



# **COVID-19 WHAT WE HAVE LEARNT**

## **May 2020**

**A BEST PRACTICE POLICY FRAMEWORK FOR DYING, DEATH AND  
BEREAVEMENT**

**Prepared by the Irish Hospice Foundation**



CHY 6830  
Registered Charity Number 20013554

## **FOREWORD**

**Every death matters – and we only have one chance to get it right.**

Many of the experiences of dying, death and bereavement during the COVID-19 pandemic have fallen short of the expressed wishes of the Irish people in relation to what they want for themselves or their loved ones at end-of-life.

While under the shadow of COVID in the months, perhaps years, to come, we as a society owe it to each and every person dying, and to those who love them, to enable them to have the best possible death while taking into account the infection control measures needed.

Crises bring with them opportunities. So let us seize this opportunity to significantly improve the experience of death, dying and bereavement in post - COVID-19 Ireland. Now is the time we need to start discussing and planning.

We are all part of this. Dying is everyone's business.

**Jean Callanan | Chair.  
The Irish Hospice Foundation.**

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**May 19<sup>th</sup>, 2020**



## The People's Charter on Dying, Death & Bereavement in Ireland



Prepared by the IHF from inputs of 3000 people of Ireland

### I want to live and die in an Ireland where:

Death is talked about and not hidden away.

I can prepare for what lies ahead.

I can get relief from pain, no matter where I am being cared for or what condition I have.

I am treated as an individual and my wishes, choices and beliefs are respected.

I, and the people who care for me can get the practical services and support that we need.

I can get information to understand what is happening to me.

I can die, surrounded by the people I love, in a calm and comfortable place, in my home, if at all possible.

I am supported to stay in control of my own decisions.

My dignity is respected and maintained to the end of my life, and after my death.



### For the people who matter to me, I want Ireland to be a country where:

People understand grief and do not avoid thinking or talking about it.

Family and friends are supported during a loved one's illness and after their death.

People get space and time to grieve, talk and remember.



[www.hospicefoundation.ie](http://www.hospicefoundation.ie)

## Introduction

The COVID-19 crisis has brought into sharp focus issues relating to death, dying, care, loss and bereavement. The Irish Hospice Foundation (IHF) has long advocated for a more strategic approach to these issues and believes that, in post COVID-19 society, there is a significant opportunity to equip all of our State services – including health and social care - to meet the challenges presented by the aftermath of this pandemic.

Each year approximately 30,000 people die in Ireland and over a quarter of a million are bereaved. Ireland's population is ageing, with more people aged 65 and over. It is projected that the number of annual deaths in Ireland is set to rise to approximately 38,000 in 2030, a 25% increase. It is inevitable that these demographic trends will lead not only to an increased demand for end-of-life care services and increased deaths in all settings - acute, community and residential – but will also have a greater societal impact.

The Irish Hospice Foundation is the only national organisation dedicated to dying, death and bereavement in Ireland. Our mission is to strive for the best end-of- life and bereavement care for all. Our vision is that no-one should face death or bereavement without the care and support they need.

This vision is derived from *the People's Charter on Dying, Death and Bereavement*, which was developed by the IHF in response to nearly 3,000 submissions from the Irish public (<https://hospicefoundation.ie/haveyoursay/charter-death-dying-bereavement>). The Charter gives us a blueprint as to how to achieve the best end-of -life and bereavement care for all in Ireland (see appendix 1).

Death is an inevitable and universal experience with grief as our common ground. In pre-pandemic times, in the reality of our everyday lives - serious illness, care, dying, death, loss and bereavement occur – sometimes without warning. Despite the universal certainty of death and loss, the issues they presented have always challenged us – as individual citizens and as a State. It really is true that **dying is everyone's business**, not just because of our common mortality and bereavement.

This pandemic and the unavoidable response to it has shown us – painfully - that dying, death and loss are collective responsibilities we share, across all sectors and in all communities. The challenge is all the more demanding in current circumstances. Sadly, each and every one of us will be collectively and individually directly impacted by the effects of death and dying in these extraordinary circumstances. These will include the families and friends of those who are facing death or have died. They in turn are public servants and private citizens, employers and employees, colleagues, parents and children, teachers and students, healthcare workers and patients, carers and those who are cared for, older and younger people. The effects are cross-sectoral and inter-generational.

The difficulties are compounded in present times by the essential limitations on visiting and being present with loved ones approaching death and at funerals, the increased burden on those in health and social care who have to step into the breach, and those who have to grieve alone without those societal supports which normally provide such comfort.

The IHF have already written to the Minister for Health, NEPHET and associated stakeholders outlining our immediate recommendations for more compassionate care at end of life to include

avoidance of any person dying alone, visiting guidance, guidance for funerals, the use of PPE and subsequent isolation. These communications are contained in appendix 1.

Since COVID-19 has presented us with whole-society difficulties, it is essential that a whole of Government response is framed. We believe that the Department of Health's role in determining national older persons & palliative care policy is critical, and in particular the refreshed national policy on palliative care, currently under development, will be very welcome. However wider policy on services and supports for the whole Irish population has been impacted by COVID-19, and how we respond to dying, death and bereavement in the future. All departments of State have their roles to play.

**The COVID-19 pandemic has challenged how we, as a nation, address and confront dying, death and bereavement. We now have a responsibility to shape how we respond in the future. One of the main challenges will be to create this whole of government response – to coordinate, replicate, progress and embed innovative, evidence-based solutions to issues which arise in care of the dying and the bereaved, whether these solutions are provided by the statutory or voluntary sector. There is no time to be lost in planning and shaping future services and response.**

What does this mean for future policy making?

1. It means we must frame a whole-society, whole of Government strategy on dying, death and bereavement, taking into account end-of-life care in health and social care, but encompassing all of the non-health aspects of state services and society.
2. It means encouraging, enabling and supporting our citizens to engage with end-of-life issues and to reflect on how COVID-19 has shaped us regarding dying, death and bereavement
3. It means ensuring people can have a loved one with them as they die.
4. It means recognising the impact of bereavement as a consequence of COVID-19 and supporting individuals and communities in responding to this at work and at home, individually and collectively in practice and in policy.
5. It means prolonged grief and complex bereavement are acknowledged within Mental Health policy and that the mental health services are trained and resourced to identify and respond to these.
6. It means securing the future of excellent, equitable and comprehensive palliative care and hospice services throughout the country in all care settings and for all conditions.
7. It means embedding first-class end-of-life and bereavement care practices in our nursing homes and supporting staff in providing that care.
8. It means sustainably funding end-of-life services in community and primary care to further support people who wish to die at home.
9. It means bringing into full effect the Assisted Decision-Making (Capacity) Act which provides for Advance Healthcare Directives, including the need to support planning ahead for end-of-life.
10. It means providing dignified and appropriate spaces for the dying and those who grieve for them in our hospitals and recognizing that mortuaries in our public hospitals are places which invoke feelings of respect and reverence for the dead and the bereaved and are safe working spaces.

The purpose of this document is to reflect on the implications of COVID-19 on end-of-life issues from the experience and expertise of the IHF. We are well equipped to assist in the process of development of a new and robust strategy taking into consideration the views of the public and the

State, as well as those dealing professionally with end-of-life in all care settings, in palliative and bereavement care.

In this document we set out seven policy pillars to shape a new and informed approach to policy.

