

# Enhancing adult bereavement care across Ireland:

## A study

Commissioned by: The Irish Hospice Foundation  
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**“Whether death is sudden or prolonged, whether young or old, it is the time when life ends forever or is altered forever.”**

Marie Louise O'Donnell, *Finite Lives* 2017

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# Foreword from the Irish Hospice Foundation

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For the past thirty years, the Irish Hospice Foundation (IHF) working in partnership with others has sought to keep a focus on the centrality of loss in each of our lives.

Bereavement is the most human and predictable experience, it teaches us about our strengths as much as our pain, yet it is also the most isolating and, for some debilitating experience. For many of us, the decisions we make, the people we become, the help we give as carers, the help we receive from others and the lives we live each day are all carried out in the context of our own personal bereavements and loss.

Within the Irish Hospice Foundation, we are committed to working collaboratively to make excellence in bereavement and end-of-life care a national priority. The core issues that we believe must be addressed are:

- Inconsistency in end-of-life and palliative care services
- Inconsistency in bereavement services
- Inadequate staff training and lack of quality improvement in bereavement and end-of-life care
- Dying, death and bereavement are difficult topics and require greater public knowledge & awareness.

Through our work in public engagement, in awareness-raising, in training and education up to postgraduate level, and most importantly, in collaborative working, we are seeking to address some of these issues. Further, we work to build capacity and build shared commitment and consensus in delivering new models of bereavement care (e.g. complicated grief therapy, group support programmes, grief pyramid for children). Over the past years, we have joined with our partners to develop dynamic networks to generate shared visions and resources to serve bereaved families (e.g. the Irish Childhood Bereavement Network) and create and provide bereavement information (e.g. leaflets, website).

In 2017 IHF commissioned the 'Enhancing Adult Bereavement Care Across Ireland' report to set out the views of bereavement care providers and consider the options for clarifying and building bereavement care in Ireland through collaboration. The project was overseen by a Project Advisory Committee (PAC) whose members were stakeholders involved in bereavement care in Ireland.

## The experience of bereavement

The 'Enhancing Adult Bereavement Care' report reiterated that each year 30,000 people die in Ireland, equating to 80 deaths each day. Each deceased person is a family member, a parent or a friend, so it is reasonable to say that estimates of newly bereaved people are a significant multiple of the number of deaths in the country. The Irish Hospice Foundation estimates that approximately four to ten people are significantly impacted by each death, thus 300,000 people are newly bereaved each year, 800 each day – these very recently bereaved people represent up to 6% of our population<sup>1,2</sup>. It is clear, bereavement and loss affect large numbers of people in Ireland, in many ways, over many years.

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1. Scottish Government Health Directorate (2011) *Shaping bereavement care. A framework for action for Bereavement Care in NHS Scotland*. Available online: [http://www.sehd.scot.nhs.uk/mels/CEL2011\\_09.pdf](http://www.sehd.scot.nhs.uk/mels/CEL2011_09.pdf)

2. Nucleus Group. (2004). *Final report: Review of specific grief and bereavement services*. Melbourne, Victoria, Australia: Metropolitan Health and Aged Care Services Division, Department of Human Services



People die, and others are bereaved, at all ages; in infancy through to old age and from a variety of causes. Each of these circumstances suggests a different pattern of care prior to death which may impact grief and therefore it highlights the need to have a variety of bereavement supports available.

Bereavement and grief are legitimate fields of study and we now understand more about how people grieve i.e. uniquely in their own way, yet with recognisable common features. We know that bereavement is a normal, if painful life experience. The overall pattern in bereavement and grief is one of adjusting, of accommodating the memory and influence of the person who died into life, of living a different life and creating a 'new normal'.

Finally, although bereavement is an individual experience, it is firmly set in a collective and societal context and that context is changing e.g. an ageing demographic, changing family structure and a more multicultural society. Most people rely heavily on social support during and after bereavement and sometimes we look outside our circle for additional support. We therefore need to support communities to respond better to grief and loss and work with those who are directly reaching communities.

**We believe that sensitive bereavement care needs to be planned to meet life-stage and individual circumstances and other changing needs, as well as ensuring additional supports are available on a needs basis.**

## The impact of bereavement

The impact of bereavement is well documented, we know from studies and our experience that it includes intense psychological, physical and emotional disturbance and pain in the early days, weeks and months.

We also know that bereavement can impact on health and there is increased awareness of the long-term consequences of bereavement for families and individuals. Low income and socioeconomic disadvantage are known indicators of higher levels of grief related symptoms, psychological distress and increased likelihood of experiencing mental and physical health problems<sup>3,4</sup> and can compound their grief during an already difficult time.

We know that there are a number of factors which influence the grief journey and can add to vulnerabilities, e.g.;

- The relationship a grieving person had with the person who died (e.g. parent of a child, young widows/ers)
- The cause and nature of the death (e.g. unexpected or traumatic deaths)
- The support available from friends and family
- The bereaved person's age, personality, outlook, beliefs, resilience and their previous experience of loss.
- Other circumstances, such as financial strain, carer's responsibilities, access to social support.

We have a growing consensus about when grief becomes a more serious problem. Prolonged Grief is when grief becomes stuck and people experience disabling and persistent symptoms that don't improve. Its impact if unresolved means strong feelings of yearning and distress continue to be experienced, often coupled with feelings of anger, guilt, bitterness, and an inability to reengage with life.

3. Burke, L.A. & Neimeyer, R.A. (2013) 11 prospective risk factors for complicated grief. In M. Stroebe, H. Schut & J. van den Bout (Eds.), *Complicated Grief: Scientific foundations for healthcare professionals* (pp. 145-161). London: Routledge.

4. Garratt, E.A., Chandola, T., Purdam, K., & Wood, A.M. (2016) The interactive role of income (material position) and income rank (psychosocial position) in psychological distress: A 9-longitudinal study of 30,000 UK parents. *Social Psychiatry and Psychiatric Epidemiology*, 51 (10), 1361-1372.

Of interest, there are now proven therapies for the minority (10%) that develop *Prolonged Grief*<sup>5,6,7</sup>, one of which has recently been introduced in Ireland through the Complicated Grief programme at IHF.

In summary, it is clear that grief matters, if neglected it can have far-reaching implications<sup>8</sup>. **We believe that with a coordinated, informed and considered approach much can be done to meet needs.**

## Bereavement services

We know that bereavement support in Ireland is generally provided by a wide range of services and individuals operating from different structures, ethos and codes of practice. This provision is generally provided by voluntary & community support or self-help groups, by the health system (primary care teams/counsellors, hospitals, hospices and mental health services) and by the private sector which includes private counsellors and psychotherapists. As noted in the 'Enhancing Adult Bereavement Care Across Ireland' report these services are not co-ordinated through an agreed approach and can be relatively fragmented and patchy in their geographical coverage.

We also know that bereavement services in Ireland rely heavily on the voluntary sector and these services are under pressure to be sustainable due to their high dependency on fundraising. In addition, these services are becoming increasingly burdened with additional administration due to the recent Charity Regulations introduced in 2017.

In terms of supply and planning to meet bereavement needs not all services need to be professional counselling – indeed this goes against accepted models of bereavement care. The pyramid model outlined in the report<sup>9</sup> indicates that approximately a third of those who are bereaved require additional supports outside family and friends (eg listening, befriending, peer and support services) while up to 10% present with a more complex need requiring a specialist intervention (e.g. mental health services). Currently, we cannot say that this level of specialised service is accessible to all who need it and this can only result in continued suffering. In addition, the report highlights the professional and public lack of awareness of bereavement services as a challenge to service provision.

This further highlights the lack of standardised assessment and means of identifying vulnerable bereaved people throughout the system. It is increasingly clear that mechanisms for assessing and identifying a diagnosis of Prolonged Grief is required in Ireland, as are training routes to ensure evidence-based therapies are applied and available. A recent review of the attitudes, knowledge and skill of a range of professions concluded there is a likely training gap around Prolonged Grief (and indeed in grief in general). **We believe services that provide any level of bereavement support should have clarity about the people they seek to help, the means by which they provide that help, and their mechanisms for referral to other supports if these are more appropriate.**

5. Lundorf, M., Holmgren, H., Zachariae, R., Farver-Vestergaard, I. & O' Connor, M. (2017) Prevalence of prolonged grief disorder in adult bereavement: A systematic review and meta-analysis. *Journal of Affective Disorders*, 212, 138-149

6. Shear, K., Frank, E., Houck, PR. and Reynolds, C. (2005) Treatment of complicated grief: a randomised controlled trial. *Journal of American Medical Association*, 293(21) 2601-2608.

7. Shear, K., Wang, Y., Skirtskaya, N., Duan, N et al (2014) Treatment of complicated grief in elderly persons: a randomized clinical trial. *JAMA Psychiatry*, 71(11): 1287-1295

8. Stroebe, M., Schut, H. & Stroebe (2007). Health outcomes of bereavement. *Lancet*, 8 370, 1960-73.

9. Aoun, SM, Breen, LJ, Howting, DA. (2015) Who needs bereavement support? A population based survey of bereavement risk and support need. *PLoS ONE*; 10: e0121101.

## Policy and direction in bereavement care

The 'Enhancing Adult Bereavement Care Across Ireland' report also highlights the invisibility of bereavement in formal policies. Bereavement does not feature as an issue in overarching health strategies / frameworks. Although bereavement is considered within mental health, suicide, cancer care and palliative care policies/ frameworks, some of these considerations are minimal. Many of these documents consistently recommend that government departments should work with other agencies to initiate a process aimed at developing and implementing national guidance for bereavement care. The implementation of two policies 'Connecting for Life, Ireland's National Strategy to Reduce Suicide, 2015-2020 and 'Palliative Care Development Framework 2017-2019' holds some promise<sup>10,11</sup>.

**We believe that bereavement should be present in policies ranging from education to social protection to health in order to promote healthy and resilient responses and to ensure supports for those most in need.**

## A way forward: A framework for bereavement care based on the pyramid

Significantly, the 'Enhancing Adult Bereavement Care Across Ireland' literature review brings together the evidence and public health language underpinning a coherent approach to bereavement care i.e. one that is both evidence and value driven. It is clear that bereavement is a national issue of concern affecting many people every year. Some continue to be highly impacted by grief and loss. The evolving nature of Irish society means that needs and responses to grief and loss are changing and the presumed family and community support may not in fact be in existence. Current services are not yet developed significantly to meet need – at community, voluntary and professional specialised levels.

Within the Irish Hospice Foundation **we fully endorse the pyramid model and advocate for this approach to shape bereavement care policy, planning and service delivery.** The approach prioritises:

- public education and awareness about grief and loss to promote natural support (for all)
- access to appropriate peer and community bereavement services (for some)
- access to specialised therapeutic services (for few)

This pyramid model also highlights the role of informal support in helping grieving people and that the majority of individuals cope by accessing this natural support and help offered from those around them. However, bereaved people do not always receive the quantity or quality of social support that they would like<sup>9,12,13</sup>. It could be that the general public may not be prepared, capable or willing to support grieving family, friends, colleagues or neighbours<sup>14</sup>. Perhaps with the increasing professionalisation of dying, death and bereavement communities have become disempowered. It seems clear that more can be done to strengthen community responses – compassionate communities has shown some promise in this regard. More work can be done to support the development of compassionate communities as illustrated in the report.

Local and regional networks can also work to strengthen local responses. **We support the development of local networks to streamline and provide up-to-date information on accessing services locally and of national and local signposting of bereavement information.**

<sup>10</sup>. Department of Health (2015) *Connecting for Life, Ireland's National Strategy to Reduce Suicide, 2015-2020*. Available online: <https://www.healthpromotion.ie/hp-files/docs/HME00945.pdf>

<sup>11</sup>. Health Service Executive (HSE) (2017) *Palliative Care Services Three Year Development Framework (2017 – 2019)* Available online: <http://www.lenus.ie/hse/handle/10147/622650>

<sup>12</sup>. The Irish Hospice Foundation (2016) *What is to be bereaved? Experience of bereavement and grief support in the Irish population* (unpublished manuscript)

<sup>13</sup>. Aoun, SM., Breeb, LJ., White, I., Rumbold, B. & Kellehear, A. (2018) *What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach*. Available online: <http://journals.sagepub.com/doi/full/10.1177/0269216318774995>

<sup>14</sup>. Logan, E.L., Thornton, J.A., Kane, R.T. & Breen, L.J. (2017) Social support following bereavement: The role of beliefs, expectations, and support intentions. *Death Studies*, DOI: 10.1080/07481187.2017.1382610



In Ireland the suggestion to work to an ascending needs-led model of bereavement care is not new<sup>15,16,17,18</sup>. However, this model is not yet as widely adopted as it should be and **we believe a new framework of bereavement care, building on the pyramid model should be promoted and resourced in the coming 1-2 years**. This will provide a foundation for further collaborative work and in time the development of a more standardised approach to bereavement care in Ireland.

Bereaved people struggle to find services that meet their level of need and we know that services are more effective when targeted correctly. We believe that service development, regulation, standards and making bereavement care available and known about across Ireland can all be progressed if a common framework is adopted. Therefore we believe it is imperative that the Irish health and social service begin to recognise the importance of bereavement care in national policy and regulatory processes. These processes could take place in the short to medium term and represent the collective voice of those involved in bereavement care.

Finally, more work can be done to strengthen community responses towards bereavement.

## Final Recommendation:

It is essential that we develop a framework for bereavement care, based on the pyramid model, that will incorporate a national agreed statement for bereavement services in Ireland, including mechanisms to;

- Provide clarity on the type of bereavement support required to meet bereavement at all levels;
- Assist services to be clear at what level their service sits;
- Recommend education and skill required to underpin all levels of service provision;
- Advocate for sufficient supply of services at all levels;
- Enable professionals and volunteers to identify what level of service provision someone needs, including pathways for referral;
- Recommend that each service meets the criteria/standards set out for their level;
- Promote equity of service provision (e.g. affordability, geographic spread & service provision regardless of type of death);

As a first step towards progressing some of the priorities identified in the 'Enhancing Adult Bereavement Care Across Ireland' report the Irish Hospice Foundation is committed to facilitating this collective working to develop and advocate for a framework for bereavement care which we envisage will enhance the care provided to bereaved people in Ireland.

We would like to thank the wide range of people who shared their views and experience from different locations in Ireland and those who guided the project to its conclusion. The process of consulting with those involved in supporting and understanding bereaved people in Ireland has established that there is a strong appetite for and a belief in working together at a local and national level to make a difference. We look forward to working together on the next steps.

