

Pre-Budget Submission 2022

Dying, death & bereavement are everyone's business



**Irish
Hospice
Foundation**

To die and grieve well wherever the place

September 2021

Budget 2022 Priorities

“Dying, Death and Bereavement are Everyone’s Business”

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 FOR BUDGET 2022 – INVESTMENT OF €2.4 million IN DYING, DEATH AND BEREAVEMENT

Priorities for Budget 2022

1. Support people to die well at home, if that is their wish and is possible - €500,000
2. Fund improvements in the delivery of person-centred palliative, end-of-life and bereavement care in residential care settings - €1.5 million
3. Investment in bereavement community supports - €250,000
4. Support people to plan for their care at end of life - €150,000

Introduction

This Pre-Budget Submission sets out the need for increased investment in dying, death and bereavement to ensure that these are indeed everyone’s business.

The above priorities are urgently needed in order to provide support for a nation that has been profoundly changed by COVID-19. The pandemic has shown us, perhaps like never before, that dying, death and bereavement – always present - have unavoidably come to the forefront of our collective consciousness.

Investment in the priorities highlighted in this submission will support improvements in palliative and end-of-life care which is a commitment of Government policy. “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 from Irish Hospice Foundation calls on Government to invest €2.4 million in four priority areas to address the key needs of those facing dying, death and bereavement in the wake of COVID-19. This Pre-Budget Submission also sets out the rationale and costing for these priorities.

We remain committed and are ready to work in partnership with Government and in collaboration with other agencies 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

Death is - an inevitable and universal experience – a fact of life. 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
- Less than 1% of the healthcare budget will be spent on Specialist Palliative Care⁴
- The preference of most Irish adults is to die at home⁵ but only 23% will do so⁶
- 43% will die in a hospital and 23% in residential care⁷
- 8% of people will die in a hospice⁸

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

Priority 1 - Support people to die well at home, if that is their wish and is possible - €500,000

Actions required in Budget 2022:

1. Sustained multi annual funding of €500,000 to cover 50% of the nursing costs for the Nurses for Night Care service
2. Engage with Irish Hospice Foundation, and other stakeholders, to explore how more people can be facilitated to die well at home, if that is their wish and is possible
3. Commitment to the roll out of a statutory home care scheme to enable more people to remain, and die well at home, if that is their wish and is possible

Priority 2 – Fund improvements in the delivery of person-centred palliative, end-of-life and bereavement care in residential care settings – €1.5 million

Actions required in Budget 2022:

4. Financial commitment (over five years) to partially fund a partnership programme, aimed at delivering good quality end-of-life care in residential care settings, which is being led by Irish Hospice Foundation in partnership with All-Ireland Institute of Hospice and Palliative Care (AIHPC)

Priority 3 - Investment in bereavement community supports - €250,000

Actions required in Budget 2022:

5. Commitment to co-fund Irish Hospice Foundation's Bereavement Support Line - €75,000

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 Calculation based on 2017 HSE Specialist Palliative Care budget of €76.5m in 2017

⁵ Weafer, J. (2014) Irish attitudes to death, dying and bereavement 2004-2014. Dublin: Irish Hospice Foundation

⁶ Matthews, S., Pierce, M., Hurley, E., O'Brien Green, S., Johnston, B.M., Normand, C. and May, P. (forthcoming in 2021) Dying and death in Ireland: what do we routinely measure and how can we improve? Dublin: Irish Hospice Foundation.