## Seven Policy Pillars

1. The Development of a 'Whole of Government' Strategy to End - of - Life Care
2. Starting a Renewed National Dialogue on Dying, Death and Bereavement
3. Forward Planning for Emergent Needs and Community Supports
4. Establishment of a Programme of Work to Improve End-of- Life and Palliative Care in Nursing Homes
5. Enabling More People to Die in Their Home or Place of Preference
6. Facilitating Dialogue and Planning for End - of - Life
7. Introducing a New National Mortuaries Programme

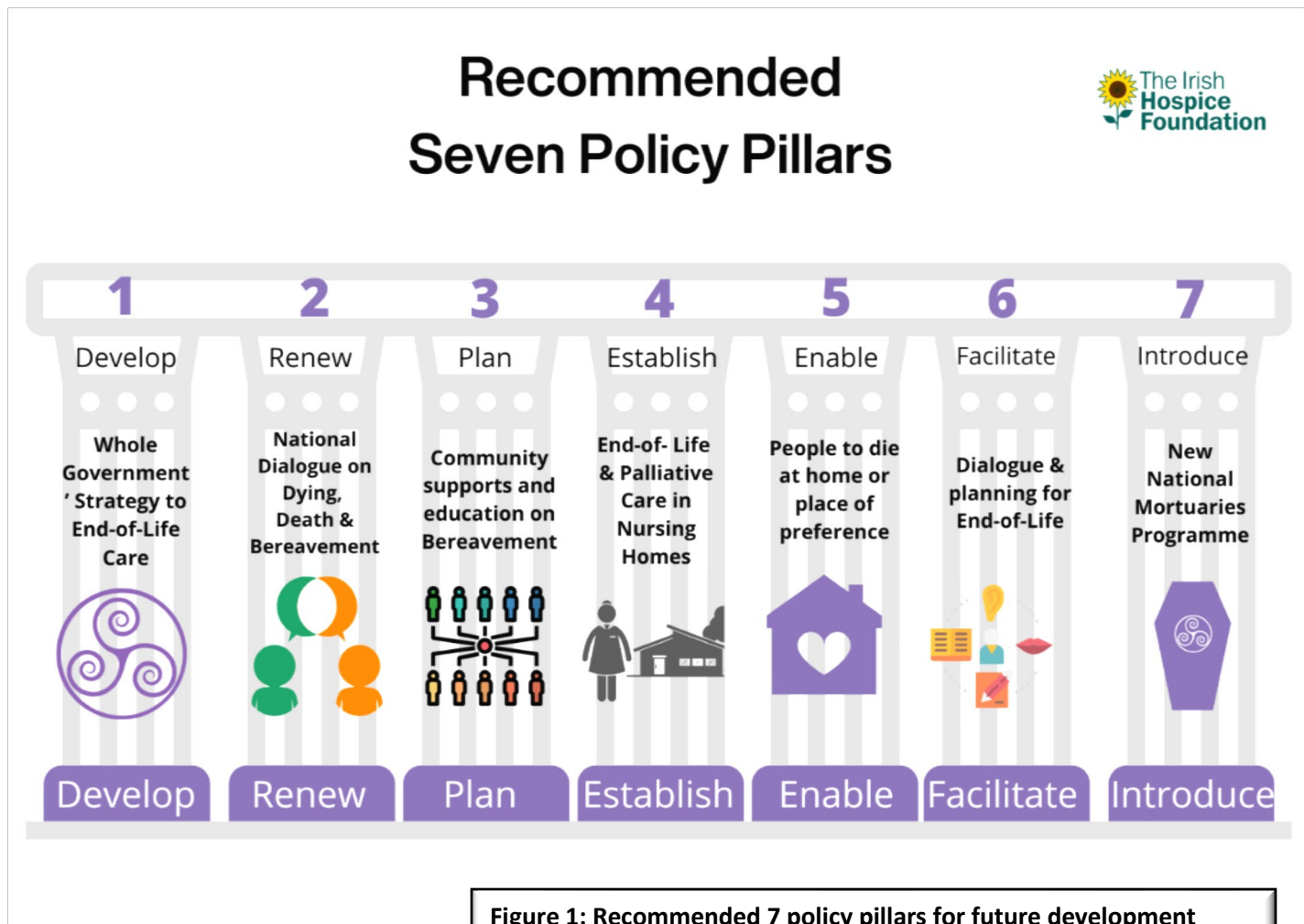


Figure 1: Recommended 7 policy pillars for future development

## Table 1: The Irish Hospice Foundation – Contributions to Debate

The Irish Hospice Foundation has a long history in facilitating debate on dying, death and bereavement in Ireland.

Some key steps on this journey are set out below.

- Publication of seminal research reports on specialist palliative care including a baseline
- Survey 'A Palliative Care Needs Assessment for Children', a national needs assessment for children's palliative care in 2006
- Publication of the first ever 'National Audit of End-of-Life Care in Hospitals in Ireland' (2010)
- Creation of the first ever National Forum on End-of-life in Ireland, led by President Mary McAleese and resulting in the report entitled 'Perspectives on End-of-life; Report of The Forum 2009' <https://hospicefoundation.ie/programmes/public-awareness/forum-on-end-of-life-useful-publications/>
- Facilitation of the work of the Council of the Forum on End-of-life: 2010-2016 chaired by former Supreme Court Judge, Mrs. Justice Catherine McGuinness.
- Hosting of 6 national biennial Forum on End-of-life in Ireland Conferences between 2009 and 2019 with national and international speakers and delegates.
- Support for series of public hearings and report on end-of-life care before the Oireachtas Joint Committee on Health and Children, chaired by then Deputy Jerry Buttimer in October 2013 which recommended an end-of-life strategy including health and non-health sectors.
- Commissioning or supporting research studies on dying, death and bereavement including Amarach Research (2011), Weafer (2014), O'Donnell (2015 and 2017), McLoughlin (2018) and IHF (2019).
- Support for Marie Louise O'Donnell in the completion of two reports - Finite Lives Part 1 – How the State deals with dying, death and bereavement among its own employees and Finite Lives 2 – Dying, Death and Bereavement: An examination of State Services in Ireland (2017). All available on <https://hospicefoundation.ie/welcoming-finite-lives-report/>

## 1.0 The Development of a ‘Whole of Government’ strategy on End-Of-Life-care

Our health and wellbeing are intimately bound up with the State and its services, as well as wider society. So too is dying, death and bereavement. The State has no power to take away death. But what we as citizens can legitimately expect, is that the State equips us to cope with the myriad of practical, social and emotional issues that present before, during and after a death.

The response to the recent pandemic has been driven by a public health approach with the health and safety of the population being given priority. This has, of course, has the greatest effect on the health services and ensuring that it is equipped to deal with the increased influx of people infected by COVID 19. It has also affected the delivery of other public services and all aspects of people’s lives – education, employment, transport, leisure, access to services, commerce and religious practice. Since these are whole-society difficulties, it is essential that a whole of Government response is framed. When the pandemic has subsided, we may well live in its shadow for many months and years to come. How we as a nation post COVID-19, respond to dying death and bereavement is critical.

The IHF has long advocated that strategic, better coordinated end-of-life and bereavement care can make a real difference to both the quality of health and social care provided to the patient and will better support and equip the health professionals and care staff. However, these issues cannot be neatly packaged and handed over to the health services as their sole remit. All departments of State have their roles to play.

