



**Irish  
Hospice  
Foundation**

To die and grieve well wherever the place

# Time to Reflect

## Irish Hospice Foundation Survey About Dying, Death and Bereavement During the COVID-19 Pandemic

### Briefing Paper

Time to Reflect is the findings from a survey commissioned by Irish Hospice Foundation to explore the impact of COVID-19 and public health measures on the experiences and perceptions of the Irish population in relation to dying, death, and bereavement during this time.

A total of 2,259 participants completed the national survey between November 2021 and February 2022.

**Time to Reflect is their story.**

The results of this study provide valuable insights into the end-of-life care and bereavement experiences of the Irish public during the pandemic. It also includes the experiences of healthcare workers in supporting patients and their families at end of life.



# Survey Methods

The Time to Reflect study was conducted in two phases.

1. A scoping review of the literature on COVID-19 and its impact on dying, death, and bereavement.
2. Survey data collected by Irish Hospice Foundation between November 2021 and February 2022\*.

The survey questionnaire collected both quantitative and qualitative data on:

- a) People's views on dying, death and bereavement during the COVID-19 pandemic
- b) People's experiences of the death of someone close to them during the pandemic and their subsequent bereavement
- c) Demographic data about the study sample.

## Results from the Time to Reflect Survey

### 1. Perceptions of Dying, Death, and Bereavement

All participants (N=2,259) were asked about their views on dying, death, and bereavement since the pandemic began.

- Many participants (41%) reported that the pandemic changed their views about dying, death, and bereavement 'quite a lot' or 'a lot'.
- Over two-thirds (67%) reported that they have a greater awareness of grief and the impact of loss since the pandemic.
- Nearly half of participants (47%) have given more thought to their own end-of-life wishes because of the pandemic.

**“I have made a will; I have made a living wishes document and myself and my siblings and parents have had honest discussions about this. Covid forced us to have these conversations in our family.”**

### 2. End-of-Life Care during COVID-19

Over half (54%) experienced the death of someone close to them (mostly a parent) during the pandemic. Nearly 40% reported that the death of their loved one was unexpected or sudden.

- Only just over half (54%) reported that their loved one received the level of care they needed at end of life.
- Over 70% of participants reported that the pandemic completely or partly prevented their loved one from having the death they would have wished for.
- 30% reported that their loved one was not surrounded by the people they would have liked to be with at their time of death.

**“My uncle passed away in hospital, earlier this year with Covid. I was able to attend the funeral (12 people). His daughter and sons are still grieving hugely. He passed away alone. No one had checked on him all night and he was found the following morning. This is a huge grief for his children.”**

### **3. Healthcare Workers' Experience**

There were high levels of personal and professional grief among those working in healthcare. 20% of the survey participants classified themselves as healthcare workers.

They highlighted the emotional burden they faced being with patients in their final hours, when loved ones were unable to be with them and supporting families to say goodbye, as well as caring for their patients in very difficult circumstances.

**“As a healthcare worker, the impact of patients not being able to physically see their loved ones is one of the hardest parts of my nursing career. To see a family looking in a window, viewing their dying father was so traumatic and heart breaking. It is a moment in time I will never forget.”**

The findings also showed that healthcare workers were resilient and had higher self-reported scores for general health, mental health and financial wellbeing compared to non-healthcare workers.



#### 4. Funerals and Mourning Rituals

Many participants mentioned difficult experiences due to the guidance that was in place at that time for funeral arrangements e.g. capped attendance numbers and social distancing.

- 24% of bereaved participants were unable to attend the funeral of a loved one.
- Almost 70% reported that family and friends were excluded from funerals due to the public health measures.

Despite many participants saying they had lost an opportunity to have the traditional aspects of a funeral, the survey highlighted that Irish people sought other ways to extend their support to those grieving in their communities.

**“We walked to the church; kind neighbours lined the route but only the immediate family were allowed into the graveyard.”**



#### 5. Experience of Bereavement and Grief

Participants highlighted a lack of bereavement support during the pandemic. This was often a lack of support given by a professional or difficulty accessing support while grieving.