⁷ Ibid

⁸ Ibid

6. Funding for the identification and treatment of more complex / prolonged grief - €75,000
7. Funding for an awareness programme to support people to deal with their grief in the wake of COVID-19 – €100,000

Priority 4 - Support people to plan for their care at end of life - €150,000

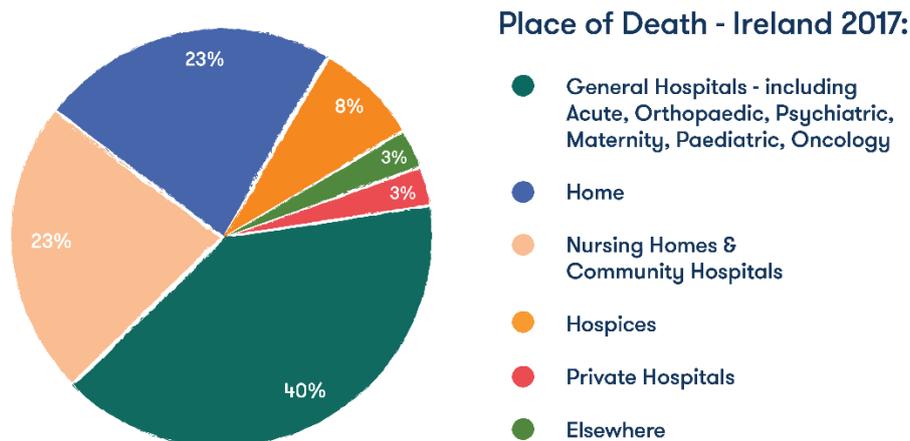
Actions required in Budget 2022:

8. Initiation of a Register of Advance Healthcare Directives, by the Decision Support Service, as outlined in legislation
9. A public awareness campaign “Putting Your House in Order” to encourage and enable Irish people to think, to talk and to plan ahead for their end of life and promote awareness of the Decision Support Service - €100,000
10. Scope, design and disseminate “Think Ahead” for Children and Young People - €50,000

Priority 1 - Support people to die well at home, if that is their wish and possible - €500,000

Overview

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, COVID-19 has strengthened our view that 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. This can be achieved with support from their GP and Primary Care Services, Nurses for Night Care, Specialist Palliative Care community teams and a statutory entitlement to home care.



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

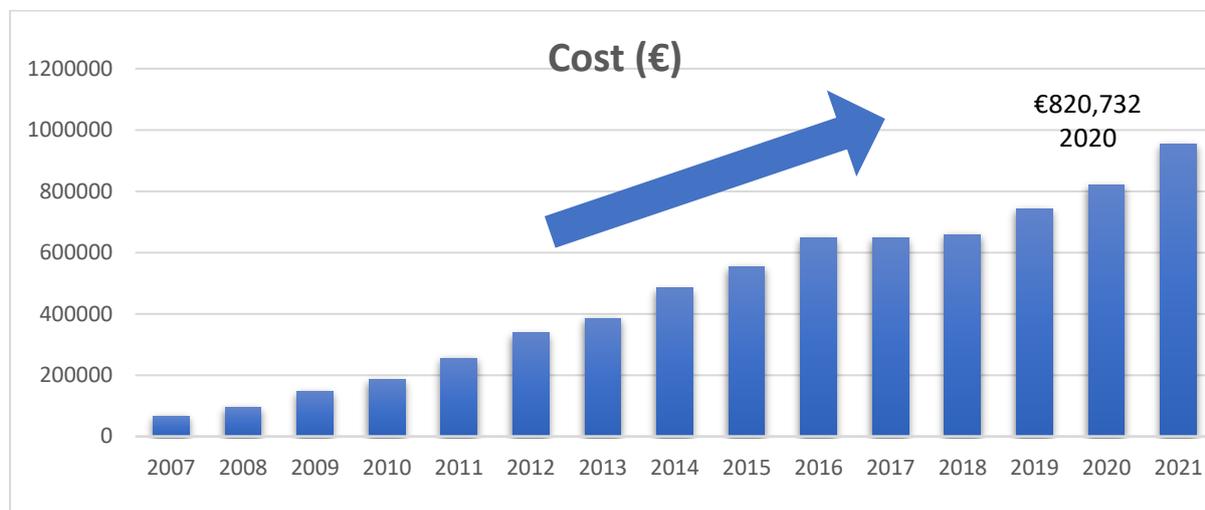
Ireland’s ageing and expanding population will impact on the number of overall deaths. This will require the State to plan for the care of people at end of life. Due to the inevitable constraints on healthcare and hospital bed capacity, part of this demographic increase could be potentially accommodated in the home setting if the right supports are put in place for the person and their family. If planning and investment for this increased demand is not managed, these trends will have the potential to result in a severe, unnecessary and preventable strain on existing healthcare services in Ireland. It is also important to note that both home based care and hospital care lead to a significant strain on family carers and the impact of this needs to be considered as their needs are often very hidden.