In 2017, two cross departmental studies completed by Senator Marie O’Donnell<sup>1</sup>, produced a ground-breaking evidence for a more co-ordinated and strategic approach to dying, death and bereavement by all of the agencies and Departments of State. The primary recommendation of the second report Finite Lives was that **the State should develop a whole-of-Government strategy on end-of-life care, which is wider than healthcare and extends into bereavement.** Her work shows the breadth of involvement of the many agencies state outside of the health services not only in the lives of citizens, but also in their deaths and their grief. The reports also recommend practical changes to each Government Department or Agency to improve their response.

The role of the health services is critical and the IHF welcomes the promised development of a refreshed **national policy on palliative care**, currently under development. The palliative care programme model of care can also inform future delivery of palliative and end-of-life care. This will underpin the provision of palliative care services all over Ireland.

### What needs to happen post crisis COVID-19 phase?

In our recent research, 69% of the population now feel that COVID-19 has made Irish Society rethink the way it deals with death and bereavement. (IHF, 2020). There has never been a more opportune time to talk and think about how we deal with dying, death and bereavement.

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<sup>1</sup> Senator Marie Louise O’Donnell produced two ground-breaking reports – Finite Lives Part 1 – How the State deals with dying, death and bereavement among its own employees and Finite Lives 2 – Dying, Death and Bereavement: An examination of State Services in Ireland. All available on <https://hospicefoundation.ie/welcoming-finite-lives-report/>



**We would strongly advise that the state should develop a post COVID-19 End-of-life and bereavement strategy to cover all aspects of dying, death and bereavement in Ireland.** This should include appropriate health and social care provision in all care settings. It should take into consideration best models of healthcare including the recently developed palliative care model of care. This strategy should be multi-sectoral, supported by all Departments and Agencies of State since dying, death and bereavement affect all aspects of people's lives and the State should take a lead role to drive change across all sectors. The newly established COVID-19 committee is well placed to lead this work.

This is an opportunity not to be missed. It will be very important for the State to reflect upon, and learn from, COVID-19 as they relate to quality of life, dying and bereavement. Such an initiative would position the State as listening and responsive as well as providing a platform for discussion on the wider aspects of dying death and bereavement.

## 2.0 Starting a Renewed National Dialogue on Dying, Death and Bereavement

In 2016, we remembered Ireland's achievements over the previous century. At that time The Irish Hospice Foundation asked the Irish public, in the spirit of the Government's declaration to "*remember, reflect and re-imagine*", to remember and reflect on their experiences of death and bereavement and to re-imagine what living, dying and grieving in Ireland could be like. The expressed wishes of 3,000 people are distilled into the People's Charter on Dying Death and Bereavement in Ireland (see appendix 2). The IHF's mandate and mission is to make these aspirations a reality.

People told us they want to live and die in an Ireland where death is talked about and not hidden away; addressing the age old 'death denial' experience by society. They noted want to be pain-free – speaking to the need to excellent palliative and end-of-life care services; Equally they want to be treated with and die with dignity; they want to be secure in the knowledge their wishes will be respected; they want to feel comfortable and cared for, ideally at home; to have access to good services and information and to know their grieving loved ones will be supported after their death.

In COVID-19 Ireland, many of those aspirations have become vain hopes as necessary public health restrictions were and are in force. People are necessarily separated from those they love and many who love and care for them. We know that people died alone. We know that there is an increased burden on health and social care staff who step into the breach left by the restriction on visiting, and that they themselves are often overwhelmed by both the circumstances and the scale of the deaths and grief. We know that many people are unable to attend the funeral or take part in other rites or rituals. Coupled with social distancing prevents even the comforting hugs of family members. Many people have had to start their grief journey alone without those societal supports which normally provide such comfort. These censures have affected all deaths from COVID-19 and non-COVID-19 causes. Many live with the fear of death, with the isolation, with the terror of dying alone or of loved ones dying alone and unprepared.

Those who deal with death as part of their professional lives may also be struggling with grief and fear in their personal lives.

Through COVID-19, death and its aftermath are to the fore in all of our lives. The post COVID-19 period will require us to listen, to reflect, to reimagine. Framing the narrative surrounding dying, death, loss, care and grief can inform future policy. It can also perhaps more importantly, allow for a sensitive period of national healing and open discussion of previously taboo subjects.

### **What needs to happen post crisis COVID-19 phase?**

There is room for Irish citizens to experience the government as compassionate and enabling a dignified process of death through a process of active consultation and reflection. This dialogue should be informed by consultation with the people of Ireland, together with creative thinking. The questions might include;

- How do we frame national reflection and debate on how to commemorate all who have died in recent months?
- How do we collectively commemorate? Do we need a national remembrance event?
- Consulting with those impacted by COVID-19 – what does a good death and good grief look like in this new normal?
- How do we include marginalised communities, especially communities affected by poverty and isolation?
- Can we include organisations at national and local level, linking with local authorities and service providers, mutual aid groups and local resilience forums?
- How do we support health and social care workers, first responders, paramedics, the Gardai, ancillary staff in the health services, teachers and others dealing with the fallout from their own grief and stress in their day to day work?

Critically, this debate should encourage people to have important conversations with those they love about their wishes for end-of-life. The IHF, through our many years of experience would be privileged to work with other stakeholders in this area to reflect on our capacity to grieve and management bereavement.

### **Table 2: Results from Irish Hospice Foundation Research on Attitudes to Bereavement** (Commissioned by IHF, May 2020; Research completed by Behaviours and Attitudes; available on request.)

**In preparing this submission, we asked the Irish people to reflect on dying, death and bereavement in these extraordinary times; The survey, conducted by B&A for the IHF shows:**

- **68% agree the current pandemic has made Irish Society rethink the way it deals with death and bereavement;**
- **10% think we talk too much about death, while 34% think we don't talk about it enough;**
- **89% say that being together with extended family and friends is a key part of the grieving process;**
- **55% of people say they struggle to know what to say to someone who is bereaved or to know how to support them (this rises to 77% among those under 34 years of age);**
- **29% believe there are not enough supports available in Ireland for those who have been bereaved – with 27% believing there are enough such supports.**

## 3.0 Planning for Emergent Needs and Community Supports for Bereavement

**Understanding how grief impacts on Irish adults and children in the intermediate and long-term is an issue of national importance as planning will be required to meet emergent needs and to support our communities.** The COVID-19 pandemic is characterised by a range of loss experiences, including loss of certainty, loss of freedom, loss of physical family contact and loss of financial stability for some. We know that, pre COVID-19, an average of 80 people died each day in Ireland. We know that the number of deaths has increased, and a proportion of bereaved people will have had a relative or friend die with COVID-19.

The restrictions around visiting, being unable to be physically present with a dying person, the reduction or cessation of wakes and funerals and the consequent grieving in isolation which the response to the pandemic have caused has resulted in suffering for many individuals and families. Reports and first-hand accounts of bereaved people's experiences means our communities are more sensitised than ever before to the needs of grieving people and the core role of social support. How these experiences will impact on Irish adults and children in the intermediate and long term is an issue of national importance as planning will be required to meet emergent needs.

