

Pre-Budget Submission 2023

Investing in the best end-of-life and bereavement care for all



**Irish
Hospice
Foundation**

To die and grieve well wherever the place

July 2022

About Irish Hospice Foundation

Irish Hospice Foundation 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, Irish Hospice Foundation works to ensure that every person in Ireland can die and grieve well, whatever their age and wherever the place.

OVERALL ASK

TO DIE AND GRIEVE WELL REQUIRES AN INVESTMENT OF €1.75 million

IN BUDGET 2023

Priorities for Budget 2023

1. Resourcing a national approach to palliative, end-of-life and bereavement care - €500,000
2. Quality end-of-life care, wherever the place - €650,000
3. Investment in community bereavement supports - €500,000
4. Support the public to plan for their end of life - €100,000

Introduction

Budget 2023 represents a real opportunity to achieve an integrated approach to the issues related to dying, death and bereavement but investment is needed to address the key needs. Investment in the priorities highlighted in this submission will support improvements and the best end-of-life and bereavement care for all.

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. This Pre-Budget Submission sets out the rationale and costing for these priorities that help meet this policy commitment.

This Pre-Budget Submission is based on our mission to work towards the best end-of-life and bereavement care for all – this mission is something that is shared by the people of Ireland. To deliver on this mission a population-wide, whole society response is required to the issues highlighted.

Perhaps like never before, dying, death and bereavement are at the forefront of our collective consciousness. Irish Hospice Foundation remain committed and ready to work in partnership with Government and other state bodies to encourage, support and enable innovation and excellence in palliative, end-of-life and bereavement care.

Facts and figures about dying, death and bereavement in Ireland

It is essential we plan to meet the needs of people facing dying, death and bereavement to ensure equal access to good care and support. In the next 10 years in Ireland¹:

- Over 300,000 people will die
- Over 3,000 of those deaths will be children
- Over 250,000 of those deaths will be people over 65 years of age
- Almost 3 million people will be bereaved²

If current trends continue:

- Number of deaths will increase by 25% up to the year 2040³
- The preference of most Irish adults is to die at home⁴ but only 23% will do so⁵
- Hospitals remain the most common place where people die (44%)⁶
- 23% of people will die in long stay residential care⁷
- 8% of people will die in a hospice⁸
- Cancer (31%) and heart-related disease (29%) are the leading causes of death in Ireland⁹

¹ Figures estimated from CSO statistics of 2017: Vital Statistics 2017 Yearly summary (30,484 deaths in 2017)

² Estimate based on 10 people directly affected by each death

³ May, P., Johnston, B.M., Normand, C. et al. (2020) Population-based palliative care planning in Ireland: how many people will live and die with serious illness to 2046? HRB Open Res

⁴ Weafer, J. (2014) Irish attitudes to death, dying and bereavement 2004-2014. Dublin: Irish Hospice Foundation

⁵ 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.

⁶ Ibid

⁷ Ibid

⁸ Ibid

⁹ Ibid

Overview of priorities for Budget 2023

Priority 1 - Resourcing a national approach to palliative, end-of-life and bereavement care - €500,000

Actions required in Budget 2023:

Societal wide investment

1. Commitment to launch and resource the forthcoming National Adult Palliative Care Policy with an associated implementation plan and appropriate costings to support the work
2. Explicit support for the development of an infrastructure within the HSE that supports a coordinated approach toward end-of-life care

Irish Hospice Foundation specific investment

3. Investment that will further support the meaningful and supportive role that the creative arts play in end-of-life and bereavement care across society as a whole– €500,000

Priority 2 - Quality end-of-life care, wherever the place - €650,000

Actions required in Budget 2023:

Societal wide investment

4. Political commitment to capital investment to secure the building of a hospice for the Midlands and North East in partnership with the regional hospice entities and the HSE
5. Delivery of the proposed investment in the National Mortuaries Programme through the HSE Capital Plan 2022

Irish Hospice Foundation specific investment

6. Sustained multi annual funding to cover 50% of the ever-increasing nursing costs to deliver the Nurses for Night Care service - €650,000
7. Sustained political support for the work programme that is being jointly delivered by Irish Hospice Foundation, All Ireland Institute of Hospice and Palliative Care and the HSE to deliver person-centred palliative, end-of-life and bereavement care in nursing homes

Priority 3 - Investment in community bereavement supports - €500,000

Actions required in Budget 2023:

Societal wide investment

8. Commitment to fund a scoping study of a national bereavement policy, led by the Department of Health - €100,000
9. Continued investment in a national bereavement awareness campaign, led by the HSE - €200,000