Action 1: Sustained multi annual funding of €500,000 to cover 50% of the nursing costs for the Nurses for Night Care service

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 1,080 new referrals in 2020, with over 800 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 €820,732 in 2020. 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 was based on a shared understanding of the value of this service, yet this has still not been achieved.

Commencing this year (2021) recurring funding of €250,000 will be allocated by the HSE to the service on an annual basis. In 2021 an additional €150,000 will be allocated on a once off basis from the HSE. While this funding is greatly welcomed by Irish Hospice Foundation, it falls short of the commitment to fund 50% of the nursing costs made in the HSE Palliative Care Development Framework 2019.

The service will cost an estimated €1,000,000 in 2021. Irish Hospice Foundation has committed to fundraising the remaining shortfall in costs of €600,000. However, relying on fundraising for a vital service such as this is unlikely to be sustainable and this situation that cannot continue.

Multi annual funding of at least 50% (or €500,000) must be committed to in Budget 2022 for the continuation of the delivery of this vital service. Nurses for Night Care gives people the option to die well at home, if that is their wish and should be funded accordingly.

Action 2: Engage with Irish Hospice Foundation, and other stakeholders, to explore how more people can be facilitated to die well at home, if that is their wish and is possible

Sláintecare Strategy & Action Plan 2021-2023 identifies the need to support people to live independently in their own community for as long as possible. The pressures posed by the pandemic on acute services and the emphasis on cocooning and public health messages urging people to remain at home, especially older people and those with life-limiting illnesses, have resulted in a shift towards the delivery of care in the community and in particular, to care in the home. More can be done to facilitate people at end of life to be cared for and to die in their home, if that is their wish and where it is possible. This can and should be a real option for those who choose it and should become part of national health and social care policy.

In Budget 2022, Government need to provide investment to enable dying patients to have a safe and supported discharge home from hospital, if that is their wish and is possible. If we want to give people meaningful end-of-life care then we must invest in the key service providers that can enable this to happen – such as Community Healthcare Networks, mainly the primary care teams involving General Practice (GPs), Specialist Palliative Care community teams, Nurses for Night Care and critically families caring for their loved ones. There is a need to provide specialist training to a greater number of generalists (the term ‘generalist’ refers to health and social care providers who provide a ‘palliative care approach’ or ‘general’ palliative skills) working in the community to meet this growing demand. Investment in Budget 2022 to enhance capacity and skills of primary care professionals providing palliative care is needed to sustain improvements particularly in the areas of care coordination, communication and transitional care.

In this regard, Irish Hospice Foundation proposes to continue its long-standing collaborative work with the HSE and Irish College of General Practitioners aimed at enhancing the capacity of GPs to provide good generalist palliative and end-of-life care. By building the capacity of GPs and facilitating them to use effective methods of communication many unnecessary and distressing emergency hospital admissions will be prevented.

Evidence from literature suggests that most critical factor to supporting a person to die well at home is their family. We cannot expect a person to be facilitated to die well at home without enabling and supporting their loved ones to make this happen. Often, families will have cared for their loved one through long, progressive and life limiting conditions. Frequently families are not equipped or supported to provide that vital end-of-life care and their loved one may not be able die at home, in the place they wish to be and have been cared for throughout. It is also important to acknowledge that not everyone has family available or able to provide care at home to people at their end of life.

Irish Hospice Foundation proposes that in Budget 2022 there is investment in appropriate training and support for family carers to provide them with basic palliative and end-of-life care knowledge to support them to care for their loved one and enable them to die at home.