### Building on evidence

The COVID-19 experience is a unique and ongoing one, for other countries as well as for Ireland. The research literature on consequences of bereavement in epidemic, in disaster situations and the impacts of isolation is relatively small but straddles both trauma and grief. This research will inform future planning. The evidence base for bereavement care has strengthened and over the past 2 years, the IHF has led the Irish bereavement sector (a

mixture of statutory and voluntary providers under the National Bereavement Forum) to discuss and ultimately agree and develop the national **Bereavement Model of Care**. This model identifies four types of bereavement needs and indicated appropriate bereavement care being provided over 4 levels; ranging from informal supports at level 1 to specialist therapeutic supports at level 4. The diagram below illustrates the Adult Bereavement Care Pyramid. A similar model has already been adopted for children's bereavement care in Ireland. These model remains relevant for planning short-term and more long-term responses and services to meet bereaved people's needs in a COVID and post-COVID-19 Ireland.

### Responding to Need

Both bereavement and trauma research strands shows us that **the majority of people can and do cope with difficult and complicated losses over time**. Most people require and rely heavily on social support during and after bereavement and sometimes we look outside our circle for additional support (level 1 of the pyramid). We therefore need to support communities to respond well to those in grief and loss and to work with those who are directly reaching communities. However, our recent research into attitudes to bereavement (Table 2) confirm that many people find bereavement hard – with over a half noting they struggle what to say to someone who is bereavement (IHF, 2020). **Given our sensitised communities, we now have an opportunity to engage in effective public health education around grief and coping with grief. We have a great opportunity to empower and encourage everyone in the community to play their role in supporting bereaved people.**

We know that bereaved people process their grief in their own unique way. Bereavement experience and outcomes are influenced by many factors. We know parental grief or sudden death can pose particular challenges. The experience of COVID-19 itself, and the restrictions it has brought

about, will impact of grief. We believe it will result in an increase in the proportion of people who may need organised level 2 supports and the proportion who require professional help or counselling at level 3 or 4. In our recent research, only 27% of the Irish population say there are enough supports available for people who have been bereaved (Table 2, IHF 2020) **Post COVID-19, an estimation of that prevalence will be required, as will an assessment of the capacity of voluntary, psychosocial, counselling and mental health services to meet need in an appropriate and evidence-based way – at level 2,3 and 4. This work needs to inform future mental health policy.**

For those with additional needs (level 2), services are provided generally through the community and voluntary sectors, the services are generally face-to-face. Even prior to COVID-19, many of the local and national organisations have been stretched to continue their supports. COVID-19 has challenged all services. **A coherent plan for bereavement care into 2020-2023 will necessitate a review of resources required to maintain and grow, to standards, these important peer-based and community services.**

The professional, therapeutic and specialised help indicated at higher levels of the pyramid need to be available in a consistent and accessible way to those who require them, over time. We have a growing consensus about when grief becomes a more serious problem. In 2018 **'Prolonged Grief Disorder (PGD)'** was noted 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). Of interest, there are now proven therapies for the minority (10%) that develop Prolonged Grief one of which has recently been introduced in Ireland through the Complicated Grief programme at IHF.

Prevalence of PGD in a bereaved population is generally estimated at approximately 10%. We don't yet know the impact of COVID-19 but available research involving people bereaved through disaster (e.g. airplane crashes, earthquake/ natural disaster) has shown the proportion of prolonged grief disorder could be high as 25%. One of our main concerns is that we may see a rise in prolonged or complicated grief as a result of how people died through the 'experience' of COVID-19 and we are concerned that the mental health system is not adequately resourced and prepared. To date, PGD it is not recognised in mental health policy and the mental health services are currently not sufficiently trained or resourced to diagnose and support those with PGD. Future mental health policy needs to address bereavement through evidence-based approaches.

### **The special case of children and bereavement during COVID-19**

One of the first principles of caring for bereaved children is to ensure that those around them, their trusted adults, are having their own bereavement needs met and are in a position to listen, to respond and to comfort children honestly and openly. To date many services have been underfunded and have had to operate long waiting lists. Through our work with Irish Childhood Bereavement Network (ICBN), we call for development in children's bereavement services in partnership with the ICBN and the IHF.

### **What needs to happen post crisis COVID-19 phase?**

Given the extensive experience of grief through COVID-19, we now need to:

- Recognise, bereavement, prolonged grief/complex bereavement within Mental Health policy and that the mental health services are trained and resourced to identify and respond to these.
- Engage in effective public health education around grief and coping with grief.

- Estimate current and future bereavement needs post COVID-19 and in particular the need to services to support prolonged grief disorder.
- Consider how the bereavement needs of children are addressed and resources.
- Develop a coherent plan for bereavement care into 2020-2023 will necessitate a review of resources required to maintain and grow, to standards, these important peer-based and community services.

Post COVID-19, Ireland will welcome a national debate as to how best meet bereavement needs of the population over time. The IHF are willing to assist in facilitating this discussion.