Irish Hospice Foundation specific investment

10. Increase in co funded support from the HSE to deliver the Irish Hospice Foundations' Bereavement Support Line - €75,000
11. Funding to implement key recommendations from "The Economic Impacts of Bereavement in Ireland" report including the development of a specific online bereavement information service - €125,000

Priority 4 - Support the public to plan for their end of life - €100,000

Actions required in Budget 2023

Societal wide investment

12. Initiation of a Register of Advance Healthcare Directives, by the Decision Support Service, as outlined in legislation

Irish Hospice Foundation specific investment

13. Funding for Think Ahead programme of work 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 throughout 2021 and 2022.

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. Yet 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 those most in need.

Dying, death and bereavement all form core parts of the work delivered by the HSE and the community and voluntary sector, often working together in partnership. COVID-19 has shown that a more strategic approach to dying, death and bereavement would benefit all of us, as the repercussions of the pandemic are being deeply felt across many areas of health and society in general.

The benefits that arts, culture and creative engagement bring to people's mental wellbeing is increasingly recognised and acknowledged. There is an increasing commitment in Government to bring forward targeted, evidence-based initiatives that deliver benefits to health and wellbeing through arts, culture and creativity in a sustainable manner.

Action 1 - Commitment to launch and resource the forthcoming National Adult Palliative Care Policy with an associated implementation plan and appropriate costings to support the work

The 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. 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 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 very hard to ensure our asks are addressed. In the main we will be advocating for Generalist Palliative Care, bereavement care and more care in the community, including Primary Palliative Care.

Our key asks in the National Policy on Adult Palliative Care will be:

1. Equity of access 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 national policy (see action 8 on page 15 for more details).
4. Investment in night nursing and the nurses for night care service (see action 6 on page 12) to reflect that this service is a core part of the care for people facing end of life.
5. More clarity, commitment and support for the delivery of palliative care in the primary care setting including support for out of hours care services.
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 support 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 the statutory home care scheme as access to homecare hours is critical for people with palliative care needs in the community and their families. Also upcoming workforce policies that aim to address the difficulties recruiting and retaining staff as these are barriers to the delivery of quality palliative care.
8. More public information and signposting of palliative care will be required.
9. Clarity on the provision of level II beds in all regions, building on the research "Report of the First National Palliative Care Support Bed Review" completed by HSE/Irish Hospice Foundation in 2014.
10. Recognition of palliative care provision as part of service development within all Clinical Care Programmes and multi-disciplinary professions to ensure that people have access to appropriate palliative care regardless of diagnosis or setting.
11. The policy must be appropriately funded and also allow for the increasing demands of the future.
12. There must be clarity about how the policy will be overseen and implemented and that ALL aspects pertaining to dying, death and bereavement are included.
13. 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 will be needed.
14. 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.

Budget 2023 must ensure that this new policy has an agreed implementation plan that is financed appropriately so that it can be delivered now and in the future.

Action 2 - Explicit support for the development of an infrastructure within the HSE that supports a coordinated approach toward end-of-life care

The delivery of palliative, end of life and bereavement care by the HSE cuts across many areas of implementation. At present, in the HSE there are a range of flagship programmes in the area of palliative, end of life and bereavement care including:

- A clinical care programme of work to improve the provision of Specialist Palliative Care and to identify and fill gaps in inpatient units, community and acute hospitals
- Hospice friendly Hospitals - a national programme run in partnership with acute hospitals and Irish Hospice Foundation that brings a strategic and focused approach to the improvement of end-of-life care
- National Development Committee for Children's Palliative Care which oversees the implementation of the recommendations contained within government policy on children's palliative care through collaborative action
- A new national nursing home programme supporting the delivery of compassionate, person centred palliative, end of life and bereavement care, delivered by Irish Hospice Foundation working in partnership with the HSE and AIHPC
- HSE led awareness raising campaign with a focus on grief and bereavement care, particularly to reflect the impact of COVID-19

Each of these programmes require a significant amount of time and resources from the HSE and partners such as Irish Hospice Foundation. This investment means that it is imperative that there is clarity on how these functions will be managed and coordinated within the HSE – given there is extensive change at corporate level.

We would advocate that Budget 2023 is an opportunity to highlight explicit support for the development of an infrastructure within the HSE that supports a coordinated approach toward end of life care under palliative care. The role of this infrastructure would be to coordinate existing work programmes in these areas and bring a strategic, cohesive and collaborative approach to the work. Irish Hospice Foundation is very open to supporting this work within resources.