Action 3: Commitment to the roll out of a statutory home care scheme to enable more people to remain at home towards end of life, if that is their wish and is possible

There is a pressing need for home support services to be sufficiently funded to ensure this is a viable option for older people and their families to remain living at home, in a familiar environment linked to their communities. Many also wish to have the option to die at home. COVID-19 has strengthened the case for appropriate home care and in this regard, the protracted pace of implementation of a statutory home care scheme is of serious concern.

The Sláintecare Implementation Strategy sets out plans to introduce the statutory scheme for home care to support people to live in their own homes by 2021, implementation of this must be given priority. Home care should be viewed as an integral part of the health and social care system and not just a response to the hospital and delayed discharge crisis.

In Budget 2022 we call for significant investment in a Statutory Home Care Scheme that is enshrined in law to meet the highly individualised and complex needs of people requiring care, including at end of life. The current Programme for Government states a commitment to introduce a Statutory Home Care Scheme. The Department of Health must prioritise this and every effort should be made to progress its development without delay.

Priority 2 - Fund improvements in the delivery of person-centred palliative, end-of-life and bereavement care in residential care settings – €1.5 million

Overview

COVID-19 has changed our world, and in particular the residential and nursing home care sector. Irish Hospice Foundation (IHF) have for many years been highlighting, along with our partner organisations, the significant pressures on the nursing home sector due to demographic, staffing and economic factors. However, it has taken the COVID-19 crisis to bring many of these issues into the public and political arena.

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

The COVID-19 crisis has highlighted the considerable number of challenges faced by the sector. However, there is now an opportunity, for all stakeholders, to review the nursing home sector and identify the longer term and immediate changes that are required. The findings of the COVID-19 Nursing Homes Expert Panel are informing these changes. 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*”.

The following sets out IHF’s response to how this Expert Panel recommendation can be implemented, in collaboration with the All-Ireland Institute of Hospice and Palliative Care (AIHPC).

Action 4: Financial commitment (over five years) to partially fund a partnership programme, aimed at delivering good quality end-of-life care in residential care settings, which is led by Irish Hospice Foundation in partnership with All-Ireland Institute of Hospice and Palliative Care (AIHPC)

There are approximately 580 Residential Care Settings RCS (private, voluntary and public) providing an estimated 32,000 places for residents. On average 7,000 deaths take place each year in RCS, this number is anticipated to increase as the population ages and are living with more comorbidities.

The aim of this programme will be to improve the delivery of compassionate, person-centred palliative, end-of-life and bereavement care in the RCS through a nationally-mandated, well-designed, multi-strand, integrated quality improvement programme which will enable all RCS in Ireland to engage at a level appropriate to them.

The programme will be achieved by stimulating, enabling and encouraging settings to develop the systems and cultures to support the provision of such care, and by ensuring that individual staff members are personally equipped to deliver it. The work will be led by a national programme office, and importantly will be supported by regional Palliative, End-of-life and Bereavement care Coordinators (PEBC), one of whom will be based in each of the nine CHO regions. The PEBCs will drive the initiative locally and provide a key point of contact for RCS and specialist palliative care in each region.

Programme Objectives

1. To ensure the delivery of compassionate, person-centred, palliative, end-of-life and bereavement care to residents of RCS, which is appropriate to their needs and wishes;
2. To ensure that families are provided with compassionate support and, subject to the resident's consent, given information before, during, and after the resident's death;
3. To promote and support a compassionate culture within RCS where the delivery of excellence in palliative, end-of-life and bereavement care is a source of pride, and is a valued and recognised part of its day-to-day ethos, work and life;
4. To improve the competence and confidence and resilience of staff in RCS to deliver excellent, compassionate palliative, end-of-life and bereavement care, in particular staff capacity to engage with residents on advance care planning and end-of-life care as per the residents wishes;
5. To play a role in facilitating better two-way communication between the individual residential care setting and the clinical supports for palliative, end-of-life and bereavement care within the community which it needs to access;
6. To establish a robust national and regional infrastructure which will not only facilitate the delivery of the specific supports for this programme, but which will also provide a vehicle for other related palliative, end-of-life and bereavement care initiatives which might otherwise have difficulties penetrating this diverse and geographically dispersed sector;
7. To provide a partnership based governance structure for the programme based on the successful Hospice Friendly Hospitals (HFH) model of oversight engaging with state services, NGOs and residential care ownership, management and staff;
8. To put in place measures to monitor and evaluate the programme through a rolling programme of evaluation.