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

Sharon Foley  
**CEO, Irish Hospice Foundation**

15. National Advisory Committee on Palliative Care (2001) *Report of the National Advisory Committee on Palliative Care*. Available online: <http://lenus.ie/hse/handle/10147/42522>

16. Walsh, T., Foreman, M., Curry, P., O' Driscoll, S. & McCormack, M. (2008) Bereavement Support in an Acute Hospital: An Irish Model, *Death Studies*, 32:8, 768-786 [https://www.researchgate.net/publication/23440270\\_Bereavement\\_Support\\_in\\_an\\_Acute\\_Hospital\\_An\\_Irish\\_Model](https://www.researchgate.net/publication/23440270_Bereavement_Support_in_an_Acute_Hospital_An_Irish_Model)

17. Petrus Consulting, Bates, U., Jordan, N., Malone, K., Monaghan, E., O'Connor, S. & Tiernan, E. (2008). *Review of General Bereavement Support and Specific Services Available Following Suicide Bereavement*. Dublin: National Office for Suicide Prevention

18. Jones, A.M., Deane, C. and Keegan, O. (2015) The development of a framework to support bereaved children and young people: the Irish Childhood Bereavement Care Pyramid, *Bereavement Care*, Vol. 34 (2) 43-51

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**Sharon Foley** Chief Executive Officer, Irish Hospice Foundation, Dublin

**Christopher Hall** Chief Executive Officer, Australian Centre for Grief and Bereavement

**Debbie Kerslake** Chief Executive Cruse Bereavement Care, UK

**Josephine Kieran** Senior Therapist Bereavement Coordinator, Pieta House,

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**Irene Murphy** Director of Bereavement & Family Support Services, Marymount Hospice, Cork and Board member of the European Association of Palliative Medicine

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Anam Cara  
 Barrettstown  
 Bethany Bereavement Support  
 Care Alliance Ireland  
 Citizen Information Service  
 Community Mental Health Nursing, HSE  
 Embrace Farm  
 Feileacean  
 Fingal Counselling Service  
 GP based in Dublin  
 Jigsaw  
 Kilkenny bereavement support group  
 Le Cheile FRC  
 Marymount Hospice  
 Mater Hospital  
 Milford Care Centre  
 Mount Tabor Care Centre  
 Pax Counselling  
 Pieta House  
 Private Psychotherapist  
 Rainbows  
 Samaritans  
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# Steering Committee Membership

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The Irish Hospice Foundation commissioned this feasibility study and set up a Project Advisory Committee (PAC) to oversee and support the study.

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**Orla Keegan** Head of Education, Research & Bereavement, The Irish Hospice Foundation

**Margaret Chambers** Chairperson, Bethany Bereavement Support

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**Peter Hanlon** Bereavement Therapist / Clinical Nurse Specialist, A Little Lifetime and Barretstown

**Margaret McGoldrick** Psychotherapist, FirstLight

**Ger O'Brien** Director of Services, Firstlight

**Vincent Fox**, Social Worker, Mater Hospital, Dublin.

**Josephine Kieran**, Senior Therapist Bereavement Coordinator, Pieta House,

**Dr. Amanda Roberts**, Bereavement Development Officer, Irish Hospice Foundation.

# Executive Summary

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This report outlines the key findings of an independent feasibility study to enhance bereavement care in Ireland, commissioned by The Irish Hospice Foundation (IHF) and overseen by an independent project advisory committee representing stakeholders with an interest in bereavement care and support in Ireland. The main aims of the study were to establish a vision for a national approach to bereavement care in Ireland and to develop an implementation framework to enhance bereavement care.

The methods used to meet the agreed aims were diverse and included (1) a rapid systematic review of international evidence; (2) one-to-one interviews with 12 national key informants; (3) telephone interviews with international bereavement leads (n=4); (4) a focus group with the project advisory committee; (5) four focus groups with stakeholders (n=41) involved in the provision of bereavement care and support in Ireland; (6) analysis of survey data relevant to bereavement collected by the Irish Hospice Foundation and (7) analysis of the records of two national bereavement forum meetings held in 2016 and 2017.

From the range of evidence considered, there is a clear need and desire within the sector to develop a national structure to enhance bereavement care for adults in Ireland. With agreed governance and a solid membership base, over time a national network or alliance could:

- Agree levels of bereavement support and develop standards / guidance to assist bereavement support providers
- Develop, implement and evaluate a public awareness campaign with a focus on normal responses to grief and loss and how the public can support each other
- Advocate and lobby on bereavement related issues
- Develop a signposting and resource based website for professionals and the public

- Map all services and supports to inform the development of a directory / database of services and support
- Facilitate regional and/or national networking meetings / conferences to include self-care information
- Support small services with policies, procedures and governance issues through the development of template and frameworks
- Input into the development of job descriptions / training of people working in health and social care, primary care and mental health
- Lobby clinical psychology, psychiatry and social work education providers to adopt competency training around grief and complicated grief
- Develop and deliver education and training
- Establish a national research brief / unit around grief and complicated grief
- Promote and support the self care of service providers

Based on this report a phased plan is now required and it may be pertinent to consider an alliance based around a single project as a first step. This minimizes any potential risks and would help develop ways of working collectively.

# 1.0 Introduction

This report outlines the key findings of an independent feasibility study to enhance bereavement care in Ireland, commissioned by The Irish Hospice Foundation (IHF) in July 2017. The study was overseen by an independent steering committee representing stakeholders with an interest in bereavement care and support in Ireland. The study was funded by The Irish Hospice Foundation.

## 1.1 Background to the feasibility study

In 2016, 70 people representing 33 organisations with a focus or interest in bereavement care and support in Ireland attended the inaugural Bereavement Forum hosted by The Irish Hospice Foundation. At this forum, participants called for a nationally coordinated approach to bereavement care that promotes connection and collaborative working. The need for bereavement to become a national priority at government policy level was emphasized, together with the need for the development of a framework, guidance and standards for services offering support. At the forum, a similar approach, developed for childhood bereavement in Ireland (the ICBN) was examined, together with consideration of developments in England and Scotland presented by Alison Penny and John Birrell. Furthermore, the need for a public health approach to bereavement support was also emphasized, whereby social support, community engagement and partnerships with key institutions and organisations (e.g. education and industry) are promoted and nurtured.

A second meeting was held in 2017, where 34 people from 26 organisations outlined their vision for bereavement care in Ireland. This vision included:

- (1) Broad initiatives to recognise and promote awareness of bereavement in Ireland;
- (2) A national approach to the development of standards, pathways of support, guidelines and services;
- (3) The need for education for the public, volunteers and professionals;
- (4) The need for organisation, good governance, networking and funding.

Detailed summary reports from both meetings are included in Appendix A. Participants agreed that a feasibility or scoping study would be useful to examine a broader array of perspectives. A project advisory committee was subsequently established to oversee a feasibility study to explore the development of a pathway toward a national approach to bereavement care. The terms of reference for this committee are included in Appendix B.

This document summarises the methodology used to conduct the national feasibility study, synthesises the key findings emerging and makes a number of preliminary conclusions for the Steering Committee to review and reflect upon as they set out to develop a pathway in 2018.

## 1.2 Study objectives

The agreed objectives for the feasibility study were to:

### 1. Establish the vision for a national approach to bereavement care in Ireland

- Describe current bereavement care in Ireland
- Identify strengths, weaknesses and opportunities in current bereavement care
- Identify relevant policy context for development of bereavement care aligning to mental health and other appropriate areas
- Prioritise needs for action

### 2. Develop an implementation framework for enhancing bereavement care in Ireland

- Based on current situation, literature, and international models propose:
  - o structures/ models for a network or alliance in bereavement care in Ireland
  - o governance and
  - o an outcome driven workplan for a network/alliance in bereavement care in Ireland.
- Identify key deliverables in a three to five year timeline
- Identify resource requirements, staffing and potential statutory or non-statutory supports
- Conduct a risk analysis



## 2.0 Methodology

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The study methodology included:

- (1) A **rapid systematic literature review** of international evidence to understand and compare bereavement care, policy, standards, structures, guidance and support in Ireland, UK, Canada, Australia and The Netherlands with consideration to both the empirical and grey evidence (see Appendix C for detailed systematic review methodology). Studies obtained from the review have been used to contextualise the need for a bereavement structure in Ireland.
- (2) **One-to-one telephone interviews** with key informants (n=12), nominated by the Steering Committee, to consider in depth the structure of bereavement care in Ireland (see Appendix D for topic guide) with a focus on strengths and weaknesses and practical consideration for future developments.
- (3) **Telephone interviews with bereavement care leads** in England (n=2, Scotland (n=1) and Australia (n=1) to understand their experience of the national development of bereavement care and associated risks in their countries. These interviews were unstructured and conversational based on the person interviewed and their area of focus.
- (4) **Focus group discussion** with the project Steering Committee to consider in-depth the structure of bereavement care in Ireland (see Appendix D for topic guide) with a focus on strengths and weaknesses and practical consideration for future developments.
- (5) **Four focus groups with stakeholders involved in the provision of bereavement care and support** in Dublin, Cork, Limerick, and Sligo (n=41) (see Appendix E for topic guide and all supporting documentation) to consider the strengths and weaknesses at a more local / regional level and to enable groups to prioritise recommendations collated via telephone interviews.
- (6) **Analysis of Omnibus research survey data** relevant to bereavement collected in 2016 by Amarach for the Irish Hospice Foundation and data from the Irish Hospice Foundation's #haveyoursay 2017 survey.
- (7) **Analysis of the records** of the two national bereavement forum meetings (2016 & 2017).

# 3.0 Bereavement Care - Why does Ireland need structure?

## 3.1 The experience of bereaved people

Approximately 30,000 people die in Ireland each year. Varying estimates indicate that between 4 to 10 people are significantly impacted by each death (Irish Hospice Foundation, 2017; Stephens et al., 2015; Nucleus Group, 2004). Therefore, at some point in life, bereavement will touch the life of each and every citizen. The impact of bereavement varies from person to person across time and is influenced by a number of factors including (a) the nature and circumstances of the person's death (e.g. suddenness or preventability); (b) the relationship between the person who has died and the bereaved person (e.g. strong, secure or ambivalent) and (c) individual factors related to the person who is bereaved (e.g. developmental stage, mental health, social support network) (Strada, 2009). Recent studies indicate that the prevalence of those at high risk of mental ill health post bereavement is 6.4% with another 32.5% requiring some degree of formal bereavement support (HSE, 2017 quoting Aoun (2015)). The Petrus (2008) review of bereavement support services available in Ireland highlighted that, in a typical year, bereavement care can be provided to up to 19,000 people. All bereaved people require information about loss, social support and understanding and to know about the existence of local services. For the vast majority (60%) this is all the bereavement support required (HSE 2017). Where a death is not sudden or tragic in nature, bereavement care may involve both pre and post death.

Not all bereaved people suffer a significant and long-term grief reaction following the death of a loved one (Bonanno, Boerner, & Wortman, 2008); however, some bereaved caregivers do exhibit elevated levels of distress and for most this distress is often short lived. However, a significant minority (about 10-20%) experience persistent psychiatric difficulties (Kersting et al, 2011; Prigerson, Vanderwerker, & Maciejewski, 2008) and would benefit from professional intervention. Grief

interventions show differential efficacy according to level of need. A comprehensive meta-analysis of 61 controlled studies of psychotherapeutic interventions for bereavement (Currier, Neimeyer, & Berman, 2008) demonstrated greater efficacy for interventions targeted to grievers with higher levels of distress (e.g. clinical symptomatology). Grief interventions for individuals with 'normal' grief tend to offer minimal to no efficacy and may even result in greater distress (e.g. Schut & Stroebe, 2005). The move to offering support according to need is strengthened by recent empirical studies that indicate support for targeted interventions for people who meet the criteria for complicated grief/ Prolonged Grief Disorder/ disturbed grief (e.g. Boelen & Smid, 2017; Shear et al., 2016; Bryant et al., 2014; Rosner, Pfoh, Kotoucova & Hagl, 2014). Clearly, a blanket approach to bereavement care is not appropriate; instead, the focus needs to shift towards service delivery models predicated upon individual need. Modern approaches to bereavement care consider such statistics and evidence, recognising that most people who experience bereavement do not require counselling or intervention from specialist services but will benefit from support.

*"...from the outset it is important that we caution ourselves not to become too prescriptive about grief reactions and their effect on bereavement and to remember that bereavement as a process is affected by religious and cultural beliefs and by a range of mediators. The meaning of the loss to the person, the combination of risk and protective factors and the level of internal resilience and coping skills are important aspects. Moreover, grief is mediated by social factors such as the age of the bereaved person, the circumstances of the death, the social background of those who have been bereaved and the extent to which mourning, as the public face of grief, takes place"* (Scottish Framework 2011, p. 11)

The three levels of intervention for bereavement care (Schut, Stroebe, van den Bout, & Terheggen, 2001) are: primary – targeting all bereaved

people; secondary – targeting people at-risk of complications of bereavement; and tertiary – targeting people with complicated bereavement<sup>1</sup>. These levels of intervention align with Neimeyer's (2008) differentiation of grief support (informal compassion and information from people who do not have professional bereavement training), grief counselling (provided by trained professionals), and grief therapy (provided by trained professionals to people with mental health concerns). Whilst grief is considered to be a normal process, there is a growing consensus that bereavement should be considered a public health priority issue for all governments (Kellehear, 2008; Higginson and Koffman, 2005; Rao et al., 2002).

Two recent surveys of the public commissioned by The Irish Hospice Foundation provide an insight into the general public's perception of bereavement care and support in Ireland.

The #haveyoursay survey informed the development of a Charter for Death, Dying and Bereavement in Ireland. 2,224 people responded to a question regarding how their community could support the bereaved better. The most important theme emerging from the findings is the need for people to support each other through bereavement. Other suggestions included the need to:

- Raise awareness to supports and information available
- Improve access to low cost non-denominational support and counselling
- Hold a media campaign to enable people to understand more about bereavement, supports available and how to access them
- Hold community gatherings to facilitate open conversation and remembrance rituals
- Plant memorial gardens
- Have access to 24/7 support

The findings informed the development of the People's Charter on Dying, Death and Bereavement in Ireland. Specific to bereavement, the Charter states

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

- *People understand grief and do not avoid thinking or talking about it.*
- *Family and friends are supported during a loved one's illness and after their death. People get space and time to grieve, talk and remember."*

The 2016 Omnibus survey conducted by Amarach for the IHF (n=908) indicates that 1 in 5 respondents had experienced the bereavement of someone close in the previous year with more than 8 in 10 people experiencing the loss of someone close within their lifetime. A quarter of respondents (24%) say their physical health has deteriorated since the loss of someone close, with 3 in 10 (29%) stating that their mental health has deteriorated and 1 in 5 (20%) reporting that their financial situation has deteriorated since the loss of a loved one. Males were less likely than females to say their physical or mental health has deteriorated since the loss of a loved one, but more likely to say their finances have deteriorated. Respondents reported that friends and family are the most useful sources of support and there was generally a low use of mental health support services. However, more than 1 in 3 respondents stated that they did not get all the help they required during the bereavement. Respondents were open to using external support sources, with 1 in 5 (19%) stating that professional supports (e.g. counsellors and psychologists) would have helped them during their bereavement. Younger people were more likely to feel that counsellors or therapists could help them during bereavement.

We now examine why, based on the literature, policy gaps and experience both nationally and internationally a structured approach to bereavement care in Ireland is considered necessary.

### 3.2 Policy

Ireland does not have a national bereavement strategy or any overarching structure coordinating bereavement services, support and information. Bereavement does **not** feature as an issue in any of the following current overarching health strategies / frameworks:

- Slaintecare (May 2017)
- Healthy Ireland – A Framework for Improved Health and Wellbeing (2013 – 2025)
- The Department of Health's Statement of Strategy (2016 – 2019)
- Health Service People Strategy (2015 – 2018)

<sup>1</sup> While Schut et al use 'primary', 'secondary' and 'tertiary' the terminology 'universal, selective and indicated' has been used by Currier, Neimeyer, Aoun and the EAPC.