There are other effective examples of this approach such as the HSE National Office for Suicide Prevention and the National Dementia Office which were established to strategically lead on suicide prevention and dementia respectively in Ireland. A key element of both their work is their collaboration across the HSE and with multiple other sectors.

Action 3 - Investment to further support the meaningful and supportive role of the creative arts across society as a whole - €500,000

Over the last two years Irish Hospice Foundation have been supported by Creative Ireland to develop a creative arts programme arising from the needs of COVID-19. In this time, we have delivered a unique and influential Arts and Creative Engagement programme designed to reduce the impact of grief and loss on Irish communities – in both public and professional domains.

We have supported and delivered:

- 39 Seeds projects with micro grants and resources to develop their own tools
- Our Compassionate Culture Network programmes trained 14 people to facilitate exploring loss in a creative way in 6 counties – with view to national roll-out
- Creative practice to frontline workers in HSE – through development of creativity-based health and wellbeing tools for staff regularly facing dying and bereavement

In order to continue the growth of this work we are calling on Budget 2023 to invest €500,000 to further support our objective to continue to facilitate creative practice and community engagement as well as raising awareness and health/wellbeing promotion.

We are working towards: an all of Government approach that has a focus on collaborating with existing All-Island initiatives and local authorities.

Specifically, this funding would enable us to:

1. Develop an All Island approach to working through the arts to address the impact of grief and loss. The work would include a focus on the losses created by displacement, conflict, and their long-term impact on mental health and social disruption.
2. Creatively explore issues arising from dying, death and bereavement in less heard communities of place and interest. Rural communities where formal health care is geographically distant, new communities in particular their traditions around death that are less familiar in Ireland, those faced with professional loss including health care staff, people identifying as LGBTQ and those living in formal or residential care. This strand would aim to build self-supporting tools for resilience in these communities.
3. Invest in the creative community support networks that we have identified through our current work. The supportive role that locally run social groups, like knitting groups, Men's Sheds, community centre programmes take to address the emotional journeys of those grieving deserves investment.

The Government recently published their second report on Ireland's Well-being Framework – 'Understanding Life in Ireland: A Well-being Framework'. The Framework is about helping improve our understanding of quality of life in Ireland and measuring how we are doing overall as a country.

Cultural participation and cultural expression are both included in the set of 35 indicators around well-being assessment. There is still work to be done on ensuring that these indicators get measured appropriately and the work Irish Hospice Foundation is seeking investment for presents a real opportunity to inform these measures.

Priority 2 - Quality end-of-life care, wherever the place

Overview

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

We have advocated for many years for the removal of inequities and disparities in the delivery of Specialist Palliative Care. Two regions in Ireland (Midlands and North East) remain without an in-person hospice unit and the people living there must not wait any longer. This is a critical opportunity to ensure that all those living with a life limiting conditions can have access to the care they need regardless of their diagnosis or location.

The dying, deceased and bereaved should be afforded the best possible care in the most appropriate and dignified spaces. Equally that those who care for and interact with the dying, deceased and bereaved should have both optimum working conditions and on-going support. Accelerating progress on refurbishment of our mortuary facilities is a positive step to realising that goal of delivering compassionate end-of-life care.

Most adults in Ireland 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 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. Nurses for Night Care play a very special role in achieving that wish for the person and their families and sustained investment in this valuable service is very necessary.

Nursing homes constitute a significant part of healthcare delivery in Ireland, including palliative and end-of-life care. It is the setting where up to 23% of the Irish population die and this figure is expected to increase (CSO, 2019).

COVID-19 highlighted the considerable challenges faced by the sector. It also presented an opportunity, for all stakeholders, to review the nursing home sector and identify the changes that are required. The findings of the COVID-19 Nursing Homes Expert Panel are informing how these changes will be delivered.

The Expert Panel called for *'systematic reform in the way nursing home care and older persons care is delivered'* (Department of Health, 2020). Specifically, the Expert Panel recommended the implementation of: *"a joint HSE-IHF collaborative national programme on palliative, end-of-life and bereavement care for the nursing home sector that engages all stakeholders and improves quality of care across the sector. This initiative would be established along the same lines as the HSE-IHF Hospice Friendly Hospitals Programme"*.

