

# **The Economic Impacts of Bereavement in Ireland: An Exploratory Qualitative Study**

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## Contents

<b>ACKNOWLEDGEMENTS</b> .....	<b>1</b>
<b>RESEARCH TEAM MEMBERSHIP</b> .....	<b>2</b>
<b>EXECUTIVE SUMMARY</b> .....	<b>3</b>
<b>1.0 INTRODUCTION</b> .....	<b>5</b>
1.1 BACKGROUND TO THE STUDY .....	5
1.2 STUDY OBJECTIVES .....	7
<b>2.0 METHODOLOGY</b> .....	<b>7</b>
2.1 APPROACH TO SAMPLING .....	7
2.2 DEMOGRAPHIC PROFILE OF STUDY PARTICIPANTS .....	8
2.3 DATA ANALYSIS .....	9
<b>3.0 FINDINGS</b> .....	<b>10</b>
3.0.1 OPENING STATEMENTS .....	10
<b>3.1 GROUPS AT RISK OF ADVERSE ECONOMIC IMPACT DUE TO BEREAVEMENT</b> .....	<b>11</b>
<b>3.2 PLANNING TO MITIGATE THE ECONOMIC IMPACTS OF BEREAVEMENT</b> .....	<b>13</b>
<b>3.3 FUNERAL COSTS</b> .....	<b>17</b>
3.3.1 FUNERAL AND BURIAL RELATED COSTS .....	17
3.3.2 ECONOMIC IMPACT OF INDIVIDUAL CHOICES .....	18
3.3.3 FUNERAL CULTURE .....	19
3.3.4 GEOGRAPHICAL DISPARITY .....	20
3.3.5 PAYING FOR FUNERALS .....	21
3.3.6 ROLE OF FUNERAL DIRECTORS AND OTHER PROFESSIONALS .....	23
3.3.7 SOCIAL WELFARE SUPPORTS FOR FUNERAL COSTS .....	25
<b>3.4 HOUSEHOLD INCOME AND EMPLOYMENT STATUS</b> .....	<b>29</b>
3.4.1 CHANGES TO HOUSEHOLD INCOME .....	29
3.4.2 ACCESSING OTHER SOCIAL WELFARE PAYMENTS .....	29
3.4.3 EMPLOYMENT TENURE AND PROGRESSION .....	31
3.4.4 EMPLOYMENT PROSPECTS FOR BEREAVED CHILDREN/YOUNG ADULTS .....	32
<b>3.5 MITIGATING HEALTH-RELATED ISSUES AND ASSOCIATED ECONOMIC IMPLICATIONS</b> .....	<b>33</b>
3.5.1 NEED FOR MENTAL HEALTH SUPPORTS .....	33
3.5.2 AVAILABILITY OF COUNSELLING SUPPORTS .....	34
<b>3.6 OTHER COSTS OF DEATH &amp; DYING</b> .....	<b>36</b>
3.6.1 COSTS ASSOCIATED WITH CARING AT END OF LIFE .....	37
3.6.2 CHILDCARE COSTS .....	38
3.6.3 IMPACT OF ANTICIPATORY GRIEF .....	38
3.6.4 LEGACY DEBTS .....	39
<b>4.0 DISCUSSION AND CONCLUSION</b> .....	<b>40</b>
4.1 INTRODUCTION .....	40
4.2 GROUPS AT RISK OF ADVERSE ECONOMIC IMPACTS OF BEREAVEMENT .....	40
4.3 PLANNING AHEAD .....	41
4.4 THE ECONOMIC IMPACT OF FUNERAL EXPENSES .....	43
4.6 ECONOMIC IMPACTS OF BEREAVEMENT ON HOUSEHOLD INCOME .....	45
4.5 HEALTH RELATED COSTS .....	46

4.6 OTHER COSTS ASSOCIATED WITH DEATH AND DYING.....	46
CONCLUSION.....	47
<b>5.0 RECOMMENDATIONS .....</b>	<b>47</b>
<b>5.1 PARTICIPANT RECOMMENDATIONS.....</b>	<b>47</b>
1. FINANCIAL ASSISTANCE .....	47
2. ACCESS TO COUNSELLING.....	48
3. INFORMATION BOOKLET .....	48
4. BEREAVEMENT INFORMATION SERVICE .....	48
5. EDUCATION.....	49
6. FUNERAL DIRECTORS.....	49
<b>5.2 RESEARCH TEAM RECOMMENDATIONS.....</b>	<b>49</b>
<b>REFERENCE LIST .....</b>	<b>51</b>
<b>APPENDIX 1: RESEARCH ADVISORY GROUP .....</b>	<b>53</b>
<b>APPENDIX 2: ECONOMICS OF BEREAVEMENT INTERVIEW TOPIC GUIDE .....</b>	<b>54</b>

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The opinions expressed in this report are of the research participants and research team and are not necessarily those of the Department of Social Protection, the Irish Hospice Foundation or University College Cork.

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## Executive Summary

Approximately 80 people die in Ireland daily (30,000 annually) and between four and ten people are significantly impacted by each bereavement. For some these impacts are temporary, while for others they can significantly impact on the ability and capacity to continue with daily life. These impacts are multifactorial and intertwined, and their severity often depends on context of the death and existing personal and economic situation. This report outlines the key findings of a qualitative study exploring the economic impacts of bereavement from the perspectives of people who have been bereaved and professionals supporting them. The study was commissioned by the Irish Hospice Foundation (IHF) and funded by the Department of Social Protection.

Primary data was collected using individual interviews with people who were bereaved in the last three years and focus groups with professionals who support bereaved individuals in September and October 2021. The interviewees (n=7) were all female, aged 35-60, 86% were in employment and they had experienced the death of a child, spouse or parent in the past three years. Four focus groups were conducted with professionals (n=24) working in a variety of public, commercial and voluntary organisations.

Study participants emphasised that the impact of bereavement is complex and multifaceted. While acknowledging the adverse economic impacts of bereavement, participants highlighted how these were intertwined with the emotional impact of bereavement. The interviewees described their lives before and after the loss of their loved one and indicated that their lives would never be the same.

Bereavements always have some form of economic impact, however particular groups in society are more susceptible to being adversely impacted by these. These include older widowed pensioners; full time carers; families with young children, particularly where the parents were co-habiting (not married); members of the Travelling Community and migrants.

Several factors increase the risks of adverse economic impacts. These include lack of preparedness for immediate funeral costs as well as longer-term household income and budgeting, and access to financial supports and support services, including counselling.

Funeral costs vary depending on the variety and type of services employed, often driven by cultural expectations and personal preferences. In addition, there are regional disparities in costs across the country. For example, burial plots in Dublin are more expensive than elsewhere. State financial support is available for funeral costs through the Exceptional Needs Payment (ENP). However, these payments often fall short of the full costs of the funeral, and participants expressed concerns with regards to awareness about and difficulties accessing ENPs. Where individuals spend beyond their means on funerals, they can accrue debt and experience funeral poverty.

Following a bereavement there is a direct impact on household income, particularly if the deceased was the main or sole earner. Furthermore, where one parent dies the surviving parent needs to balance the needs of dependent children, their own grief and employment. While some may be able to return to work their career focus may lessen impacting career progression, elsewhere people may reduce their working hours or drop out of the workforce. The latter may have to rely on savings or state supports and often seek assistance from MABS, Department of Social Protection and charities.

The availability of local, timely and affordable counselling supports was highlighted as imperative to assist bereaved family members managing their grief and to mitigate longer-term health and economic impacts of bereavement.

The economic impacts of bereavement can have long-term effects, possibly exasperating prior economic hardship arising from care at end-of-life, anticipatory grief, legacy debts etc. While supports are available for bereaved individuals there appears to be access barriers in terms of a lack of awareness about entitlements and difficulties navigating systems.

To support bereaved individuals and their families, accessible, appropriate, locally based services are essential to mitigate the economic impacts of bereavement.

## 1.0 Introduction

This report outlines the key findings of a qualitative study, undertaken to explore the economic impacts of bereavement from the perspectives of people who have been bereaved and professionals supporting them. The study was commissioned by the Irish Hospice Foundation (IHF) and funded by the Department of Social Protection. It forms part of a larger programme of research on the economics of bereavement that the IHF is managing. The study was overseen by a Research Advisory Group (Appendix 1).

### 1.1 Background to the study

Approximately 80 people die every day (30,000 annually) in Ireland. Bereavement is when someone experiences the death of someone close to them. Each bereavement affects a range of family members and friends, and it is estimated that between four and ten people are significantly impacted by each bereavement. This means that up to 6% of the Irish population are impacted by grief and bereavement on a daily basis (McLoughlin, 2018).

Bereavement is associated with intense distress for some people. The term grief is primarily applied to the emotional reaction to the loss of someone significant through death. Bereavement and grief can significantly impact on the individuals' ability to continue with their daily lives. The extent of this impact is influenced by several factors including:

- The nature of the relationship between the deceased person and the bereaved individual
- Cause and nature of death
- Support networks available to the bereaved person
- Personal characteristics of the bereaved individual including age, outlook, personality, beliefs, resilience and previous experiences of loss
- Other factors (financial strain, caregiving responsibilities, access to social support) (McLoughlin, 2018)

Given the distress associated with bereavement, it is not surprising that the 'consequences of bereavement' are a key theme in bereavement research. Some long-term impacts of bereavement, such as psychological distress, mental and physical health problems have been well documented. While the need to broaden the focus beyond health consequences has been highlighted (Stroebe et al., 2008), the economic consequences associated with bereavement are often overlooked.

The economic impacts of bereavement are a relatively new and emerging topic of interest in research on bereavement. For example, in a recent Irish study, McLoughlin (2018) highlighted that bereavement is often accompanied by financial and economic impacts for those who have been bereaved. These economic impacts are multifactorial, impacting on the physical, psychological, emotional and mental health of individuals (Genevro & Miller, 2010; Stephen et al, 2015; McLoughlin, 2018).



Bereavements have a varied impact on people's financial situation. From an Irish perspective, in a population-based bereavement survey conducted by Amarach Research on behalf of the IHF (Aoun et al., 2020) the majority of respondents (80%) indicated their financial situation 'remained the same' or 'improved' following a bereavement. However, 14% of respondents reported that their financial situation was 'a bit worse', and 6% that it was 'a lot worse' following a bereavement.

A range of costs are associated with bereavement, including direct financial costs. For example, following a death there are funeral expenses. For some, financial support is needed to help with the costs of a funeral, to avoid or mitigate funeral poverty. In Ireland, the Exceptional Needs Payment,(ENP)<sup>4</sup> is a single state payment available to help meet essential, once-off exceptional expenditure which a person could not reasonably be expected to meet out of their weekly income. It can be sought by people on low incomes for funeral related expenses. Between 2016 and 2019 there were 11,000 ENPs for funeral costs, representing up to 9% of annual deaths. The average amount paid out per ENP for the period was €1,852<sup>5</sup>.

Indirectly, bereavement can impact on household income and employment. The death of a partner can impact on the employment of the bereaved person, which can vary according to people's circumstances including gender, age, health status, the nature of the death, and workplace flexibility. One Scottish study found that bereaved individuals were less likely to be in work two years' post-bereavement (Stephen et al. 2015). On the death of a partner, some people may experience a reduction in household income, resulting from the loss of the partners' earnings, loss of savings and investments, or loss of state pension or changes in state benefits. Following the death of a child, families' incomes can drop as much as 72% and funeral poverty is a concern (Corden et al 2016). Furthermore, the loss of a child increases the probability of parents leaving the labour force owing to declined mental health (Van den Berg et al 2017).

Bereavement, especially spousal bereavement, has been associated with poorer health outcomes, which may lead to higher utilisation of and increased spending on health care by the bereaved person. Medical costs arising from increased morbidity and mortality, such as increased health care utilisation (primary and secondary care), home care, and non-medical costs such as travel to doctors' appointments, productivity losses and intangible costs related to a loss of satisfaction are all costs that can be associated with bereavement (Genevro & Miller, 2010; Stephen et al, 2015; McLoughlin, 2018). Counselling services are available, but waiting lists and affordability are key barriers to access. Again, here the extent of the economic impact of bereavement has been linked to the nature of the relationship between the the person who has died and the bereaved person. For example, a Scottish study found that spousal bereavement was associated with increased hospital stays costing between £16 and £23 million per year and increased primary care consultations costing approximately £2 million per year (Stephen et al. 2015).

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<sup>4</sup> An Exceptional Needs Payment is a single payment to help meet essential, once-off, exceptional expenditure, which a person could not reasonably be expected to meet out of their weekly income. See here: <https://www.gov.ie/en/service/80b24c-exceptional-needs-payments-swa/>

<sup>5</sup> Approximately 31,000 deaths annually in Ireland (CSO, 2021), average 2,778 ENPs annually 2016-2019.

To conclude, it is evident that bereavement and grief impact significantly on individuals, in terms of their ability to continue with their day-to-day lives. However, the economic impacts of bereavement and the role of supports in minimising these economic impacts are often overlooked. This report presents the findings from a study exploring the economic impacts of bereavement from the perspectives of people who have been bereaved and professionals supporting them in Ireland.

