HOSPICE AND PALLIATIVE CARE SOCIAL WORKERS GROUP

Guidance for Bereavement Support provided by Specialist Palliative Care Social Workers in Ireland

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1. Introduction

All bereaved people require access to good quality information about grief and will manage their bereavement with the support of friends and family. Most people experience healthy or uncomplicated grief when their loss is accepted, their ability to function in everyday life is regained (Boelen et al, 2007) and they adapt to the death of a loved one without therapeutic intervention (Eisma et al, 2015). A significant minority of bereaved people (approx. 40%) may require extra support to make this adaptation (Aoun et al, 2015). However, evidence suggests that without appropriate support some of these people may develop a range of physical and mental health problems (Stroebe et al, 2007), including major depressive disorder (Zisook et al, 1994), anxiety (Jacobs et al, 1990), post-traumatic stress disorder (Schut et al, 1991) or prolonged grief (Maercker et al, 2013). Bereavement care is an integral part of specialist palliative care, and all members of the multi-disciplinary team, including administrative staff, have a valuable contribution to make (NICE, 2004; WHO, 2002; Hall et al., 2012; Ryan et al, 2014; Hudson et al., 2017; HSE & RCPI, 2019). According to the National Institute for Clinical Excellence (NICE) Guidance *Improving Supportive and Palliative Care for Adults with* Cancer (2004: 157), those who experience bereavement should receive, at a minimum, information on loss and support to facilitate grieving, where necessary in order to prevent the detrimental consequences of bereavement.

Internationally, it is recommended that all palliative care services have bereavement guidance outlining the range of bereavement services they offer and the pathways for service delivery (Scottish Government Health Directorates, 2011; Hudson et al, 2017; HSE & RCPI, 2019). Hence, the primary aim of this document is to provide evidence-informed guidance for specialist palliative care social workers who deliver bereavement care services to families of patients with a life limiting illness. It also acknowledges the potential use by other health and social care professionals in palliative care settings, involved in bereavement care.

2. Context

The way we manage death, dying and bereavement care within our health service is vitally important to the health and wellbeing of patients and families but also for the public health system in general (IHF, 2013). This is particularly pertinent in the palliative care arena, with figures showing that in 2010, there were 6733 deaths in Ireland which were supported by specialist palliative care services. This accounts for 25% of all deaths nationally and 72% of all cancer deaths (IHF, 2013).

Historically, palliative care services in Ireland were established in response to localised need, and were funded from a variety of sources, including statutory, voluntary and charitable organisations. This may explain the significant variance in the availability and delivery of palliative care services throughout Ireland, and the manner in which bereavement care can be delivered (IHF, 2006; IHF, 2013). The Report on the National Advisory Committee for on Palliative Care (DOHC, 2001) recommended specific staffing levels for specialist palliative care social work posts. However, eighteen years later, there are still parts of the country with no access to a specialist palliative care social work service, with other geographical areas being serviced by single-handed posts, which has limited the level of bereavement care available from individual teams and agencies (HSE & RCPI, 2019).

It is hoped that this guidance document promotes a level of standardised practice for specialist palliative care social work within bereavement services offered nationally. It acknowledges that specialist palliative care social work services should collaborate with other organisations in their immediate locality, to enhance the level and type of service available to bereaved people (Hall et al, 2012; HSE & RCPI, 2019) and should promote a public health approach to bereavement (Aoun et al, 2012; HSE & RCPI, 2019). This guidance recognises that bereavement occurs along a continuum, and proposes designing and delivering bereavement services to provide care from pre-death support right through to post-death bereavement care, in line with the competency framework for specialist palliative social work (Ryan et al, 2014).

Drafting this guidance document commenced with a review of internationally published bereavement guidelines and standards (Aranda and Milne, 2000; Department of Health, 2008; DHSSPS, 2009; Relf et al, 2010; Agnew et al, 2011; Hall et al, 2012;

Bereavement Services Association/CRUSE, 2014; HSE, 2016; Hudson et al, 2017; Irish Childhood Bereavement Network, 2017), taking account of the competency framework for palliative care (Ryan et al, 2014) and the national Model of Care for palliative care services (HSE & RCPI, 2019).