Action 4 - Political commitment to capital investment to secure the building of a hospice for the Midlands and North East in partnership with the regional hospice entities and the HSE

Where a person lives should not be a barrier to accessing the very best care at end of life, including access to Specialist Palliative Care. There is currently no Specialist Palliative Care inpatient unit (Level 3) in the Midlands and North East region – despite the provision of this service being national policy for over 20 years. This has had a great impact on place of death and the investment into end-of-life care in these regions.

We firmly advocate that the people living in the Midlands and North East region are being denied the same care at end of life as people in other areas. The Midlands has one of the lowest levels of state investment nationally. Although, the plans to ensure a Level 3 hospice unit is built in the Midlands region have progressed substantially in 2021 and we understand that there is significant philanthropic investment in the North East to enable one to be built there, the fact remains that these areas still do not have an in-patient hospice unit.

To see this work fully progressed and the hospice builds to be realised there needs to be political commitment and engagement in negotiations with local hospice entities and the HSE to agree how the capital costs can be shared. It is increasingly likely with escalating building costs that the local hospice entities will be unlikely to be able to raise the excess €16 million required to complete the hospice builds.

Projects in other areas, including the North East have progressed in recent years and the Midlands remains the most under-developed region in terms of in-patient hospice care. There also remains very real challenges in achieving consensus and support from the four Midland Counties – Longford, Westmeath, Laois and Offaly to building this hospice.

This is despite the compelling evidence that the provision of comprehensive Specialist Palliative Care services across all care settings (hospital, home, in-patient hospice and day care) 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.

Budget 2023 is a pivotal opportunity to ensure equitable access to palliative and hospice care in every region of Ireland. We are calling for urgent political commitment and engagement in negotiations with local hospice entities and the HSE. This dialogue will allow for an opportunity to agree how the capital costs can be shared for the development of in-patient hospice units in the Midlands and North East regions that are currently without this vital service.

While the palliative care needs of the populations in these regions continues to grow so do spiralling building costs. The time has now come where it is imperative for the Government to engage in negotiations about providing this urgent capital investment to enable the delivery of an in-patient hospice for the Midlands and North East. It is no longer acceptable that these regions are left behind.

Action 5 - Delivery of the proposed investment in the National Mortuaries Programme through the HSE Capital Plan 2022

Irish Hospice Foundation has been advocating for a National Mortuaries Programme for many years. We welcome the commitment in the HSE Capital Plan 2022 to review existing facilities and upgrade or refurbish sub-standard public hospital mortuaries to ensure they are compliant with best practice standards. Budget 2023 must ensure that the funding is available to deliver on this proposed investment.

Mortuaries are often dilapidated, old buildings and yet are a critical point of contact for grieving loved ones – our vision is that they would be dignified, calm spaces where families can gather in peace and privacy. Over the past number of years, the provision of mortuary and also post-mortem facilities have been brought into sharp focus, highlighting the complexities which can arise when providing services to the deceased and the bereaved.

We know that 43% of 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. Such environments can add additional stress and distress to those grieving the loss of a loved one at a time when they are most vulnerable. This can have a huge impact on the relatives’ memories of their loved ones death and on their grieving experience.

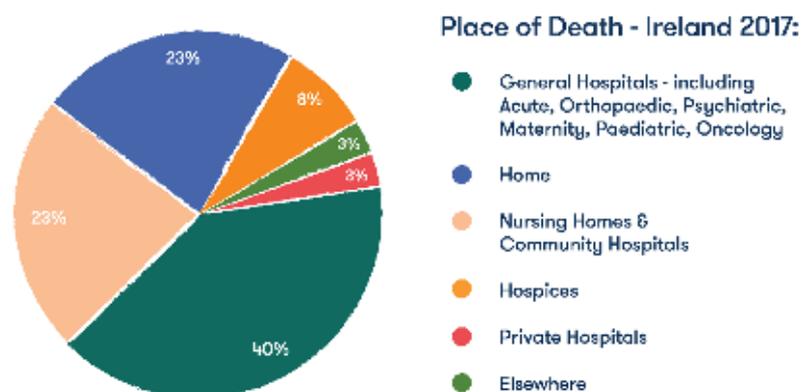
Irish Hospice Foundation remain committed to supporting the delivery of this vision of dignified, calm spaces through our Design & Dignity Programme. With the support of HSE funding, we aim to ensure that every hospital in Ireland has a dignified and comfortable sanctuary for people to experience the death of someone close to them. To date Design & Dignity has funded over 47 projects across Ireland, including 13 mortuaries. Design & Dignity is part of Irish Hospice Foundation’s Hospice Friendly Hospitals programme.