## Adult Bereavement Care Pyramid

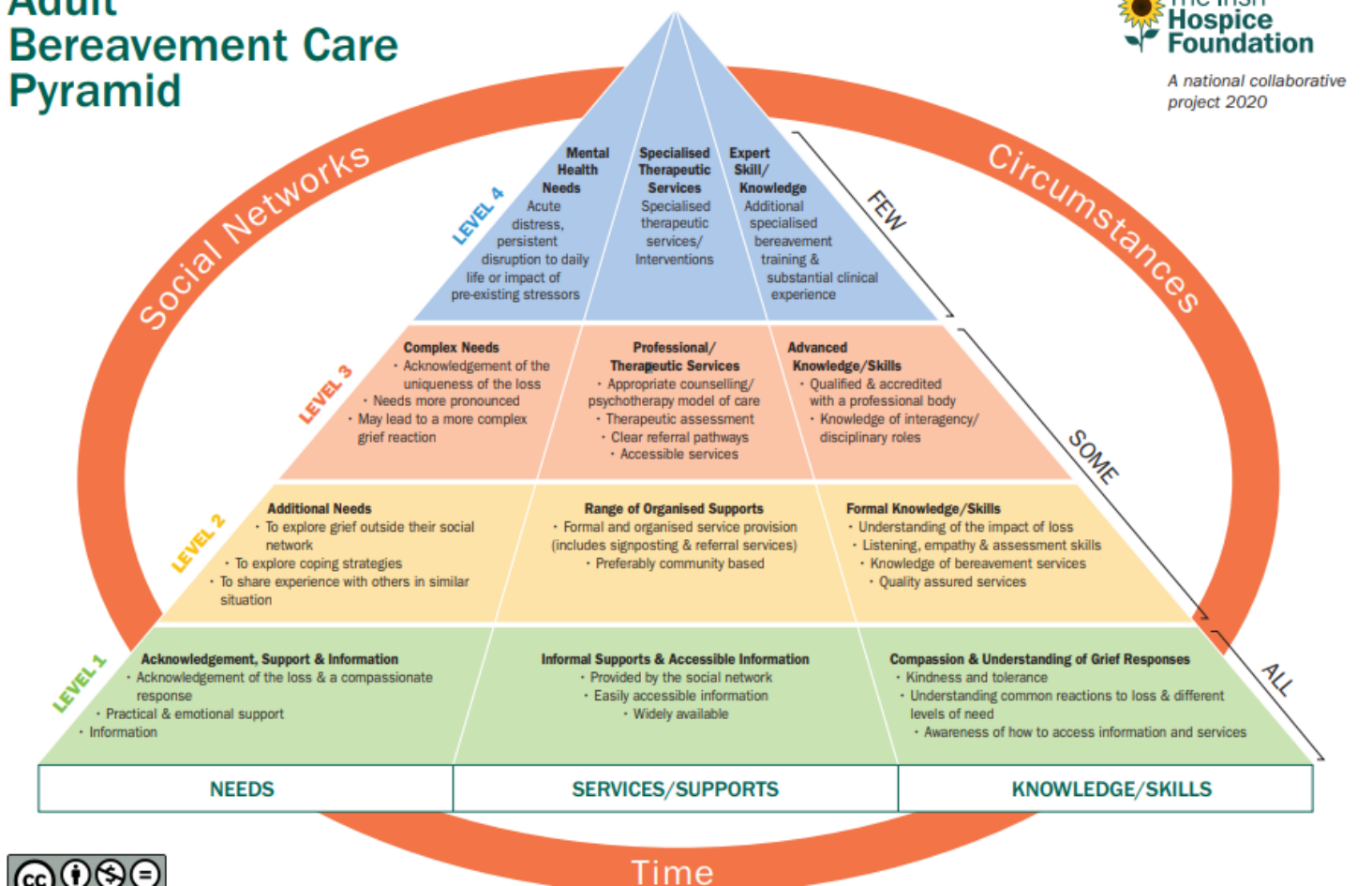


Figure 2: Adult Bereavement Care Pyramid: IHF 2020

## 4.0 A Dedicated Programme of Work to Improve End-Of-Life and Palliative Care in Nursing Homes

Specialist palliative care is now excellently provided by the voluntary hospice movement and the HSE in inpatient and acute hospital settings. The support provided to the sector is essential to maintaining and growing these services. The forthcoming new national policy on specialist palliative care will be welcomed by the sector.

COVID-19 has highlighted other areas of end-of-life and bereavement need – primarily in the community and generalist palliative care settings, such as residential care<sup>2</sup>. At the time of writing 64% of deaths from COVID-19 are in residential care settings<sup>3</sup>. Through the pandemic, people living in congregated setting were most at risk of COVID-19.

We are all aware of the extremely high death rate and COVID readiness of this sector. At a macro level, the provision of care within nursing homes and how this is supported is set to become a national debate. While a number of sectoral representatives have highlighted the significant pressures on the nursing home sector due to demographic, social and economic factors, it has taken the COVID-19 to bring many of these issues into the public arena.

In particular, there is a need to develop better approaches to end-of-life, bereavement and palliative care in the nursing home/residential care sector as a matter of urgency. The sector was least prepared and the approach towards dying, death and bereavement has been very variable. At present, there is no national programme of improvement focused on end-of-life care in nursing homes, with different programmes and engagement provided by the IHF (CEOL programme for nursing homes), local hospices in many areas and via webinars (project ECHO) by the All Ireland Institute of Hospice & Palliative Care (AIHPC). In comparison, our Hospice Friendly Hospitals programme (HfH), now in its 12th year, was a key conduit for information and resources to the acute hospital sector during the past months in relation to COVID-19. The IHF believes it is time to develop one strong national programme on palliative & end-of-life and bereavement care for the nursing home sector that engages all stakeholders and improves quality across the sector.

This is not a simple ask. End-of-life care (EOLC) is a core part of the work of nursing home staff. However, over the years engaging and working with nursing homes, the IHF have noted that the general preparedness for end-of-life care and palliative care in nursing homes can be very variable. While some sites are excellent, others need a lot of capacity building and support. Dying, death and bereavement are difficult topics. Furthermore, staff turnover is often high with varying skills and experience amongst the work force. Our experience is that there is a need for onsite, sensitive, tailored, ongoing supportive training in order to bring about real and sustainable change.

There is variable GP care provided in nursing homes, which can be problematic. According to legislation, patients can select the GP of their choice which could mean several GPs potentially

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<sup>2</sup> Nursing homes constitute a significant part of healthcare in Ireland, including end-of-life care, where up to 25% of the Irish population die in a long-stay residential setting. In 2014, there were 437 private and voluntary homes in Ireland, providing a total 22,342 beds, which accounted for more than 80% of all long-term care beds in the country, and the employment of 25,000 staff, (Nursing Homes Ireland, 2015).

<sup>3</sup> Figure provided by HSE, correct to 18th May 2020.

providing care into the same nursing home. Ideally, one/two practices would provide all the care to each nursing home and engage in a quality improvement programme with these care homes. We have received reports from several stakeholders that during COVID-19, this variability has become even more problematic. It is true that some of this relates to expectations of in-person delivery versus remote/virtual versus onsite consultations. However, it also is as a result of the overall model of provision of medical care to nursing homes and, in the present crisis, has been unhelpful to quality of care. We are conscious that a review of the Medical Officer contract in relation to GPs and nursing homes is overdue and would be especially timely at this point – this review could also influence the GP care into private nursing homes.

In response to this need, the IHF has provided a programme of interventions to nursing homes and residential care settings. The aim of this programme, called *Compassionate End-of-Life*, (CEOL), is to promote a quality improvement approach to dying, death and bereavement, and includes reflection on previous deaths, a bereaved relatives survey, staff reviews of end-of-life care, initiation of quality improvements, development of staff resources, peer support and training and ongoing capacity to engage with community, medical and palliative care services. The IHF have been running this programme in nursing homes for seven years, with participation from approximately 160 nursing homes.

### **What needs to happen post crisis COVID-19 phase?**

There is now an opportunity to review the nursing home sector and identify the challenges that are required. While some of the changes will result from the State's response to COVID-19, other changes may be sectoral specific e.g., staff training in end-of-life care, access to appropriate medical and palliative care, opportunities for advance care planning, and HIQA inspections that would include a wider range of themed inspections in end-of-life.

The IHF believe that a dedicated national and sustained programme of work should be implemented and funded by the State to improve end-of-life care and palliative care in nursing homes, which would involve all relevant stakeholders.

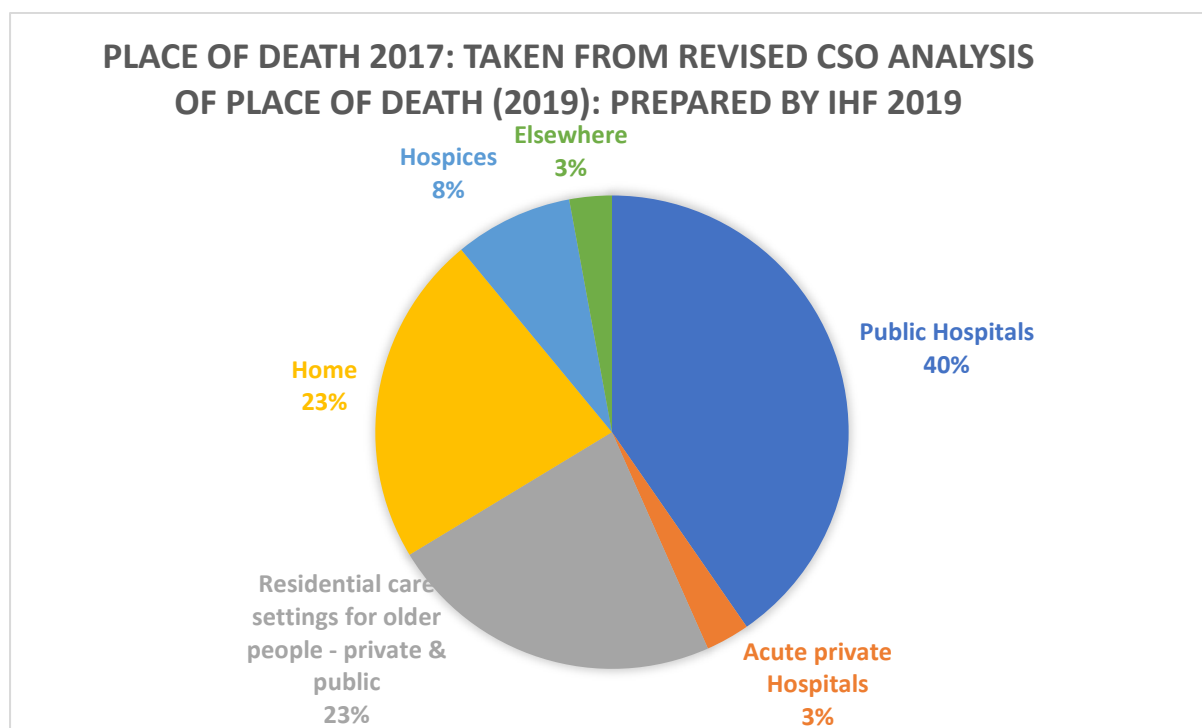
The IHF is very willing to contribute their experience and expertise in the provision of such a programme.