## 1.2 Study Objectives

The overall aim of the study is to explore the economic impacts of bereavement from the perspectives of the bereaved and professionals supporting them, in an Irish context.

To meet this aim, several specific objectives were identified:

- To describe the economic impact of bereavement on a variety of cohorts, including those who have been bereaved and those providing services to support the bereaved.
- To provide insights into how bereavement can lead to economic disadvantage.
- To identify policy and practice implications for organisations supporting people who are bereaved.

## 2.0 Methodology

A two-pronged approach was used to identify participants for this exploratory qualitative study. Individual interviews and focus groups were employed to gather data on the experiences of participants, comprised of both bereaved individuals and professionals who support them.

### 2.1 Approach to sampling

First, this study sought to identify and interview bereaved individuals across the lifespan. This included those:

- (1) aged 18 years and over (categorised into three age groups: 18-34 years, 35-64 years, 65+ years)
- (2) who have been economically impacted by bereavement in the past 3 years.
- (3) type of cost impact, i.e., funeral costs, loss of income, employment-related costs, and health-related costs

Second, the study sought to identify professionals who:

- (1) Work for service provider organisations supporting people who have been economically impacted by bereavement
- (2) Have supported individuals' experiencing adverse economic impacts because of a bereavement over the past 3 years

Ethical approval for the study was granted by the Social Research and Ethics Committee at University College Cork in August 2021. Data protection legislation and relevant data management principles were adhered to throughout the study.

Organisations that could assist with identifying and recruiting potential study participants were approached linked with the UCC research team through IHF staff.

Within each organisation assisting with the study, a person was nominated to liaise with the UCC research team and support recruitment and, if needed, provide support to study participants. An information pack was developed by the research team and made available to nominated persons. It included invitation letters and participant information sheets, for circulation to potential study participants.

From an ethical perspective and given the topic's sensitivities it was decided that bereaved individuals would only be approached by staff in these organisations, who were directly in contact with them. This safeguard proved to be important during the recruitment phase as two individuals who initially agreed to participate later withdrew as they did not feel able to proceed. They were able to discuss their concerns with this liaison person, who then conveyed their decision to the research team. In one organisation, individuals who were identified as potential liaisons, indicated that due to changes in work practices, they did not have enough direct contact with bereaved individuals to support them and therefore declined to be involved in the recruitment process. These factors impacted on the recruitment process, leading to a smaller than anticipated sample size.

Focus group participants were recruited through a range of service providers including the Department of Social Protection, Money Advice and Budgeting Service (MABS), St Vincent de Paul, Citizens Information Board, the IHF Hardship Fund, Irish Association of Funeral Directors, campaigning/advocacy groups in this area and the Irish Neonatal Healthcare Alliance or through links with the IHF. All focus group participants either represented organisations supporting economically disadvantaged individuals or had supported someone who had been economically impacted by bereavement in the past three years. For example, funeral directors were engaging with bereaved families daily, as were social workers attached to several in-patient services across Dublin. Whereas, for representatives from MABS, Citizens Information Services and Department of Social Protection representatives, bereaved individuals were one of many groups to whom they provide services.

In reporting the findings of this study, we have honoured the data provided by the participants and retained the exact terminology they used. Foot notes are used to reflect updates and clarifications as required.

## 2.2 Demographic Profile of Study Participants

### (1) Individual interviews with people economically impacted by bereavement.

Individual, semi-structured interviews were conducted online in October 2021, with individuals experiencing economic impacts owing to bereavement (n=7). All participants were female, aged between 35 and 60 years of age (males and those in the 18–34-year age group are not represented in the sample). All participants were educated to Leaving Certificate level or higher.

Most individuals (86%) were in either part-time or full-time paid employment, the remaining participant worked full time in the home. These individuals lived in various locations across Ireland.

The individual participants had lost either a child (at the perinatal stage and after birth), a spouse or a parent in the past three years. The average length of interviews was approximately 55 minutes, (ranging from 35 to 75 minutes). The interviews were guided by a topic guide (see Appendix 2).

(2) Focus groups with professionals supporting people economically impacted by bereavement.

Focus groups (n= 4) were undertaken with professionals (n=24) working in a variety of public, commercial, and voluntary sector services that support people who have been bereaved and economically impacted by bereavement. The focus groups were conducted online between September and October 2021. They were facilitated by the UCC research team and guided by a topic guide (see Appendix 2). During the focus groups, participants were asked to describe their role in supporting people who have been bereaved and to discuss their perspectives as to the economic impacts of bereavement in Ireland at individual, service, and societal levels.

**Table 1: Focus Group Participants**

<b>Focus Group Participant</b>	<b>Number of persons involved</b>
Citizens Information Services	3
Department of Social Welfare	4
European Anti-Poverty Network	1
Irish Neonatal Health Care Alliance	1
Money Advice and Budgeting Service (MABS)	3
Social Justice Ireland	1
Social workers	3
St Vincent de Paul	1
Funeral Directors	7
<b>Total</b>	<b>24</b>

### 2.3 Data Analysis

All individual interviews and focus groups were recorded and transcribed verbatim. Data analysis was iterative and concurrent with data collection. Both focus group and individual interview data were analysed using inductive thematic content analysis. Braun and Clarke's (2006) six step thematic analysis methodology was adhered to during the analysis process. All transcripts were thematically analysed by members of the research team, who followed the same process when analysing the data to ensure data management consistency. For quality assurance purposes, the codes and themes identified by individual team members for three focus groups and three interviews were independently reviewed by other members of the team. The findings of this qualitative exploratory study are presented in Section 3.

### 3.0 Findings

This section presents the findings of the study. Particular issues recurred during the individual interviews and focus groups and have guided the structure of this chapter. In addition to the common concerns or issues explored with families and reflected in the discussions with professionals, some concerns raised by professionals in the focus groups were not referred to by families (likely owing to small sample size).

Beyond the initial and most obvious costs associated with funerals, a range of other factors impacting the economic wellbeing of individuals were identified. A total of six additional overarching themes were identified. These were groups at risk of adverse economic impact due to bereavement; planning to mitigate the economic impact of bereavement; the impact of bereavement on income; the economic impact on employment; the cost of health related issues and the impact of costs accrued prior to bereavement.

The following abbreviations are used in the report:

- Family member (IP)
- Focus Group Participant (FGP)

#### 3.0.1 Opening Statements

At the outset, interview and focus group participants emphasised that the impact of bereavement is complex and multifaceted. While acknowledging the importance of addressing the adverse economic impacts of bereavement, those interviewed firstly spoke of the importance of recognising the emotional impact of bereavement on individuals and families, and how these impacts are intertwined. Bereaved individuals, when interviewed, spoke movingly of their loved ones, their children, partners, and parents and how their loss changed their lives completely. These individuals spoke of their lives before and after the loss of their loved one and indicated that their lives would never be the same.

“People say, ‘Oh in time you’ll get back to normal’. There isn’t a getting back to normal. There is a moving forward and bringing your memories with you. And it’s a new normal. And in that new normal, like we’ll never be the people we were before [name of person] died. And we don’t want to do that either. Because to do that is to betray the memory of something that’s very important” (IP2).

The professionals involved indicated that certain deaths such as a sudden death, the death of a child, of a young parent, death by suicide or death while a person is abroad can be particularly traumatic for those involved, advocating that bereaved individuals in this situation will need considerable support.

“If it’s a death of a young parent, children, if it’s a sudden death, an unexpected death, if it was suicide, if it was death that happened abroad, all of these factors are going to play in...[but] the loss of this person is the number one thing that is happening to people” (FGP 6).

While acknowledging the emotional impact of the loss of a loved one, the professionals were cognisant of the additional issues facing those economically impacted by bereavement.

“That emotional loss, trying to manage that as well as trying to deal with the financial costs on top of a bereavement can be incredibly significant for them” (FGP3).

Bereaved individuals too indicated that the stress of dealing with the economic impact of bereavement, extends beyond just managing finances.

“It’s not all about money, it’s the hidden stress, the psychological impact of working around it” [managing financial issues after a person has died] (IP4).

While professionals and bereaved individuals had considered and, in many cases, had first-hand experience of the emotional and economic impacts of bereavement, they believe general societal awareness and acknowledgement is lacking. It was felt that the long-term economic impacts of bereavement on people need to be recognised and understood if those impacted are to have a chance to reach their full potential in the future. To address this and to inform the design of better supports for those economically impacted by bereavement, the study participants identified a diverse range of concerns, reflective of the economic complexities facing bereaved individuals and the professionals supporting them.

### 3.1 Groups at risk of adverse economic impact due to bereavement

Professionals supporting people who have been bereaved believed there will always be some form of economic impact for every person who has been bereaved.

“[A] bereavement is an additional expense no matter what way you look at it ... even very well-prepared people, they are going to leave some expenses behind, ...so whatever your means are [it] still doesn’t mean that you can cover these additional unexpected expenses [such as paying for the funeral]” (FGP2).

However, certain sectors in society are more at risk of being adversely impacted by these costs.

“The economic impact is greater on those who come from economically challenged situations to begin with because those who are better economically off often have support networks, better education and better ability to research for themselves” (FGP16).

Study participants identified a range of groups and circumstances where bereavement was most likely to have an adverse economic impact. One such group are widowed pensioners reliant on the state pension. For them, the loss of one pension can significantly impact the household economic situation. Furthermore, recently bereaved pensioners may need support in understanding and applying for applicable social welfare payments, which can take a considerable amount of time. In the meantime, money will be needed to ensure bills are paid etc, and, to bridge this gap, other family members may have to step in and provide financial support.

“A year and a half down the road, we still don’t have my mother’s pension sorted out” (IP4).

Full time carers are also an economically vulnerable group following the death of the person they cared for. A number of specific payments are available to carers including Carers Benefit, Carers Allowance and the Carers Support grant. Individuals who have forgone paid employment to care for a person before they died, are entitled to Carers Benefit. Those on low incomes or who work less than 18.5 hrs a week can be entitled to Carers allowance, subject to a means test. Carers benefit will continue to be paid for up to 6 weeks after the death of the person being cared for and Carers Allowance continues to be paid for 12 weeks after the death of the person being cared for. Thereafter, carers must either re-join the workforce or apply for an alternative social welfare payment, subject to eligibility requirements.

“[M]aybe the bits they’ve saved over their lifetime are gone and they get their Carer’s Allowance which has been propping things up but then ... the payment stops it’s just another [financial] drop” (FGP3).

Also, where a carer such as an adult child was residing with the person who died, accommodation issues can also arise if the house needs to be sold. This may occur for a variety of reasons ranging from the need to pay outstanding debts or issues relating to inheritance.

“[I]f it was ... an adult child caring for her mum in the family home, when the parent dies, the rest of the family would want to sell the house and, in some cases, it can make the person homeless or trying to get accommodation” (FGP3).

The economic impact of bereavement on young families was highlighted by professionals and bereaved individuals. Specifically, the economic impact of the death of a partner (who is a parent) on a family with young children can be significant, as the family adjusts to life without their loved one, and the loss of their income. Where the deceased person was the sole wage earner, these families can be left in precarious financial positions.

“The income is halved but the outgoings are still the same and that has a huge impact on people” (FGP 10).

This economic impact escalates if the bereaved parent cannot work due to the impact of the bereavement on themselves and/or their dependents. Practical issues such as child minding and/or emotional supports for children going through the grieving process, and/or the mental health impacts of the bereavement on both the parent and child(ren) may prevent the surviving parent from returning to paid employment:

“You can imagine a couple with dependent children... they’re paying a mortgage, household, things for children and so on. So, the death of one of those partners is going to have a very big impact on that household in terms of income and child support...the surviving partner may have to give up work or reduce their hours” (FGP6).

Within this cohort co-habiting couples with young children where one parent dies were identified as disproportionately economically impacted in comparison to couples who are married or in a civil partnership. Like married couples, the household will lose the wage of the deceased person. However, cohabiting couples do not possess the same legal rights and obligations as couples married or in civil partnerships. The limited legal recognition of cohabiting couples can have significant implications with regards to social welfare and other entitlements. Bereaved individuals who had been in a cohabiting couple were referred to by participants in focus groups as being “invisible in the system”.

“She is not entitled to a widow’s pension; she’s not entitled to the lump sum that would be given if they had been married...her only entitlement is to look at applying for the one parent family payment” (FGP16).

In such situations the surviving partner of a co-habiting couple with children are eligible to apply for the One Parent Family Payment. However, this is not an accurate representation of the household and the deceased and can cause psychological distress, further affecting their bereavement experience, as they feel the role of their deceased partner is not acknowledged.

“There’s a certain embarrassment as well [about] ... being told that they have to apply for one parent family..., some people don’t want to do that because [they’re] saying I’m not a single parent family, my partner has died” (FGP16).

People from migrant communities, particularly those who are undocumented, were identified as another group at risk of adverse economic impacts after a bereavement. Some of these individuals have limited entitlements to statutory social welfare supports and can find themselves in particularly difficult economic situations, without family support.