In advance of an application to the National Mortuaries Programme, each hospital can avail of additional specialist architectural expertise funded by Irish Hospice Foundations’ Design & Dignity programme to support the planning of exemplar dignified mortuaries.

Budget 2023 must ensure that the required funding is in place for the HSE Capital Plan to deliver on refurbishment and the upgrading of the front of house/public areas within mortuary facilities. This work can no longer be pushed down the list. COVID-19 has added impetus to this need to deliver mortuaries that are a sanctuary and convey a sense of reverence and respect for life, death and bereavement. Currently, many mortuaries do not have the capacity required to cope with additional pressures, such as the COVID-19 pandemic presented. This work cannot wait any longer.

Action 6 - Sustained multi annual funding to cover 50% of the ever-increasing nursing costs to deliver the Nurses for Night Care service - €650,000

The 2020 Programme for Government cites the importance of delivering the right care in the right place, aligned to this our studies have found that 74% of Irish people wish to die at home yet only 23% of people will achieve this.

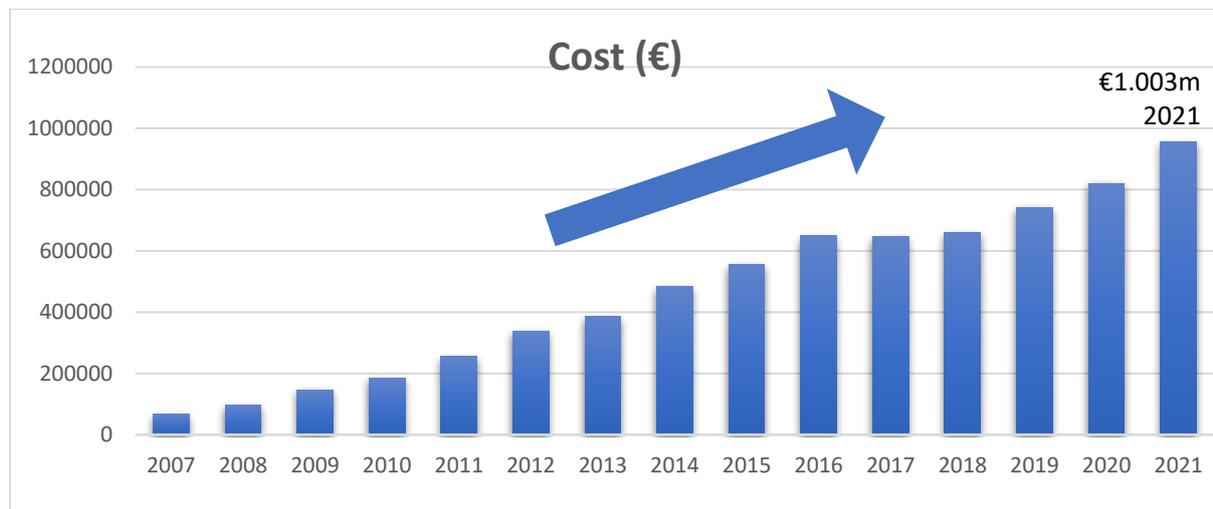


Place of Death 2017: Taken from Revised CSO Analysis of Place of Death (2017), prepared by Irish Hospice Foundation 2019

Irish Hospice Foundation’s Nurses for Night Care is a service that enables people who are dying at home with a non-malignant condition to access nursing care at night. It is run in conjunction with the Irish Cancer Society. It is considered a critical element to the support of family carers when caring for a person at end of life in the home setting. The service responds to the nursing needs of persons who have an illness other than cancer and who are in the final stage of their illness. Persons availing of the service must be referred by and are under the care of the local Specialist Palliative Care community team.

Since the establishment of the Nurses for Night Care service for those with non-cancer related illnesses in 2006, demand has grown year on year and the rate of growth increases each year. While there were 8 referrals in 2006, this has increased to 1,241 new referrals in 2021, with 921 people and their families supported by Nurses for Night Care last year.

Irish Hospice Foundation has funded the nursing costs for this essential service since 2006. Increasing demands for the service translates into increasing costs as more nursing care is required. Nursing costs alone have risen from €25,510 in 2006 to just over €1million in 2021 (€1,000,003). We anticipate these nursing costs will increase by at least 10% each year. The growth of the service has also led to a substantial increase in the administration and co-ordination costs within Irish Hospice Foundation.



A commitment was made in the HSE Palliative Care Development Framework 2017 – 2019 to fund 50% of the cost of Nurses for Night Care by the end of 2019. This commitment was achieved for the first time in 2021 and will be repeated again in 2022 when 70% or €700,000 in funding will be received from the HSE.