The programme of work would be aligned and informed by existing work undertaken by IHF and AIIHPC through their CEOL (Compassionate End Of Life) programme and Project ECHO respectively. The programme would also align with the Sláintecare Strategy & Action Plan 2021 – 2023, in particular with Reform Programme 1: Improving Safe, Timely Access to Care and Promoting Health & Wellbeing and Workstream 2: Enhanced Community Care. The Sláintecare plan also commits to progress the implementation of the COVID-19 Nursing Home Expert Panel recommendations which this proposal does.

IHF will be the lead partner for the initiative and is proposing that the programme will cost a minimum of €9.657m over five years. Of this IHF will contribute €2.55m of its own resources, AIIHPC will contribute €0.284m. IHF will seek a philanthropic contribution of €1.0m over the five years (an amount which we are hopeful of attaining). Excluding IHF & AIIHPC contributions, the programme needs an initial set up investment of €0.35m in Budget 2022 as well as the annual running costs of €1.150m per annum for a period of five years.

IHF and AIIHPC will work with the HSE under an agreed Memorandum of Understanding to deliver this work. We want to see the programme take place from 2022 to 2026, with initial pilot programmes taking place in 1-2 regions, prior to the national roll out.

Priority 3 - Investment in bereavement community supports - €250,000

Overview

There is widespread agreement that the current pandemic has made Irish society rethink the way it deals with death and bereavement. The pandemic has left a legacy of complicated and difficult deaths for thousands of Irish people whose loved ones died over the past 18 months. At Irish Hospice Foundation we have seen just how difficult this time has been for people experiencing dying, death and bereavement. This pain will not stop or get easier because restrictions are easing, many people are now vaccinated or the country is “opening up”. No matter what the grief or its cause, we must recognise, that there is more we, as a society, can do to support people experiencing bereavement and invest accordingly in the supports needed.

The daily confrontation with death has also been a catalyst for conversations about grief and the, often, lifelong impact of loss. This has happened at a time when many of the usual social and cultural opportunities to support people who have been bereaved have been unavailable during the COVID-19 crisis.