“[I]t sends them into quite a spiral of debt over indebtedness and that on top of being bereaved” (FGP17).

Department of Social Protection representatives indicated, that in many instances, bereaved individuals from migrant communities can get lost in the system.

“They just drift out of the net, end up going back to their home country ... and suffer disproportionately because of their lack of access to support networks” (FGP16).

### 3.2 Planning to mitigate the economic impacts of bereavement

The issue of preparedness was consistently raised in focus groups and individual interviews, in terms of its role in helping people mitigate and manage the economic impacts of bereavement in the short-term. Study participants pointed out that some individuals and households have the financial capability to absorb the economic impact of bereavement, but others will be significantly impacted and require supports.



“From where we were standing, it wasn’t a huge sum of money [to pay for the funeral] because €6,000 or €7,000 which is a huge sum of money to others, wasn’t going to be a huge sum of money to our family, given our jobs and our economic needs” (IP4).

The families of people who had planned for their funeral and its costs were identified as being able to absorb the immediate costs associated with a bereavement. The experience of many focus group participants was that older people are more inclined to plan and pre-arrange their funerals, including arrangements for the associated costs using insurance policies or savings. Furthermore, immediate family members of older deceased persons are also of an older age profile and may be better insulated against the economic impact of a bereavement and have access to funds to pay for funeral expenses.

“I suppose in the normal course of events where an older person would have passed away there possibly was savings, some of them might have put money aside, maybe the family are more mature or older, so they probably are in a better position to cover the funeral costs” (FGP7).

However, both bereaved individuals and professionals supporting them were of the view that many individuals are not prepared for the economic impact of bereavement on their lives, often leading to chaotic situations for them and their families.

“Death causes [financial] chaos [in families]” (FGP11).

According to the professionals, several excellent resources are available to support people to plan ahead, including those developed by the Irish Hospice Foundation. When encouraged by professionals to plan, many families were open to using these resources. However, despite encouragement, they were of the view that most people do not plan. This lack of planning can place a significant burden on bereaved individuals, as they try to come to terms with the economic impact of bereavement on their lives.

“[T]he fantastic resources from the hospice foundation but if they don’t [use them], that leaves a huge burden on those left behind” (FGP2).

Several reasons were identified by study participants to explain why families do not plan ahead either for the funeral costs or other indirect costs associated with bereavement. Reasons included cultural issues, reluctance within families to discuss the issue and prioritisation of other issues.

With respect to cultural issues, professionals felt that Irish people do not want to talk about death and dying, resulting in economic issues that could be addressed in advance not being dealt with before the person dies.

“[I]t’s an Irish thing, I think they don’t want to talk about death, so as a result there’s no planning or financial planning put in place for it either; then all of a sudden it happens [ the person dies]” (FGP3).

Study participants referred to meeting individuals who wanted to plan ahead but had encountered resistance from their own family members when they tried to put arrangements in place. This had been the experience of a bereaved person in this study, who had wanted to prepare, but could not do so, as her loved one, even though terminally ill, did not want to engage in the process. The interviewee attributed this to her partner's preference to focus on prolonging his life, as opposed to planning for his death.

“We had made a will a couple of months prior [to his death]. [Name of deceased person] didn't want it, I pressed for it because I wanted to know his wishes. ... So, he was pushing not to do it and I was pushing him to do it I didn't want to come closer to the time when he was really ill and ask him to do something so serious” (IP3).

Study participants noted some people are reluctant to make changes relating to names on utility bills, bank or credit union accounts or learning to manage household budgets. Traditionally, there has been a tendency in Ireland to have only one individual's name, usually a man's, on utility bills, such as electricity or telephone bills. This is obviously an issue for single person households as well. Participants suggested that there was almost a fear amongst some older people that planning ahead was tempting fate; that putting arrangements in place such as changing or adding a name to bills would “hurry up” the death of the other person.

“I suppose, culture, custom, when household bills are only in one name – the surprise expressed by the elderly ... “what? I should put my name onto it, but they always took care of that” and you explain [that] putting these arrangements into place won't cause the other person to drop down, it's just good housekeeping practice” (FGP5).

Failure to make these changes creates difficulties for bereaved individuals. A bereaved person who cannot gain access to the bank account of the deceased person may have to borrow money until the death certificate has been issued, probate completed and access to the bank account has been granted. Those working in utility companies and financial institutions also face challenges when trying to assist these individuals to access accounts and manage their financial affairs.

“[T]he front teller has a wild job trying to support a bereaved person... what's in the account, who has access, all of that, so it's very difficult” (FGP4).

Furthermore, in households where the deceased person had taken on all of the responsibility for managing household finances, the bereaved person can be unprepared or ill-equipped to take on financing and budgeting duties and is left trying to figure out the rudimentary elements of budgeting at a difficult time in their life.

Additionally, some participants pointed out that financially planning ahead for a death is not regarded as a priority issue by everyone, especially people in younger age groups.

“Some do, some are great. We’ve had families in and like that again they just want to do that, and have it sorted and forget about it, of course for others [their] just trying to get through the day to day, it’s not [a priority], especially in your 40s, you’re not thinking Jesus I better put something together for the funeral” (FGP7).

Study participants highlighted that there are some circumstances where there is little or no opportunity to plan ahead, such as a sudden death that was completely unexpected. This was linked most often to the death of a child or a peri-natal death.

“... so we need to remember that not every family has the opportunity to plan, even if they want to so that’s really important to remember” (FGP3).

Finally, professionals participating in the focus groups expressed concern about people’s understanding of the financial legalities associated with bereavement. It was suggested that people often did not realise that debts would have to be paid from the person’s estate.

“There was and I don’t know why this this understanding that [when] you die, your debts die with you and obviously that’s not the case” (FGP2).

More broadly, it was suggested that many people, and particularly people on lower incomes, did not fully understand the legal complexities around a deceased person’s estate. It was felt that people with means had more insight and awareness of these issues. So often people were shocked and upset when told that the cost of funeral, for example, had to come from the deceased person estate.

“Maybe people with money understand, who are used to probate and estates and wills who have what we would call assets to leave ... but people on limited incomes don’t see their house as their estate or their insurance policy or their €10,000 that’s saved in the bank as their estate” (FGP13).

Department of Social Protection representatives participating in the focus groups felt that many people did not realise they would not be eligible for the ENP, if there was enough money in the deceased person’s estate, to cover the costs of the funeral. This was especially true, if the deceased person had bequeathed money to their loved ones, who were under the impression they would have this money immediately after they died. As a result, the situation can be very emotive for families involved.

“And I’ve come across say where people say, “well no that money was intended to be divided between the children or that money was intended for us all to do something in memory of Mammy or Daddy or whoever” and we’re saying, “well I’m sorry but it’s there, it’s enough money to pay for the funeral” and they get quite a shock to think that the money that the deceased left has to be used for the funeral...it’s a delicate thing”(FGP1)

Assumptions about debts dying with the person and a lack of understanding of legal matters relating to death, contribute to individuals not effectively planning ahead. The professionals in the focus group felt that solicitors should play a greater role, in making sure, that when making a will, all parties involved were fully au fait with not just the legal but the economic aspect of their estate.

### 3.3 Funeral costs

The economic impact of bereavement also includes the immediate financial costs associated with funerals.

In the focus groups and interviews, study participants spoke about a wide range of issues related to funeral costs including the importance and expense of funerals, influence of individual choices and cultural expectations, geographical disparities in costs, paying for funerals, the role of funeral directors and other professionals, and social welfare supports for funeral costs.

#### 3.3.1 Funeral and Burial Related Costs

There are a range of costs associated with funerals, many of which were identified by study participants including the cost of a grave, funeral directors' and disbursement costs, such as the cost of flowers, the grave digger, the ceremony officiator, cremation, and hospitality services if refreshments are provided after a funeral. Awareness of these costs varies from very little to very comprehensive.

“The double plot that will cost €1,600 and the single plot will cost €800 you know this type of thing. So, by the time you pay the singer, I think we paid the singer €500, the plot was €800, the funeral directors like, they didn't charge us for the coffin like they were very good in fairness, but you do have to pay for engraving because someone else does that, now it's €70 or something. The car, we had to get a car. Then you have the priest, the person that helps the priest, the sacristan ..., the musician like, the gravedigger, I'd mean I'd say you're probably talking a couple of grand ya know probably coming up 3 or 4 grand” [IP6].

Study participants identified the purchase of a burial plot as a significant cost for bereaved families. In some instances, bereaved people may have access to a grave, already owned by the family and will choose to bury their loved one there, thus lessening the economic impact of the funeral.

“The other kind of decision was where to lay [name of deceased person] to rest. My husband's family had a single plot where my husband's grandparents were, so we did get to use that plot, which saved on costs as we didn't have to get a new plot” (IP3).

Upon the death of a child, “Angel Plots” are available for families in some areas, at varying costs depending on location. However, for some families, the fact that their child might be sharing a grave with up to six other children can be extremely distressing and not appealing to them. For other families, they did not fully comprehend what an “angel plot” was, given the grief and trauma they were experiencing and therefore did not consider burying their child there at the time.

“We were told like ye can bury her in the angel’s plot or you can bring her home and bury her in a private plot. But again, I had no idea what an angel’s plot even was ... I had no idea, now I know Glasnevin is gorgeous and it’s a beautiful, beautiful area but I didn’t know anything like that at the time. I’m happy with my decision now” (IP5).

Headstones was also identified as a significant cost. Participants suggested headstones are becoming more elaborate and therefore more expensive.

“[T]he headstones themselves to me have got very elaborate, they’re huge, they’re costing absolute thousands and thousands of euros, and I don’t know if it puts pressure on other people maybe, [to buy elaborate headstone too]” (FGP1).

### 3.3.2 Economic Impact of Individual Choices

Participants made a distinction between families that are pragmatic about the costs of the funeral and those who are not, signalling the impact of individuals’ choices and preferences on funeral expenses.

“We [the family] are not the type of people to go for a gold-plated coffin with mother of pearl handles, we’d be sensible that way” (IP4).

For families who are less pragmatic about costs, funeral costs can rise significantly beyond their means, leading to funeral poverty and future economic difficulties.

“[This love is shown] in the forms of these ... big, huge wreathes and all that but they cost a fortune, I mean you’re talking thousands extra on top of the standard costs of a funeral...but it’s a choice they make but they haven’t got the money to pay for it” (FGP4).

For bereaved parents’ certain aspects of the funeral and the burial of their child have a specific significance. Families referenced the headstone, and its importance as a tribute to their child. They indicated it is of great importance to parents to get the right headstone, irrespective of cost.

[T]his is the only tribute as a parent, that I can do something as a parent for my child is put up a headstone and you want to get that right, you want to get the wording right, you want to get the right one... I spent €x,xxx on the headstone” (IP7).

In some instances, families may be too traumatised to comprehend the costs, associated with the choices they are making at the time, and are not best positioned to retain information and make decisions, including financial decisions, even with support.

“[P]eople are in shock, they’re traumatised, they don’t know what kind of conversations they’re having with funeral directors and then they’re coming back into us with bills of ten, fifteen thousand, no idea where these expenses and costs came from and are completely overwhelmed” (FGP5).

### 3.3.3 Funeral Culture

Study participants felt there is a strong cultural significance attached to how funerals are conducted in Ireland and that Irish people, in general, do funerals well. Bereaved individuals appreciate family and community members' supports.

“Culturally for the Irish we do funerals and send offs really well. It’s just an interesting cultural aspect around how we send off people really well. They say I remember meeting so and so at the mother’s funeral or the father’s funeral and it meant the world to me that they turned out” (FGP5).

Reflecting on the importance of the funeral in Irish society, one bereaved interviewee spoke of her upset at not being able to give her father a traditional funeral due to the Covid-19 epidemic.

“We [the family] felt very robbed of a proper country funeral, for my father, they would have come from far and wide [to the funeral]” (IP4).

For the families involved, organising their loved one’s funeral can be an emotional experience and the funeral itself is perceived as a tribute to the person, and reflective of the deep love felt for the person who has died. For many people it is important to ensure an individual has a respectful send-off, irrespective of whether it results in debt.

“It’s got that real import[ance] to it that if you get yourself into debt well, at least ya got the send-off done ya know? I think that’s quite important for a lot of people irrespective of background and culture” (FGP2).

However, participants indicated that meeting specific cultural expectations whilst trying to avoid incurring debt can be particularly difficult. One bereaved interviewee in extremely challenging financial circumstances used a “go fund” page on Facebook to pay for the funeral of a loved one, explaining that she raised and used the money solely to ensure all the deceased person’s wishes for his funeral had been fulfilled.

“I never touched it, I kept it all for [name of deceased person] to finish off his grave and everything properly. His wishes like, a couple of the most random things, So, I did, I got a headstone out of that money as well. I kept the money until I could get planning permission to do that” (IP 2).

The pressure families feel to ensure their loved ones get a respectful burial is significant and many will go into debt to do this. It was suggested that in many ways, bereaved families almost need someone to step in and give them “permission” not to go into debt to pay for the funeral.