However, within mental health, suicide, cancer care and palliative care strategy / frameworks bereavement is considered as follows:

### 3.2.1 Mental health strategy

Following the publication of *Reach Out – the National Strategy for Action on Suicide Prevention (2005-2014)* the National Office for Suicide Prevention (NOSP) selected Petrus Consulting to examine and report on general bereavement support services and specific services available following suicide bereavement. The 2008 report made a number of recommendations regarding the information provided to those bereaved by suicide, the role of self-help groups, models of service provision, training, qualification and standards for those involved in suicide bereavement support and discussed future service delivery including associated costings. The Petrus report's final conclusion calls for investment in core generic support:

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**“A bereavement support service should not necessarily put an emphasis on the type of death, but rather concentrate on the bereaved person and the consequences of their loss, and screen for complicated grief.”** Petrus Report (2008)

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More recently, there are passing references to bereavement in *Mental Health – a Vision for Change* where bereavement is first mentioned as a life course issue that can result in mental health issues or distress that usually resolves over time and can benefit from the provision of community based support, including that from friends and family (p21). Later in the document bereavement is used as an example of a situation whereby an individual could deal with the distress by drawing on their own interpersonal resources and illustrates that for some people the outcome will be referral to a GP or mental health services with prescription for anti-depressants (p45). The document notes that GPs often deal with bereavement issues (p63), that social support, self-help and volunteering can be protective factors against poor mental health for older people when faced with bereavement (p117) and is also an issue for people with intellectual disabilities as they age (p132). The document outlines that bereavement support is a key priority area in *The National Strategy for Action on Suicide Prevention* and also refers to counselling as a brief intervention for those presenting with mental health difficulties due to an underlying life events such as sudden bereavement (p246).

In *Connecting for Life – Ireland's National Strategy to Reduce Suicide (2015-2020)* it is noted that increased provision of bereavement counselling is a key success of the previous strategic document 'Reach Out'. Action 4.3.1 states that enhanced bereavement support will be offered to people and their families known to mental health services and affected by suicide and in 4.3.2 it states that a national evaluation of bereavement services will be commissioned.

### 3.2.2 Palliative care strategy and frameworks

More focused consideration is offered to bereavement in the *HSE Palliative Care Services Three Year Development Framework (2017-2019)* where in Section 2.3, a population needs approach to bereavement is recommended. The framework advocates for the development of national guidance and standards for bereavement care at all levels and more explicitly recommends that:

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**“The HSE, in conjunction with other agencies, should initiate a process aimed at developing and implementing national guidance for bereavement care at all levels of provision, based on a population needs approach. The guidance should explicitly look to develop national and local coordinated networks, and standards for bereavement care, with a reach beyond palliative care services.”**

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p.14 HSE Palliative Care Services Three Year Development Framework (2017-2019)

*The Palliative Care Competence Framework (Ryan et al. 2014)* indicates that all health care professionals require a level of bereavement care competence and this up-skilling will require allocation of appropriate resources and access to education. The framework specifies that all health care professionals should:

- Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced
- Recognise the range of individual physical, psychological, spiritual, emotional and social responses to loss and grief
- Recognise the factors which may put a person at risk of encountering difficulties in their grief, whilst also remaining aware of the resources and resiliencies that are particular to each person and family

- *Demonstrate an ability to engage with a person who is experiencing loss in the context of professional scope of practice and/or role*
- *Assist the family to access bereavement information and support at a level that is appropriate to their needs*
- *Be cognisant of the psychological impact of death and dying on individuals with increased stress vulnerability*
- *Understand the personal impact of loss, grief and bereavement and recognise your own loss responses and engage in activities that maintain your resilience on an on-going basis*
- *Possess a level of self-awareness that prevents your own experiences of loss from negatively impacting on the person with a life-limiting condition or their family.*

#### **Palliative care for children with life limiting conditions in Ireland - a National Policy (2009)**

calls for the development of bereavement services in Ireland where greater access to services and support is made available during the child's illness and following their death. More specifically, the document states that:

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**“Caring for a child with a life-limiting condition impacts on the whole family and can create enormous strain on parents, siblings and other family members. After the death of a child, bereavement services need to be responsive to this need. Bereavement support is ideally provided by a person known to the family, such as a key worker, who has the appropriate training, supervision and support and who is able to assess and refer on to specialist bereavement services if required. Bereavement education and training should be provided for all staff involved in the care of children with life-limiting conditions and their families.”** Palliative care

for children with life limiting conditions in Ireland - a National Policy (2009)

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The **Evaluation of the Children's Palliative Care Programme (CPCP) Report (2016)** which was a jointly funded programme of work arising from the Palliative Care for Children with Life-limiting Conditions – A National Policy made a number of recommendations for action which included bereavement care. The evaluation highlighted the

lack of available and standardised bereavement care and recommended that bereavement care needs to be ‘*prioritised by the HSE as current service provision is failing to provide adequate support to families bereaved by the death of a child with a life-limiting condition*’ (p.42). It further recommended that the findings of the evaluation be discussed by the Department of Health and the HSE and used as evidence for the development of priorities for policy and service development, which included bereavement services.

#### **3.2.3 National cancer strategy**

The **National Cancer Strategy (2017-2026)** refers to bereavement just once in the context of a comprehensive cancer care model for children and young people delivered by the National Paediatric Haematology and Oncology Centre (NPHOC) (p89).

### **3.3 National standards**

The most recently published standards for bereavement care in Ireland relate to the provision of support for children, published by the Irish Childhood Bereavement Network and endorsed by Tusla. The **Standards for Supporting Bereaved Children (2017)** can be used to plan, provide and review the quality of childhood bereavement care in Ireland. The five standards relate to the child, the family, the local community, service providers and national policy and infrastructure as follows:

- **Standard 1 - Child:** *Children's experience of bereavement will be recognised, acknowledged and supported in accordance with their needs over time.*
- **Standard 2 - Family:** *The family is generally the main source of care for the bereaved child and may require access to reassurance, information, guidance and support to provide this care.*
- **Standard 3 - Local community:** *All bereaved children should have access to bereavement information, guidance and support services in their local community.*
- **Standard 4 - Service providers:** *All service providers must ensure that governance, procedures and protocols are in place to ensure ethical, safe and appropriate bereavement service delivery to the children in their care.*
- **Standard 5 - National:** *National policy and local infrastructure includes appropriate responses to, and integrates the needs of, bereaved children.*



The suicide prevention strategy refers directly to the **National Quality Standards for the Provision of Suicide Bereavement Services: A Practical Resource (2012)** that cover information, support, counselling and psychotherapy services to establish national standards for all levels of suicide bereavement support services in Ireland. These practical standards stemmed from the Petrus Report (2008) and were developed by the National Office for Suicide Prevention, Console, and Turas le Cheile bereavement support service to help to ensure a consistent quality of such services nationwide.

Other national standards relevant to bereavement include **The HSE National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death (2016)**. These standards clearly define the care parents and families can expect to receive following a pregnancy loss or perinatal death. The standards are being implemented and applied across the health service in all appropriate hospitals and settings. The standards are built around four central themes

1. **Bereavement Care** which is central to the mission of the hospital and is offered in accordance with the religious, secular, ethnic, social and cultural values of the parents
2. **The Hospital** to ensure a system is in place to provide bereavement care and end of life care for babies that is central to the mission of the hospital and is organised around the needs of babies and their families
3. **The Baby and Parents** to ensure each baby/family receives high quality palliative and end of life care appropriate to his/her needs and to the wishes of his/her parents
4. **The Staff:** so that all hospital staff have access to training education and training opportunities in the delivery of compassionate bereavement and end of life care in accordance with their roles and responsibilities

The **HIQA National Standards for Residential Care Settings in Ireland (2016)** refers to bereavement in Standard 2.5.12 as follows:

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**“Upon the death of a resident, practical information (verbally and or in writing) is offered to family and friends on what to do following the death and on understanding loss and bereavement. This includes information on how to access bereavement care services and how to register the death”.** HIQA 2016

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**HIQA National Standards for Safer, Better Healthcare (2012)** refers to bereavement once within the definition of end of life care.

Without question, the most comprehensive examination of bereavement from a policy perspective in Ireland outside of health is the recent publication by Independent Senator Marie Louise O'Donnell in 2017 of **Finite Lives: An Examination of State Services in Ireland**. The report is the first comprehensive analysis of end-of-life issues across all government departments outside health. The Report recommends specific to bereavement:

- The need for a whole government national strategy on end-of-life
- A national public consultation process on people's views around dying and death
- A socio-economic review of the costs of dying, death and bereavement including funeral poverty
- Regulation of the Funeral Services Industry
- Reinstatement of the Bereavement Grant
- The development of modules within teacher training on supporting grieving children.
- Increase in the Living Alone Allowance
- Promotion of the Think Ahead planning tool
- Updating the Coroners Bill 2007 and enacting it as a priority
- Development of a dedicated website outlining all State services that are available to support people at end of life.
- Exploration and adaptation of services in the UK such as “Tell Us Once” and the Bereavement Service Helpline to reduce the administrative burden facing individuals and families.
- A review of income support for people who are bereaved with particular attention paid to the needs of young widows with children. Anomalies should be addressed such as the situation facing those who are unmarried with children who lose a partner.
- Relieving the financial burden on families when the remains of their loved ones are being repatriated by providing funding to the Kevin Bell Repatriation Trust
- Encouraging all Departments to develop end of life plans towards an overall national strategy.

The analysis of policy documents above indicates that whilst bereavement is referred to in some policies and frameworks, there is a lack of an overarching, population health based approach to the development of bereavement services in Ireland. Over the years, many recommendations have been made, however there is no central body driving implementation of these recommendations and this may explain the manner in which bereavement care has evolved in Ireland to date. One respondent to the interviews captured their ambition for bereavement in policy well

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**“I think it’s really having an ambition that bereavement needs to not dominate but be part of really all health policy developments. That seems almost massively ambitious, but it’s a little bit like palliative care in health services. Palliative care needs to be part of all parts of our health services. In the same way, I think bereavement needs to be part of all parts of policy development within the health and social care structures. For example, we’re about to start the revision of Vision for Change. Vision for change is over 10 years old now, and the Department of Health is initiating a review of it. That has the potential to have a major impact on bereavement policy development, but being part of an overall policy remit. Really if it isn’t significantly detailed in that type of large policy, it’s very difficult then to develop appropriate services following that”.** Interviewee 1

Statutory Provider

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### 3.4 Current bereavement care in Ireland

While acknowledging that many professionals such as nurses have a ‘normal support role in bereavement and that there is continuum of support, this section looks specifically at sectors where bereavement care is a formal part of individual or agency activity.

It is difficult to accurately summarise current bereavement care for adults in Ireland since there is no national database of organisations or individuals providing bereavement support and there is no national strategy for bereavement care. Bereavement support in Ireland is provided by a combination of national charitable organisations,

local voluntary groups, HSE mental health services, primary care counsellors, and private practitioners (often independent counsellors / psychotherapists) working across the country. Tusla grant funds family support centres and counselling groups countywide that offer bereavement counselling as part of their remit. It is estimated that hundreds of bereavement support organisations/individuals are operating, however in the absence of a comprehensive mapping exercise, this is very much a ‘guestimate’.

Depending on the way bereavement impacts upon us, different levels of intervention are required. Internationally, approaches to bereavement care have been developed based around the potential for complication (e.g. NICE three tiered model approach to bereavement care (Nice, 2004)) and, more recently there is a shift toward a public health, assets based approach that focuses on community capacity building to offer support (Aoun et al., 2012; Rumbold and Aoun, 2014). The bereavement care and support provided in Ireland varies depending on the manner and place in which a person dies (e.g. in a hospice or by suicide), the geographical location of the person experiencing bereavement and their actual need for support and information. The driving force behind the establishment of many bereavement support providers is often a personal experience of loss. This experience fuels the passionate commitment of individuals to help others and instigate change, often resulting in the establishment of a service to meet a need in a local area, or to provide support to people experiencing a similar type of loss. In Ireland, bereavement interventions offered vary in type and intensity and include 1-1 sessions, group sessions, information evenings, remembrance events, activity weekends, home visiting, information giving and signposting.

Support is provided by a range of different types of people and professionals including volunteers, members of religious orders, social workers, nurses, GPs, clinical psychologists, counsellors and psychotherapists. Friends, families and members of local communities also play an important role in the provision of bereavement support and this is particularly noted in rural communities.

Many organisations provide bereavement support at a ‘no or low cost’, whilst other private practitioners charge an hourly consultation fee. Services are often funded through a combination of grants from agencies such as HSE, TUSLA and schemes such as the National Lottery or the Dormant Accounts fund. Local and national fundraising campaigns also support the provision of bereavement services and some are funded via local Parishes.

All charitable organisations providing bereavement support are required to register with The Charities Regulator and this offers some assurance regarding the governance of providers regarding their compliance with the Charities Act. However, there are no national standards or accreditation pathways for bereavement care and support services in Ireland and no agreed minimum qualifications for individuals providing support. Bereavement education and professional development is offered at different levels from one off lectures or workshops within communities, to longer bereavement educational support programmes offered as part of a hospice education programme, to a Master's programme delivered by RCSI and The Irish Hospice Foundation.

While the label 'bereavement counsellor' exists in the public vernacular there is no formal designation of such a post and in fact the general regulation of counsellors and psychotherapists is only beginning in Ireland, under the auspices of CORU.

### 3.5 Stakeholders' perceptions of bereavement care

At the national bereavement fora held in 2016 and 2017, hosted by The Irish Hospice Foundation it was clear from the feedback obtained from stakeholders involved or interested in bereavement, that a nationally coordinated approach to bereavement care that promotes connection and collaborative working is required (see Appendix A). In making this recommendation, the fora noted their perceived strengths and weaknesses of bereavement care and support in Ireland. In addition, as part of this study, participants in one-to-one interviews and in focus groups shared their views. The key themes arising from the strengths and weaknesses analysis can be largely summarised within six headings as follows:

- Bereavement support in changing communities
- National structures, services and developments
- Community based, person-centered, bereavement support based on shared experience
- Public awareness and education
- Support for those working in bereavement care
- Need for a national adult bereavement network.

Each of these themes is now described in more depth.

