



Irish
Hospice
Foundation

To die and grieve well wherever the place



Time to Reflect: a survey about life, death and bereavement during a pandemic

Every story counts. Share yours.

Questionnaire

Welcome to the Time to Reflect Survey

Thank you for your interest in Time to Reflect, where we invite you to share your thoughts and experiences about dying, death and bereavement in Ireland during the COVID-19 pandemic.

Whether or not you were bereaved during the pandemic, we would like to hear from you. We are also keen to hear from those of you who worked on the frontline in any health, residential, social or community setting, whatever your role.

You are welcome to use the open text boxes to share as much or as little as you feel comfortable with. Please know we will use whatever you and others share with us in our work to improve end-of-life care and bereavement support for everyone in Ireland who needs it.

If you are affected by taking part in Time to Reflect, please remember that the **Irish Hospice Foundation Bereavement Support Line** is open from Monday-Friday from 10am-1pm at **Freephone 1800 80 70 77**.

Before you fill in the survey, it is important that you take time to read the Time to Reflect Information Leaflet. It will tell you everything you need to know so you can make an informed decision about taking part. You can access it at www.hospicefoundation.ie/timetorefectsurvey.

If you want more information about Time to Reflect, please contact Dr. Helen Coughlan at helen.coughlan@hospicefoundation.ie or **01 679 3188**.

Thank you
From all of us at Irish Hospice Foundation.



Consent

To take part in this study, it is important that you agree to all of the statements and terms below. Please read each carefully and **only consent to take part if you agree to all of them.**

- I have read and understood the Information Leaflet about this research project.
- I am aged 18 years or older.
- I have been provided with the contact details of a member of the research team and was given the chance to ask any questions I had about the study.
- I understand that I don't have to take part in this study and that I can opt out at any time up until the time I submit my answers.
- I understand that I will not be asked to provide any identifying information about myself.
- I have been informed that, to protect my identity, I cannot include any information that might identify me.
- I understand that, as this is an anonymous study, I will not be able to withdraw my consent or to have my data deleted once I have submitted my responses.
- I am aware of the potential risks and benefits of this research study.
- I consent to the study team to use my responses in any outputs that are written or created to share findings from this study.
- I give permission for data to be stored for possible future analysis and research by Irish Hospice Foundation related to the current study without further consent being required.

By ticking Yes, you confirm that you agree to all of the statements and terms above and consent to take part in this study knowing a) the risks and benefits of taking part, b) how your information will be stored and used, and c) your right to withdraw at any time before your survey is sent to the study team at Irish Hospice Foundation.

Yes, I consent to take part

Section A: Your views on dying, death and bereavement since the COVID-19 pandemic began.

In this section, we ask about if and how the pandemic has influenced your views on death and bereavement. If you want to tell us more about your answers, we've included open text boxes after some of the questions.

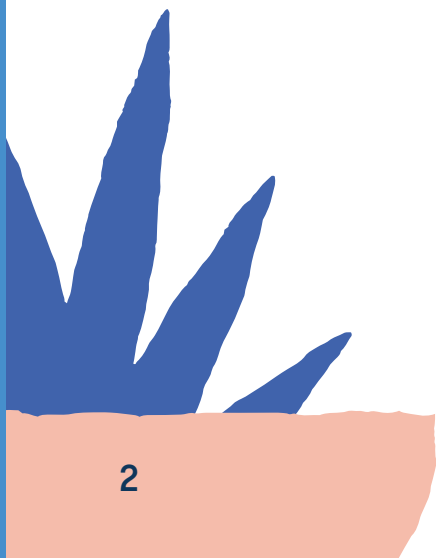
A1. The COVID-19 pandemic has changed my views about dying, death and bereavement...

- Not at all Not much A bit Quite a lot A lot

A1a: If you'd like to tell us more about your answer to this question, please do so here.

A2. Since the pandemic began, I have spoken about death and dying to my family and friends...

- A lot less than usual Less than usual About the same amount as usual
 More than usual A lot more than usual



A3. Because of the pandemic, I have a greater awareness of grief and the impact of loss.

- Strongly Disagree
- Disagree
- Neither agree nor disagree
- Agree
- Strongly Agree

A3a: If you'd like to tell us more about your answer to this question, please do so here.

A4. Because of the pandemic, I have given more thought to my own end-of-life care wishes.