“[Families need] some permission [around not needing to spend a fortune on funerals, that can go a long way as well I think [to mitigate the economic impact of bereavement].” (FGP4).

Participants recognised that certain communities, such as the Travelling Community, incur significant debt due to cultural expectations around a funeral. The economic needs of these communities are recognised by organisations such as the Money Advice Budgetary Services (MABS) who offer support. However, in some cases, people feel forced into having big expensive funerals due to the weight of expectation of those in their local communities and addressing these cultural issues can be challenging.

“Members of the Travelling Community, their way of having funerals is very different. It’s not a small affair, it’s whoever turn up is ya know is welcome, is fed and watered and all the rest. And that can be very expensive and comes along with a lot of other issues obviously” (FGP1).

Despite the expectations around funerals, those interviewed indicated that from a cultural perspective, Irish people are traditionally reluctant to engage in conversations about death and dying. This reticence has the knock-on effect of curtailing conversations about any of the financial costs associated with death and dying. However, focus group participants had noticed that people’s willingness to broach the subject of funeral expenses is changing, suggesting that people are more likely to ask about the price of the funeral now than in the past.

“We’re finding more and more now that people are actually looking for that even before we say it to them at the end they’ll actually so “like how much?” or “what is the cost of that?” (FG7)

### 3.3.4 Geographical Disparity

It was widely acknowledged by professionals and bereaved individuals interviewed that there are significant regional disparities in terms of the overall cost of funerals across the country. In some instances, the reasons for these disparities are well known. For example, focus group participants made specific reference to the additional costs borne by people living in the Dublin region in comparison to the rest of the country for burial plots (linked to supply and property prices in Dublin versus rest of Ireland). As a result, the cost of a funeral varies from €5,000 to €10,000 according focus group participants.

“[People in Dublin would be] paying 6,7, 8 times that amount for a plot in Dublin [in comparison to other parts of the country]” (FGP15).

Elsewhere, in the case of the death of a child some county councils will not charge for a plot, if the child is under 18 months of age, as is the case with Kildare County Council, for example, but this is not practised nationwide. In other contexts, it is unclear why there are such disparities, despite their real economic consequences for the families involved, compounding their grief and economic situation, particularly for families already experiencing economic hardship. Focus groups participants accepted geographic disparities in costs and some queried why the level of the ENP was not reflective of this geographic disparity.

“we’d really have to look at the costs of funerals and how that varies across the country to ensure the type of support is responsive to the actual costs that people are faced with” (FGP4).

### 3.3.5 Paying for funerals

Bereaved families pay for funerals in a variety of ways. In some instances, it is planned, the deceased may have saved money or made other financial arrangements, or the funeral may be paid from the deceased person’s estate. Focus group participants also referred to insurance plans, for example “Life Savings Insurance” and “Death Benefit Insurance” (a service offered by some credit unions to help pay for end-of-life expenses). Such plans require pre-registration and/or financial contributions.

Alternatively, where such plans are not in place the family may have to pay out-of-pocket. For those who are economically comfortable and have the means to pay this is not a financial strain. For others, they may have to use credit cards or seek financial support from money lenders, charities (including Saint Vincent de Paul, the Kevin Bell Repatriation Fund, Irish Hospice Foundation Hardship Fund), state supports, or their family or social networks (loans or “go-fund pages”).

“[We] had to pay €2,500 for your plot before any funeral could be organised so that was huge but luckily my [family member] had it and he lent it to us.” (IP5).

Social workers supporting economically disadvantaged bereaved individuals and families also direct them to charitable supports, for example the Irish Hospice Foundation Hardship Fund.

“From my own personal experience, we would do an awful lot of work in supporting people access finances when somebody dies for the funeral itself and again this is something that has come up through the Irish Hospice Foundation so much” (FGP17)

Sometimes such supports are temporary or conducted as part of an advocacy role. For example, immediately after the death bereaved individuals find it difficult to engage in any conversations about the cost of a funeral and it is left to other family members to address the financial arrangements for the funeral.

“[Family member] would have actually settled the bill for us initially and we ended up paying for it but money was something I didn’t want to end up worrying about” (IP3).

Financial supports can also be provided indirectly. One bereaved individual indicated they were gifted a plot by another family member (IP2), or in other cases where hospitals provide coffins when a baby dies. In addition, funeral directors may decide to forgo their costs, such as in the case of the death of a child.



A funeral director and an individual interviewee cited examples of this:

“At the end of the day there was about €1,200 ... which we didn't collect... we just took it on the chin. We couldn't in all honesty go back to a family and tell them sorry there's a shortfall (FGP7).

“The funeral directors. They didn't charge us for the coffin, they were very good in fairness” (IP6).

Unfortunately, some bereaved individuals who have difficulty accessing credit or supports may be forced to use a money lender or some other form of high interest loan, which can compound any financial difficulties these individuals are already facing. Focus group participants, especially those working for charitable organisations and MABS were concerned about low-income individuals taking out high-risk loans at the time of bereavement, and the long-term financial implications of this.

“It varies of course but yeah people can take on a lot of high interest debt in order to cover the immediate costs and then of course that chases them or follows them into longer term difficulty” (FGP7).

Furthermore, some bereaved individuals may have more than one loan, further exacerbating their financial problems, especially if availing of money from lenders who charge high interest rates.

“It's where people access the money as well. If people access the money from different lenders and so on, the high interest rates cause additional problems” (FGPP16).

Focus group participants felt that most people are determined to pay the funeral bill. Even when experiencing significant economic hardship, many bereaved people will prioritise paying the funeral bill. For some families, the financial burden of having an outstanding bill for a funeral will also have a negative psychological impact on them; people can become quite anxious about paying this bill.

The funeral directors participating in the study also talked about situations where individuals were unable to pay for the funeral. On rare occasions a bereaved individual will stop engaging with funeral directors and not pay the bill. However, usually either the bereaved individual or family will approach the funeral director, or the funeral director will approach them, and a payment plan can be put in place. This plan could be in place for up to eight or nine years after the funeral, necessitating cuts backs.

“If they had debt, if they had taken out a loan or if they had a payment plan with a funeral home that would be cutting back on food and energy to make those repayments” (FGP1).

In such situations of economic hardship families will also be referred to Money Advice Budgeting Service (MABS) for advice on how to manage their finances, debt and to work out a new household budget. On occasion MABS will liaise directly with funeral directors and other creditors.

Here families are facing long term, not short-term, debt and this whole process can be extremely stressful for them.

“They now found themselves having to go to social welfare and look for an urgent needs payment or something like that which is different criteria for eligibility around it and that doesn’t make it easier and you’re sending someone from billy to jack with their same story asking them to see how best you can get some support financially when this the most emotionally tough time for them in their lives” (FGP5).

Other bereaved individuals indicated they had support from other family members, such as fathers, aunts, grandparents and siblings, while organising and paying for their loved one’s funeral. The advocacy role of medical social workers was also referred to as they can engage with funeral directors on behalf of families, making them aware of the family’s specific situation, including their economic circumstances.

“[W]e’ve been kind of bridging a lot of conversations between families and funeral directors even around what a family can afford, the fact that we’re there advocating for them, saying that we’re accessing support, here, here and here and could they be mindful of that, and I think that funeral directors respond very well” (FGP2).

### 3.3.6 Role of funeral directors and other professionals

Funeral directors taking part in the focus groups felt that the public in general do not understand the role of a funeral director. In explaining their role, funeral directors stated they are there first and foremost to support bereaved families and to ensure that the deceased person has a respectful funeral.

“We’re there to care for families, to look after families, to let them say goodbye to their loved ones and hope that we’ll get paid back” (FGP 12).

Families who come to arrange the funeral of a loved one will not ordinarily have immediate access to the funds required to pay for everything. The funeral director will then step in and make the arrangement and pay these costs in advance, on behalf of the family, expecting to be refunded later.

“We step in, we pay for everything that has to be done today so they can have the dignified funeral and that’s what we do” (FGP 12).

To manage the associated costs, funeral directors will attempt to guide family members through the decisions they must make, by, for example, suggesting a veneer as opposed to a solid wood coffin. Due to the significant costs associated with the purchase of a grave in certain parts of the country, funeral directors might suggest cremation as an option, whereby the deceased person’s ashes can be buried in a grave already owned by the family.

Furthermore, to manage people's expectations about the funeral, and to therefore manage the associated funeral costs, funeral directors may decide not to go into detail regarding all the discretionary services which are available.

"We don't even mention things that are discretionary like getting booklets for instance or newspaper notices, wouldn't even suggest those things that would just add cost. Maybe .... a less elaborate floral arrangement, this one is perfectly fine, and it costs less than that one" (FGP6).

Aligned to this, the focus group participants emphasised that most funeral directors will not "up-sell".

"We never upsell, we never encourage people to go more expensive, we'd probably do the opposite in most cases" (FGP6)

Likewise, none of the family members participating in this study indicated they had been overcharged or were unaware of the costs of the funeral, although most did struggle to pay for the funeral. In the main, families were positive about the role the funeral directors played.

"We got very good advice" [about the cost of the funeral] (IP4).

However, the funeral directors attending the focus group indicated that not all funeral directors are transparent about their fees and not all will engage in practices to keep the costs of a funeral down.

"There are 900 funeral directors across the country and they're not all of [the same quality], there's no standardisation first of all, there's no licencing, there's no regulation" (FGP 9)

It was suggested during the focus groups that there should be some form of regulation of funeral directors, as is the case in other countries such as the United Kingdom<sup>6</sup>.

"I personally feel that looking at the range of costs of funeral cross the board there should be some sort of regulation or price list the same way there is with legal fees" (FGP 9).

Funeral directors suggested they can be hesitant about having discussions about money straight away for fear of causing offence. It was suggested that this is more of an issue in rural as opposed to urban areas, where the funeral director might know a family well.

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<sup>6</sup> <https://www.gov.uk/government/publications/summary-of-the-funerals-market-investigation-order-2021>

“I’m not from Dublin myself so I understand the cultural differences, the situation that happens with a lot of non-city based funeral directors is that you sit down to make arrangements with the family and the funeral director feels that maybe it would be inappropriate to talk about costs of funerals at this time that ... you might be being crude or whatever it is, to bring costs up at such a sensitive moment” (FGP6).

Similarly, family members may also be worried about the appropriateness of starting a conversation about the potential cost of the funeral with the funeral director.

“The family sitting opposite from them, ...are thinking “I’d like to know how much this is going to cost but maybe he might think it’s inappropriate for me to bring up costs” so they’re both thinking the same thing” (FGP6).

However, many funeral directors suggested that family members are relieved when the funeral director broaches the issue of costs. Being open with families about the cost of the funeral allows for more transparency in relation to the costs and choices available to them. In an example of good practice, some funeral directors have introduced a policy of providing a quote to the family so they can review it and cut back if necessary. Another funeral director indicated that his business provides training to its staff on how to engage in these forms of conversations with people. Transparency and good communication were cited as essential for supporting people to make informed decisions about funeral costs and ensuring families have control over the funeral budget.

“[By providing a quote] you’re giving far more power and control to people when they’re making these choices because that will have an impact on poverty down the line” (FGP9).

However, all focus group participants acknowledged that these conversations, which are beneficial and bring about positive outcomes for families, are not the norm in Irish society.

### 3.3.7 Social Welfare Supports for Funeral Costs

Bereaved individuals needing financial assistance to pay funeral costs can currently apply for the Exceptional Needs Payment (ENP), under the Supplementary Welfare Allowance Scheme. Each case is decided based on its merits by the Department of Social Protection representative (formerly Community Welfare Officer), who can be very supportive of bereaved families. Currently, the ENP may not cover full funeral cost and geographic disparities may not be taken into consideration, as was the experience of interviewees in this study, where it was not sufficient to cover the cost of a grave in the Dublin region.

“One low-income family who lives in a county outside of Dublin, they can afford to bury their child, have the comfort of ... being able to tend a grave... families in the same circumstances have a wholly different experience because they are located in Dublin” (FGP15).

The Bereavement Grant which was a once-off payment for funeral costs, was discontinued after 1<sup>st</sup> January 2014. Unlike the ENP, eligibility for the Bereavement Grant was not related to ability to pay for the funeral. Some study participants were supportive of its discontinuation, as it was not means tested and they felt that not all families who previously received this grant needed it.

“I suppose the big thing [name of person] with the €850 was that an awful lot of the families didn’t need it” [FGP 11]

However, a minority of funeral directors expressed a desire for the non-means tested Bereavement Grant to be reinstated, mainly due to frustration about how the ENP is administered, as opposed to a specific issue with the phasing out of the Bereavement Grant per se. However, most study participants suggested a middle ground between the previous and the current system was optimal.

“Some sort of halfway house of what the grant was there before and what’s there [now]” (FGP9)

Specific concerns with the process of applying for the ENP were delineated in relation to; signposting the payment, eligibility criteria, concerns with means testing, reasons for refusal and disparities in terms of how the payment was administered across the county. With regards to signposting the existence of this fund, even though funeral expenses are a distinct category (with a specific application form under the ENP) funeral expenses are still just one of many exceptional needs covered under the payment. The focus group participants stated that having funeral expenses classed as one of many exceptional needs made it difficult to signpost this form of support and ensure bereaved individuals were aware that this payment was available to them. Department of Social Protection representatives also identified the need for greater awareness of this payment.