3. Fundamental Principles

A number of fundamental principles underpin this guidance, to promote best practice by specialist palliative care social workers when working as an integral part of a multi-disciplinary team and when delivering bereavement care. These principles were identified following a review of relevant national standards, frameworks and policy and are aligned with the national competency framework for palliative care (Ryan et al, 2014). See Table 1 for more details. These fundamental principles for bereavement care are as follows: access, values and diversity, partnerships, quality assurance and governance.

Table 1. National Standards, Frameworks and Policies reviewed

Authors	Year	Title of document
CORU	2019a	Social Workers Code of Professional Conduct and Ethics
Department of Health and Children	2001	Report of the National Advisory Committee on Palliative Care
Department of Health and Children	2010	Palliative Care for Children with Life-limiting conditions
HSE	2016	National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death
HSE & RCPI	2019	Adult Palliative Care Services Model of Care for Ireland
ICBN	2014	Irish Childhood Bereavement Care Pyramid
ICBN	2017	Standards for Supporting Bereaved Children and Young People
Ryan et al	2014	Palliative Care Competence Framework - Social Work chapter

3.1 Access

All people have a right to information to facilitate continuous access to support, according to need, both pre and post death

- Palliative care services should have defined pathways to facilitate seamless access to additional services, if required.
- Family or carer need for bereavement support should be identified via the multi-disciplinary team (MDT) as part of the overall needs assessment process.
- People can self-refer or be referred to services as individuals, a family or as a group for an assessment of need. Services need to get consent from individuals to make a referral.
- After the death of a family member, bereaved relatives should have access to information which should:
  - o Normalise grief and explain how to access support, if required.
  - o Be made available in different languages and formats.

3.2 Values and diversity

Support must be based on respect for the person and their familial, social and cultural context. Services provided should promote:

- Confidentiality.
- Consent.
- A safe environment.
- Respect for the individual and his/her unique experience and expression of grief.
- A family systems perspective.
- Recognise and acknowledge loss over time including the social, financial and practical implications.
- Equity of provision and access regardless of race, ethnicity, sexual orientation, gender, age, culture, disability, socio-economic status or religious beliefs.
- Diversity in response based on identified / assessed needs.
- A prompt response to any concerns regarding a patient or family member's immediate mental health needs, with onward referral to appropriate professionals or agencies as necessary.

- Children and vulnerable populations merit particular attention in the needs assessment process and require a proactive approach to the provision of bereavement support.

3.3 Partnership

People live within geographic and social network. Linkages and partnerships with a range of agencies and institutions are a means of ensuring multiple and accessible routes to bereavement support. Specialist palliative care social workers should work in partnership with others as appropriate to:

- Develop links with external bereavement support agencies and local communities, to ensure a full range of accurate bereavement service information is available.
- Promote self-assessment and empower individuals to explore and engage in the most appropriate service in terms of location, identified need and level of service.
- Adopt a systematic approach to the assessment of bereavement needs, taking account of family resilience, coping and vulnerability.
- Develop clear processes for making onward referrals which avoid duplication of services and manage delays when requesting specialist services.

3.4 Quality Assurance

People have a right to high quality, evidence based support appropriate to their level of need

- All staff in a palliative care service who have contact with family members during the illness trajectory and with bereaved individuals will require bereavement awareness training, to ensure they meet the competency requirement for specialist palliative care staff (Ryan et al, 2014), which should be provided by members of the Social Work team. The content should raise awareness of risk or vulnerability factors and factors that may enhance resilience (See appendix 1 and 2).
- Agencies should acknowledge the impact of working in a context of loss, grief and bereavement for staff and volunteers and provide support.

- Where services have volunteers engaged in bereavement support, clearly defined roles outlining their responsibilities and commensurate training must be provided by the agency. The social work team are responsible for the clinical management of these volunteers and assessing the level of need of individuals or groups prior to them attending a bereavement volunteer.

- Systems will be in place to obtain user feedback when individuals exit the bereavement support service. (See appendix 3 for suggested evaluation form.)