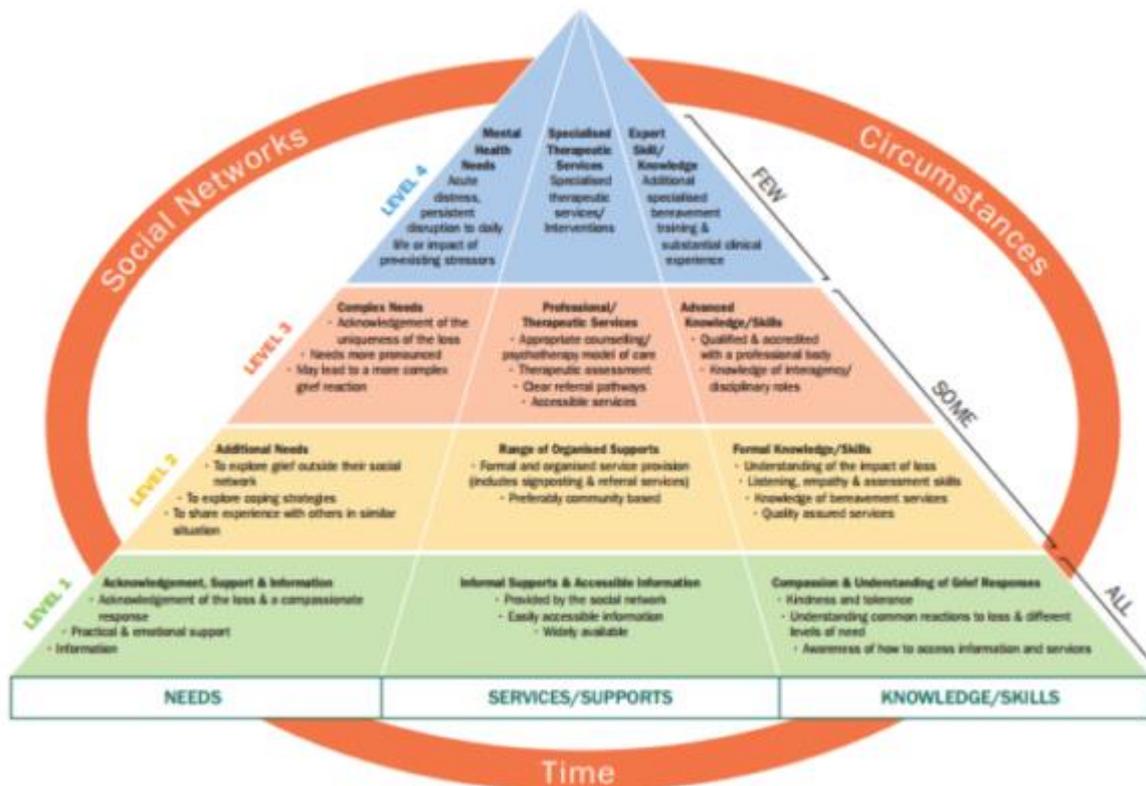
It is estimated that for every death in Ireland approximately ten people are affected. By this calculation 800 people are newly bereaved each day and in a single year 300,000 people experience a bereavement. Bereavement is a universal and painful life experience. Grief affects bereaved people in a myriad 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 rely heavily on social support during and after bereavement. People may also look outside their informal networks for additional support.

For some, grief is more complex and can affect a person’s physical and mental health. How a person dies can lead to more complex grief reactions. It is vital that anyone who is experiencing complex and problematic grief, such as some of those experienced during COVID-19, are identified and have access to appropriate treatment.

In June 2021 Minister of State with responsibility for Older People and Mental Health, Mary Butler, launched the Adult Bereavement Care Pyramid which provides a national framework approach to adult bereavement care in Ireland. This was developed through a national collaborative process facilitated by Irish Hospice Foundation. This tiered framework was developed to guide those working and supporting bereaved people.

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).

Communities need to be supported to respond appropriately to those experiencing grief and loss at each of these levels. The COVID-19 crisis reinforces the need to engage in effective public health education around bereavement and coping with grief, to empower and encourage communities to play their role in supporting bereaved people. This public health education must have associated investment to build professional supports for those in need.



Adult Bereavement Care Pyramid, Irish Hospice Foundation (2020)

Action 5: Commitment to co-fund Irish Hospice Foundation's Bereavement Support Line - €75,000

As noted, people process grief in their own unique way, influenced by a complex mix of factors. The experience of COVID-19, and the restrictions it has brought about, have impacted on people's experiences of grief. This may result in an increase in the proportion of people who need to have access to more formal supports and those who require professional help or counselling. The newly-established Irish Hospice Foundation Bereavement Support Line, in partnership with the HSE, helps to address some of the additional needs people will have in the community.

This service, developed during the pandemic crisis, is meeting a very real and continuing need for those who are bereaved. The Bereavement Support Line to date has taken over 1,600 calls, not only from people who have been recently bereaved during COVID-19 but also from those who were bereaved before the pandemic. This highlights that currently the bereavement support needs of people in Ireland are not exclusive to those who experienced the death of a loved one during the pandemic. The Bereavement Support Line 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 are seeking state funding of €75,000 to co-fund this service to ensure that we can continue to meet the needs of people who are bereaved. We want to ensure that the public is aware of this vital service at a time when they may need it most. This funding would enable us to raise public awareness about the Bereavement Support Line. We want to ensure that we can meet the enduring needs of people who have been bereaved long after the immediate impact of COVID-19 has faded.