“I think it’s really important around signposting and people being made aware of what supports are available to people if they have experienced a bereavement” (FGP1)

“Everything is exceptional really with community welfare. It’s an exceptional payment so a funeral expense has its own application but it’s an exceptional payment” (FGP 4)

Funeral directors indicate a lack of awareness too, whereby if no one tells families about the ENP when arranging funerals, then some people entitled to and in need of this support might not get it.

“Unfortunately, with a lot of these things if you’re unaware of it you could end up never getting it, there’s no one to tell ya about it” (FGP 6)

Funeral directors considered the ENP to be means tested, and the means testing process undertaken was at the discretion of individual Department of Social Protection representatives. To them these means testing processes are unclear. They cannot understand the criteria involved and find it hard to support families with the application process.

In some instances, funeral directors contacted Department of Social Protection representatives about specific families but were frustrated by the responses provided.

“I rang [the Department of Social Protection representative] to say can you please explain your criteria to me because I can’t understand that ... this lady ya know had no finance, .... her daughter’s on social welfare and she [representative] said ‘well look we look at families as a whole’ and she said she couldn’t tell me this and that’s what upset me then” (FGP 12)

Funeral directors also indicated that there were disparities in terms of the information sought by Department of Social Protection from bereaved individuals applying for the payment. In some instances, information relating the deceased estate was requested, or information relating to the person paying for the funeral was requested. In other instances, information pertaining to the entire family was requested.

Funeral directors reported that bereaved individuals and families were often shocked and upset when they when they were told they did not qualify for the ENP. For others the ENP awarded (on average of 1852) is insufficient and families have to make up the shortfall, by borrowing money or entering into payment plans with funeral directors. Department of Social Protection representatives’ participating in focus groups suggested that some families were misinformed in terms of the eligibility criteria and the amount of money they would receive towards funeral expenses.

“I think it’s a total shock that we won’t pay anymore than €2,000<sup>7</sup>. There’s definitely that chat out there that if you’re on the dole social welfare will pay for your funeral, but the max limit is as I say €2,000” (FGP 4).

When faced with this situation Department of Social Protection representatives continued to try to support people and often referred them to MABS for advice and to arrange a payment plan.

Overall, it was felt that the ENP process made it difficult for people to navigate the system, to determine eligibility and apply for appropriate supports. While focus group participants did not demand the return of a non-means tested payment, it was felt a specific stand-alone payment for funeral expenses would be clearer.

“I think having the bereavement grant itself is a much clearer delineation where people may not know that they’ll qualify for funeral expenses under the exceptional needs payment so. having it as a separate payment also has benefits in terms of awareness” (FGP1).

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<sup>7</sup> This amount was identified by 1 focus group participant. The Department of Social Protection (DSP), in their feedback on this report, indicated the DSP do not have a cap on ENP’s for funerals and this amount may be a guideline amount that the official involved, has in mind for a dignified funeral in the geographical area that they operate from.

Concerns were also raised about the process for applying for the ENP by both funeral directors and Department of Social Protection representatives. It was suggested that families who had previously engaged with the social welfare system understood how the system worked and could navigate it.

“Some families are very ok with the social welfare system and ya know they’ll come into me and they’ll be aware they can get this assistance” (FGP6).

However, for other families, the application process could be onerous. It was acknowledged that while the Citizens Information Services, MABS and Department of Social Protection representative do make information and the appropriate paperwork available to people, some bereaved individuals find the process overwhelming due to both the number of forms to be completed and the need for other supporting documentation such as the death certificate, bank statements, copy of a will etc. to be provided. Individuals often concluded that they were simply not eligible for the payment before they even began the application process.

Department of Social Protection representatives indicated that in some instances, people began the application process but then failed to pursue it

“What I have found is they have fallen away; they have just not bothered proceeding with the application ...we give them ...a period of 21 days<sup>8</sup> “if you don’t have all your documents in we’re going to close your claim”. I don’t know if that’s the reason [the complicated application process] but I would figure it is”. (FGP 4)

In other instances, participants shared experiences of families not applying for the ENP due to the means test or fears that it would impact on their eligibility for other social welfare payments in the future. One specific case cited was that of a widow with children approaching college-going age. Despite the funeral director informing her of the ENP payment and the Widowed or Surviving Civil Partner Grant she refused to apply as she felt it might impact on the children access to the Student Universal Support Ireland (SUSI) grant in college.

“[S]he did not want to apply for the grant because she was afraid of having some impact down the line on the college grant” (FGP 9).

Participants suggested that the application process ran more smoothly where the Department of Social Protection representative was involved prior to decisions being made about the funeral and that in many instances Department of Social Protection representatives were supportive and engaged with funeral directors to support families and limit the economic impact of funeral costs.

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<sup>8</sup> The Department of Social Protection has indicated that this 21-day period is an indicative period for following up for more information.

### 3.4 Household Income and Employment Status

Throughout the study, all participants discussed the economic impact of bereavement within the context of family budgets and employment. These discussions focused on concerns relating to changes in household incomes and employment.

#### 3.4.1 Changes to Household Income

Both bereaved individuals and focus group participants spoke at length about the short- and longer-term economic impacts of bereavement on household incomes. Some families are immediately impacted by bereavement if the deceased person was the only or main earner in a household. Families are faced with an immediate drop in household income, without a commensurate reduction in expenses and often need supports to manage such situations. One woman is now a full-time home maker and explained how she availed of supports from MABS to manage the economic impact following bereavement:

“I contacted MABs, and they did a lot for me. They sorted out the mortgage, electricity, the loans, all that kind of stuff because we’re a two-income family, we were bringing in the guts of €5,000 a month ya know” (IP 5).

In addition, participants described immediate and future potential earnings lost by bereaved individuals. For example, focus group participants discussed situations where bereaved individuals returning to the workforce may not return to the same job or wage compared to before the bereavement. It was also suggested that women were disproportionately impacted in such situations compared to men.

“Tends to have longer reaching consequences in terms of their ability to regain what they were earning prior to the death ...and it affects not only their current earning potential but also their future earning potential and would impact on women disproportionately as opposed to men” (FGP16).

It was suggested that in some instances, people can become less career focused having experienced a bereavement, impacting on their performance and perceived interest in their job, and consequential earnings.

“So, I would have probably been a lot more career focused before [name of deceased person died]. I definitely would feel that I would probably have moved on to a different position in another company if he hadn't died and that my earning potential has definitely been affected by that and by the challenges that that brought” (IP1).

The combined income losses from the deceased and the actual and potential income of the person bereaved lends itself to a complex and challenging financial situation for the household involved, with far reaching implications for contribution to the workforce.

#### 3.4.2 Accessing Other Social Welfare Payments



During the study, interviews and focus group participants spoke about issues relating to a range of social welfare payments, including the Carer's Allowance, State Pensions, the Exceptional Needs Payment (ENP) and the Widowed or Surviving Civil Partner Grant and their role in mitigating the economic impacts of bereavement. The role of all professionals supporting bereaved individuals to access social welfare payments was widely acknowledged, including support from family members of the bereaved to staff at Citizens Information Services, MABS, Revenue and Department of Social Protection representatives.

Several concerns around awareness of social welfare entitlements were identified by both focus group and individual participants. It was suggested that many people are unaware of their social welfare support entitlements generally and payments available through the Department of Social Protection, and revisions/updates on same.

“[People are] completely unaware of the bereavement grant [now the ENP] ... of the widow's payment if the person is working... the difference between the contributory and the non-contributory [pension]” (FGP14)

Bereaved individuals found the social welfare system very difficult to navigate, even those who considered themselves to be capable and well informed.

“My father died in October, we didn't get the PPS number [for my mother] sorted out until March or April [of the following year] so my mother didn't get her entitled pension, which helped to pay for her care, so we were robbing Peter to pay Paul” (IP4)

In other instances, applying for specific social welfare payments, such as Maternity Benefit after a stillbirth or miscarriage could be an emotional process. To demonstrate proof of entitlement to Maternity Benefit parents must provide evidence of the age of gestation of the baby (from the beginning of the 25<sup>th</sup> week). This makes the application process for benefits particularly challenging for bereaved parents. Furthermore, affected fathers are also not entitled to Paternity Benefit in instances where there is a gestation period of less than 25 weeks<sup>9</sup>.

“[R]inging up and having to provide the evidence in relation to the death of the baby is sometimes very challenging in terms of being in a mental health position to apply for the benefits that you're entitled to” (FGP4)

Interviewees also spoke of the complexities associated with accessing social welfare payments, many of which were exacerbated by GDPR and the need for multiple forms of identification. The latter is a particular issue for the older generation, when for example multiple forms of identification were required when making changes to pension entitlements.

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<sup>9</sup> : <https://www.gov.ie/en/publication/b746e4-operational-guidelines-paternity-benefit/>

“[They] needed identification; a passport or a driver’s licence, my mother is 86, she has no passport ...no driver’s license, you run into brick walls” (IP4)

Over the course of the study, interviewees spoke of the importance of the attitude and approach of the professionals they engaged with. In some instances, these interactions were not positive and left families feeling demeaned.

“She was just a stickler, she wasn’t nice, and she belittled me” (IP2)

Conversely, other interviewees spoke of how interacting with professionals who engaged with them and were understanding of their situation could quickly and efficiently address their issues when trying to access social welfare payments for their loved ones.

“Eventually, we got onto a nice person, who had a mother in a nursing home; we got it done like that” (IP4)

Specifically, the role of Department of Social Protection representatives in supporting bereaved people was widely acknowledged. Funeral directors, medical social workers and representatives from charities recognised the importance of their role and their willingness to engage with bereaved families and to support them.

“[Department of Social Protection representatives] have never had any problems dealing with any of the funeral homes. I feel they’re very good, they’re very attentive, they’re very supportive to families” (FGP 18)

### 3.4.3 Employment Tenure and Progression

Following a bereavement, employees may need time away from the workforce owing to the physical and/or mental health impact(s) of their bereavement. During this time an individual may be entitled to Illness Benefit for a protracted period. However, there is often a disparity between actual wages and these payments, reducing the household’s income.

“Like illness benefit... so people who are earning a good wage and find themselves through bereavement not being able to work, illness benefit is obviously a lot less than their wage might have been (FGP16)

The ability and capacity to return to work following a bereavement will vary between individuals owing to both personal and family circumstances, as well as the work environment. Following a bereavement, some interviewees indicated that they could not return to work, due to the nature of their job and the impact of the bereavement on them. For example, one bereaved person worked in childcare and did not want to return to this after the death of her child. Another bereaved person did not want to return to the same working environment they had been in prior to the death of their

loved one and therefore, retrained and began a new career. Others may reduce their working hours.

In other instances, a person might want to return to work, but must stay at home to provide emotional support and stability for household/family members impacted by the bereavement. An example of this was where the loss of a parent on children can be significant, making it difficult/impossible for the remaining parent to return to work (even if they felt ready to return to work).

“[T]he impact of the bereavement on the children can affect their ability to attend school and function in their world and then the parent needs to take time off work, maybe a year or two, to maybe re-stabilise the family in a way and be emotionally there to support them with say school refusal... I'm just thinking of the self-harming aspects, suicide ideation that some of the children would have” (FGP30).

For some bereaved parents the practicalities of supporting children on one's own following the death of a partner, and the added costs of childcare, impacts on their ability to return to work at all or means reducing hours / working part time.

“It ended up being the job that suited me, and the boys best was a xx-hour week one. Where I wouldn't get caught for childcare, I would be able to work with the school, the job is very flexible as well” (IP2).

Others may try to return to the workforce, but find themselves unable to cope and leave again, making their employment unsustainable. This may be applicable to bereaved individuals who were caring for their loved one prior to their death, and perhaps dropped out of the workforce to do so for many years.

“[D]ue to the emotional impact of the bereavement and because of being out of work maybe caring for the person is that they don't feel they're able to go back into the work force. But they might go back for two weeks, find they can't manage and may come out of the work force (FGP3)”

Career advancement can also be impacted, as a result of a bereavement, as people may lack confidence going for promotions or were not offered promotions as employers were conscious of the impact of bereavement on them.

“When I went on maternity leave, I was two people away from the CEO, I'm now four people away, but it did take me nearly a year to feel the confidence [to go for roles] or maybe I was not considered for roles because people [were] conscious of what we had been through” (IP3)

#### 3.4.4 Employment prospects for bereaved Children/Young adults

While the impact on those in employment at the time of bereavement is evident and immediate, several focus group participants identified the longer-term impact on young adults and indeed children which is less obvious but equally significant.

“Bereavement can [impact] not only their current earning potential [young adults] but also their future earning potential” (FGP16)

The focus group participants also stated that from their experience there are specific implications for young adults experiencing bereavement whilst in education and taking examinations. This can have adverse implications on the opportunities available to them in the immediate and longer-term and consequently their future contribution to the workforce.