We welcome the recurring annual funding of €250,000 for Nurses for Night Care that was commenced in 2021 by the HSE. In 2022 there has also been an additional €450,000 in funding allocated on a once off basis from the HSE. While this funding is greatly welcomed by Irish Hospice Foundation, with costs coming in at over €1million in 2021 and costs estimated to increase to €1.15 million in 2022, we are extremely concerned about the precarious nature and variances year on year of this funding.

We will have received funding of €500k in 2021, €700k in 2022 and as it stands this will drop back to €250k in 2023. We have always committed to fundraising the remaining shortfall in costs each year. However, relying on fundraising for a vital service such as this is unlikely to be sustainable and this situation cannot continue. Multi annual funding of at least 50% of the increasing costs must be committed to in Budget 2023 to ensure the continued delivery of this vital service.

Action 7 - Sustained political support for the work programme that is being jointly delivered by Irish Hospice Foundation, All Ireland Institute of Hospice and Palliative Care and the HSE to deliver person-centred palliative, end-of-life and bereavement care in nursing homes (private, public and voluntary)

In late 2021 Irish Hospice Foundation and the All Ireland Institute of Hospice and Palliative Care (AIHPC) were successful in their call for funding for a National Nursing Home Programme. This national programme will support the delivery of improved palliative, end-of-life and bereavement care in Irish nursing homes. The work programme arose in response to the findings of the COVID-19 Nursing Homes Expert Panel.

Whilst there have been various single agency initiatives aimed at nursing home settings, to date there has been no integrated and resourced national standardised programme of improvement focused on palliative, end-of-life and bereavement care for these facilities.

This work programme led by Irish Hospice Foundation and AIHPC with funding from the HSE is a multi-strand, five-year programme of support for the nursing home sector. It is being developed to ensure that regardless of size, diversity and geographical spread, every nursing home can engage with the proposed supports at a level appropriate to them. Over five years, up to 580 nursing homes nationwide, and their estimated 42,000 staff will be able to freely access information, networking opportunities, palliative care skills support and quality improvement training.

Irish Hospice Foundation will be the lead partner for the initiative which will cost a minimum of €9.635 million over the next five years, of this Irish Hospice Foundation will contribute €2.328 million of its own resources and AIHPC will contribute €0.284 million. Irish Hospice Foundation have secured a philanthropic contribution of €1 million over the five years. Excluding these contributions, the programme needs funding of €6.023 million to meet the annual running costs of €1.2046 million for a period of five years.

The HSE have committed to funding and supporting this work for the next five years. Budget 2023 is an opportunity to give political assurances to the commitments that this work can be meaningfully developed over the next five years and provisions are made to sustain the programme of work beyond this time.

Priority 3 - Investment in community bereavement supports - €500,000

Overview

COVID-19 has made Irish society rethink the way it deals with death, grief and bereavement. At Irish Hospice Foundation we have seen just how difficult it has been for people experiencing dying, death and bereavement. We must now fully acknowledge that no matter what the grief or its cause, there is we, as a society, must do more to support people experiencing bereavement and invest accordingly in the supports needed.

Bereavement is a universal and painful life experience. Grief affects bereaved people in a myriad of ways as people process it in their own unique way. Bereavement research shows that most people will find a way to navigate through their grief and they rely heavily on social support during and after bereavement.

Communities need to be supported to respond appropriately to those experiencing grief and loss at each of these levels. 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 bereaved people.

Action 8: Commitment to fund a scoping study of a national bereavement policy, led by the Department of Health - €100,000