## 5.0 Enabling More People to Die at Home

**Most adults in Ireland say that they want to die at home. It's a simple vision; yet, anecdotal and scientific evidence suggests that this is becoming rarer and harder to achieve.**

While interpretations of a “good death” may vary, for many Irish people the wish to die at home is a fundamental part of a good death. A national study commissioned by the IHF in 2014, for example, found that 74% of Irish adults would prefer to be cared for at home if they were dying, compared with just 5% who would prefer to be cared for in a hospital. This represents a significant rise from 66% ten years ago (IHF, 2014<sup>4</sup>). However, as the following chart indicates, the reality of death in Ireland is different, with most people dying in hospital. COVID-19 showed us that the safest place for people with life limiting illness, or indeed facing end-of-life, was in fact their own home.



COVID-19 has strengthened our belief that more can and should be done to enable people live and die at home. However, there have been a number of unintended consequences relating to remaining at home:

- A reduction in the use of mainstream health services and decreased supports to older persons within the home. Service usage fell during COVID-19 with many services reporting a decreased in regular usage
- As a measure of protection, the HSE moved early to restrict the number of external ‘visitors’ to homes of older people. This resulted in many people being unable to visit their loved ones. This was particularly challenging if their loved one was nearing end-of-life.



- Demand for nurses for night care (IHF funded) and night nursing (ICS funded) rose by 20-25% as families dealing with the imminent death of a loved one at home needed more supports during the night. We are working with our partners the Irish Cancer Society to try to meet this demand. We welcomed the additional funding provided this year but funding to be sustained beyond 2020 to at least 50% as per the commitment in the HSE's 3-year development framework for palliative care.
- Exhaustion on the part of carers as there has been little respite relief during COVID -19.

Not everyone can, nor should die at home. Further work from the IHF shows that death in hospital and other settings can be experienced as having occurred in the right place and being of high quality. However evidence gathered by the IHF<sup>4</sup> and other age sector partners suggests that more can be done to enable more choice of place of care as death approaches - to allow people to be cared for as long as possible and if possible to die at home. COVID-19 has strengthened that belief.

As we age, and as an illness progresses, our preferences may, of course, change where we die is not just a matter of personal preference. IHF recognises that there is a myriad of factors that influence whether a person can die at home. It clearly depends on what supports are in place to allow us to die at home at peace and with good care. Factors that increase the likelihood of dying at home include the presence of a carer, the nature of the illness itself and the symptoms associated with it, socio-economic and demographic status and, of course, the availability of quality local services.

With the correct supports and interventions, we can ensure post COVID-19 that people can still experience a good end-of-life with quality care in their homes, supported by GP and primary care services, hospice homecare and in-house homecare schemes.

*'The more we support delivery of care at home, the better we address the needs of patients, their family caregivers and professional staff. This approach will support the wishes of many patients to be kept comfortable at home, reduce the stress on families and simultaneously reduce the burden on hospices, care homes and hospitals'* (Professor Susan O'Reilly, Irish Hospice Foundation Board member).

As part of this work, there is an urgent need to invest in and support palliative and end-of-life care in the community via primary care. The IHF has been active in supporting **primary palliative care** by hosting a national committee on primary palliative care since 2010. Many challenges facing the Irish acute health care system could be alleviated by enhancing primary care in the community, especially in the context of the emergence of new models of care for chronic disease management and in the provisions and changes outlined in Sláintecare. The 3,980 GPs and cohort of practice nurses are a critical resource that needs to be grown and supported.

We know that people are living longer with more illnesses; these illnesses can be unpredictable in nature, often have a long trajectory and are associated with a symptom burden similar to cancer. Increasing numbers of people with these and other long-term, life-limiting illnesses can present to their General Practitioner (GP) after experiencing a sudden deterioration. The need to expand specialist knowledge to generalists working in the community is necessary to cope with these and

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<sup>4</sup> In recent years The IHF produced a perspective paper *Enabling More People to Die at Home: Making the Case for Quality Indicators as Drivers for Change on Place of Care and Place of Death in Ireland...* which explored whether place of care at the end-of-life, and place of death, could become part of a wider set of key measures of the effectiveness of the Irish healthcare system. <http://hospicefoundation.ie/wp-content/uploads/2014/12/Enabling-More-People-to-Die-at-Home1.pdf>.

future shifts in addition to enhancing out of hours capacity and skills. As a result, investment in more palliative, end-of-life and advance care planning and bereavement care in the community allows for GPs and primary care teams to provide and co-ordinate care for those patients who are imminently dying, in their own home and also in nursing homes.

The IHF has researched many of the gaps in primary palliative care. In addition, we have a formal partnership with the ICGP which has already in 2020 seen the re-development and rollout of the ICGP Certificate course in Palliative Care with (support from the HSE) this year. In addition, plans have been submitted to Sláintecare as how to demonstrate how this sector can be enhanced which we are happy to share.

### **What needs to happen post crisis COVID-19 phase?**

Notwithstanding the wide range of influences on home death, the Irish Hospice Foundation believes that more can be done to facilitate people at end-of-life to be cared for and to die in their home setting if that is their wish. This can and should become the norm for those who choose it and should become part of national health and social care policy, post COVID 19.

The following is an example of critical supports will assist people to die at home in comfort;

- Ensure the restoration of respite care and other services (as soon as public health advice deems it safe to do so).
- The provision of rapid access to palliative care and support at all times of the day and night, including hospice homecare teams to fulfil local community needs.
- Enhanced capacity of primary care services to support GPs, public health nurses and other community care providers to provide good generalist palliative and end-of-life care. This should facilitate effective methods of communication between mainstream and out-of-hours services, thus preventing unnecessary emergency hospital admissions
- Commitment of 50%+ State funding for the Nurses for Night Care service.
- The provision of facilities and supports for rapid discharge from hospital for dying patients, including the provision of necessary community services.
- Development of a statutory home care scheme to enable more people to remain at home towards end-of-life, regardless of whether there is a family carer in place. The provision of a statutory home care scheme should be considered by political parties in the formation of Government talks
- Appropriate training for family carers providing basic palliative and end-of-life care in the home.
- Develop research projects such as bereaved relative's survey to measure the quality of deaths in the home setting.