- Over 60% stated that the pandemic made their grieving process more difficult.
- Almost 40% said they did not get the support they needed after the death of a loved one due to public health measures.

The pandemic reinforced the importance of community support and participants reported how they came to realise the significance of this.

**“The need to be able to share a death with your community was something I took for granted. Having sadly been at a number of close relatives’ funerals, I see that the funerals with restricted numbers do not permit a family to hear lovely stories about the deceased or feel the support of the community.”**

## 6. Complications of Grieving

While grief is a natural and normal response to painful or traumatic loss, at times, and for smaller numbers of people, grief can be more complex and require specialist help.

A Brief Grief Questionnaire, which is a short and simple screening tool, was used to screen bereaved survey participants (N=1,095) who may be experiencing difficulty or what is termed 'Prolonged Grief Disorder' (PGD).

PGD makes it challenging for a person to accept the reality of a loss and to move forward. It can include intense feelings of grief that are long-lasting and can interfere with everyday life. In general, only 10% of bereaved people would be expected to fall into this category.

- Findings from survey indicated that PGD was present amongst 14% of participants.
- A further 26% had scores which indicated they may be at risk of developing PGD and may need closer monitoring and bereavement support.

There were a number of statistically significant associations showing that those experiencing more difficult grief also demonstrated other characteristics, for example:

- **A participant's relationship to the deceased** - indicators of PGD were more prevalent in participants who lost a parent or a spouse.
- **Whether the person was with their loved one when they died** - there were higher scores of PGD indicated for those that were with their loved one at the time of death (26%) compared with those that were not with the person (10%).
- **Bereaved participants access to support during the pandemic** - those who agreed or strongly agreed that they did not get the support they needed during the pandemic had higher scores of PGD.





# Recommendations

The public health measures that were put in place during COVID-19 pandemic ensured that the spread of a highly transmissible disease was curtailed. In turn, this meant that many lives were saved, as well as helping to reduce the burden on the healthcare system.

However, the public health measures also caused major disruption and the findings from this study emphasise the struggle of bereaved participants, many of whom did not have the opportunity to be present with their loved ones as they approached end of life.

Irish Hospice Foundation will use the findings to inform their future policy and advocacy asks on public health planning and to inform their own work.

Based on the findings of the literature review and the results of the Time to Reflect survey, recommendations are made in the following areas:

## 1. Importance of End-of-Life Care during Public Health Crises and Emergencies

Investment is needed to raise awareness and actively promote the importance of people planning ahead to reflect their end-of-life care wishes.

In future planning, an emphasis must be placed on the importance of maintaining compassionate end-of-life care which is patient focused with family involvement.

Alongside this, all healthcare staff, across all care settings, should receive targeted education and continuous training to equip them to deliver quality end-of life and bereavement care.

## 2. Enhance Bereavement Support

Greater resourcing and investment into bereavement support, skills and screening as well as the expansion of bereavement services through the public health system.

Develop healthcare policies and services which acknowledge the impact of professional and personal grief and provide appropriate organisational and clinical responses.

## 3. Inform Health Policy and Practice

The findings must be used to inform future public health responses to similar emergencies, as well as the proposed inquiry into the handling of the COVID-19 pandemic.

In the event of future public health emergencies, Irish Hospice Foundation would welcome early and continuous engagement with public health officials to support the dying, death and bereavement experience.

## 4. Invest in Future Research

There is a need for further research to explore the longer-term impacts of people's experiences of dying, death and bereavement during the pandemic. This should include large population-based samples, as well as studies that focus on more specialised groups (e.g. migrant healthcare staff and marginalised communities) and those who were bereaved.

## IHF Programmes, Resources & Information to Support End-of-Life Care



### Hospice Friendly Hospitals (HFH)

The HFH Programme, seeks to ensure that end-of-life, palliative and bereavement care is central to hospitals. The programme aims to improve the experiences of patients and their families in acute hospitals and supports staff well-being by using a strategic and focused approach, which is underpinned by the Quality Standards for End-of-Life Care in Hospitals.