- Bereavement services should be audited annually and reviewed regularly based on findings from audits and service evaluations or new research evidence or policy developments. See appendix 4 for suggested audit tool. The Irish Childhood Bereavement Network (ICBN) has national standards for supporting bereaved children and young people, which includes a Self-Assessment Tool for Bereavement Services (ICBN, 2017). See appendix 5. We recommend all services self-assess using this tool.

3.5 Governance

Services must have a clearly defined, transparent structure and model of care with appropriate safeguards to ensure good governance at all times

- To ensure ethical, safe and appropriate service delivery, all social work staff should have the appropriate skills and competence for the roles they undertake (CORU, 2019a) which will reflect the social work competencies in the Palliative Care Competence Framework (Ryan et al, 2014).

- Each agency has responsibility to ensure that there is sufficient staffing to respond to the needs of individuals and families who may experience high levels of difficulty before and following the death of a patient.

- Specialist palliative care services should have a designated bereavement co-ordinator (DOHC, 2001) within the social work team (HSE & RCPI, 2019).

- Clinical supervision should be made available to Social Work staff involved in the delivery of bereavement services. This supervision should be on a monthly basis and can be individual and/or group supervision.

- Bereavement Support Volunteers actively engaged in providing bereavement support must receive regular supervision.

- All Social Workers should regularly attend education and training events for their continuous professional development in line with the CORU (*Guidance on CPD Framework*, 2019b) requirements (e.g. 30 CPD credits in every 12 month period).

4. Guidance for Bereavement Care

In acknowledging that loss, grief and bereavement occurs along a continuum, this guidance outlines the role of the specialist palliative care social workers when providing care from the initial point of contact with the specialist palliative care service, around the time of death and into post-death bereavement care (HSE & RCPI, 2019). We acknowledge the role that other members of the multi-disciplinary team also have, particularly during the patient's illness, but this guidance is for specialist palliative care social workers.

4.1 Pre-death: Balancing and exploring risk and resilience

End-of-life care and the death of a family member create multiple transitions for individuals within a family, as well as the family as a whole. The context within which families live, including previous experiences of loss and illness, influence how they cope with this illness, any impending and actual losses after the death and their response to grief. Preparedness for death has also been found to be a key factor for individuals and can help ameliorate psychological morbidity (Hebert et al, 2009). Assessment should be multidisciplinary and interdisciplinary in nature (Hall et al, 2012) and where possible, should involve direct input from the patient, their relatives or family carers and professionals involved in their care. Consequently, a family's bereavement needs should be continuously assessed from the point of referral to the service and into bereavement with their consent (DOHC, 2001; HSE & RCPI, 2019). It should consider both the needs of individuals and of families, adopting a family systems perspective. It should consider the individual and family's needs from both a resilience and risk perspective (Relf et al., 2010; HSE & RCPI, 2019). (See appendix 1 and 2 for more details.)

Upon referral or admission to specialist palliative care services, all families should be made aware of the availability of the services provided by the social work team. A family's needs, risks, vulnerabilities and resilience should be continuously explored with them by members of the multidisciplinary team, including social work. The social

work service can be offered to a family via referral from a member of the multi-disciplinary team, or directly by the social worker. Individuals and families may also self- refer.

The social worker's role in the pre-death phase is to work within the context of the family system to explore and support the patient and family's preparedness for death by:

- Facilitating and supporting transition and adjustment to a relative's life-limiting illness and their impending or actual death.
- Advocating for a patient's prognosis to be communicated in an appropriate and timely manner.
- Facilitating shared decision-making between the patient, family and members of the wider multi-disciplinary team. This includes:
  - Facilitating and exploring preferences around place of care and/or place of death.
  - Acknowledging its impact on the patient and family's ability to plan ahead, and on the bereavement process.
  - Advocating for consideration of the physical environment in which care takes place, where and when bad news is communicated or sensitive conversations take place.
  - Engaging with the patient and family members to assess perceived risks and anticipated coping mechanisms, underpinned by knowledge of bereavement risk factors and resilience (Appendix 1 and 2)
  - Supporting individuals and families to negotiate different coping mechanisms and communication styles, particularly where conflict arises.
  - Providing information and advice to families on communicating with children and adults who are perceived or assessed as vulnerable, that promotes their inclusion and understanding of their relative's condition.
  - Undertaking direct work with children and vulnerable adults where indicated.
  - Maximising input from existing support services utilised by any children or vulnerable adults in the family.