## 6.0 Facilitating Dialogue and Planning for End-of-Life

The concept of a good death as articulated in the Peoples Charter on Dying, Death and Bereavement illustrated what the Irish public wanted for themselves and their loved ones at end-of-life. The first desire within the Charter was that 'Dying is talked about and not hidden away'. This speaks to 'death literacy' and our reluctance to engage with topics concerning dying, death and bereavement. COVID-19 challenges our response towards dying, death and bereavement. Death is so prevalent and demanding at the moment; families and friends are disenfranchised in their experience of death and funerals and our existential fears on death are closer than ever before. For many of us, we do not have the vocabulary and skills to support ourselves and each other.

COVID-19 has put dying, death and bereavement firmly in front of us and we have to find new ways of talking about dying, death and bereavement. The IHF in addressing the concept of death literacy has long encouraged us to think, talk, and record our choices for our end-of-life and for our future healthcare. Unfortunately for many people, the concept of putting plans in place only comes into focus when they have been jolted by a diagnosis that brings living and dying into a new light. For many of us that jolt is happening now, during COVID-19.

Advance Planning (AP) refers to a broad range of decision-making activities that relate to end-of-life. It is essentially a mechanism that makes provision for people to consider, amongst other things, issues associated with healthcare, finances, administration, legal matters, and what happens to their bodies after death. The IHF believes that we all have a right to be involved in this decision-making process regardless of illness, age, ability or life circumstance. The Irish Hospice Foundation has been to the forefront in the development of a citizen-led tool for advance planning, called Think Ahead. 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.

Advance Planning for end-of-life for every individual is a process, not a once-off event and done properly, it can enable people to think, record and share with others their wishes, values, beliefs and preferences so they are heard and understood should a time come when they cannot speak for themselves.

In healthcare, the concept of Advance Care Planning is considered to be part of good healthcare for those nearing end-of-life. However, some people wish to be more specific and seriously consider what treatments they would not like to receive in the future and document these in an Advance Healthcare Directive (AHD). The Oireachtas has legislated for Advance Healthcare Directives (part 8 of the Assisted Decision Making (Capacity) Act 2015). Under the provision of this legislation, an adult with capacity can make a legally binding statement to refuse any form of treatment, including life-sustaining treatment, thus providing a firmer legal framework to support the use of AHDs in Ireland. However, the Directive only comes into effect if, in the future, the adult loses capacity and is unable to make decisions for themselves. This provision is in line with the European Convention on Human Rights, and the 2006 Convention on the Rights of Persons with Disabilities and Council of Europe recommendations from 2009 and 2014. The ADMA was enacted in 2015. However, it needs financial, political and general support for its full implementation.

The IHF has been working with the HSE ADMA group since it was established in 2016 to prepare guidance for health and social care professionals in relation to the ADMA in its entirety. In addition to this the IHF is represented on the HSE AHD subgroup to prepare draft codes of practice in relation to the use and implementation of AHDs in Ireland.

### **What needs to happen post crisis COVID-19 phase?**

- Support for citizen led initiatives, such as Think Ahead, to encourage and enable people to think, to talk and to plan ahead for their end-of -life.
- Support for the full commencement of the ADMA to include part 8 and crucially, the establishment of a register for AHDs. In addition, the ADMA must be resourced in order to allow a complete and speedy commencement process in line with the plans of the Director of Decision Support Services (DDSS).
- The development and agreement of the Codes of Practice and Guidelines for Health and Social Care professionals.
- A public awareness campaign about the provisions of the Act (a responsibility of the DDSS under ADMA) must be supported by Government and others such as the IHF.

## **7.0 Introducing a National Mortuaries Programme**

COVID-19 has further exposed the condition of many of Ireland mortuaries. In 2019, the IHF began concerted advocacy for a National Mortuaries Campaign to enable hospitals to refurbish or rebuild mortuaries, thus improving the national standard and responding to an evident need. According to the IHF Design & Dignity Guidelines (adopted by the HSE), mortuaries should be a sanctuary and convey a sense of reverence and respect for life, death and bereavement: however, as many of mortuaries in public hospitals are in a state of disrepair and many are far from being a place which invokes a serene, respectful and reassuring atmosphere. Many mortuaries in addition do not have the capacity required to cope with pressures, such as the COVID-19 pandemic.

Using the knowledge and experience from the successful and collaborative IHF Design & Dignity programme significant work has been undertaken to identify the sites in most need and this can be provided on request. This assessment will be augmented by further information from the HSE conditions survey of all acute hospitals across Ireland commenced in 2019.

### **What needs to happen post crisis COVID-19 phase?**

A €15 M mortuaries renovation programme was under discussion with the HSE prior to COVID-19 and this is required even more urgently now than prior to the pandemic.

## Appendix ONE: Correspondence Regarding Compassionate Care at End Of Life – COVID-19



Morrison Chambers  
32 Nassau Street, Dublin 2, Ireland  
D02 YE06  
Telephone 00 353 (0) 1 6793188  
Fax 00 353 (0) 1 6730040

**14th May 2020**

**To: Dr Tony Holohan, Chief Medical Officer, Department of Health and Chairperson of NPHE (tony\_holohan@health.gov.ie; marita\_kinsella@health.gov.ie )**

**Re: Easing of Restrictions to enable compassionate Care at End-of-Life and in Bereavement.**

Dear Tony,

On behalf of the Irish Hospice Foundation, I wish to congratulate you and NPHE, on your work to 'flatten the curve' with respect to COVID-19. We can only guess at the scale of the challenges you face in addressing all the demands of economic, environmental, employment and societal recovery. Our collective actions in Ireland have indeed saved many lives. The Irish Hospice Foundation is steadfast in our support for the work of NPHE and of our colleagues working in the front line<sup>1</sup>. The vision of the Irish Hospice Foundation is that no-one should face death or bereavement without the care and support they need. In 2016, The Irish Hospice Foundation asked the Irish public to remember and reflect on their experiences of death and bereavement and to reimagine what living, dying and grieving in Ireland could be like. The expressed wishes of 3,000 people are distilled into the People's Charter on Dying, Death and Bereavement, in Ireland (see end of letter). The IHF's mandate and mission is to make these aspirations a reality. People told us they want to live and die in an Ireland where death is talked about and not hidden away; they want to be pain-free; they want to be treated with, and die with dignity; they want to be secure in the knowledge their wishes will be respected; they want to feel comfortable and cared for, ideally at home; to have access to good services and information and to know their grieving loved ones will be supported after their death.

<sup>1</sup> Through IHF programmes and our ongoing work we continue to support these crucial staff with many of these issues. See. <https://hospicefoundation.ie/covid19careandinform/>

During recent months as a result of COVID-19 Ireland, many of those aspirations have become vain hopes as necessary public health restrictions were and are in force. In many cases, people's desire for autonomy and capacity to participate in decisions regarding their care have been severely challenged. Many have been necessarily separated from those they love and many who love and care for them. Many have died alone. We know that there is an increased burden on health and social care staff who step into the breach created by restrictions on visiting, and that they themselves are often overwhelmed by both the circumstances and the scale of deaths, trauma and grief. We know that families, neighbours and friends are unable to attend the funeral or other rites. These rites and rituals are truncated, and social distancing prevents even the comforting hugs of family members and friends. Many people have had to start their grief journey alone without those societal supports which normally provide such comfort. These restrictions have affected all deaths from both COVID and non-COVID causes. Many live with the fear of death, with the isolation, with the terror of dying alone or of loved ones dying alone and unprepared.