NOTE: Your *end-of-life care wishes* are what you'd like to happen in the future, when you come to the end of your life. For example, it may be about where you'd like to die, what kind of funeral you would want, your spiritual needs at the end of your life, etc.

- Strongly Disagree
- Disagree
- Neither agree nor disagree
- Agree
- Strongly Agree
- Don't Know

A4a: If you'd like to tell us more about your answer to this question, please do so here.

A5. Did you find meaningful ways to participate in any rituals of mourning during the pandemic?

NOTE: *Rituals of mourning* are symbolic activities that people use to express their feelings and to support others after someone has died. For example, lining out on the roadside as a funeral cortège passes by, watching a funeral online, attending a funeral mass, lighting a candle, etc.

- No Yes
- Does not apply / No one I knew died during the pandemic

A6. Did any of your friends or colleagues experience a bereavement during the pandemic (i.e., someone close to them died from any illness or cause)?

NOTE: If *you were bereaved* during the pandemic, you will be asked about *your experiences* in *Section B* of the questionnaire.

- No Yes

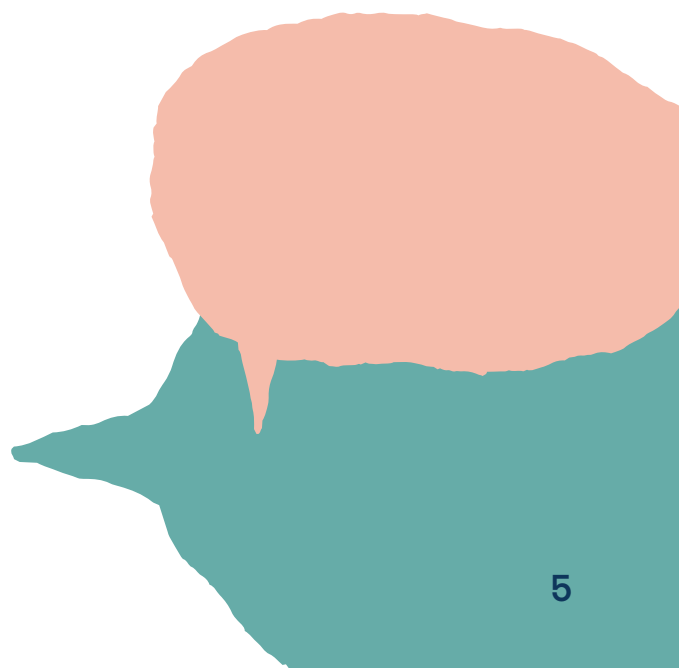
A6a: If you answered ‘Yes’ to this question and would like to tell us more about your experience of supporting someone who was bereaved during the pandemic, please do so here.

A7. From the list below, please tick the statements that best reflect your views on what the top 3 priorities for end-of-life and bereavement care in Ireland should be.

NOTE: *End-of-life care* is about how we look after people at the end of their life wherever they are and however they die. *Palliative care* is an approach that improves the quality of life of patients and their families living with life-threatening illness.

Please tick 3 options only.

- More public awareness and discussion about end-of-life care, death and bereavement
- Providing emotional support to those living with life-threatening illness and their families
- Ensuring that people are supported to die with dignity, free from pain in a calm and comfortable place of their choosing
- Better home-based supports for people at the end of their life (e.g. home help, carers, practical supports, etc)
- Ensuring every person has equal access to palliative care, wherever they live and whatever their age
- Ensuring that there is bereavement support available to anyone who needs it, wherever they live and whatever their age
- Training of all healthcare staff to deliver person-centred end-of-life care across all health and home care settings
- Other. If we have missed something important to you, please tell us here



Section B: Your experiences of death and bereavement since the COVID-19 pandemic began.

We understand that every person's experience of death and bereavement is deeply personal to them. As someone who was bereaved (i.e. experienced the death of someone close to you) during the pandemic, we hope you'll feel able to share some of your thoughts and experiences with us. In this section, we ask about some of your experiences. If there are other parts of your story that you want to share with us, you will be invited to do so at the end of this section.

PLEASE NOTE

For the following questions, we would like to ask you about **one death** that you experienced during the pandemic. If you experienced the death of more than one person in your life, please just focus on one of those people. You may wish to focus on the most recent death you experienced or the death of the person you were closest to. We will ask you about other deaths you experienced at the end of this section.

B1. Please tell us about your relationship with the person who died during the pandemic that you have chosen to answer about in the following questions.