#### 3.5.1 Bereavement support in changing communities

Respondents described how good communication and positive support offered to people at the time of death from both professional and community perspectives are vital in the immediate response of people who have experienced a bereavement. It was generally agreed that in Ireland, **we are usually good at offering this professional and community support at the time of death** and that this support, together with the **comfort associated with religious organisations, ritual, custom and tradition** was considered to be beneficial. However, there was some concern that **we can become too complacent about 'the Irish who do death well' mindset** and it was generally agreed that there is a **need for improved community support post death.**

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**"Ireland has a very good tradition of doing death and dying and grief and loss well but it's important not to oversubscribe to this but to support it. We have a flair and a strong tradition and recognise that this part of life. We need good structures but it is important that it isn't led from the top in a rigid way. There needs to be both art and science of bereavement and loss,"**

Interviewee 2 Statutory Provider

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**"We're still a death denying culture. We do our rituals very, very well. But when they are over, we haven't a clue, actually you just have to get on with it, and that's it. That's the Irish attitude. So you look and you say 'No' you need to be actually able to interface first and deal with it, and we need to help people to do that."** Interviewee 3

Voluntary agency

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It was noted that **people are becoming more proactive in seeking and availing of bereavement support.**

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**"People in society are now talking about things, that traditionally people would have found upsetting...people seem more prepared to tap into services and supports than they used to be"** Interviewee 2

Statutory Provider

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Whilst there is a **perception that women seek out support and want to talk more than men, it is also clear that men are seeking help and availing of support too.**

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**“There is a hunger, but the hunger doesn’t get met. When something comes up in an area, like a bereavement talk, people hone in on it. We’ve talked around the country and 150 people turn up. Many of the people attending are fairly recently bereaved...what’s fascinating is the number of men who turn up... sea tragedies, traumatic death, road accidents.”** Interviewee 3 Voluntary agency

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It was noted that as Ireland becomes more culturally diverse, **we have responded positively and respectfully to cultural differences and societal changes regarding death and bereavement.** This has included staff in health, social care and the death industry seeking education and training in culturally appropriate responses to care, death and bereavement to meet the diverse needs of people they are working with. The **funeral industry has modernised** its practice to include funerals online to ensure that the Irish diaspora are offered an opportunity to engage in ritual remotely and civil ceremonies for those people where formalised religion is not important.

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**“The whole funeral ritual is adapting, there are lots more civil celebrants now. So people can be as true to their values in death and is life”.** Focus Group

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Local **community based and national remembrance events** e.g. Embrace Farm’s remembrance service for families bereaved as a result of farm death and hospice light ceremonies were also considered to be of immense value in acknowledging publically a person’s loss and bringing people at different stages of loss together to support each other and remember.

### 3.5.2 National structures, services and developments

National initiatives including **‘The Irish Childhood Bereavement Network (ICBN)’** and the **‘Hospice Friendly Hospitals Programme (HFH)’** were referred to positively by respondents as they discussed the strengths of bereavement care and support in Ireland. In particular, the ICBN has brought together and strengthened the childhood bereavement sector in Ireland through networking, education and the development of standards. The HFH programme has improved bereavement support and communication at the time of death in acute and community

hospitals and residential services for older people. Work in the area of complicated grief, led by the Irish Hospice Foundation was also noted positively.

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**“With complicated grief the plan has been to have at least one practitioner in every county. I was seeing people that were travelling hours to see me and I mean, that’s just not good practice. It’s not what we want...but we now have a publically held list of therapists trained in complicated grief...I think to ensure parity and affordability of service has certainly been our vision for a long time”**

Interviewee 4 Voluntary agency

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National organisations including **The Irish Hospice Foundation, Bethany, First Light, Pieta House, Anam Cara and the Men’s Shed** were held in particularly high regard for their focus on bereavement and loss. The recently published **Bereavement Care Maternity Standards (2016)** are considered to be a positive development from the policy, practice and patient experience perspectives as is the bereavement pyramid.

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**“The bereavement pyramid that is in circulation is very useful. To say ‘Not everyone needs counselling, but everyone needs support.’ That support can be anything from cooking a meal or picking up the kids to information regarding the normal grief trajectory...not everyone needs counselling or psychotherapy... people move up and down the pyramid.”**

Interviewee 4 Voluntary agency

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National champions such as **Marie Louise O’Donnell** for her work on bereavement in public service was applauded.

One area of significant concern amongst many respondents is the **variation in practice amongst coroners at the time of an inquest.** It is considered that there is an urgent need for a review of coroners court / inquest practices with a view to reducing the trauma and distress to those who are bereaved.



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**“The process of an inquest is to determine the cause of death and that can determine the reading out of a medical report. Some coroners read them out. Some don’t. Some hold them in a courtroom, some hold them in a hospital, and some hold them in a hotel. So each is different to the next. Some show great compassion and empathy to the family and try to explain details beforehand. Others have families just arriving in and next thing reels of information is given to the family and then everyone’s gone and the family is left going “What in the name of God was that? I would like to see a more unified approach by the coroners... More consideration is needed around publication of reports. I know an inquest is a matter of public record but we had a case of a man driving to his wife’s inquest and listened to the medical report on the local radio before he got there. There need to be media guidelines.”** Interviewee 5 Voluntary agency

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Other areas for review include post mortem information and practices, particularly where children are involved.

### **3.5.3 Community based, person centered, bereavement support based on shared experience**

The commitment at a **grassroots, community level to offering person centered bereavement support, often through volunteers based on a model of listening and shared experience** was considered to be a positive aspect of bereavement support in Ireland.

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**“I think shared experience for people is so important. To sit in a room with another parent who has lost a child. To sit in another room with a person who has lost their mother. I think that reduction of isolation, that sense of compassion and care are really important.”** Focus Group

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In particular, the work of **Kilkenny Bereavement Support** group was noted as a model of best practice due to manner in which they offer training to volunteers and support people experiencing a range of bereavement types working right across the community.

However, it was noted that **services vary according to geographical location and type of loss** and this leads to under representation in some areas.

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**“Nationally...geographically some areas are totally bereft. Areas of Ireland like Donegal, parts of Mayo, Kerry have nothing and there is a hunger to get something to be of support to people in these regions.”** Interviewee 3 Voluntary agency

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**“In Dublin there’s a concentration of services It’s easier for people to access services that they need when they need them. But it shouldn’t depend on where you are.”** Interviewee 4 Voluntary agency

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There is a perception that there is a lot of support for those bereaved by suicide or cancer but supports for other groups e.g. travellers or bereaved parents is lacking.

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**“I feel like there’s an awful lot of suicide support groups and they are all doing different things. There is nothing pulling them together. There is such an absence of other services and an abundance of suicide services”** Focus Group

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There is evidence that **people are not always receiving the level of service to meet their needs** and there was some concern that **volunteers were not always aware when a person may require a higher level of bereavement support.**

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**“It all works well when someone finds the help they need when they need it. When the match works, it’s wonderful. But I think we have still a long way to go on that...we certainly get quite a bit of feedback from people saying ‘Well I went to see someone and they were very nice, but we didn’t really talk about the death”**

Interviewee 4 Voluntary agency

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There is often **a lack of awareness of services and supports amongst the public and other professionals.**



**“There are a lot of great services out there now doing great work but who are they and what do they do and how can you have access to them?”**

Interviewee 5 Voluntary Agency

The **lack of a central database** of service provider information was discussed as a significant issue and resulted in frustration for both professionals and people experiencing bereavement.

**“So you have someone come back [to the social worker in an acute hospital] after 7 months and we say ‘ring this number and they will help you’... they rang them and they weren’t there anymore or they weren’t very helpful. You’re left scratching your head - who is next on the list. Is the list I have viable?”**

Focus Group

Models of **bereavement support offered by hospitals and hospices** were considered beneficial where follow up for people is offered as part of their service.

### 3.5.4 Public awareness and education

Respondents overwhelmingly discussed a **need for improved public awareness regarding grief and loss**.

**“Please improve public awareness of grief and loss in this country. I think of our pyramid of education and support - community education and public awareness campaigns. We need to bolster this because we can’t meet everybody. But if we can educate everybody”.**

Interviewee 3 Voluntary agency

**“Bereavement care requires a stepped approach depending on presentation. I think society needs to be educated. Actually the best support for someone in loss is the natural supports that are around them. Sometimes there is this leap to a bereavement counselor, that may not be required or indeed effective”.**

Interviewee 1 Statutory Provider

The need for **improved training regarding bereavement for health and social care professionals** to include primary care staff, managers, HR specialists and therapists and training for people at the front line interacting with bereaved families to include health and social care staff, emergency service personnel, professionals working in the death industry and those involved in after death investigations was also discussed in depth.

**“We need to improve the training of counselors, social workers, people who are working with individuals on a one-to-one. The majority of people have only done a couple of hours on bereavement and loss in their training”.**

Interviewee 3  
Voluntary agency

The **education in the area of grief and loss provided by The Irish Hospice Foundation in partnership with the Royal College of Surgeons** was noted beneficial to services throughout the country.

**“Children and loss postgrad and Bereavement Studies post-grad...I think they have been very influential in that students have gone through those programmes and gone back and have become kind of champions in the area of bereavement and loss in their workplace. I think have been a tremendous contribution to the area of bereavement nationally.”**

Interviewee 4 Voluntary Agency

The **need for the public to understand what to say and when to listen** was also discussed at length

**“I think the Irish have a good ability to meet people and to talk about death. I think we are probably better at it than we know. But we get ourselves all caught up in trying to do no harm. Sometimes we do no good. I would say bereaved people are more resilient that we give them credit for.”**

Interviewee 4 Voluntary Agency

However, it is **important that the public health message is clear** and well thought out, supported by adequate frameworks of referral and based on evidence.

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**“The risk is completely over pathologising or completely under pathologising grief”.**

Interviewee 1 Statutory Provider

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### 3.5.5 Guidance and supports for those working in bereavement care

Respondents called for *agreed, evidence based common assessment tools* for people working in bereavement support and many noted the lack of *agreed standards and accreditation pathway for practitioners and services* working in this area.

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**“If you have an assessment tool you can see for example that coping style is poor and it allows you to work on specifics”.**

Interviewee 3 Voluntary Agency

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**“Standards and quality as part of contracting are now key...to make sure the service we [TUSLA] are funding are robust and quality assured”.**

Interviewee 6 Statutory Agency

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The importance of self-care for people providing bereavement support was also discussed, with one respondent noting

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**“We need to make sure practitioners are looking after themselves. This is different to other work, because we are the bereaved. So we are walking this path alongside bereaved people, and I don’t think we always pay enough attention to that.”**

Interviewee 4 Voluntary Provider

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The positive benefits of networking through other structures, such as the ICBN were discussed, as was the positive association with attending the recent bereavement fora and the previously bereavement work hosted by The Irish Hospice Foundation in the 1980s/1990s.

### 3.5.6 Need for a national adult bereavement network

Without exception, every person interviewed agreed that there is a **need for a national adult bereavement network/alliance in Ireland.**

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**“Ireland isn’t too big to pull together everyone in the field. Let’s see what’s out there. Let’s see what the expertise is. Let’s notice where the gaps are. Let’s work strategically together to fill them”.**

Interviewee 4 Voluntary Provider

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**“A national alliance would ensure that a stepped approach to bereavement care and support is developed”.** Interviewee 1

Statutory Provider

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The structure, priorities and risks associated with the development of such an alliance are described in Chapter 5.

# 4.0 Bereavement support structures - The international context

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As part of this feasibility study a systematic review of academic and grey literature was conducted to identify, understand, compare and appraise bereavement care, policy, standards, structures, guidance and support in Ireland, the UK, Canada, Australia and The Netherlands. The full methodology for the review is outlined in Appendix C. This Chapter summarises the main findings from both the empirical and grey literature.

## 4.1 Literature reviewed and experts identified

The search strategy resulted in 2173 empirical studies for review by title and abstract, of which 56 were initially considered potentially relevant to this study. However, on further review of these studies, those of most relevance to this study focus on public health and bereavement (n=7), the economic impact of bereavement (n=2) and those detailing national or provincial bereavement structures within the reference countries (n=3). The other empirical studies, whilst relevant to bereavement, are not specifically relevant to the focus of this report. A list of these studies is included in Appendix F for information purposes. The committee identified three important studies as missing from the empirical search - Petrus (2008), Aoun (2015) and Jones et al (2015). On further reflection however, the ICBN pyramid described by Jones et al is focused on children and is therefore excluded from this review. The work of Petrus has been included earlier in this report within the policy section. Key findings from Aoun's study (2015) are integrated below.

A review of grey literature resulted in a body of documents related to bereavement standards and some strategies / framework documents that are relevant to the focus of this study. These are also discussed in detail below.

## 4.2 The economics of bereavement

Two empirical studies (Stephen et al. (2015) and Genevro and Miller (2010) considered the emotional costs of bereavement. In the earlier of the two studies, Genevro and Miller (2010), as part of a wider review of literature noted that the knowledge associated with the cost effectiveness of bereavement interventions is limited due to challenges associated with measurement, collection of data and definitions. They consider four types of cost important: (1) Medical (e.g. cost of hospitalisation, consultation, homecare); (2) Non-Medical (e.g. parking / travel); (3) Productivity (e.g. work time lost due to illness or time spent at appointments) and (4) Intangible costs (e.g. stigma or loss of satisfaction). Genevro and Miller's review identified four studies and one report relevant to the cost of bereavement in health care settings but concluded that it was not possible to draw conclusions about the cost effectiveness of bereavement services from these studies, even in one country. They recommend that larger scale studies are required, proposing a framework for further investigation and measurement of economic factors.

Five years later, Stephen et al (2015) published estimates of the economic cost of bereavement in Scotland from three datasets noting that in 2012, there were 54,937 deaths and 220,000 people affected by grief. The authors note in their introduction that the average cost of dying in the UK in 2013 was £7,622 and at any one time 5% of the workforce may be on bereavement related leave. The study estimated that spousal bereavement significantly impacts hospital inpatient days and adds to the cost for healthcare services by between £16.2 million and £23.3 million per year. Furthermore, bereavement impact on inpatient days increases over time. Estimated cost of GP consultations

for bereavement from the period 2009-2010 was £2,030,720 based on the data available, however the authors caution that this only represents patients coded for bereavement by the GP, so it is expected that this figure in reality is much higher. Stephen et al. (2015) also noted that the bereaved group reported significantly worse health 2 years pre-bereavement ( $p < .001$ ), 1 year pre-bereavement ( $p < .05$ ), in the year of the bereavement ( $p < .001$ ), and in the year after bereavement ( $p < .001$ ) compared to the non-bereaved matched controls. In the 10 to 16 years post-bereavement, bereaved people also reported significantly higher GHQ-12 scores indicating more distress relative to non-bereaved matched controls ( $p < .05$ ). In terms of employment, when compared with non-bereaved matched controls bereaved individuals were significantly less likely to be in work during the year of bereavement ( $p < .05$ ) and 2 years post-bereavement ( $p < .05$ ). The authors urge other countries to use existing data to estimate costs for the purposes of comparison with Scotland and to increase the knowledge base regarding the economic cost of bereavement worldwide.

**Points of note:** Where available, using existing data estimate the costs of bereavement in Ireland considering (1) Medical (e.g. cost of hospitalisation, consultation, homecare); (2) Non-Medical (e.g. parking / travel); (3) Productivity (e.g. work time lost due to illness or time spent at appointments) and (4) Intangible costs (e.g. stigma or loss of satisfaction). This data could be invaluable to aid lobbying and advocacy work by a national alliance.

### 4.3 National bereavement support structures outside of Ireland

Three empirical studies reviewed considered national or regional bereavement support structures in Scotland, UK and Canada. Grey literature led to developing an understanding of Northern Ireland developments.