The Irish Hospice Foundation fully appreciates that robust the infection control measures are required and understands visiting restrictions are utilised to prevent further infection to visitors, their families and to staff. We also acknowledge the sacrifices families are making at this point in time and the very difficult challenges faced by staff. The IHF, through myself, is assisting in the update of guidance for Funeral Directors being developed by HPSC and I have provided feedback and input on our experiences to date. As we move towards a post crisis response to COVID-19, where we expect to live with COVID-19 as an ongoing reality, the Irish Hospice Foundation feels it is time to rethink some restrictions with a view to enabling more compassionate care at end of life and in bereavement. There is much we can do to make the aspirations of the People's Charter on Dying, Death and Bereavement a reality in coming months. We specifically ask for the following proposed solutions to be considered;

- Many people and staff in health care settings have raised concerns regarding any person dying alone in a healthcare setting where family/loved ones are not permitted to visit, or be with the person, at end of life. There is only one chance to get end-of-life care right and we know that dying alone is hugely problematic both for the dying person and their families – creating a lasting memory of distress for families and no doubt impacting on their bereavement experiences. In our Press Release on April 16th<sup>5</sup>, we called on all bodies to ensure that one family member is allowed be with every person who is dying in hospitals and care settings – even if PPE is required for a COVID-19 patient/resident. We reiterate that recommendation and are glad to see so many care settings adopt compassionate practices.
- We reiterate the need for all care settings to provide clarify to families on visiting arrangements and ways to engage with their relative who may be dying. Specifically visiting in nursing homes needs to be examined to avoid undue ongoing distress for older and frail adults.
- Development of specific clarification for all members of the public on the use of PPE and subsequent requirements for isolation. We have been informed of cases where family members visiting loved ones at end of life, whilst wearing full PPE, were then told they needed to isolate (potentially keeping away from the family funeral etc.). We would recommend the development of a clear statement and communication that a person who

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<sup>5</sup> (<https://hospicefoundation.ie/statement-from-ihf-on-dying-alone-in-hospitals-and-care-settings>)

visited a COVID-19 positive person at end of life and was wearing PPE may attend the funeral, if symptom free.

- Expansion of numbers allowed to attend family funerals. We appreciate the need for minimal social contact but the restriction of 10 people to funerals is very problematic.
- Consideration of language within all guidance of the need to consider the person who is dying or bereaved - dying, death and bereavement requires an additional level of compassion and care from every service provider and regulatory body.

The IHF looks forward to supporting you in your work. We are more than happy to engage with any member to provide further detail and discussion. With kind regards.

Sent electronically Sharon Foley | CEO

Sent from Sharon Foley | CEO Irish Hospice Foundation | Sharon.foley@hospicefoundation.ie / 087 1213844

*This letter was also sent to the Minister for Health, and senior executives in the Department of health and HSE.*



THURSDAY APRIL 30, 2020.



## **IRISH HOSPICE FOUNDATION CALLS FOR MORE SUPPORTS FOR FAMILY CARE-GIVERS TO ENSURE THOSE NEARING END OF LIFE AT HOME DURING COVID-19 CRISIS ARE NOT FORGOTTEN**

### **Analysis of data shows increase in non-Covid-19 deaths**

Thursday April 30, 2020: The Irish Hospice Foundation is today calling for an increased package of supports for family care-givers providing end-of-life care at home. The call coincides with the publication of new analysis from the Foundation which shows a week-to-week excess death rate of non-Covid-19 deaths in the last 6 weeks, since restrictions on movement were put in place.

The analysis (see table in notes to editors) of the number of deaths reported (excluding those reported as Covid-19 related) during March and April show unusual increases in some weeks- up to 23.5% - when compared to the same period in 2019. This pattern reflects trends seen in Italy and other places. The Foundation says the figures could be evidence that people may not recognise the signs of end-of-life and therefore are not seeking services provided by GPs, specialist palliative care teams and Emergency Departments during the crisis.

Surveys have shown that as many as 75% of people would like to die at home, but less than 25% of people do. The Irish Hospice Foundation has long campaigned for services and supports to be in place to enable more people to die at home if they wish to do so. The presence of a family carer has been shown to be essential to good end-of-life care in the home.

Sharon Foley, CEO of the Irish Hospice Foundation said: *“It is important to remember that even during this Covid-19 crisis, services are available to people in the community – GPs and specialist palliative care continues to be available to patients and their families, even if it is just over the phone. With the correct supports and interventions, people can still experience a good end of life with quality care at this time. We also know that because of the restriction on home supports, and a concern about attending inpatient settings, many carers are experiencing little respite during Covid-19 which is particularly challenging if their loved one is nearing end of life.*

*“We have seen an approximate 20% increase in our Nurses for Night Care service as families dealing with the imminent death of a loved one at home need more supports during the night. We welcome the additional funding provided this year but call on this State funding to be sustained beyond 2020 to at least 50%.”*

The key supports and services the Irish Hospice Foundation is calling for at this time are:

- Sustained commitment to 50%+ State funding for the Nurses for Night Care service;
- More supports for GPs and Public Health Nurses in the provision of end-of-life and palliative care and assistance to family carers;
- Ensure the restoration of respite care and other services (as soon as public health advice deems it safe to do so).
- Establish a statutory home care scheme to enable more people to remain at home towards end of life, regardless of whether there is a family carer in place. The provision of a statutory



home care scheme to be considered by political parties in the formation of Government talks; and

- Appropriate training for family carers providing basic palliative and end-of-life care in the home.

The Irish Hospice Foundation has already produced a new resource – ‘**Caring for someone nearing end of life at home during the Covid-19 crisis**’, as part of their Care & Inform online resource hub. This resource supports and complements the HSE resources for supporting someone at end of life.

Professor Susan O’Reilly, Irish Hospice Foundation Board member said: *“The more we support delivery of care at home, the better we address the needs of patients, their family caregivers and professional staff. This approach will support the wishes of many patients to be kept comfortable at home, reduce the stress on families and simultaneously reduce the burden on hospices, care homes and hospitals”*.

ENDS.



## The People's Charter on Dying, Death & Bereavement in Ireland



Prepared by the IHF from inputs of 3000 people of Ireland

### I want to live and die in an Ireland where:

Death is talked about and not hidden away.

I can prepare for what lies ahead.

I can get relief from pain, no matter where I am being cared for or what condition I have.

I am treated as an individual and my wishes, choices and beliefs are respected.

I, and the people who care for me can get the practical services and support that we need.

I can get information to understand what is happening to me.

I can die, surrounded by the people I love, in a calm and comfortable place, in my home, if at all possible.

I am supported to stay in control of my own decisions.

My dignity is respected and maintained to the end of my life, and after my death.



### For the people who matter to me, I want Ireland to be a country where:

People understand grief and do not avoid thinking or talking about it.

Family and friends are supported during a loved one's illness and after their death.

People get space and time to grieve, talk and remember.



[www.hospicefoundation.ie](http://www.hospicefoundation.ie)