Please only tick one box here. We will ask you about other bereavements you experienced at the end of this section.

- | | | |
|--|--|--|
| <input type="radio"/> My spouse or partner | <input type="radio"/> My mother | <input type="radio"/> My father |
| <input type="radio"/> My son | <input type="radio"/> My daughter | <input type="radio"/> My brother |
| <input type="radio"/> My sister | <input type="radio"/> My grandchild | <input type="radio"/> My grandmother |
| <input type="radio"/> My grandfather | <input type="radio"/> My aunt or uncle | <input type="radio"/> My parent-in-law |
| <input type="radio"/> My sister- or brother-in-law | <input type="radio"/> My friend | <input type="radio"/> My colleague |
| <input type="radio"/> My neighbour | | |
| <input type="radio"/> Someone I provided care for (e.g. a resident, patient or client) | | |
| <input type="radio"/> Someone else close to me (please specify) | _____ | |

B2: Please tell us the month and year the person died.

Month _____ Year _____

B3. Did this person die suddenly and unexpectedly?

Sudden and unexpected deaths are deaths that are caused by things such as accidents, suicide, or an unexpected medical event (e.g., heart attack, stroke, brain haemorrhage, etc.).

Expected deaths are deaths that happen because of a medical condition or illness (e.g., cancer, dementia, COPD, COVID-19, etc.).

- Yes **Please go straight to Question B4**
- No **Please answer Question B3a**

B3a. Did this person experience any of the following at the end of their life?

	Yes	Somewhat or partly	No	Don't know	Does not apply
They had access to the level of care I think they needed when they were dying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They had their spiritual/religious needs met at the end of their life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COVID-19 prevented them from having the death I think they would have wished for	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

B4. Please tell us where the person died.

- In their own home
- In a nursing home
- In a hospice
- Prefer not to say
- Somewhere else (please specify) _____
- In my home or the home of another member of my family
- In another kind of residential or care home
- In a hospital
- I don't know

B5. What was the cause of this person's death?

- Confirmed COVID-19 infection Suspected COVID-19 infection
- Cancer
- Cardiac condition (e.g., Heart attack, Heart failure, or other disease of the heart or circulatory system)
- Respiratory disease (e.g., Chronic Obstructive Pulmonary disease (COPD), Chronic bronchitis, Cystic Fibrosis)
- Dementia (e.g., Alzheimer's disease, Vascular dementia, Lewy Body dementia, etc.)
- Other Nervous system disorder (e.g., Motor Neuron Disease, Multiple Sclerosis, Parkinson's Disease, Huntington's Disease, Meningitis)
- Death due to perinatal or pregnancy complications
- Suicide Accident
- Don't know Other (please specify) _____

B6. Thinking about the time of this person's death, please let us know about the following.

	Yes	Somewhat or partly	No	Don't know	Does not apply
I was able to spend the time I wanted with them before they died	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My experience around the time of their death was negatively affected by COVID-19	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
They died in the place I think they wanted to die	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The professionals involved in their end-of-life care gave me the support I needed at that time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was with them at the time they died	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Yes	Somewhat or partly	No	Don't know	Does not apply
They were surrounded by the people I think they wanted when they were dying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COVID-19 prevented them from having the death I wished for them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

B7. Thinking about the time of this person's funeral, did you experience any of the following?

	Yes	Somewhat or partly	No	Does not apply
We were able to have the kind of funeral service/ritual we wanted for them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Even with the COVID-19 restrictions, people in my community found a meaningful way to honour them on the day of the funeral	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unable to attend their funeral in person because of the COVID-19 restrictions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some family members and/or close friends were excluded from the funeral because of the COVID-19 restrictions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Even with the restrictions some aspects of the funeral were a comfort to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

B8. Thinking about your experiences of grief and loss, please let us know about the following.

	Strongly Disagree	Somewhat disagree	Partly disagree and partly agree	Somewhat agree	Strongly agree
The impact of COVID-19 has made my grief more difficult	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Even with the restrictions, my family and friends have found meaningful ways to support me in my grief	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't get the kind of support I needed after the death because of the COVID-19 restrictions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

B9. In the past 4 weeks...