Action 6: Funding for the identification and treatment of more complex / prolonged grief - €75,000

The adult bereavement care pyramid shows that people at levels 3 and 4 will have more complex and pronounced needs. A significant minority of people (10%) will develop Prolonged Grief Disorder (PGD), where their lives are seriously disrupted in an enduring way due to the death of someone close to them. The professional, therapeutic and specialised help needed must be available in a consistent and accessible way to those who require it.

To date, PGD is not recognised in Irish mental health policy and the staff in mental health services are currently not sufficiently trained or resourced to diagnose and support those with PGD. Yet, there is growing consensus that grief can become a more serious problem. In 2018, PGD was included in the International Classification of Diseases (ICD-11) and is likely to be adopted in the upcoming edition of the Diagnostic and Statistical Manual of Mental Disorder (DSM-5).

While the impact of COVID-19 is not yet fully understood, available research suggests that the proportion of people bereaved during the pandemic who will develop PGD could be high as 25%. Therefore, it is likely we will see a rise in the numbers experiencing prolonged or complicated grief as a result of death experienced during COVID-19.

This anticipated increase in the numbers experiencing PGD will bring an increased demand for highly skilled professionals and services to meet people's complex needs. In Budget 2022, Irish Hospice Foundation calls for an initial commitment of €75k to commence a national training programme on PGD for clinicians. This training will provide clinicians with the skills to support a proportion of those who will remain traumatised and severely impacted by their grief. 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/complicated grief. Another key element would be a train the trainer programme in identification of grief complications and appropriate therapeutic interventions.

Aligned to this, in response to the COVID-19 pandemic, key stakeholders from across the HSE came together to develop a detailed framework, focused on the psychosocial impact of the public health emergency. A report, titled the "*HSE Psychosocial Response to the Covid-19 Pandemic*" (2020), was produced. The report provides detailed guidance and direction for HSE leadership, staff and partners on implementing a psychosocial response to the pandemic, based on a layered care framework of support. The psychosocial framework takes a population-wide approach, but specifically recognises the needs of those at levels 3 and 4, to ensure access to specialist mental health services for those who may need them.

The funding being called for in Budget 2022 for the national training programme for clinicians should be targeted at HSE specialist mental health services in community settings e.g. through General Adult Community Mental Health services, CAMHS and other specialist mental health services. This funding would enable the HSE Psychosocial Response to deliver some of the recommendations set out in the report.

Action 7: An awareness programme to support people to deal with their grief in the wake of COVID-19 – €100,000

It has been noted that bereavement is a very unique experience. The adult bereavement care pyramid shows that most people who are bereaved will adapt to their loss with level 1 support by acknowledgement of the loss and a compassionate response from family, friends, professionals and the wider community. Practical and emotional support is also helpful. People will need information such as how to register a death; information about the various reactions to loss including emotional reactions and information about more formal supports/services available.

However, many of the practical supports and acknowledgments of loss that people normally have access to have been seriously eroded due to COVID-19. Families have been isolated from one another, visiting restricted, funeral rituals and attendance severely limited and spontaneous social support compromised. Where a loved one dies with COVID-19, even more severe restrictions came into play and many of these deaths could be classed as unexpected, sudden and / or complex. It is more important than ever that we ensure the general public and key stakeholders are aware of the bereavement supports and services which are available.

Bereavement services are also reporting increased demand and longer waiting lists, having observed a lull through the initial phases of the pandemic (Irish Hospice Foundation, 'National Bereavement Support Service Survey - The impact and challenges of COVID-19', 2021).