“So, two of them are in exam years at the time of the death, that’s impacted on their results and then their economic [outlook] so it’s a knock-on effect” (FGP16)

For this cohort, the impact of the loss of the income of a deceased parent, and in some cases the loss of the surviving parent’s income, and subsequent changes to the household’s economic situation can cause a seismic shift and long-lasting impact on their lives.

“The family situation has changed and it’s very much about changing schools, changing house and just suddenly being aware of how limited money can be or the resources can be, not maybe even just money but parent’s attention and things like that. Those secondary implications on them is a lot for them to sort through and deal with” (FGP3).

### 3.5 Mitigating Health-Related Issues and Associated Economic Implications

Participants in the study identified that bereavement impacts the health of individuals, both children and adults, and most specifically their mental health, in the short and long-term. In particular, the mental health of children and young people can be significantly impacted by a traumatic death and where issues related to complicated grief arise. One bereaved woman expressed her fears for the long-term impact of bereavement on her son, specifically his mental health and what the future would hold for him following the death of his sibling.

“what’s the long-term economic impact say for my eldest who’s not [age of adolescent]? This definitely had had an impact on him. Will it longer term kind of follow him through and that’s something that we won’t know obviously for years” (IP1).

#### 3.5.1 Need for Mental Health Supports

Throughout the study participants acknowledged and highlighted the importance of mental health supports, specifically counselling. For example, one bereaved person was very focused on ensuring that her children had access to counselling, having witnessed the impact that a lack of counselling services had on older adult members of her family following a bereavement. This woman was determined that her children would not be left to live with the impact of their bereavement for the rest of their lives.

“And I was just adamant that the boys wouldn’t use the death of their father as an instrument for their life or a walking aid. I needed them to express every kind of emotion before they become adults and that they have some form of life” (IP2).

The importance of supporting and investing in families through the provision of appropriate and timely mental health supports, was emphasised by professionals. As well as the health improvements such supports can help mitigate economic impacts.

“Managing the economic impact of bereavement...it’s about looking to the long term...it is about investing in these families, to ensure that whatever supports are needed, are provided” (FGP 3).

Participants indicated that without a recognition of the long-term impact of bereavement and the provision of appropriate supports, the adverse economic impacts initially caused by the bereavement could persist and even multiply into the longer term. Therefore, children could potentially experience the cumulative disadvantage of bereavement, across the lifespan.

“I think sometimes there’s a lack of understanding of the long-term economic impact, particularly for those who are impacted by traumatic deaths that we would see people coming into us in maybe their mid-20s, early 30s, and they would have suffered a traumatic bereavement 10 years ago and that impact, they’re maybe on disability allowance or social welfare” (FGP 4).

The participants suggested that this lack of recognition or understanding of the long-term economic impact of bereavement at a societal level permeates down to the services for bereaved individuals, leaving many ill-prepared to manage the economic impact on their daily lives. Thus, the need for a sustainable combination of immediate and longer-term supports was emphasised:

“[Providing] support.... is not just about the here and now, it’s about the long-term impact ... because sometimes especially with children .... providing counselling support is not necessarily immediate, it’s ... 6 months or a year later. That’s why we follow all our families for at least a year after the bereavement” (FGP15).

### 3.5.2 Availability of Counselling Supports

From the interviews and focus groups it was clear that a range of counselling services, with varied cost structures, are available to bereaved individuals from a variety of sources (state bodies, charities, employment assistance schemes etc.). The wide range of service providers, their fee structures and quality were emphasised:

“The counselling services that you receive from them such as a Little Lifetime<sup>10</sup> is absolutely excellent and that’s long-term, you can attend that forever if you wish and they do lots of other things, keeping memories and stuff like that of your child. Also, ... Féileacáin<sup>11</sup> and they’re absolutely excellent as well and they do it for free but if you like to give a donation, they’d gratefully accept it” (FGP18)

However, it was emphasised that despite the best efforts of voluntary organisations providing free or subsidised counselling supports, not enough services are available to meet the needs of all of those requiring supports.

“These are voluntary organisations who are getting no funding from the state and their resources are completely limited” (FGP21).

It was also stated that time limited counselling (where people are given a set number of sessions only) can be counterproductive and does not provide sufficient support to move families forward.

“It just was never going to go anywhere because it was never, it never had longevity to it, it probably got me over a bit of a hump but ya know it never would have had longevity so in a way it’s sort of a waste of money ya know. Yes, it gets people over a hump, but it doesn’t really lead them anywhere (IP6).

It was also evident in conversation with bereaved individuals and focus group participants, that accessing the right form of counselling was important, and this could prove to be an obstacle both in terms of accessibility and costs.

“[Y]ou might have to drive an hour to get to the local support group...because they’re offered in regional areas.... and if you have other children that’s difficult” (FGP21).

The focus group participants and family members emphasised that counselling is essential in ensuring that bereaved individuals deal effectively with both the emotional and economic impacts of bereavement. It was also suggested that appropriate, timely access to counselling could be instrumental in mitigating the long term adverse economic impacts of bereavement.

“People who avail of counselling and get the supports for their emotional difficulty at the time will have a much better chance of returning to their pre-bereavement income quicker if they get the emotional supports” (FGP13).3.5.3 Financial Barriers to Accessing Counselling

Bereaved persons identified that the cost of counselling could be a significant economic burden on families, particularly in economically vulnerable households.

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<sup>10</sup> A Little Lifetime Foundation (formerly Isands) was established in 1983 by a group of bereaved parents. We are an Irish registered charity, providing supports and services to parents whose baby has died around the time of birth or shortly afterwards and parents who receive a diagnosis of fatal foetal abnormality in pregnancy.  
<https://alittlelifetime.ie/about-allf-2/>

<sup>11</sup> <https://feileacain.ie/>

“So, like at one point I think we would have been spending, I think my counsellor was €80, my husbands was €75 or something so we were spending that each a week. I’m going every week which is sizeable” (IP6).

Professionals also recognised that while accessing counselling was essential, cost is a barrier to bereaved people, who cannot afford to pay for it. Unfortunately, those unable to access counselling face greater issues in comparison to those who could afford to pay for, and access supports in a timely manner.

“... obviously it’s a barrier for people on low incomes if they have only privately available counselling available for people and that can compound issues for people obviously as well if they aren’t getting that support that they need. ... (FGP1).

Therefore, not only are bereaved individuals struggling with the emotional and economic impacts of bereavement they were also struggling to access essential services such as counselling for their family. Waiting lists and indirect costs (e.g., travel) associated with accessing counselling services were highlighted as significant barriers by families and professionals. For example, one interviewee (IP2) stated that she waited over 18 months to access counselling supports for her children. She was not able to pay for these supports privately and when they become available, she had to ask the service to reduce the amount of counselling sessions provided as she could not afford to drive the children to them so often.

“Diesel is phenomenal at the moment; I’m getting nowhere near my mileage. And it’s just with the counselling, I was [thinking] will I drop the counsel[ling]? And I said no, that’s what matters. I’m seeing results in the [names of children]” (IP2).

To limit the economic impact of bereavement in the short and long term, “people want counselling locally, easily accessible and that is free” (FGP21). While paying for counselling (and its associated costs) may exacerbate individuals and families’ economic situation in the short term, counselling is worth investing in. Delaying or refraining from counselling could prolong and worsen the adverse emotional and economic effects into the longer term.

### 3.6 Other Costs of Death & Dying

It was evident from the individual interviews and the focus groups that, for some individuals, the economic impacts of bereavement appear or arise from spill overs from when their loved one is at end of life. During this period costs and debts can accrue, owing to outstanding loans and other financial commitments that cannot be serviced if the person has stopped working or owing to the costs associated with caring for the person at the end of life or the impacts of anticipatory grief. Focus group participants in particular referred to these costs as “hidden costs”, which at first glance, might not be associated with the economic impact of bereavement.

“There can often be a lot of expenses for a family so I think it’s important that that would be mentioned and included in relation to those sort of hidden costs” (FGP 16)

### 3.6.1 Costs associated with caring at end of life

In some situations, changes to employment and household income may have already occurred if the bereaved individual gave up their job to support their terminally ill relative. As one family member in this study explained.

“I was in administration all my life, I worked in the banks, I worked in [name of company] for 12 years, I went into caring for [name of loved one]. And I wasn’t working during that time” (IP2).

Such changes in employment status and associated reduction in household income can place a significant economic burden on families prior to the bereavement.

Additional costs were linked to expenses spilling over from the deceased person’s end-of-life care. These costs (and potential debt) included expenses associated with accessing end-of-life treatment. For example, travel (fuel and parking) and or accommodation expenses if a family member had to travel and stay overnight while their loved one was having treatment.

One woman explained that there were times when she fed her loved one but not herself and would have to sit in the car wrapped in a duvet, outside hospitals while her loved one received treatment. She was informed that she entitled to put in for petrol expenses and other items, to cover travel costs, but she stopped submitting the expenses.

“I remember social welfare were meant to pay travel expenses for us up and down to [place]. And I was providing expense sheets and providing diesel [receipts] one of the ladies in the social welfare wasn’t...she wasn’t very nice. And I just stopped putting in the expenses and I used to be sitting in the hospital for hours. And I wouldn’t even buy a sandwich because I didn’t have it, as long as we had diesel in the car to get home, that’s all that mattered” (IP2).

It was emphasised that costs were greatly increased if a family had to travel to and stay in Dublin, which many do, to access specialist national services. Despite the efforts of social workers supporting families such costs accumulate.

“Costs of ... being in the capital city where everything is more expensive while obviously, we work very hard to [provide] as much financial support as possible as a social work team” (FGP15).

In other instances, the carer involved might be an older person, who has let their own health deteriorate while caring for the deceased and they then are facing into increased medical costs for their own health needs.

“You’d find their main carer is exhausted and then they’ve let their medical conditions go and then suddenly these suddenly rise to the surface. It’s a whole medical, even taxi services to get to places, it’s just bills, bills, bills for them” (FGP3).



### 3.6.2 Childcare Costs

The deceased adult might have been at home for several years while ill, negating the need for formal childcare, but as their condition deteriorated, formal childcare arrangements might have to be put in place.

“You had a parent that they were sick home for four years maybe before they died, you had someone in the family home to do a piece of childcare that suddenly you have to pay in or get someone to do so” (FGP 3).

Families also experienced additional childcare costs when a loved one was at the end of life. In some cases, they needed a babysitter to mind the siblings of the child in hospital, or to allow a parent to spend time with his or her loved one.

“I was staying in the hospice all the time with [name of deceased person]. But I was coming home every couple of days, if the boys had a match or that and that I’d come and watch the match and go back in” (IP2)

### 3.6.3 Impact of anticipatory grief

In some instances, the economic impact of bereavement may be felt before the person dies owing to anticipatory grief. This makes the surviving family member feel like they are unable to continue working prior to the death of a loved one. This may be the case amongst particular individuals, such as expectant mothers, whose unborn child has been diagnosed with a life-limiting condition. Here the mother may feel they cannot stay at work,

“[Meeting] people that would be very difficult knowing and people saying, “how far along are you now, when is your baby due, what is it is it a boy or girl” and you’re like \*sighs\*. Now that’s grief, you know they’re not staying, your dreams, your hopes, and dreams for them is gone, everything is dashed” (FGP7).

In other instances, they may change their employment status to work part time, or on reduced hours. However, availability of this is at the discretion of their employer and the extent to which they can support their employees.

“I’ve started working part-time because I said I just cannot cope” (IP 7)

Some women have no choice but to keep working, despite the difficulties they are facing or the options available may not be enough. This woman spoke of reducing to a four-day week, when she did not feel that she should be working at all.

“I had to cut down to four days a week partly because I had so many hospital appointments and things like that and also just because I couldn’t ya know physically do it but to be

honest I shouldn't even have been doing four days a week, but I had to and that's the whole thing, I still had a mortgage, we still had all our bills" (IP6)

In addition, for many in this situation, there is fear as well that they might not qualify for Maternity Benefit dependent on when their child is born. The potential economic impacts of this caused much concern for these women.

"I distinctly remember thinking when I pass the 24-week mark thinking a tiny bit of relief going thank God I'll get at least the state maternity benefit, now because I didn't know definitely whether my employer was going to pay me or not as in would he top me up because it wasn't in my contract" (IP6)

### 3.6.4 Legacy Debts

Professionals raised issues reflective of the long-term economic impact of the financial crisis and resulting recession (2008/09), and the associated mortgage crisis and the knock-on effects for people who were bereaved whilst in this risky economic situation. Specifically, the focus group participants outlined how many families fell into mortgage arrears, so were already significantly indebted and could not afford life assurance prior to the death of their loved one.

As previously mentioned, planning for death and funeral costs through products like life assurance mitigate the economic impact of bereavement and funeral poverty.

"Then the partner ..., when that person dies that partner expects to have a mortgage paid off [but] is obviously left then with the full extent of the debt and any other debts" (FGP2).

Bereaved individuals were also open about the impact of mortgage arrears and how families could have accrued significant debts (known or unknown) prior to the death of their loved ones.