#### Scotland – Perception of bereavement care

A study by Stephen et al. (2009) explored the views and practice of bereavement care and identified priorities for service development drawing from the feedback of 59 stakeholders from a wide range of sectors relevant

bereavement care and support in Scotland e.g. NHS, Education, Funeral Industry etc. The authors framed their study questions around 13 key messages for bereavement care in Scotland developed by Wimpenny et al (2007) based on a review of the literature. These messages are:

1. Education for health and social care professionals needs development.
2. A compassionate approach can impact positively on bereavement.
3. Grief is a normal process.
4. Interventions should be tailored to need.
5. Cultural and spiritual factors are important.
6. Risk factors for abnormal responses are amenable to assessment.
7. Follow-up has been identified as important, particularly by the bereaved.
8. There are a range of information needs at local and national levels.
9. Standards, policies, and guidelines should be considered in all settings.
10. A coordinated approach to bereavement care is required.
11. Research into bereavement and bereavement care is essential.
12. There are “hidden” socioeconomic factors.
13. A national center for bereavement care should be established.

The authors concluded that there was a need for a tiered model of support, public awareness, coordination of services, guidance, and professional education specific to bereavement in Scotland. Stephens et al suggest that a center, such as that in Australia (The Australian Centre for Grief and Bereavement, 2007), could become the focus for such co-ordination providing a national platform for networking, co-ordination, discussion and raising awareness about death, dying, and bereavement (Arnason & Hafsteinsson, 2003). Such a center would also have a role in highlighting the health and economic consequences of bereavement (Parkes, 2001; Ribbens-McCarthy & Jessop, 2005).

Based on this work the Scottish NHS devised guidance 'Shaping Bereavement Care: a framework for action' which saw the plan for designated bereavement coordinators in each health board area and further implications for training, education and service development set out.

**Points of note:** Consider the 13 key messages for bereavement care developed by Wimpenny et al. (2007), the NHS Shaping Bereavement Care structure, and later developments when examining the principles of a national structure for Ireland.

### Canada – Mapping bereavement services

Wilson and Playfair conducted a mapping exercise in 2016 to identify and describe all bereavement support programs and services in the province of Alberta, to compare availability with that four years previously to determine development. They note that they were unable to find any similar mapping studies published in any country or region upon searching the literature in 2016 and therefore consider their work to be novel. The authors used the following questions to conduct the mapping exercise:

1. Name of program/organization and contact information?
2. A general description of the bereavement grief supports/services offered?
3. When did you start and how long have you been in operation?
4. How many bereaved people (approximately) do you assist each year?
5. What types of evaluation information is collected and how is it collected?
6. How are you funded?
7. How many people are employed and how many volunteers are involved in your program/services?
8. Do you have any other information you feel is important to share with us about your services/program?
9. Do you know of any other bereavement programs or services in the province, as we are using a snowball technique to try to get a list of all programs/services/providers in the province?
10. Are you OK with your information appearing in the Alberta Hospice Palliative Care Association (AHPCA) database and website for the public to see?
11. Are you OK with your information being summarized in a published report of bereavement services?

Using a snowballing technique Wilson and Playfair found considerable (330%) growth, in services with greater diversity in providers, programs, and service. 79 programmes responded. They noted that bereavement programs were no longer publicly funded but were usually grassroots in origin, with individuals and community groups largely designing and providing bereavement support services. Services were usually provided by volunteers, led by people who had a personal experience of bereavement and were supported through local fundraising. The majority of services were in cities, and there was a greater number of internet based supports available. The catalysts for service growth were due to a number of factors including (a) increased public and professional awareness of their services, as indicated by more calls about and direct requests for services; (b) increased acceptance of their services by a wider or more comprehensive range of individuals and organizations, with health care providers such as physicians, nurses and other people increasingly suggesting to bereaved persons that there is bereavement support available to them; and (c) increased desire among bereaved individuals to obtain help. Services grew through word of mouth, advertising, awareness raising through presentations in the community and education programmes to health and social care providers. Many service engaged in service evaluation, assessing the quality or outcomes of the services from a user perspective using pre/post surveys.

The services offered were often targeted at specific groups, designed for individuals or families as required and catered for almost every type of grief possible. Some focused on the provision of community grief support, offering support to groups such as schools following the death of a pupil, for example. The services provided were mainly peer support, individual or group counselling and included candlelight vigils, annual memorial events, retreats, education and training and social gatherings. The format of services also varied and included books,



DVDs, online tools and services to include supportive and educational emails, text and video messaging, summer camps etc. Some services were time limited and others were open for people to receive them for as long as needed. The focus of most services was that bereavement is a normal, natural part of life, for which support from peers is considered to be helpful. Hospices provided most bereavement support. Support was also offered through funeral directors and many providers operated on a sliding scale basis with fees based on what a person could afford. The authors conclude by celebrating the rise of grass roots model and note that a one size fits all generic model is certainly not desirable. However, they question whether these models should be government funded, given their potentially health promoting benefits.

**Points of note:** Use the Wilson and Playfair (2016) framework to conduct a national mapping exercise of all bereavement care providers to identify and describe all supports available.

### Northern Ireland

In 2006 the Department of Health, Social Services and Public Safety established the Health and Social Care Trusts Bereavement Network (HSCBN), appointing a Trust Bereavement Coordinator (TBC) to each Health and Social Care Trust. The initial remit of the HSCBN was to develop bereavement care standards and in 2009 a service strategy was launched. Standard implementation continues to build the capacity of HSC staff to provide safe, effective and compassionate care to dying and bereaved people. The HSCBN agrees a regional management plan for the Coordinators which has included an audit of HSC practices around end of life and bereavement care. The network's vision statement is:

**To work towards continuous improvement in bereavement care - where death and bereavement are seen as part of life, where care of the dying is as important as care of the living and after death care is a continuation of good practice.**

Following an examination of the networks outputs and website <http://www.hscbereavementnetwork.hscni.net> the network appears to combine elements of end of life care that have been a focus of the HFH network in Ireland with bereavement. This echoes what the Scottish Framework states regarding good care at and around the time of death being essential to better outcomes in bereavement and that where death is expected, bereavement care before death results in better outcomes (Wimpenny et al 2006). The national bereavement strategy for Northern Ireland is available here: <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/nihsc-strategy-for-bereavement-care-june-2009.pdf> and again this echoes many of the HFH themes.

**Points of note:** Consider the overlap and common interests between HFH and bereavement

### 4.4 Public health approaches to bereavement

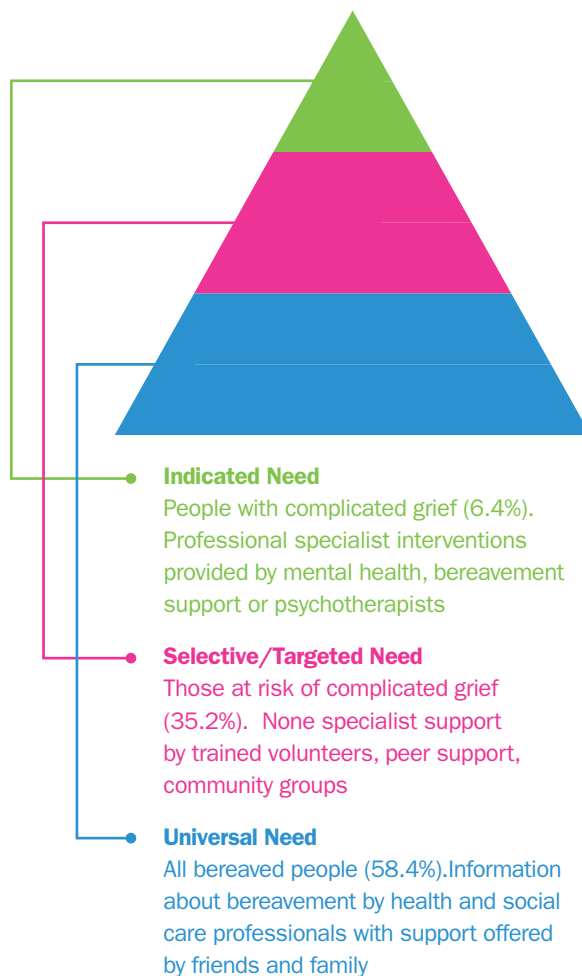
Over the last decade there has been an increasing recognition of the importance of promoting culture change and public engagement into death and bereavement. Various terms have been used to describe this approach including "Compassionate communities", "health promoting palliative care" and "public health approaches to death, dying and bereavement". The features of a public health approach include (Kellehear, 2001):

- building public policy that promotes population health improvement;
- creating environments which support healthy living and dying;
- developing and supporting communities to determine their health needs and how best to address them;
- supporting people to manage their own health; and
- ensuring the health care system promotes health.

Despite the growing volume of literature Karapliagou and Kellehear (2016) note that compared with other public health issues, such as obesity and tobacco use, interest in the

social experience and epidemiology of end-of-life experience including bereavement remains extremely low. Key authors in the field of public health approaches to bereavement include Kellehear, Aoun and Rumbold who recognise that bereavement is a normal human experience and communities require resilience to live together with loss. They argue that communities can play a central role in supporting level 1 and 2 of the NICE three tiered approach to bereavement support (in palliative care).

Based on a public health approach, Aoun (2015) proposed a three-tiered model of bereavement care as follows:



Underpinning Aoun's model is the need for bereavement care to align with people's needs and risk factors. The model requires primary and specialist bereavement care providers to work along a continuum of need and support (Aoun et al 2012). To implement an effective public health model, partnerships with primary care practitioners such as GPs are essential as are strong connections with community services and groups, including volunteers.

Specific to bereavement, seven studies were obtained through the empirical review of literature that focused on a public health approach to bereavement with five of these discussing the UK perspective. Work by Patterson and Hazelwood (2014; 2015) describes health promoting palliative care in Scotland noting that communities play a key role in supporting citizens through bereavement and yet despite this, many bereaved people still experience isolation. Their narrative work calls on palliative care services specifically to make efforts to develop community capacity to support bereaved people and they also describe national policy developments including the Short Life Working Group report that draws heavily on the work of Kellehear, emphasising the value of partnerships between the community and palliative care to build resilience. Their work also considers the importance of ritual to build community solidarity and Patterson and Hazelwoods (2015) paper described 'To Absent Friends' an annual national People's Festival of Storytelling and Remembrance designed to create a time of year when remembering dead loved ones is socially accepted and supported within mainstream culture.

Also from a palliative care perspective, Paul et al (2016) explores the role of hospices in working with schools to promote education and support around end-of-life and bereavement experiences. Paul et al describe the critical role hospices can adopt in community engagement activities that in turn encourage school staff to develop greater openness and support bereavement care for pupils.

Focusing on the lack of adequate risk assessment screening tools for bereavement support within a public health context, Breen et al draw on the work of Hansson and Stroebe (2007) who propose an integrative risk factor framework that takes into account bereavement factors (e.g. relationship to deceased, model of death), interpersonal factors (e.g. social support, family dynamics), intrapersonal risk factors (e.g. personality, religious beliefs, existing vulnerability), and appraisal and coping styles, in predicting bereavement outcome. They note that developing and validating a tool incorporating these factors would be advantageous as current commonly-used bereavement risk assessment tools are criticised for their deficient theoretical

bases, inadequate psychometrics, and limited applicability to palliative care (Agnew, Mankletow, Taylor, & Jones, 2010). Furthermore they argue that identifying the proportions of bereaved people in need of the three components of support (information and compassion, non-specialised support, and specialist intervention) will facilitate the development, and initiation of a range of community-based programs to meet the varied needs of bereaved people across society. Breen et al also call for education amongst community pharmacists and primary care professionals who could play a key role in supporting and signposting people following a bereavement.

An interesting page was located on Copeland Borough Councils website in the UK that focused on death and bereavement offering information, advice and help to people who had experienced a bereavement in that jurisdiction. This website is an excellent model of best practice for civic society to support people who are living with loss as advocated through Kellehear's Compassionate Cities Charter. See <https://www.copeland.gov.uk/content/death-and-bereavement> for more details.

**Points of note:** Consider adopting and advocating a public health approach to bereavement that considers national awareness raising, resilience development, civic engagement, partnerships between key stakeholders and tools to support identification of need.

## 4.5 Standards and guidance

Standards offer an agreed, evidence-based, common framework for care to be delivered and evaluated against, thus enhancing the potential for people to receive a level of care and support that is agreed and consistent across providers. A call for standards for bereavement care in Ireland was made by Keegan in 2002, who described the standards already in situ in both the UK and Australia. Standards for bereavement care remain available in the UK and have recently been updated (Cruse and Bereavement Services Association, 2013). In some NHS areas, guidelines have been produced to support the delivery of bereavement services for patients, relatives and carers specific to

cancer (e.g. Pan Birmingham Cancer Network). In Scotland a quality framework has been developed – Shaping Bereavement Care (2011) to guide the development and delivery of high quality bereavement care across the Scottish National Health Service. Hudson et al (2017) describe bereavement support standards and a care pathway specific to palliative care from an Australian perspective and these standards have been published by the Department of Health in Victoria, Australia (Hall et al., 2012). The lack of bereavement guidance in Europe was recently highlighted by the EAPC (2015) in a palliative care context and they have indicated that

**“To optimise support for bereaved relatives, it seems timely for the EAPC and palliative care services in Europe to formalise the planning of bereavement care. The next step for the Taskforce is to develop an EAPC statement of best practice in this area”.**

**Points of note:** Review all existing standards in depth and link with authors and the EAPC prior to developing any new standards for Ireland to share and understand their experience.

## 4.6 International alliances

The National Bereavement Alliance in the UK is a model of best practice internationally whereby bereavement service providers come together to provide a collective voice, particularly with a focus on networking, policy issues and advocacy (see [www.nationalbereavementalliance.org.uk](http://www.nationalbereavementalliance.org.uk)).

The vision of the alliance is that all people will have awareness of and access to support and services throughout their bereavement experience.

Their objectives are to

- Influence Government, other local and national bodies and the general public in the interests of people who have been bereaved
- Identify and bridge the gaps in support, working towards seamless support

- Exchange information and good practice at a local and national level
- Promote standards for the workforce to improve the quality of services
- Gather and disseminate evidence of the impact of bereavement and bereavement support to enhance practice and services provided
- Provide and enhance our own services through stronger links with other organisations supporting bereaved people.

Whilst the Alliance is not an accrediting body and does not take responsibility for the quality or delivery of members' services, the organisation subscribes to the Bereavement Care Service Standards 2013 as a benchmark against which to evaluate services.

In addition to the alliance, is the UK Bereavement Services Association (BSA), established since 2005. The BSA aims:

- To provide a national network for all those who work in providing bereavement support services.
- To provide a national forum for discussion and training for those providing bereavement support services, particularly in the NHS.
- To contribute to the improvement of the quality of bereavement services nationally
- To raise the profile and seek recognition from stakeholders of the role of those who provide bereavement support services.
- To raise awareness of the role and availability of bereavement support services.

Members of the UK Bereavement Services Association, open to anyone providing bereavement care in the UK, includes membership of the National Alliance for a fee of £50 per annum or £150 for 5 members.