### Caru

Caru is a continuous learning programme to support and empower nursing homes in the delivery of compassionate, person-centred, palliative, end-of-life and bereavement care to residents and family members. We resource and manage this initiative in partnership with All Ireland Institute of Hospice & Palliative Care (AIHPC) and HSE. [www.caru.ie](http://www.caru.ie)



### Dying Well at Home

This programme supports innovative end-of-life and palliative care in the home setting. The work includes our Primary Palliative Care programme, Nurses for Night Care, carers support and advocacy for equity in access to care. The programme aims to support people to die well at home if this is their wish and it is possible, while also placing a particular focus on supporting those who are caring for them at end of life.



### Nurses for Night Care

We fund this service for people dying with illnesses other than cancer. The service enables people with diseases like dementia, motor neurone disease, advanced respiratory disease and heart failure to receive expert nursing care and support at night in their own homes in their final days. It also provides reassurance and respite for families and loved ones caring for someone at home.



### Palliative Care

Many people associate palliative care only with cancer, but palliative care can be provided to any person living with a life-limiting disease, advancing neurological illness, chronic kidney disease and dementia. We provide information and resources for those working with patients with life-limiting conditions such as these.

Our information booklet - **Palliative Care - What is it and who is it for?**<sup>1</sup> - is for people who have been diagnosed with a life-limiting condition. It provides information about palliative care that aims to make people feel comfortable and supported throughout their illness.



### Think Ahead

A practical tool and customisable guide that helps a person document their healthcare choices and personal wishes, for a future time when they may not be able to make or express those decisions. Think Ahead is in full alignment with the recently commenced Assisted Decision-Making (Capacity) Act 2015. See [www.thinkahead.ie](http://www.thinkahead.ie)

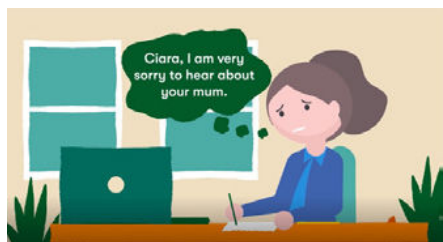
1. <https://hospicefoundation.ie/wp-content/uploads/2023/12/Palliative-Care-Booklet-Irish-Hospice-Foundation.pdf>

## IHF Resources & Information to Support People Who are Bereaved



### Bereavement Support Line

A national freephone service - 1800 80 70 77, set up by Irish Hospice Foundation, in partnership with the HSE, that provides a safe space for those who have lost a loved one, friend or colleague, to talk about their loss and grief. People can also visit [www.bereaved.ie](http://www.bereaved.ie) for more information on coping with bereavement and finding supports.



### Grief in the Workplace

We provide support, training, resources and advice to help organisations and managers to respond effectively to grief situations that can arise in the workplace. We offer a range of interactive courses which focus on coping with grief in the workplace. See [www.hospicefoundation.ie](http://www.hospicefoundation.ie)



### Local Bereavement Networks

Through our networks, which work across the country, we are committed to supporting local and national stakeholders to support best practice in the area of bereavement care in Ireland and to promote a better understanding of bereavement supports for children and adults.



### Irish Childhood Bereavement Network (ICBN)

ICBN supports professionals to deliver quality and accessible support to children who are bereaved. The ICBN signposts loved ones to a directory of bereavement support services. It also advocates for bereaved children and young people, and those supporting them. See [www.childhoodbereavement.ie](http://www.childhoodbereavement.ie)



### Education

We work with staff in a variety of settings to support and embed education and training in end-of-life and bereavement care. From our MSc in Loss & Bereavement, grief in the workplace, to our bereavement workshops, there is a wide spectrum of training to choose from. See [www.hospicefoundation.ie](http://www.hospicefoundation.ie)

\*The survey was open to all individuals aged 18 years and over living in Ireland, who self-selected and chose to participate in the survey. The survey was circulated via social media and among networks in IHF and was completed by a total of 2,259 participants.