"A couple of years prior to his diagnosis we went into difficulties, .... And we were battling to keep the house, we were fighting financially about everything, it was just very tough. We used his [credit] card for the mortgage that time when he lost the job" (IP3)

"Another one recently was a credit card bill that ... the spouse wasn't aware of €3,000 or €4,000 and it just came to light at a time when accounts were being sorted" (FGP2)

For indebted families, the economic impact of bereavement exacerbates their economic hardship, and families may even be in danger of losing their house at the time of their bereavement. The family spoke of the darkness and despair at that time, when there was no income coming in and the crucial role MABS played:

"Because MABS are the reason that I personally feel that I didn't do anything to myself after [name of deceased person] dying. I just saw darkness afterwards. I knew my bills, I knew my debts, but the fact that I wasn't going to have an income coming in... Well, you know yourself you are bringing in that wage. I was at home, we had a mortgage, and it was just

MABS, I'm not messing. The financial advising of MABS was so personal and so caring and so on my side" (IP2).

## 4.0 Discussion and Conclusion

### 4.1 Introduction

This study explores the economic impacts of bereavement. Overall, four focus groups (24 participants) and seven individual interviews were conducted. While it is a relatively small sample, given that this is a small-scale exploratory study and qualitative in nature the sample size is purposeful and sufficient to support in-depth analysis which is central to this model of inquiry (Sandelowski et al., 1996) and has the capacity to provide richly textured information (Vasileiou et al., 2018). The sample size is smaller than anticipated (7 individuals as opposed to a maximum of 12). The short time scale for recruitment and challenges in recruiting adolescents and young adults in particular, impacted the sample size.

As reported by interview participants, it is important to acknowledge that the economic impacts of bereavement occur in the context of families' grieving experience.

The physical, emotional and psychological impact of bereavement impacts on the capacity of bereaved individuals to address their own and the households' economic situation, including their dependents and in some instances, on the deceased towards the end of life.

Professionals participating in the focus groups emphasised the importance of recognising the economic impact of bereavement when engaging with bereaved individuals irrespective of their professional role. All professionals were cognisant of the impact of anticipatory grief, as well as the immediate and the long-term impact of bereavement after the death of a loved one. Thus, the study findings concur with previous literature in the area which identified that the economic impacts of bereavement are multifactorial (Genevro and Miller, 2010); Stephan et al., 2015).

### 4.2 Groups at risk of adverse economic impacts of bereavement.

Whilst acknowledging that a bereavement will always lead to additional expenses both professionals and bereaved individuals indicated that families from higher socio-economic backgrounds/groups are better insulated against the economic impacts of bereavement.

Professionals including those from Department of Social Protection, MABS and Citizen Information Services and funeral directors, identified groups of people they considered to be at higher risk of adverse economic impacts, such as older people who experience the loss of a pension when their partner dies. The administrative and procedural difficulties in addressing pension related issues was emphasised by an interviewee, supporting a parent, who indicated that it could take more than six months to resolve these issues.

Both bereaved individuals and professionals spoke of the emotional and economic impact of taking on a caring role to support a loved one at the end of life. For some, taking on this caring role meant the loss of one or both incomes in a short space of time and having to rely in social welfare

support. In these situations, those experiencing economic hardships had been dependent on the Carer's Allowance to augment the family income and had to find alternative income sources following the death of the person being cared for.

Participants indicated that the loss of a partner left widows, particularly those with young children, in difficult economic situations in the short term and the longer term. Apart from the direct loss of income of the deceased (especially if they were the sole or main earner) there is also evidence of loss of income and earning potential of the person bereaved.

Furthermore, the legal nature of co-habiting couples impacts their entitlements for a broad range of social welfare benefits including the widow's pension. This is the subject of current political debates in Ireland and reforms are anticipated. For example, the Citizens' Assembly on Gender Equality (2021) has recommended that Article 41 of the Constitution be amended, to ensure that the protections afforded to the family are not limited to the marital family.

Women experiencing the perinatal death of their child before they reach a 24-week gestation period were identified as being particularly vulnerable to the economic impact of bereavement owing to current rules around maternity entitlements.

These issues and potential reforms are currently under review by government (Bacik, I, 2021). This is welcomed given previous estimates that following the death of a child, families' incomes can drop as much as 72% and funeral poverty is a concern (Corden et al, 2001).

While the groups listed above were explicitly identified, participants also indicated that it is important not to make assumptions about the economic position of individuals. Many people in Ireland are still feeling the economic effects of the 2008 financial crisis and the associated recession, high unemployment and collapse of the housing market. This resulted in significant decreases in public expenditure (including social welfare payments) and reductions in income levels across the economy. Those with low to middle level earnings were most adversely impacted (Barry and Conroy, 2013), and approximately 20% of households experienced significant debt (Social Justice, 2011).

Concerns around legal and financial literacy and awareness were only raised by the professional participants. This omission by the interviewees in this study may not be reflective of all bereaved family members. It may be owing to the participants' lack of awareness of the macro legal and economic environments, given their grief and circumstances they may not realise the issues they experience are also influenced by these environmental factors.

#### 4.3 Planning ahead

Failure to plan ahead for bereavement was identified as a concern, as it was evident from individuals participating in this study that many are not prepared for the economic impact of bereavement for a variety of reasons, including a cultural tendency to avoid discussing death, dying and bereavement in Ireland. This finding is in line with previous research indicating that less than 40% of Irish people are comfortable discussing death and dying (Europe Economics, 2021). If discussions on dying and death are avoided, discussions on the economic impact of bereavement will also be curtailed.

A reticence to discuss death and dying was not the sole reason cited for the lack of preparedness for the economic impact of bereavement. In some cases, such as the peri-natal death of a child, the suddenness of the death meant that the family did not get a chance to prepare. Respecting the wishes of a loved one, who are unwilling to plan for their own death, was also identified as a reason for not being able to prepare for the economic impact of bereavement.

Other cultural aspects of Irish society were identified as impacting on the ability of individuals to prepare for the economic impact of bereavement, including having only one name on a utility bill or a bank account. Study participants suggested this was linked to traditional gendered norms where household bills and bank accounts were in the male breadwinner's name. Funeral directors highlighted that many families face issues when attempting to access bank or credit union accounts in the days following a bereavement irrespective of the age, gender or marital status of the deceased person.

These norms spill over individuals' specific roles and responsibilities within households. So, if the individual responsible for budgeting dies, the remaining partner is left at a loss, with little insight into the everyday expenses associated with running a household, and lacking the skills required for budgeting. Finally, the deceased or their family may not have had the financial means (owing to prior debt or economic hardship) or know-how to financially prepare for bereavement through life assurance, death benefit insurance etc.

Irrespective of the reasons for a lack of preparedness identified by individuals and professionals, it leaves people at a disadvantage. So, as they struggle with the emotional impact of bereavement, they are faced with having to make important financial decisions, which some individuals may be ill equipped to make. These financial decisions may have significant implications for them and other dependents for many years to come.

#### 4.4 The Economic Impact of Funeral Expenses

Funeral costs can be significant, and some bereaved individuals can be disproportionately impacted by the cost of a funeral for a variety of reasons, resulting in what is referred to as funeral poverty (Corden and Hirtst, 2016).

Both individuals and professionals noted significant regional disparities with respect to overall funeral costs across the country. Professionals made specific reference to the additional costs (particularly burial plots) borne by people living in the Dublin region in comparison to the rest of the country. According to funeral directors the funeral costs range between €5,000 and €10,000, with much of this variation being explained by regional variations. Participants suggested the importance of acknowledging these regional variations in the supports provided to families for funeral costs.

The cultural significance of funerals in Ireland was identified as a contributing factor in exacerbating funeral poverty. It was clear that funeral traditions in Ireland can have a positive emotional impact on bereaved individuals, providing support and solidarity from their local community in their time of need. However, bereaved individuals also felt the weight of expectation and resultant financial burden, to ensure that a funeral was a fitting tribute to the deceased person. Specific communities, such as the Travelling Community, were felt to be particularly impacted by this, where funeral traditions have to be followed, irrespective of the economic impact on individual families.

Bereaved parents spoke of the need to pay tribute to their child and, in this context, headstones were particularly important. These bereaved parents stated they had spent significant amounts of money on a headstone, and some had borrowed money to finance it leading to one source of 'funeral debt' as defined by Bickerton and Morelli (2019).

It was suggested that bereaved families may need to be given "permission" not to spend significant amounts of money on a funeral (to avoid excessive debt or funeral poverty). However, in some instances the need to pay tribute to their loved one exceeded the risk of economic hardship, meaning families ended up in debt. Here short-term decisions have long term financial implications that need to be considered.

Participants acknowledged the existence of the Exceptional Needs Payment (ENP) to support families in paying for funerals but several issues around it were identified. While a minority of individuals felt that a non-means tested payment should be reinstated (to minimise ambiguity and inconsistencies), most comments were focused on two issues: signposting of the payment and eligibility criteria.

The lack of signposting (or awareness) of the ENP was felt to be an issue as currently it is unclear to many that it covers funeral expenses. While funeral expenses do have their own specific ENP form, and some precise information is available, study participants felt that it gets lost because of its classification as an “exceptional need”. This term is very broad, and it is difficult to define what an exceptional need is. It could be argued that having to pay for a funeral is not an exception but a certainty. Therefore, people who might be eligible for assistance with funeral costs might disregard the ENP, not realising it is relevant to their situation.

Study participants felt that the ENP’s eligibility criteria need to be more transparent, some participants cited the lack of detailed information on the Department of Social Protection website in relation to this issue. Study participants’ experiences suggests there are significant regional disparities in how the ENP grant is administered across the country. Correspondence with the Department of Social Protection representatives indicates that an assessment of need is undertaken as opposed to an assessment of the families means.

In determining the individuals’ level of need, information in relation to finances will be requested and compared to funeral expenditure and shortfalls, but a family are not means tested per se. It is stated on Gov.ie that the ENP is means tested (i.e., based on income, assets and savings alone) and this is also stated on Citizen information. However, during the study it was apparent that the nuances around the ENP criteria were unclear and complicated to focus group participants. They reported examples of several different approaches being taken by those administering the scheme. For example, it was reported that Department of Social Protection representatives in one area seek information on the deceased person’s estate; while in another area the person in the family paying for the funeral is means-tested; and in another it was reported that all family members are means tested prior to making a decision on eligibility. Department of social protection representatives participating in the study indicated that the disparity in approaches is reflective of the individual circumstances of each bereaved person and the information that is provided to Department of Social Protection representatives in the Supplementary Welfare Assistance Towards Funeral Expenses<sup>12</sup> (SWAS) form. In addition, professionals participating in the study indicated that individuals’ experience when accessing the ENP tended to be dependent on the attitude and approach of the Department of Social Protection representative in a specific area.

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<sup>12</sup> <https://www.gov.ie/en/publication/847761-recently-bereaved/#supplementary-welfare-allowance-assistance-towards-funeral-expenses>

Difficulties navigating the process for applying for the ENP was also an issue for participants. Individuals who had previously engaged with social welfare services were felt to be better able to navigate the system. However, individuals without this experience quickly became overwhelmed. Department of Social Protection representatives indicated that in many instances, individuals began the process of completing the form for the ENP but owing to a variety of reasons did not complete it and so the opportunity to access this financial resource was lost. None of the focus group participants referred to the appeals process for these decisions. They felt the application process was too arbitrary, and this needed to be addressed to ensure equal and equitable access nationally.

#### 4.6 Economic impacts of bereavement on Household income

All study participants referred to the significant economic impact of bereavement on household incomes. Some households experienced the loss of income from the bereaved person and in other instances, a second household income was also lost where family members left the workforce taking on a caring role (temporarily or permanently). In some instances, bereaved families returned to work either on a full or part time basis. However, in other cases, bereaved individuals did not return to employment. These individuals referred to the importance of supports such as those provided by MABS to help them address their changed financial circumstances. Many bereaved individuals in such situations have to avail of social welfare supports to augment their household incomes.

The lack of understanding about social welfare payments and lack of knowledge about where to find information about such payments were highlighted as barriers to supports by bereaved persons and professionals. They indicated that, in general, bereaved persons are not aware of available Department of Social Protection supports. It was also suggested that people do not always fully understand the nuances related to different forms of payment such as the difference between the contributory and non-contributory State Pension. It was also evident that some people did not apply for social welfare payments they might be eligible for, out of fear of knock-on effects on their eligibility for other social welfare payments. This suggests a general lack of knowledge and understanding of the social welfare system, and what people are entitled to in general.

General Data Protection Regulation (GDPR) was also felt to further complicate the situation. This was specifically raised by those supporting older persons, many of whom, as they age or become more infirm, may choose not to renew a driver's license or passport, two forms of identification which are often requested as proof of identification. These issues compounded the situation for bereaved relatives as they tried to address problems with pensions for example, after the death of a partner.

Professionals and family members also emphasised the importance of having access to supportive Department of Social Protection staff, cognisant of the needs of bereaved persons, when accessing social welfare payments.