The Australian Centre for Grief and Bereavement is a model of best practice in Victoria, Australia, established in 1996. The Centre is an independent, not for profit organisation and is the largest

provider of grief and bereavement education in Australia funded through the Department of Health and membership fees. Its mission is to build the capacity of individuals, organisations and communities in order to enhance well-being following adverse life events. In addition to a strong focus on education, the Centre seeks to:

1. build the capacity of the universal health services to provide bereavement supports and responses;
2. provide advocacy and representation on grief and bereavement issues in order to inform policy development, raise community awareness and support universal access to mainstream grief and bereavement services;
3. undertake research, program evaluation, public policy development and the production of evidence based publications and resources to enhance grief and bereavement knowledge and practice;
4. maintain cooperative links with relevant state, national and international groups and organisations in relation to grief and bereavement;
5. provide a national clearinghouse of grief and bereavement resources and literature to inform policy, practice and research into grief and bereavement and to enhance the activities of the ACGB, other practitioners, support agencies and self-help groups;
6. collect and raise funds for the promotion of the preceding objects of the ACGB.

International models are useful reference points for any emerging Irish alliance and from this feasibility study there is an apparent willingness for these international agencies to work with and share resources with Ireland.

# 5.0 Should there be a national structure?<sup>2</sup>

All stakeholders interviewed for this study agreed that a national adult bereavement alliance/network would benefit Ireland and enhance bereavement care. This Chapter outlines the specific feedback received regarding the structure, priorities and risks associated with developing such an alliance/network, together with feedback from international stakeholders regarding their experience or thoughts on the concept and national policy documents.

## 5.1 An alliance or network and who will lead it?

Respondents described both an ‘alliance’ and a ‘network’ and there was no preferred term emerging. However, there was a sense that a ‘network’ was more about grassroots organisations coming together to develop strategically, whereas an ‘alliance’ emerges as a strategic decision that is more driven from the ‘top down’. Therefore an **alliance** will ideally need to take a partnership approach between the voluntary sector, the statutory sector and the Department of Health.

**“I think our voluntary agencies have done a lot. I think the alliance needs to involve the statutory sector. I think if that doesn’t happen, I think if it remains completely in the voluntary sector then appropriate bereavement support and bereavement awareness will remain a secondary issue”**

Interviewee 1 Statutory Provider

It was generally agreed that a small fee would be payable to join the network and that fee would vary depending on whether it is aimed at the individual or an organisation. A membership based **network** will require careful consideration with regard to how it will be made accessible to private, ‘for profit’ providers of bereavement care and support since the driving force between not for profit and for profit can lead to mistrust and skepticism.

**“It can be difficult, when you are a voluntary provider and you are sharing your resources with the group and you are very conscious that there is someone else in the room who is doing this work for personal gain and profit and could just take everything you have created and use it. It reduces the sharing and thus the benefit.”** Interviewee 7 International Expert

The Irish Hospice Foundation is considered well placed to lead the day-to-day operation of a network/alliance working in partnership with other groups and agencies.

**“I have no doubt the IHF would be best placed to lead this - just look at the ICBN and how that has developed! They could teach us a thing or too!”** Interviewee 7 International expert

**“I am familiar with the work of the Foundation, they are doing great stuff. I think they would be a natural leader for this work”.** Interviewee 8 International Expert

Consideration should be given to working with the Department of Health to commission the network / alliance, bringing together policy and network supports across HSE divisions to ensure integration and compliance with policy document recommendations (particularly in the context of standards development). There is some concern that with the IHF leading the alliance, it could be confusing for the public who may consider it only relevant to hospice bereavement.

<sup>2</sup> The word ‘alliance’ vs. ‘network’ will require further debate and discussion since the term ‘alliance’ may have more lobbying political advocacy connotations whereas a ‘network’ suggests a group of similar people coming together.



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**“We can look at the IHF and I know they do so much on bereavement and loss...but they are taking on the grey areas too - it would need distinct branding.”** Interviewee 3 Voluntary Provider

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3 Voluntary Provider

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Those aware of the ICBN, considered the steering group format, comprised of representatives from the wider membership and people who have experienced bereavement, supported by a paid development officer, to be effective and suitable model for replication. However, it was noted that very often the same people are asked to join and lead such networks, and there is an appetite to involve new people in a development

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**“Model it similar to the bereavement network for children”.** Interviewee 6 Statutory Provider

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**“A paid development officer - you need someone at the top who can hold it...I scribbled down, ‘please introduce young blood!’”** Interviewee 3 Voluntary Provider

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Of interest perhaps is one person’s view that the alliance or network could be a ‘chaordic’ (chaos but with order) structure, bringing people together to design their own alliance.

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**There should be no-one managing it. It should be led by the people and the support services available.** Interviewee 9 Statutory Provider

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Statutory Provider

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## 5.2 How will it be funded?

There were mixed thoughts regarding whether the development should be funded by the Government or by members themselves.

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**“This is an issue around our population health and wellbeing, so I think it is absolutely the remit of government to take a focus on this.”** Interviewee 1 Statutory Provider

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Provider

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**“It should be funded jointly by the people and the state”.** Interviewee 9 Statutory Provider

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### 5.3 What should the priorities of the network / alliance be in the first 3-5 years?

A number of suggestions were made regarding the work the network / alliance could achieve in the early years. These included (in no particular order):

|  | Interviews | Focus Groups | Literature |
|--|------------|--------------|------------|
| Agree levels of bereavement support and develop standards / guidance / governance for bereavement support providers  | x          | x            | x          |
| Develop, implement and evaluate a public awareness / education / information campaign with a focus on normal responses to grief and loss and how the public can support each other | x          | x            | x          |
| Map all services and supports to inform the development of a directory / database of services and support  | x          | x            | x          |
| Establish a national research brief / unit around grief and complicated grief.   | x          | x            | x          |
| Develop a signposting and resource based website for professionals and the public  | x          | x            |            |
| Advocate and lobby on bereavement related issues   | x          | x            |            |
| Establish a sustainable alliance/network, solid membership and appropriate governance structure  | x          | x            |            |
| Facilitate regional and/or national networking meetings / conferences to include self-care information.  | x          | x            |            |
| Support small services with policies, procedures and governance issues through the development of template and frameworks  | x          | x            |            |
| Input into the development of job descriptions / training of people working in health and social care, primary care and mental health  | x          |              | x          |
| Lobby clinical psychology, psychiatry, nursing and social work education providers to adopt competency training around grief and complicated grief.                                | x          | x            |            |
| Develop and deliver education and training to all stakeholders   | x          | x            | x          |
| Promote and support the self care of service providers   | x          | x            |            |

The top four priority areas identified in the focus groups, through a prioritisation exercise were:

- Develop a signposting and resource based website for professionals and the public
- Develop, implement and evaluate a public awareness / education / information campaign with a focus on normal responses to grief and loss and how the public can support each other
- Mapping of services and development of a database
- Utilisation of existing local networks and services

However, developing a membership base and effective governance structures must be the priority in the first instance.

## 5.4 Potential risks

Interview respondents were asked to consider the risks associated with the development of a national network or alliance. The risks considered included:

- Services in competition not working together within a network or alliance
- Fear and feelings of inadequacy (particularly amongst smaller providers)
- Personal / service agendas overpowering the purpose of the network
- Resistance to change
- Over or under pathologising of grief and loss

## 5.5 Benefits of working together

Despite the risks, there is a sense from those interviewed, that the overall benefits of working together greatly exceed them. The benefits described include:

- Development of a strategic approach
- Sharing of information and experience
- A sense of solidarity and reduced feeling of isolation
- Peer support
- Networking
- Knowing who you are referring a person to
- Ease of access to information and education
- Strength in numbers to advocate and lobby

# 6.0 Points for the committee to consider

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Based on this report a phased plan is required. For example, it may be pertinent to consider an alliance based around a single project as a first step. This minimizes potential risks and would help develop ways of working collectively. Should the time come to formally constitute a more permanent alliance or network, sample objectives and associated actions are provided in Table 1. In this case the following would also need to be considered.

- Development of explicit items that the group will collaborate on and agreement of how the group will work using action words such as ‘signpost, support, advocate, inform, generate’ etc.
- Agree best practice when working with bereaved adults
- The creation of a ‘network’ or ‘alliance’ considering the issues raised in Chapter 5. Will it be bottom up or top down? Consider policy recommendations too.
- The title of the group with the inclusion of the words ‘adult’ and ‘bereavement’ in the title to distinguish from the ICBN. The name should be clear and simple and not duplicate the name of any other providers or alienate any group.
- The development of a mission statement, depending on the outcome of the discussion regarding the name, and the purpose of the network.
- Agree the values for the network/alliance.
- Agree the work plan for the network / alliance – suggested actions are outlined on Table 1.

**Table 1: Sample Objectives and Associated Actions**

| STRATEGIC OBJECTIVES   | ACTIONS   |
|--|---|
| Agree whether any group is a 'network' or an 'alliance'  | Steering committee to agree whether the group is a 'network' or an 'alliance' and agree the logo, mission, vision, values and principles of working as appropriate.   |
| Establish a sustainable network and solid membership base  | <p>Secure host organisation and develop MoU</p> <p>Secure funding</p> <p>Develop membership protocols and membership information / benefits</p> <p>Develop a work plan for 3 years</p>  |
| Signpost professionals and the public to sources of bereavement support  | <p>Mapping of services by county</p> <p>Develop online directory</p> <p>Develop directory of members</p> <p>Maintain and update directory as required</p>   |
| Support professionals to find and share the knowledge and resources they need to deliver high quality, effective, safe, evidence-based, accessible bereavement support | <p>Work with all stakeholders to advocate for a public health approach to bereavement and loss</p> <p>Agree and uphold frameworks for quality bereavement care to include development of standards, service evaluation and accreditation</p> <p>Disseminate policy, practice, research and education to members</p> <p>Support and advocate development in 'black spot' areas</p>   |
| Advocate and lobby on behalf of bereaved adults and service providers  | <p>Consult with bereaved adults and/or service providers to obtain their views</p> <p>Develop and maintain relationships with key bodies including representatives from DoH, HSE, Department of Justice, Third level training bodies, professional accreditation bodies, political parties and other relevant agencies.</p> <p>Represent the field, responding to calls for national submissions as required</p> <p>Respond to relevant issues emerging in the media – working proactively and reactively</p> |
| Inform and educate the public regarding issues associated with bereavement and loss  | <p>Develop information / a public awareness campaign about grief and loss and how to support others</p> <p>Develop community based and online education</p>   |
| Generate new ideas and approaches to develop education, research, policy and practice in the sector  | <p>Contribute to the development of the evidence base through research audit and evaluation.</p> <p>Provide incentives for members to engage in education and research</p> <p>Link with other international stakeholders to explore opportunities to collaborate and network.</p>   |



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# Appendix A:

## Summary Reports from 2016 / 2017 Bereavement Meetings

### Bereavement Forum – Summary Report Wednesday July 20<sup>th</sup> 2016

The Forum was attended by 70 people representing 33 invited organisations involved in bereavement care. A listing of names, organisations and contact details will be forwarded.

This report gives an account of the process, discussions and evaluation of the day.

#### Overall evaluation

**Objective one** – to share information about what is going on around bereavement care **met to a large extent =31; met to some extent = 3**

**Objective two** – to begin a discussion on bereavement care needs and strategic responses in Ireland **met to a large extent = 28; met to some extent = 5**

|                         | Excellent | Good | Fair | Poor |
|-------------------------|-----------|------|------|------|
| Morning presentations   | 31        | 3    |      |      |
| Afternoon presentations | 28        | 5    |      |      |
| Small group discussions | 24        | 9    | 1    |      |
| Plenary discussions     | 21        | 11   |      |      |
| Venue                   | 22        | 10   | 2    |      |

**Mr John Birrell and Ms Alison Penny** described the evolution of bereavement care in Scotland and England respectively. ***Their powerpoint slides will be placed in a dropbox and Maura Dunne will send you the details for accessing them.***

Key points common to both were the need:

- to strive for equity & quality in bereavement care
- to maintain a focus on strategic relationships and strategic buy-in at government and senior management level, plan for sustainability

- to keep momentum regardless of changes to local or national government/ structures
- maintain a broad focus on bereavement care acknowledging the social and economic impacts & challenges

Both talked about the time it takes to work jointly but the overall benefit is worthwhile.

**Brid Carroll and Annemarie Jones** presented on the Irish Childhood Bereavement Network describing its origins and some of the outputs of its work including the Bereavement Care Pyramid. Slides are will also be placed in the dropbox.

#### Examples of joint or coordinated working in Ireland were provided by

- Susan Delaney, Irish Hospice Foundation – the complicated grief programme and network of trained therapists
- Maire NiDhomhnaill, Mayo Suicide Bereavement Liaison Project - clarifying and building relationships with those involved in meeting & supporting suicide-bereaved people.
- Sharon Vard, Anamcara – described joint working with Milford Hospice and with Jigsaw Galway
- Breffni McGuinness, IHF and Niamh Finucane, St Francis Hospice – described the gap in bereavement information in North Dublin and plans to share information on events and available supports.



## Morning Group Discussions

### Question one - What are the bereavement care needs in Ireland?

#### A summary of the needs:

| What are the bereavement care needs in Ireland?   | No. of times mentioned on group sheets |
|---|--|
| A coordinated approach to bereavement care/ linkage & connection; working in collaboration  | 7                                      |
| National priority and government involvement. A macro approach to bereavement care, national frameworks or guidance or standards or pyramid.  | 5                                      |
| Consistent reliable information on bereavement services, register of information, PR around bereavement   | 4                                      |
| Focus on the cost and economic of implications – to individual families and to society, include focus on bereavement grants   | 4                                      |
| Sustainable approach to bereavement care, building on what's being done already   | 4                                      |
| Need to focus on social support and understanding non-counselling needs, engage with education, industry etc.   | 3                                      |
| Need research on what is effective  | 2                                      |
| Need to make access to services fair and equitable, regardless of where you live or what illness/ circumstances of death  | 2                                      |
| <i>The following issues were also mentioned on individual feedback sheets from groups</i><br>Children's bereavement needs' stillbirth; staff and nurse support; Intellectual disability; sibling support; pre-death services; death certification |  |

### Question 2 - are there some areas that we could work on strategically?

#### Summary of discussion 2

| Are there some areas that we could work on strategically?  | No. of times mentioned on group sheets |
|--|--|
| Collaboration/ linking services; national alliance, chance for networking/ forum to find out what's going on; develop advocacy issues  | 6                                      |
| An agreed bereavement/end of life strategy; wider than health agenda include county councils Seante; Champion standards  | 4                                      |
| Information on supports/ a register/ helpline or one stop shop   | 4                                      |
| Research/ outcomes/ every service needs to do what it says   | 3                                      |
| Funding  | 2                                      |
| The following single issues where working together could help: <i>Data protection legislation (prevents contacting next of kin); basic training for all 'bereavement first aid'; accessible language</i> | 1                                      |

#### Group Feedback - What needs to happen? Where do we go next?

#### Generate ONE example

#### Group One

- To have Irish Bereavement Standards (what would the consequences of deviating from standards be?)
- A directory of services
- A national individual coordinator
- County bereavement coordinators
- Challenge to keep updated
- Transparency in governance - audit, visible assessment and measureable outcomes
- Focus on partnership and collaboration
- Clarity in funding

**Group Two**

- Local level up or macro level down?
- National standard or principles of bereavement care a good macro start
- Local networks a good local possibility building into a national model
- Local directories allows updating and can feed info to national network
- There are big funding challenges

**Group Three**

- Prevent complicated grief
- National coordination but with active local activity
- In the area of maternity and children's hospitals & hospice look at natural networks – are there others

**Group Four**

- Information services showing what is happening around bereavement – bereavement information and a range of different supports and activities
- A helpline, possibly staffed by volunteers to provide the info above
- Example of blood transfusion board

**Group Five**

- Coordination nationally and local
- Overarching guiding principles and having a very clear purpose for any network or initiative – i.e. serving the bereaved person
- Acknowledge potential conflicts or strains between different players and providers working in bereavement
- What about groups merging? Organise for the best effect for bereaved people
- Avoid overlap in service provision
- Next step – more meetings but with a focus, say principles/ standards 'Bereavement care in Ireland: A vision'
- Looking for potential for group funding
- Clarity – eg a pyramid to guide

**Group Six**

- Review what is happening in each community, share information
- Describe each organisation under different categories (levels) and so support 'signposting'

**Group Seven**

- Where can models be replicated – eg the North Dublin model
- (offer from south Dublin to replicate, based in Our Lady's)
- Local networks could set up a bereavement alliance
- Aim to lobby and advocate to government
- A national telephone service with statutory funding

**Group Eight**

- Directory of services – but who gets listed? Need for accreditation in order for services to be listed. Needs credibility and organisational support
- Directory needs to be accessible to bereaved people
- Need for people working with and supporting bereaved people to come together
- Can attendees today become the first step in a national network, to meet again to plan practically ?
- Schools – do they have supports from voluntary orgs?
- Are bereavement organisations well placed to do critical incident stress management

**Conclusions**

- The final discussions indicated an interest in following up on some core issues, namely principles and standards, and a means of examining network/ collaboration feasibility.
- We will be in touch over the coming months to arrange a second meeting. Please feel free to come back with any further comments or elaborations.