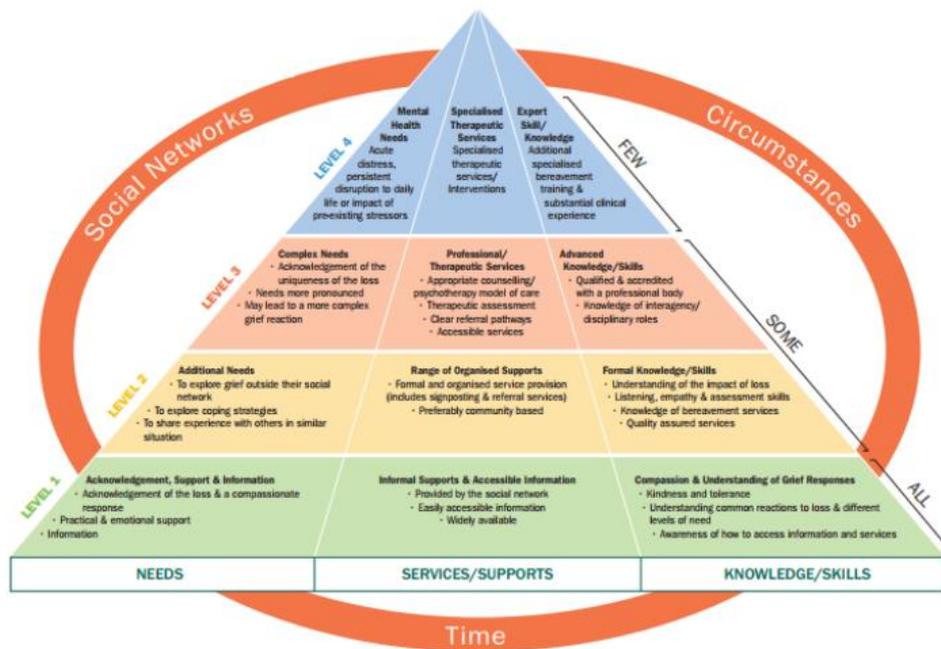
There is a lack of any sort of coherent national policy on bereavement care in Ireland and it is largely invisible in formal policies. It does not feature as an issue in many of the overarching health strategies or frameworks. Currently it is given minimal consideration within mental health, suicide, cancer and palliative care policy frameworks. There is a need for a recognition of the impact of bereavement in policies ranging from education to employment, from health to social protection.

A forthcoming report in 2022 *“The Economic Impacts of Bereavement in Ireland”* by Irish Hospice Foundation also highlights the cross-cutting nature of the impact of bereavement. The adverse economic impacts of bereavement are intertwined with the sometimes very intense adverse emotional impacts 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 neatly packaged and handed over to health and social services as their sole remit, all Departments have their roles to play.

In the absence of a national approach to adult bereavement care in Ireland, in 2018 Irish Hospice Foundation facilitated a national collaborative process to develop a framework for adult bereavement care in Ireland. The Adult Bereavement Care Pyramid was launched in 2021 and provides a national framework for adult bereavement care in Ireland.

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).



Adult Bereavement Care Pyramid, Irish Hospice Foundation

We fully endorse this 'pyramid' model and recommend that this approach shapes bereavement care policy, planning and service delivery. With this in mind, Budget 2023 is an opportunity to fund an exercise that further scopes out what is required for Ireland to have a robust and meaningful national policy on bereavement.

The purpose of a scoping exercise is both to map out a wide range of literature, and to envisage where gaps and innovative approaches may lie. It 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.

We are calling on Budget 2023 to fund a scoping paper that would identify:

- The potential need for a bereavement policy in Ireland
- The benefits, costs, and risks of such a policy
- Who the target audience and key stakeholders would be
- The Government departments with responsibility for such a policy
- 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 2023 has the opportunity to deliver and we would welcome dialogue on this.

Action 9 – Continued investment in a national bereavement awareness campaign, led by the HSE - €200,000

Bereavement is an experience that will affect most people in their lifetime – 300,000 people are newly bereaved in Ireland each year. Bereavement is an area that as a society we all need to engage with in order to understand the impact more. In the shadow of COVID-19 it is timely that Budget 2023 invests €200,000 in a national bereavement awareness campaign to ensure that the public continues to have access to effective public health education around grief and coping with grief, particularly in the immediate context of a pandemic.

We want to build on the work championed by Irish Hospice Foundation and our partners and support the continued development of a national response to grief and bereavement. Funding in Budget 2023 will continue to ensure that we promote and provide visibility, stability and magnify public health education around grief and coping with grief.

This investment would help deliver some of the recommendations set out in the HSE Psychosocial Response to the COVID-19 Pandemic Report 2020. The report highlights that there is a need for accurate and helpful information from government sources, community supports and a range of media communications promoting wellbeing, resilience and safety while also providing clear direction to further services, if needed.

Action 10 - Increase in co funded support from the HSE to deliver the Irish Hospice Foundations' Bereavement Support Line - €75,000

As noted above, people process grief in their own unique way, influenced by a complex mix of factors. The experience of COVID-19 have impacted on people's experiences of grief in so many ways. In response to the COVID-19 pandemic Irish Hospice Foundation founded their Bereavement Support Line, in partnership with the HSE, to help address some of the additional needs people were facing in the community.