	Not a lot	Somewhat	A lot
How much have you had trouble accepting the death of this person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much has your grief (e.g., sadness and longing) interfered with your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much are you having images or thoughts of this person when they died or other images or thoughts about them that really bother you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Think about the things you used to do when this person was alive that you now do not feel comfortable doing or that you have avoided. How much have you been avoiding these things? For example, going to a place you often went with them, doing things you used to enjoy together, avoiding looking at pictures or talking about them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much have you been feeling cut off or distant from other people since this person died, even people you used to be close to like family or friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**B10. Have you sought support from any of the following because of your grief?
Tick all that apply.**

- My GP (family doctor)
- The Irish Hospice Foundation bereavement support helpline
- Another support helpline
- A text support service
- Local voluntary bereavement service
- A counsellor, psychotherapist or private psychologist
- A psychiatrist or other mental health professional
- I tried to get support but there was no service available to me
- I wanted to get support but I didn't know where to go
- I didn't need support from a professional or support service
- Someone/somewhere else (please specify) _____

B11. Other than the person you have answered about, did anyone else close to you die during the pandemic?

- Yes **Please answer Question B11a**
- No **Please go straight to Question B12**

B11a. Please tell us about the other person/people close to you who died during the pandemic (tick all of the boxes that apply).

- My spouse or partner
- My mother
- My father
- My son
- My daughter
- My brother
- My sister
- My grandchild
- My grandmother
- My grandfather
- My aunt or uncle
- My parent-in-law
- My sister- or bother-in-law
- My friend
- My colleague
- My neighbour
- Someone I provided care for (e.g. a resident, patient or client)
- Someone else close to me (please specify) _____

Section C: About you

In this section, we are interested in knowing some details about you. This will help us understand how different groups of people have been affected during the pandemic.

C1. How would you describe your gender?

- Male Female Other/Non-binary Prefer not to say

C2. How would you describe your ethnicity?

- Irish Irish Traveller Any other White background
 Black Irish Any other Black background Asian Irish
 Any other Asian background
 Other (please specify) _____

C3. What age are you?

Insert here. _____

C4. Which of the following best describes the general area you live in?

- Urban Suburban Town Rural

C5. Which of the following best describes your relationship status?

- Single, never married Cohabiting (i.e. living with) with a significant other
 Civil partnership or married Separated or divorced Widowed

C6. Which of the following best describes who do you live with?

- I live alone I live with my family
 I live in shared accommodation I live in a care or residential setting
 I live in a Direct Provision centre I'm homeless
 Other (please specify) _____

C7. The following question asks about your health.

	Very good	Good	Fair	Bad	Very bad
How is your <i>physical health</i> in general? Is it...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How is your <i>mental health</i> in general? Is it...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C8. How well would you say you yourself are managing financially these days?

- Finding it very difficult
- Finding it quite difficult
- Just about getting by
- Doing Alright
- Living Comfortably

C9. Were you involved in providing any kind of care to people with serious illness or who were dying during the pandemic?

NOTE: Care for someone can include *direct care* (e.g. family, nursing, medical, allied health or other support to a person in a healthcare or home setting) and *indirect care* (e.g. working as a porter or domestic staff in a healthcare setting, etc.).

- Yes **Please answer Questions C9a and C9b**
- No **Please go straight to End of Questionnaire**

C9a. Which of the following best describes your role?

- Family carer
- GP
- Other doctor
- Nurse
- Allied healthcare professional
- Paramedic
- Support staff in healthcare or residential care setting (portering, catering, admissions, etc.)
- Residential support worker
- Trained home support worker
- Chaplain or other religious/spiritual support
- Volunteer
- Other (please specify) _____

C9b. Which of the following best describes the setting where you provided care?

- Family care
- General practice
- Specialist palliative care
- Acute healthcare setting
- Community healthcare
- Residential care
- Home support services
- Social care
- Other (please specify) _____

End of Questionnaire

Thank you for taking the time to complete this questionnaire.

Please return your completed Time to Reflect Questionnaire to:

Time to Reflect Survey
Irish Hospice Foundation
Morrison Chambers (4th Floor)
32 Nassau Street
Dublin 2
D02 YE06

Please remember that our **Bereavement Support Line** provides support to anyone affected by bereavement, whenever that bereavement happened and whatever the cause.

You can call the line **Monday-Friday from 10am-1pm** using the freephone number **1800 80 70 77**.





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Morrison Chambers, 32 Nassau Street,
Dublin 2, D02 YE06

hospicefoundation.ie
info@hospicefoundation.ie

Registered Charity 20013554
CHY 6830