## Second meeting of Bereavement Forum February 23<sup>rd</sup> 2017

### Narrative account

This half day meeting provided an opportunity to share updates on news developments (see appendix one for all the details). A total of 34 people attended the Forum and 26 organisations were represented

The objectives for the day were to agree and plan for a collective strategic approach to bereavement care in Ireland and to meet others working in and volunteering in bereavement. In the main these objectives were met.

|  | Met to a large extent | Met to some extent | Did not meet |
|--|-----------------------|--------------------|--------------|
| Objective 1: to agree a direction for a collective strategic approach to bereavement care in Ireland | 22                    | 5                  | 0            |
| Objective 2: to agree a plan for a collective strategic approach to bereavement care in Ireland      | 21                    | 7                  | 0            |
| Objective 3: to meet others working and volunteering in bereavement                                  | 23                    | 4                  | 0            |

### Vision

Each group generated 'visions' for bereavement care, namely the developments they would like to see into the future. These visions included:

- Broad initiatives (media recognition, community and public understanding of bereavement, national awareness campaigns),
- Suggestions for guidelines and guidance ( a standard approach/ national standards; bereavement support pathways; quality service and clear standards)
- Increased access to service (no waiting times, access to service regardless of location)

- Education (for the public, for volunteers and professionals)
- Organisation and governance (national coordinator; networks of providers offering groups community networks; funding; joined up thinking)

Each group's vision was recorded and is available in appendix two.

The early part of the Forum meeting set the scene by building on the February discussions and setting the vision.

### Scoping/ Feasibility Study

There was agreement that feasibility or scoping study would be useful in determining a realistic way of developing a national approach to bereavement care. The features of such a study, the stakeholders and the make-up of the steering committee were discussed and shared. The group opinions are detailed in appendix three.

The discussions have been distilled into a draft terms of reference and call for the feasibility study. This will be distributed separately for comment.

### Next steps

Receive feedback from invitees on the draft call

Release call for expressions of interest to tender for the feasibility study

Seek nominations to constitute a steering committee based on membership suggested in the draft call

Progress the study

## Appendix One Bereavement Forum, Alexander Hotel, February 23<sup>rd</sup> 2017

### National Updates

- Draft Standards for Children's bereavement care have been released by the Irish Childhood Bereavement Network (slide presentation attached) <http://www.childhoodbereavement.ie/wp-content/uploads/2016/11/ICBN-Standards-Document.pdf>
- The HSE launched Standards for Bereavement Care following pregnancy loss and perinatal death. <http://www.hse.ie/eng/about/Who/acute/bereavementcare/standardsBereavementCarePregnancyLoss.pdf>. These are to be implemented by the HSE.

### Updates from the floor since last meeting July 16<sup>th</sup> 2016,

1. Pieta House have developed a bereavement service in the wake of the wind-down of Console. Details are available on their website <http://www.pieta.ie/ive-been-bereaved-by-suicide/>
2. AnamCara have developed a leaflet for bereaved families with no surviving children <https://anamcara.ie/living-no-surviving-children/> AnamCara are also providing support in Northern Ireland, in collaboration with Northern Ireland Hospice
3. Turas le Chiele in Kilcock, Co Kildare have expanded their service to include school visits. They are also now providing one on one bereavement support.
4. Our Lady's hospice in Harold's Cross is hosting a South Dublin bereavement network. Contact is Ann D'Arcy.
5. Living Links Tipperary is providing group supports. Volunteers also attend inquests with families.
6. Sligo University Hospital bereavement information pack and leaflet has been nominated for a health award (Contact is Anne Hayes, End of life coordinator at the hospital)
7. Compassionate Communities project in Limerick is working with the Synod with a view to promoting bereavement support.

The project has also provided a seed grant to Newcastle West for the setting up of a bereavement group <https://www.compassionatecommunities.ie/>

## Appendix Two – visions for bereavement care – group discussion

### Bereavement care in Ireland – a vision: What would you like to see in three years?

#### GROUP 6

Guidelines for voluntary groups to be able to 'release' volunteers who cannot adjust to new regulation

Volunteer bereavement groups access to adequate training, access to sufficient funding, provision of adequate premises

Capacity for voluntary groups around unclear boundaries – e.g. home visits to adults when there is a child present

Media recognition of voluntary bereavement services

Early intervention part of resilience programmes in schools including teachers and counsellors

Guidelines on what to do next when someone is bereaved

Recognising the importance of supervision for carers of children – eg social workers, residential care workers

Education on bereavement for healthcare professionals and general staff

Voluntary agencies linking with government agencies such as the HSE

Community networks with a family lens to service  
A standardised approach to bereavement – national bereavement standards.

#### GROUP 5

Collaboration: Management, best use of resources and fundraising

Death education should become a natural part of Irish Society – eg children brought to funerals to normalise experience.

Access to bereavement support pathways

Don't wait for a mistake/crisis, make it available to all

Normalise bereavement support

Community – public knowledge and understanding of grief and loss in all communications

Avoid duplication – joined up thinking

Professions recognise a referral pathway and use when needed (pyramid levels)

Understanding the ‘at risk’ markers eg traumatic versus anticipated loss; not just in beginning but longer term needs monitoring

Generic funding of bereavement support across the country.

#### **GROUP 4**

Local linked up services

Inclusive, targeted services

For people to know what types of services there are out there

A national campaign to promote public awareness

Prompts to normalise the experience – e.g. a marathon, not a sprint, you are not alone, 80 people die every day; we are the bereaved, similar to dementia, put a face on it

#### **GROUP 3**

Quality of services is audited/ well policed

Clear standards of care are in evidence, so there are ‘safe’ referrals

Knowing where to refer to

Mapping of services at local and national level

Phone appointments

Network of providers who offer groups,

National co-ordinator for bereavement

Range of services available and accessible across the country (groups, individual/counselling target audience) and method in place to make people and those who come into contact with them aware of available services

Education

Professional

Ethical

Awareness

#### **GROUP 2**

Knowledge of available services; how suitable/ appropriate. Select information that can be compared

No waiting times

Affordable

That the life cycle of life and death are integrated into all aspects of society

More buy in form acute hospital management in relation to the importance of bereavement follow up

To be able to liaise with people from different bereavement teams to create better support for the bereaved persons

Importance of funeral directors – it would be great if they could have bereavement workers

Consistency across the board – regardless of location/access to service

That bereavement support – listening services, counselling and groups are integrated into the community and accessible to those who want it.

Support for people with intellectual disabilities, living in a residential setting or at home

#### **GROUP 1**

That schools should have a level of knowledge and learning on grief and loss and have an advisory service they can link to

Popular culture needs to embrace bereavement

Education for frontline staff we don’t pathologise grief

6pm Angelus, replacement thoughts/ public education

National body recognised and reputable

Undertakers to be included

To share knowledge, coach/ school guidance us a as a resource

Something on RIPie for the bereaved

### **Appendix Three: Scoping study/ feasibility study**

#### **Question 1 - What do we want to get from the scoping study?**

What is the goal?

National vision for adult bereavement, study to provide a clear pathway. Clarity of purpose and what is hoped to be achieved

Conduct a SWOT analysis

Identify pitfalls/ gaps

Identify duplication

Importance of governance

Importance of representation – geographical/ statutory/ geographic



Want a national directory of what is in existence  
Needs analysis, regional level/service level/  
voluntary/ statutory  
Identify gaps  
Outcome – provide a pathway to where to next,  
something deliverable  
Comparison to other countries and identify best  
practice  
To learn from previous mistakes/ initiatives and  
not to reinvent the wheel  
Convert people to the cause!  
Launch media campaign to promote idea

Overview of bereavement services throughout  
Ireland – what is out there?  
What are they doing?  
How are they doing it?  
What is the governance?  
Is it reputable?  
What do they need? (what are their  
qualifications? What is their understanding of  
grief and bereavement? Are people who are  
providing bereavement support qualified to do it  
and do they need to be?

To identify who would oversee the network? The  
inclusion of service providers and voluntary  
sector

To explore what services are out there  
Voluntary/statutory  
Religious groups/ church leaders  
All Ireland, particularly in poorly serviced  
areas  
Multi-cultural groups  
Needs analysis – with the bereaved  
See what went right and what went wrong  
Recognising that Ireland is multi-cultural

Clear plan for developing the network  
Structure/ governance and accountability  
Who involved?  
Potential funding sources/ stakeholders  
Host/ responsible body  
Clear objectives (clients/ beneficiaries)  
Timeframe  
Staffing  
Marketing/ awareness etc. website/ publicity  
Key deliverables 3 to 5 years –mapping/  
bereavement pyramid  
Members/ partners  
Identifying the need/ why?  
Comparable project – evidence based  
Identify target sectors and agencies

Incorporating into mental health reforms – e.g.  
Connect for life  
Creating partnerships that want to come on board  
Map the territory, identify key blocks  
Reduce ten fear of seeking support  
GPs have more non-clinical approach  
Acknowledge east/west divide

## Question 2 – Representation in a Steering group

Voluntary sector (Churches; different faith &  
non-faith representatives; specific bereavement  
organisations (targeting certain losses, eg  
suicide, perinatal, road accidents, traumatic,  
palliative care, childhood  
Statutory – Tusla; HSE

Different sectors and link to ICBN

Voluntary  
Community  
Business (undertakers, mental health,  
florists)  
Clinical (GP  
Education/ colleges  
Disability services  
Celebrities  
Hospitals  
Hospice friendly hospitals  
Hospices  
Citizens information service/ MABS

Not too big!

Voluntary and statutory, paid and unpaid  
Bereaved person  
National bereavement organisations  
Health professionals (public and private)  
Relevant go department  
Rural and urban  
Gender mix

Voluntary  
Statutory/ professional  
Bereaved  
Rural/ urban  
Non-national  
GP  
Church leaders  
Service providers  
Service users

Public health/ education  
IHF  
Voluntary agency rep  
Service development experience  
Project management

Bereavement specialist  
Bereaved people/ service users  
PR and Finance

Acute hospital sector  
ICBN  
HSE management  
Primary care (GPs)  
Current national bereavement services (national, statutory and voluntary)  
Funeral directors  
Multicultural representation  
Hospice services  
Tusla  
Third age sector – Age Action/ Sage  
Family carers Ireland  
Public representation bereaved and service users  
IHF  
Bereaved that are disenfranchised

**Question 3: Who needs to be consulted? Who are our stakeholders?**

Government representation  
Educational institutions (professional) teachers, medical students, universities, social care  
People who are bereaved (service users) through different types of bereavement  
Media  
Celebrity/ trustee

Bereaved  
Bereavement organisations  
Government  
Minister for Health  
Minster for older people  
Secretary General  
HSE  
Pobal

International/ UK networks and organisations  
Professional bodies – Institute of funeral directors, IASW, ICGP  
Potential sponsors/ face

The bereaved  
Existing bereavement groups  
First responders, Gardai, ambulance, coroners, fire brigade  
Students  
Children and young people  
Educators  
GPs

Nurses, social workers, mental health  
Hospital and community teams  
Society!  
Hse  
Social policy makers  
Politicians, local and national, Seanad  
Celebrities – key ambassadors, GAA  
Organisations (dementia)  
Rural groups ICA and IFA  
Cultural groups  
Ethnic groups, travellers  
Faith and non-faith communities  
Media – TV, radio, papers, social media  
Prisoners  
People with intellectual disabilities

Youth groups  
Emergency services – fire, ambulance  
Voluntary  
Statutory  
All at different levels, through questionnaire and surveys  
Have levels of consultation with bereaved person at the centre  
Accounts of services that failed were not available, or did not have desired impact  
Main structures, politicians and HSE buy in is important  
Use information that already exists

Joint Oireachtas Committee on health  
Cross party politicians – need to ask for a particular commitment, eg premises  
Bereaved celebrities – to generate awareness and media interest  
Champions from the sporting world – GAA

Local TDs  
Minister for health  
Minister for children  
Counselling services  
Youth groups  
Children's rights alliance, Tusla  
Multi-denominational and non-denominational  
Hospitals – general and psychiatric  
CAMHs  
Other voluntary agencies  
Rural communities  
Minority – LGBT and travellers

# Appendix B:

## Appendix B: Terms of Reference for Project Advisory Group

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### Enhancing bereavement care in Ireland Project Advisory Committee

#### TERMS OF REFERENCE

The Project Advisory Committee (PAC) is a temporary group set up to support the completion of a study which will:

#### **Establish the vision for a national approach to bereavement care in Ireland**

Describe in detail current bereavement care in Ireland  
Identify strengths, weaknesses and opportunities in current bereavement care  
Identify relevant policy context for development of bereavement care aligning to mental health and other appropriate areas  
Prioritise needs for action.

#### **Develop an implementation framework for enhancing bereavement care in Ireland**

Based on current situation, literature, and international models propose:

- structures/ models for a network or alliance in bereavement care in Ireland
- governance and
- an outcome driven workplan for a network/ alliance in bereavement care in Ireland.