Bereavement support in Ireland is generally provided by a wide range of organisations including voluntary and community or self-help groups, the health system (primary care teams, counsellors, hospitals, hospices and mental health services) and the private sector which includes private counsellors and psychotherapists. As noted in the '*Enhancing Adult Bereavement Care Across Ireland*' 2018 report, these services are often not coordinated through an agreed approach and can be relatively fragmented and patchy in their geographical coverage.

It is now timely that Budget 2022 invests €100k in a national bereavement awareness programme to ensure that the public has 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 lead the development of a national response to grief and bereavement. Irish Hospice Foundation want to co-fund this national bereavement awareness programme but require some state funding to provide visibility, stability and magnify the reach of the programme.

This investment of €100k would help deliver some of the recommendations set out in the HSE Psychosocial Response to the COVID-19 Pandemic Report 2020. This report recognises the need to provide reassurance, promote positive messaging and signpost people to support at a population-wide level. The report highlights that for the population at level 1 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.

Priority 4 - Support people to plan for their care at end of life - €150,000

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 the end of life.

From our work in this area Irish Hospice Foundation know that these are not easy topics to think or talk about. By enabling people to have these discussions with their families and clinicians' before they are needed can ensure difficult decisions that may arise later on about what the person would have wanted can be avoided. For many years Irish Hospice Foundation's Think Ahead programme has been guiding people through this process.

The importance of planning ahead will also be reinforced by the planned commencement of the Assisted Decision-Making (Capacity) Act 2015 in Summer 2022. The Act is about supporting decision-making and maximising a person's capacity to make decisions. Although, the Act was signed into law on the 30th December 2015 it has not yet been fully commenced.

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 the legal, health and social care professionals and service providers when faced with Advance Care Planning and also in the further recognition of the role of Advance Healthcare Directives.

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."*

Finally, with medical and technological advances, the number of children living longer with life-limiting conditions is increasing every year. The complexity of caring for these children is also increasing. There is an identified need for a tool that enables children, their families and their health care professionals to engage in conversations about the child's current and future life, but also a means to record the conversation and share their story.

Action 8: 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 has not fully commenced.

More importantly an Advance Healthcare Directive must 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.

However, 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 9: A public awareness campaign "Putting Your House in Order" to encourage and enable Irish people to think, to talk and to plan ahead for their end of life and promote awareness of the Decision Support Service - €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 is solely led by a charity is no longer acceptable. State investment is needed to allow people plan for their end of life.

Through funding of €100,000 in Budget 2022 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 'putting their house in order' 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.

Action 10: Scope, design and disseminate "Think Ahead" for Children and Young People - €50,000

Children with life-limiting conditions and their families also have a need to record their story and consider their wishes for the child's future in a calm and considered way, while they can. Completing a 'Think Ahead' document allows parents and sometimes the child to do this with the aim of avoiding such conversations being discussed in a stressful hospital environment when the child deteriorates and becomes unwell.

The need for this document has been identified through the use of a draft 'advance care plan' document by families in Crumlin and Temple Street hospitals. Think Ahead for Children and Young People will allow for the recording of discussions on treatment, illness, and prognosis, placing the child and family firmly at the centre of the planning. Like Think Ahead, it will focus on living but will include a section on dying and after death.

Think Ahead for Children and Young People will provide a framework for professionals working within paediatrics, including paediatricians and palliative care consultants, on which to base their conversations about the child's future with families. It will prepare them and prompt them to engage in such conversations.

We estimate that 350 children per year, their parents, siblings, extended families and friends will directly benefit from using Think Ahead for Children and Young People. There are a further 8,000 children in Ireland who have life limiting illness, that may want to access it. Think Ahead for Children and Young People will extend beyond medical goals of care and promote ongoing conversations about life and death with parents and children well before a child becomes critically ill. With the funding of €50,000, Irish Hospice Foundation, working in collaboration with a team of key stakeholders, will develop and disseminate a child and family centred document that is easy to read, colourful and user friendly.



Irish Hospice Foundation

To die and grieve well wherever the place

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