deaths were registered in 2022<sup>32</sup>
- This equates to nearly 100 people dying every day
- 83% of these deaths are people aged over 65<sup>33</sup>
- For every one death, up to 10 people are bereaved and significantly impacted<sup>34</sup>
- Over 350,000 people are grieving the death of a loved one each year
- The preference of most Irish adults is to die at home<sup>35</sup> but only 23% will do so<sup>36</sup>
- Hospitals remain the most common place where people die (44%)<sup>37</sup>
- 23% of people will die in nursing home care<sup>38</sup>
- 8% of people will die in a hospice<sup>39</sup>
- Cancer (31%) and heart-related disease (29%) are the leading causes of death in Ireland<sup>40</sup>

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<sup>32</sup> [Vital Statistics Yearly Summary 2022 - CSO - Central Statistics Office](#)

<sup>33</sup> Ibid

<sup>34</sup> <https://doi.org/10.1073/pnas.2007476117>

<sup>35</sup> Weafer, J. (2014) Irish attitudes to death, dying and bereavement 2004-2014. Dublin: Irish Hospice Foundation

<sup>36</sup> Matthews, S., Pierce, M., Hurley, E., O'Brien Green, S., Johnston, B.M., Normand, C. and May, P. (2021) Dying and death in Ireland: what do we routinely measure and how can we improve? Dublin: Irish Hospice Foundation.

<sup>37</sup> Ibid

<sup>38</sup> Ibid

<sup>39</sup> Ibid

<sup>40</sup> Ibid



**Irish  
Hospice  
Foundation**

To die and grieve well wherever the place

Irish Hospice Foundation  
Morrison Chambers,  
32 Nassau Street,  
Dublin 2.  
D02 X627

[hospicefoundation.ie](http://hospicefoundation.ie)  
[info@hospicefoundation.ie](mailto:info@hospicefoundation.ie)

Registered Charity 20013554