Identify key deliverables in a three to five year timeline  
Identify resource requirements, staffing and potential statutory or non-statutory supports  
Conduct a risk analysis

#### **Role of the PAC**

- Support the researcher in completing the project
- Help in data collection for the project by identifying key stakeholders; by negotiating access for data collection by interview or focus group and by attending focus group discussions as required.
- Ensure that a full variety of bereavement experiences are reflected in the project – including the experiences of less visible groups, eg women and couples who have accessed termination of pregnancies;
- Help in reviewing literature for the systematic review
- Ensure the project keeps on track, that the activities are conducted within the timescale indicated
- Provide feedback and discussion on the findings as these become available
- Feedback to the larger Bereavement Forum group
- Attending meetings once a month between July and December 2017
- Provide comment as requested by email

# Appendix C:

## Systematic Review Methodology

### Review Methodology:

This desk-based secondary research evidence review was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (Moher et al. 2009) and guided by systematic review methodology (Higgins & Green 2011a; Centre for Systematic Reviews and Dissemination, 2008). However, due to the resources available, all records were reviewed by one researcher only (as opposed to two working independently).

### Selection Criteria for Studies:

The PICOCS framework (Table 1) was used to develop a search strategy and to support the selection criteria for the study (Davies, 2011).

### Empirical Databases:

The following academic databases were searched: Cinahl, Medline, PsychInfo and SocIndex

**Table 1:** PICOCS Framework Guiding Selection Criteria

|               |  |
|---------------|--|
| Population    | Bereaved   |
| Interventions | Services e.g. mental health, general practice<br>Care<br>Awareness<br>Policy<br>Standards<br>Structure<br>Guidelines / guidance<br>Support<br>Groups<br>Models<br>Campaigns<br>Website<br>Funding<br>Strategy<br>Framework<br>Outcomes<br>Education<br>Counselling |
| Comparator    | No specific search criteria applied  |
| Outcomes      | No specific search criteria applied  |
| Contexts      | Ireland, UK, Canada, Australia and The Netherlands   |
| Studies       | All designs published in English in the last 10 years  |

### Search Strategy:

For each database, a specific search strategy was developed combining key word terms and their variants in title/abstract/subject headings as appropriate. Two members of the team checked the search strings for accuracy. The full search terms and combinations for CINAHL are presented in Appendix 1. PsychInfo and SocIndex do not use Mesh terms and therefore the terms offered in S1 and S4 were not required for these databases. In Medline the Cinahl Headings outlined in S1 were replaced with Mesh term "Bereavement".

# Appendix D:

## Telephone Interview Topic Guide

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1. Can you tell me a little about yourself and your professional experience / the organisation you represent in the context of bereavement and loss?
2. Why did you become interested in the area of bereavement and loss (assuming of course you are!) If not interested...can you tell me how you see bereavement and loss might be relevant to you and your role / organisation?
3. Can you tell me about how bereavement services and support is structured in Ireland / your region / relevant to your organisation?
4. Do you have a sense of what is working well for people who have experienced a bereavement in Ireland?
5. What could be improved?
6. What do you consider to be the key strengths of the services and supports currently offered?
7. What are the main weaknesses?
8. Are there any particular groups in society you perceive to be most vulnerable?
9. How do you feel Ireland is dealing with grief and loss at policy level?
10. What do you feel Ireland needs to do to improve bereavement care and support for people?
11. Is there a need for a national network/alliance for bereavement services and support in Ireland?
12. What would you envisage this would look like?
13. Where would it be led from? Who should take responsibility for it?
14. How might it be funded?
15. What would be the benefit of a national network/alliance...working together?
16. If such a national network / alliance was set up, what are the three things you would like it to achieve in the first three years?
17. Can you see any potential risks to developing a national approach to bereavement?
18. Are you aware of any policies in your area relevant to bereavement and loss...do you have access them, do you use them?
19. Anything else to add?



# Appendix E:

## Focus Groups

WE INVITE YOU TO HAVE YOUR SAY

**HOW WELL DOES IRELAND SUPPORT PEOPLE LIVING WITH BEREAVEMENT?**

FOCUS GROUP WORKSHOP  
OPEN TO ALL

Weds 8th November 2017 | 7PM  
Children's Grief Centre, Westbourne, Ashbourne Avenue, South Circular Road, Limerick

This focus group will inform the development of a national feasibility study to enhance bereavement care in Ireland for all.

Contact Kathy for more information  
0894667915 kemcloughlin@gmail.com  
Refreshments will be available

### Focus Group Format

Facilitators to arrive at least 30 mins prior to the event starting

Sign in Sheet with name, organisation, mobile and email details.

Table with bereavement support literature.

### Room Set Up

Tables with 6-8 chairs max per table.

Tea / Coffee and a treat available on arrival.

Flip chart pages and markers on each table.

Flip chart stand with flip chart pages and markers.

Sticky labels for people to write on their names.

5 sticky dots on a sheet per person

Facilitators warmly welcome people on arrival and try to ensure that tables are balanced numbers wise. Try to ascertain if the attendees belong to an organisation or if they are members of the public. Recommend tables based on this.

### Welcome introductions and housekeeping (10 minutes)

Introduce yourselves and explain why the meeting has been called. For example...

*"My name is ... You are all very welcome to this evening's focus group workshop. The Irish Hospice Foundation and a small committee representing bereavement services nationally, are doing some research to see how people and organisations in Ireland feel about bereavement support, and to see if there is a need and an appetite to develop a bereavement network or alliance.*

*The research comprises of a number of stages including a review of published literature, interviews with national experts, conversations with international experts who are involved in alliances in other countries and 4 focus groups around the country to hear your views. The focus groups are being held in Limerick, Dublin, Cork and Sligo.*

*So you are all very welcome to this focus group in... the ... of the four to take place.*

*I would like to .... for providing use of the room this evening and I hope that you all have a cup of tea".*

Fire exits / phones.

*"I'd like to take a few minutes to go around the room and ask you your name, if you are representing an organisation and why you came here this evening..."*

Go around the room and record the organisations on a flip chart. If a person is there purely due to a personal experience or if they are a member of the public just record 'personal experience' or 'public' on the sheet.

Note the broad range of people attending. Some attending in a professional capacity and others because of their own experience that may have been very positive or indeed negative.

**Ground Rules – 5 mins**

*“Bereavement is something that touches the lives of each and every citizen of our country at some point in life. The purpose of this evening’s meeting is to find out from you what you feel is working well in Ireland regarding bereavement services and bereavement support and what you feel would make things even better. I will be asking you some questions to discuss at your tables and I would like you to decide at each table who will take notes, either on an A4 page or on the flip chart sheets as it is important that we have a record of what is said. So take a few seconds to agree who will do this.”*

*“Before you begin, I would like to draw your attention to some ground rules for this evening’s focus group – see sheet on tables*

- Safe space
- Confidentiality
- Share what you feel comfortable sharing
- Recognising emotions – some wearing 2 hats
- Follow up support

Offer opportunity for questions about the plan at this point

**Question 1– 30 mins**

The first question we have for you to consider is:

***How well does Ireland support people who have experienced bereavement? What is working well? What could be improved?***

***NB: Policy, Funding, Services, Information, Community Supports, Other – is the numbers are large assign a theme to a table.***

15 mins to discuss in groups and 15 mins of feedback

Draw the feedback into themes: Policy, Funding, Services, Information, Community Supports, Other

Conclude the feedback by saying that as a country we do things well, organisations providing good support, often on a shoe-string, but there are clearly gaps, duplication and a need to do more.

**Question 2 – 30 minutes**

Note 2 national workshops that called for a joined up approach and note that this is why we are conducting this bereavement feasibility study as there seems to be an appetite and a need for a national network...take a few minutes to think

about this at your tables. Do we need a national bereavement network or alliance in Ireland? Assuming from what you have already said that something like this would be useful. What would it look like? What would it do? Take 15 minutes to list what you would like to see it do in the first 3 years.

Have a break for a cup of tea and facilitators will make a summary list of actions (NB you will be provided with a master list of these based on feedback from the 1-1 interviews – so just add anything else new that emerges).

**Prioritising– 10 mins**

Put the lists up on the wall and ask participants to go around the room and ‘spend’ their dots. One dot per action. This will enable us to consider the priority actions that everyone has identified in the final report (10 mins)

Once this exercise is complete – note the areas with the most dots – and those with the least.

End with a general group discussion with one facilitator making notes of the general discussion (15 mins max)

Thank people for attending – encourage them to take the resources available and advise them that the report will be made available in early 2018.

# Appendix F:

## All Studies Reviewed

| Authors  | Published Year | Title  | Journal   |
|--|----------------|--|---|
| Abbott J; O'Connor M; Payne S  | 2008           | An Australian survey of palliative care and hospice bereavement services.                                | Australian Journal of Cancer Nursing  |
| Agee, Margaret Nelson  | 2011           | A New Zealand perspective on suicide bereavement.  | Grief after suicide: Understanding the consequences and caring for the survivors. |
| Agnew, A; Manktelow, R; Taylor, B; Jones, L  | 2010           | Bereavement needs assessment in specialist palliative care: a review of the literature.                  | Palliative Medicine   |
| Agnew, Audrey; Manktelow, Roger; Haynes, Tommy; Jones, Louise  | 2011           | Bereavement assessment practice in hospice settings: Challenges for palliative care social workers.      | British Journal of Social Work  |
| Aoun, Samar M.; Breen, Lauren J.; Rumbold, Bruce; Howting, Denise  | 2014           | Reported experiences of bereavement support in Western Australia: a pilot study.                         | Australian & New Zealand Journal of Public Health                                 |
| Benkel, I.; Wijk, H.; Molander, U.   | 2009           | Family and friends provide most social support for the bereaved.   | Palliative Medicine   |
| Blackburn, Pippa; Dwyer, Kris  | 2017           | A Bereavement Common Assessment Framework in Palliative Care: Informing Practice, Transforming Care.     | American Journal of Hospice & Palliative Medicine                                 |
| Blackburn, Pippa; McGrath, Pam; Bulsara, Caroline  | 2016           | Looking through the lens of receptivity and its role in bereavement support: A review of the literature. | American Journal of Hospice & Palliative Medicine                                 |
| Breen, Lauren J.; Aoun, Samar M.; O'Connor, Moira; Rumbold, Bruce  | 2014           | Bridging the Gaps in Palliative Care Bereavement Support: An International Perspective.                  | Death Studies   |
| Breen, Lauren J.; Aoun, Samar M.; Rumbold, Bruce; McNamara, Beverley; Howting, Denise A.; Mancini, Vincent | 2017           | Building community capacity in bereavement support: Lessons learnt from bereaved caregivers.             | American Journal of Hospice & Palliative Medicine                                 |

|   |      |  |   |
|---|------|--|---|
| Cairns M  | 2009 | The challenges to evidence-based practice in bereavement care... Canadian Hospice Palliative Care Conference, Voyages in Care and Understanding, October 18-21, 2009, Winnipeg, Manitoba, Canada | Journal of Palliative Care  |
| Ceramidas, Dagmar; Staines, Alan; De Leo, Diego   | 2017 | Australia - Postvention Australia: National Association for the Bereaved by Suicide.   | Postvention in action: The international handbook of suicide bereavement support. |
| Connor, Stephen R.; Monroe, Barbara   | 2011 | Bereavement services provided under the hospice model of care.   | Grief and bereavement in contemporary society: Bridging research and practice.    |
| Daoust, Jean-Claude   | 2017 | Canada - Hope after loss: Suicide bereavement and postvention services of Suicide Action Montréal.   | Postvention in action: The international handbook of suicide bereavement support. |
| Erlangsen, Annette; Fleischer, Elene  | 2017 | Denmark - Support for the bereaved by suicide.   | Postvention in action: The international handbook of suicide bereavement support. |
| Fajgenbaum, David; Chesson, Benjamin; Lanzi, Robin Gaines   | 2012 | Building a network of grief support on college campuses: A national grassroots initiative.   | Journal of College Student Psychotherapy  |
| Finley, Rob; Payne, Malcolm   | 2010 | A retrospective records audit of bereaved carers' groups.  | Groupwork: An Interdisciplinary Journal for Working with Groups                   |
| Friedrichs, Judy B.; Kobler, Kathie; Roose, Rosmarie E.; Meyer, Charlotte; Schmitz, Nancy; Kavanaugh, Karen | 2014 | Combining regional expertise to form a bereavement support alliance.   | MCN: The American Journal of Maternal/Child Nursing                               |
| Genevro, Janice L.; Miller, Therese L.  | 2010 | The emotional and economic costs of bereavement in health care settings.   | Psychologica Belgica  |
| Ghesquiere, Angela R.; Patel, Sapana R.; Kaplan, Daniel B.; Bruce, Martha L.                                | 2014 | Primary care providers' bereavement care practices: Recommendations for research directions.   | International Journal of Geriatric Psychiatry                                     |
| Guldin, Mai-Britt; Murphy, Irene; Keegan, Orla; Monroe, Barbara; Reverteand, Maria Antonia Lacasta          | 2015 | Bereavement care provision in Europe: a survey by the EAPC Bereavement Care Taskforce.   | European Journal of Palliative Care   |

|   |      |   |   |
|---|------|---|---|
| Guldin, Mai-Britt; Vedsteda, Peter; Jensenb, Anders Bonde; Olesena, Frede; Zachariae, Robert                  | 2013 | Bereavement care in general practice: A cluster-randomized clinical trial.  | Family Practice   |
| Harris, Darcy L.; Bordere, Tashel C.  | 2016 | Handbook of social justice in loss and grief: Exploring diversity, equity, and inclusion.   |   |
| Hudson, Peter; Hall, Chris; Boughey, Alison; Roulston, Audrey   | 2017 | Bereavement support standards and bereavement care pathway for quality palliative care.   | Palliative & Supportive Care  |
| Ingold, Kathryn; Hicks, Fiona   | 2015 | Using a public health approach to improve end-of-life care: results and discussion of a health needs assessment undertaken in a large city in northern England. | BMJ Supportive & Palliative Care  |
| Johnstone, Rosalynde Patricia; Jones, Angela; Fowell, Andrew; Burton, Christopher Richard; Rycroft-Malone, Jo | 2012 | End of life care in Wales: evaluation of a care pathway-based implementation strategy.  | BMJ Supportive & Palliative Care  |
| Jones, Ross   | 2017 | Bereavement care in the UK: variability in resources and approaches.  | Infant  |
| Karapliagou, Alik; Kellehear, Allan   | 2016 | The forgotten people in British public health: a national neglect of the dying, bereaved and caregivers.  | BMJ Supportive & Palliative Care  |
| King, Michael; Vasanthan, Mira; Petersen, Irene; Jones, Louise; Marston, Louise; Nazareth, Irwin              | 2013 | Mortality and medical care after bereavement: a general practice cohort study.  | Plos One  |
| Klass, Dennis   | 2015 | Review of Deconstructing death: Changing cultures of death, dying, bereavement and care in the Nordic countries.  | Omega: Journal of Death and Dying   |
| Lascelles, Karen; Pitman, Alexandra; McDonnell, Sharon; Elvidge, Hamish; Gamham, Helen; Hawton, Keith         | 2017 | England - Help for people bereaved by suicide.  | Postvention in action: The international handbook of suicide bereavement support. |
| Mather, Mark A; Good, Phillip D; Cavenagh, John D; Ravenscroft, Peter J                                       | 2008 | Survey of bereavement support provided by Australian palliative care services.  | The Medical Journal Of Australia  |



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