This service continues to meet a very real and continuing need for those who are bereaved. The Bereavement Support Line to date has taken over 2,600 calls, not only from people who have been recently bereaved during COVID-19 but also from those who were bereaved before the pandemic. The Bereavement Support Line continues to provides connection, comfort and support to those who are struggling. Connection includes helping people to identify supports and services relating to their needs.

Irish Hospice Foundation is seeking funding in Budget 2023 of an additional €75,000 to continue to co-fund this service with the support of the HSE. The costs of running this service continue to increase as we invest in our staff and volunteers to build their capacity in order 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 public awareness about the Bereavement Support Line.



Action 11 - Funding to implement key recommendations from the Economic Impacts of Bereavement report including the development of a specific online bereavement information service - €125,000

The Economic Impacts of Bereavement in Ireland 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.

The report highlighted a very clear need to signpost bereaved people more appropriately and effectively to the financial and emotional supports available to them at the right times. 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 such as 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. The information would include a comprehensive listing of supports that available to people for example employment leave options, philanthropic funding organisations, financial support available for bereavement counselling.

Irish Hospice Foundation calls on Budget 2023 to make specific funding available for this information service to be developed and delivered.

Priority 4 - Support the public to plan for their end of life - €100,000

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 will also be reinforced by the imminent commencement of the Assisted Decision-Making (Capacity) Act 2015. The Act is about supporting decision-making and maximising a person's capacity to make healthcare (or end of life) decisions.

While the commencement of the Assisted Decision-Making (Capacity) Act 2015 will bring more choice to citizens, it will also present challenges for citizens and legal, health and social care professionals and service providers. When discussing advance care planning, and in the recognition of Advance Healthcare Directives, individuals, carers, and professionals all need guidance and support.

We welcome the commitment to fully commence the Act in the 2020 Programme for Government to "enshrine disability rights by finalising the legislation required following Ireland's recent ratification of the UN Convention on the Rights of People with Disabilities."

From our work in this area Irish Hospice Foundation know that these are not easy topics to think or talk about. Enabling people to have discussions about their future healthcare wishes with families and clinicians' can often avoid difficult decisions later on 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 Irish Hospice Foundation's Think Ahead programme has been guiding people through this process.

Action 12: Initiation of a Register of Advance Healthcare Directives, by the Decision Support Service, as outlined in legislation

We all have a right to be involved in decision-making processes affecting our lives regardless of illness, age, ability or life circumstance. Many people would like to express their preferences for care at end of life and an Advance Healthcare Directive provides them with an opportunity to do this. An Advance Healthcare Directive is currently legal under common law, the Assisted Decision Making (Capacity) Act 2015 enshrines people's right to make a legal Advance Healthcare Directive. However, this Act will not be fully commenced until Summer 2022.

More importantly an Advance Healthcare Directive should be registered in a place that can be easily accessed by all those involved in making decisions about a person's care throughout their life but particularly at end of life. Part 8 of the Act states that the Minister for Health *may* make regulations to provide for the notification of a making of an Advance Healthcare Directive to the Director of the Decision Support Service and for the Director to maintain a register of same. The Decision Support Service have stated that these regulations would enhance the operation of Part 8 and would benefit the person and healthcare professionals.

We are extremely concerned that a number of issues have been identified by the Department of Health which they say are obstacles that must be overcome before these regulations can be written to give the Decision Support Service the authority to set up and maintain a Register of Advance Healthcare Directives. A Register is essential to ensure that citizens can be confident that their Advance Healthcare Directive will be accessible wherever the place and to give certainty to healthcare professionals that they can carry out the patient's expressed wishes.

Action 13: Funding for Think Ahead programme of work 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. To date over 100,000 Think Ahead documents 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 in a position 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 thinking ahead and the Think Ahead tool to individuals facing end of life, public audiences and communities within Ireland – to encourage and enable them to open up conversations and plan for end of life. That this work to date has been solely led by Irish Hospice Foundation, a charity, is no longer acceptable. State investment is needed to allow people to plan for their end of life.

Through funding of €100,000 in Budget 2023 Irish Hospice Foundation would deliver a nationwide public awareness campaign. The awareness campaign would serve two purposes:

1. Provide the Irish public with good quality information about planning ahead and signposting them to resources that can enable them to think about and discuss 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 may not be currently aware of.

Information workshops and resources would be developed and delivered to cover a range of topics including Advance Healthcare Directives, making a will, the Decision Support Service, financial affairs and what happens after you die e.g. funeral and burial arrangements.



Irish Hospice Foundation

To die and grieve well wherever the place

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