Individual participants explained that one “nice” person who appeared to have insight into their situation could completely change their experience of navigating the system and support them in addressing their issues.

#### 4.5 Health Related Costs

The findings here concur with previous studies which identified that costs arising from increased morbidity and mortality, such as increased health care utilisation and non-medical costs such as travel to doctors’ appointments, productivity losses and intangible costs related to a loss are all costs that can be associated with bereavement (Genevro and Miller (2010).

Furthermore, declining financial circumstances following bereavement is associated with increased risk of poor psychological health (Corden and Hirst, 2013). With regards to health care utilisation, one participant referred to physical health decline amongst carers, whereas for most participants in this study the focus was on mental health services.

The lack of discussion around health services for physical health issues may be owing to the sample size and the fact that none of the bereaved individuals participating were in poorer health. Also, physical health deterioration and its associated costs are often considered to be indirect or hidden costs, which can be harder to track as they are less recognisable, and people may not attribute them to the bereavement and are individual/family specific. Nevertheless, these costs can be substantial. For example, Stephen et al. (2015) estimated that spousal bereavement increased hospital stays costing between £16 and £23 million per year, primary care consultations by approximately £2 million and bereaved spouses were less likely to be in work two years’ post-bereavement in Scotland.

The economic impact of bereavement on mental health was identified as a significant issue, both in the short and long term, by all study participants. The ability of individuals to continue in or to return to employment was affected by the bereaved individual’s mental health and/or by the mental health issues experienced by the family members they supported. The importance of mental health supports was underlined by all participants, particularly in relation to children and young adults. Participants clearly expressed that appropriate, timely mental health supports were imperative to mitigate longer term economic impacts of bereavement for individuals. However, issues relating to local access, time limits and costs were identified as a significant barrier to accessing counselling. All participants identified the need for locally available counselling services, in order to mitigate the mental health issues faced by bereaved individuals, particularly those experiencing complicated grief. It was suggested that without such supports, the economic impact of bereavement would persist across the life span, particularly as bereaved children transitioned into adolescence and on into adulthood.

#### 4.6 Other costs associated with death and dying

For many individual interviewees, the economic impact of bereavement was linked to events that occurred prior to the death of their loved ones. Providing end-of-life care and support to loved ones left many families participating in this study indebted, as the costs of providing supports accrued over time.

Additionally, the impact of anticipatory grief was felt and, in some cases, meant that bereaved individuals had to reduce their working hours or had to stop working completely prior to the death of their loved ones. For families who were already significantly indebted due to unemployment or the impact of the recession in 2008/09, and/or in mortgage arrears, the economic impact of bereavement are catastrophic. At a time when these individuals struggled to come to terms with the loss of their loved ones, the possibility that they could also lose the family home, was a stark reality. These bereaved individuals are particularly vulnerable and require a range of emotional and economic supports.

## Conclusion

Previous research identified that grief and bereavement significantly impact individuals, in terms of their ability to continue with their day-to-day lives. However, research relating to the economic impact of bereavement and the impact of supports to minimising its effect is limited (McLoughlin et al., 2018). Hence the importance of this exploratory investigation of the economic impacts of bereavement in Ireland. This study identified that the economic impact of bereavement on individuals and families is complex and multifaceted. This impact can continue to be felt in the years that follow as bereaved individuals adapt to their economic situation. While all sectors of society can experience the economic impact of bereavement, specific groups are at greater risk of being adversely economically impacted and require greater levels of supports. Accessible, appropriate, locally based services are essential if bereaved individuals are to mitigate the impact of bereavement to the greatest extent possible. Most specifically, children and their surviving parents, need support to manage the long-term economic impacts of bereavement on their lives. This study is a first step to evaluating the bereavement supports and services in Ireland, such as those identified in Senator O' Donnell's "Finite Lives Report" (2017) from a qualitative economic perspective.

## 5.0 Recommendations

Throughout the focus groups and individual interviews, all participants were asked if they had any recommendations to make, as to what supports could be provided to people who are economically impacted by bereavement, in Ireland. These recommendations are presented here, in conjunction with the recommendations of the research team.

### 5.1 Participant Recommendations

#### 1. Financial Assistance

Study participants acknowledged that some individuals experience funeral poverty, even if they receive the maximum ENP. It was suggested that some funds from the National Lottery could be used to support bereaved individuals and address the shortfall between the cost of the funeral and the amount provided from the ENP for those at risk of funeral poverty.

## 2. Access to counselling

The importance of and difficulties associated with accessing counselling were repeatedly discussed during the study. Free counselling supports, for those who cannot afford them and access to mental health services are required on a need's basis rather than a time-bound allocation. It was also suggested that the issue of "time limited" counselling and the location of services be examined. With regards to the latter, participants suggested having more "outreach" counselling services, so services and in particular, children's counselling services, could be accessed locally. Early and on-going access to these supports is critical to enable the bereaved (or their parent) to re-enter society and the workforce, if desired, thus reducing the impact on income and earning potential.

## 3. Information Booklet

During the focus groups reference was made to the usefulness of Bereavement: A Practical Guide<sup>13</sup>, an information booklet provided by Citizens Information Board that provides a significant amount of information. It was suggested that this booklet could be expanded on and further developed to capture both national and locally available supports for bereaved individuals. The information provided could focus on both financial support such as those provided by the Department of Social Protection and voluntary organisations and emotional supports, such as counselling services and local support groups across the country. It was also suggested that both hard and soft copies of this booklet be made available.

## 4. Bereavement Information Service

All study participants stated that they had encountered difficulties accessing information in relation to bereavement supports. It was acknowledged that there are many excellent services and supports available, nationally, and locally, but people are not aware of these services, and consequently bereaved individuals are not directed to them. The need for "a one stop shop" for bereavement information services, where all information is available was emphasised by the study participants. It was suggested that this centralised information service or platform, should be an online resource to ensure that individuals who are bereaved or supporting a person who is dying could access these resources, at a time that was convenient for them.

It was proposed that the information provided on this platform should be wide ranging, including information on death and dying, planning ahead; information on funeral arrangements, what they entail and associated costs; information on social welfare supports and entitlements; and information on support services, including national and local counselling services. This centralised approach is required and will service citizens and those providing ancillary services, ensuring the most up-to-date and accurate information is available and accessible for all.

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<sup>13</sup> Citizen Information Board (2021) Bereavement: A Practical Guide  
[https://www.citizensinformationboard.ie/downloads/guides/Bereavement\\_Guide\\_2021.pdf](https://www.citizensinformationboard.ie/downloads/guides/Bereavement_Guide_2021.pdf)

## 5. Education

According to participants in the focus groups and interviews there is a reluctance to discuss the issues of death and dying and the economic impact of bereavement amongst people in Ireland. Post-primary school education on death and dying, with a particular focus on financial preparedness for death (loss of income, funeral expenses etc.) is required.

## 6. Funeral directors

Transparency among funeral directors regarding all funeral and burial costs at point of engagement is recommended to avoid overspending and unnecessary debt.

## 5.2 Research Team Recommendations

### 7 Social Welfare Payment for Funeral Expenses

Social welfare payments for funeral expenses need to be separated from the Exceptional Needs Payment Scheme. The payment of funeral expenses needs to have its own distinct payment.

### 8. Pathway to support services

While supports and services exist the report has identified the issues facing people when accessing these supports. Both bereaved people and professionals find it difficult to access these supports. Information breakdown has happened across all stakeholders. Given that this study has identified that Support pathways are difficult to navigate these pathways need to be examined and the reason for information breakdown identified.

### 9. Accessible information

While participants made recommendations around an information 'one stop shop' and virtual and hard copy adaptations to existing resources it is noted that in practice much of this service may already exist, and in one location (e.g., <https://www.citizensinformation.ie/en/death/>).

Literacy as a concept includes the ability to navigate and access such information, as well as process it and make decisions based upon it. The experiences of these participants suggests further attention is needed. Social and practical factors impact on how people engage with information and clear pathways need to be evident. Further research needs to be undertaken to identify where information breakdown occurs and how to mitigate these.

Legal and financial literacy is a significant barrier to accessing much needed supports. It is imperative that documents need to be in plain English language and where required free translation supports for people whose first language is not English. The development of this information booklet could be undertaken in conjunction with the National Adult Literacy Agency to promote accessibility.

### 10. Greater collaborations between stakeholders

Greater collaboration, knowledge exchange and transparency are needed between support services to ensure consistent information is provided to citizens and equitable supports are offered regardless of location in Ireland.

This should include the continued development of a bereavement services network (with representatives from each stakeholder group) and an annual Knowledge Translation and

Exchange conference. This could include the continued development of the bereavement services network.

11. Supports for bereaved individuals returning to employment.

Employers need to support bereaved employees re-entering the workplace. This could include providing additional training to bridge career gaps and flexi time to allow support for bereaved parents to work around childcare and school and/or additional leave for counselling. Employers would also need advice and support to provide this.

12. Public education campaign

There is the need to devise a public media campaign to raise awareness of the financial impact of death and dying in Ireland, with a call to action for citizens to have a financial health check/stress test of their finances to see the impact of their death on those around them now and into the future. However, this would need to be underpinned with services/information that would support people to undertake such an exercise and act when stresses are found.

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## **Appendix 1: Research Advisory Group**

### **Research Advisory Group Chair**

**Ita Mangan:** Irish Hospice Foundation Board member

### **Research Advisory Group Membership**

**Bennett, Collette,** Research and Policy Analyst, Social Justice Ireland

**Colvin, Rachel,** Medical Social Worker, Mater Hospital

**Diamond, Ciaran,** Department of Social Protection

**Edghill, Angela,** Former policy and advocacy, Irish Hospice Foundation

**Foley, Sharon,** CEO, Irish Hospice Foundation

**Ginnell, Paul,** Director, European Anti-Poverty Network

**Jones, Anne-Marie,** Principal Medical Social Worker, Temple Street Hospital

**Keegan, Orla,** Head of Bereavement, Irish Hospice Foundation

**Keilthy, Tricia,** Head of Social Justice and Policy, St Vincent De Paul

**O'Connor, Joan,** Citizens Information Board

**O'Shea, Eamon,** Professor, School of Business and Economics, National University of Ireland,  
Galway

**Roberts, Amanda,** Bereavement Development, Irish Hospice Foundation

**Rooney, Andrew,** ALONE Charity

**Nicola K Fox,** Monetary Advice and Budgeting Service (MABS)



## Appendix 2: Economics of Bereavement Interview Topic Guide

Demographics	<ul style="list-style-type: none"> <li>- Age /</li> <li>- Gender</li> <li>- Household composition</li> </ul>
Socio-economic background	<ul style="list-style-type: none"> <li>- Employment status</li> <li>- Job type</li> <li>- Highest level of education attained</li> <li>- Transfer payments / benefits received</li> <li>- Housing tenure</li> </ul>
R-ship to	<ul style="list-style-type: none"> <li>- Child/parent/partner</li> </ul>
Funeral Costs	<ul style="list-style-type: none"> <li>- How was funeral paid for?</li> <li>- Financials supports sought<sup>14</sup></li> <li>- Debt arising from funeral.</li> <li>- Financial pressures / cost cutting measures<sup>15</sup></li> </ul>
Post Bereavement Economic Impact	<ul style="list-style-type: none"> <li>- Changes in the following as a consequence of the bereavement <ul style="list-style-type: none"> <li>o Employment status<sup>16</sup></li> <li>o Employment impact/ performance<sup>17</sup></li> <li>o Household income / earnings</li> <li>o Household debt</li> <li>o Living arrangements<sup>18</sup></li> <li>o Household composition</li> <li>o Health resource use<sup>19</sup></li> <li>o Household consumption / spending patterns</li> <li>o Financial distress</li> <li>o Legal expenses</li> </ul> </li> <li>- Economic hardship<sup>20</sup></li> <li>- Financial supports sought?</li> </ul>

<sup>14</sup> used own savings/investments, credit card, borrowed £ from friend/relative, got loan (bank), sold belongings, installment plan with funeral director, applied for subsidy from govt/local authority

<sup>15</sup> cheaper coffin, spent less on flowers, held wake at home, decided not to embalm, chose a direct cremation/cheaper cremation time, didn't use a hearse/limousine, buried deceased on their own land, kept deceased at home until the funeral

<sup>16</sup> premature retirement or resignation, demotion, leave w/out pay, absences, selling/leaving a business, loss of entitlements, inability to do weekend or shift work; leave without pay – after exhausting all other types of leave

<sup>17</sup> work performance: lack of concentration, motivation, depression. Absenteeism (leave days) & presenteeism (ability to perform job at 30 days, 6 months)

<sup>18</sup> household formation / residential mobility (moving to join households or new household members, moving house (e.g., downsizing) re-partnering

<sup>19</sup> hospitalisations (LOS), GP visits, counselling, prescriptions etc. general & mental health; out of pocket expenses

<sup>20</sup> Subjective measure like: "How hard is it for you to pay for the very basics like food, housing, medical care, and heating?" This question was rated on a 4-point scale ranging from 0 (not difficult at all) to 3 (very difficult).