- o Addressing practical and financial stresses associated with illness and death.
- o Acting as a key resource to the wider multidisciplinary team around the issues raised above.

4.2 Around the time of death

In palliative care settings where a social worker is available around the time of death, their role may be to assist families in preparing for change and managing intense emotion.

As death approaches, the multi-disciplinary team (MDT) is conscious of the need to be as inclusive as possible regarding all family members. However, strained relationships may be intensified around the time of death, and some individual family members may benefit from the support of the social worker to acknowledge their distress and to help them to implement strategies to diffuse the situation.

Discussions may need to take place regarding who wishes to be present when the patient dies, which should acknowledge any particular preferences stated by the patient and should be communicated to the MDT.

For many individuals, anticipating and being present at a death is unfamiliar and they may welcome guidance on their presence and interaction towards the end of life. Similarly, the decision of some individuals who do not wish to be there at the time of death may require negotiation with other family members, as this can create discord.

Maintaining an environment that is restful and dignified as death approaches is paramount. Where family tension or conflict impinges on this, the social work role is to facilitate open communication in the family at end of life, or assist them in managing their distress.

Social workers can offer guidance on communicating the news of the death to family members who are perceived to be vulnerable, such as adults with an intellectual disability, mental ill health or children and young people. The social worker can also be an important resource in supporting families in their response to the death and the

rituals following the death, including providing practical information on organising a funeral or accessing financial supports.

Some patients and families will wish to explore the possibility of Repatriation before death or repatriation of the body for burial abroad. It is important that they receive appropriate information in a timely way about the medical, legal, national, and international procedures and protocols and associated costs. They may also require support around exploration of cultural priorities/values in order to make decisions.

There is evidence that financial distress can be associated with adverse outcomes in bereavement (Newsom et al, 2017; Nielsen et al, 2017) and it is recommended that priority should be given to assessing the financial needs of individuals and families from lower socio-economic backgrounds (Roulston et al, 2016). The social worker can assist families in accessing appropriate resources, where possible, in order to ensure a dignified burial for the patient.

4.3 Bereavement support after the death of a patient

Following the death of the patient, it is the responsibility of the MDT to review the circumstances of each patient's death, the family's perception of the death and their capacity to cope with the loss, in order to highlight people who may need an additional level of bereavement support or counselling (Relf et al, 2010; Ryan et al, 2014). Each service should develop their own bereavement care policy, outlining service provision and onward referral pathways within the local community and service context (Scottish Government Health Directorates, 2011; HSE & RCPI, 2019). Some individuals and families will only make themselves known to services in the post death period (HSE & RCPI, 2019).

5. Referrals to the service

Where individuals self-refer to the bereavement service or are referred by a member of the MDT, with the consent of the family, there should be contact within 10 working days of the referral. This includes a screening or initial assessment. Contact may be by telephone or face to face, where contact is not established a letter should be sent.

6. Assessment

An assessment of bereavement support for family or carers should be conducted as part of the palliative care needs assessment process (HSE & RCPI, 2019). The purpose of the initial contact with a bereaved individual, regardless of the source of referral, is assessment, which will review the individual's grief experience, how they are coping, their level of perceived support and their capacity to access and utilise that support. This should include screening of vulnerability, risk and resilience factors (as outlined in Appendix 1 and 2) drawing on the social work code of ethics (CORU, 2019a) and competencies (National HMSW Forum, 2013; Ryan et al, 2014). The Confidential Working Agreement (Appendix 6) may be used to capture relevant information and illustrate the proposed action/care plan.

In line with the Public Health Approach to bereavement care (Aoun et al, 2012) different levels of bereavement support and counselling may be provided to meet the range of support needs of bereaved individuals and families (Petrus Consulting et al, 2008; HSE & RCPI, 2019). The initial assessment must uphold the ethical responsibility of specialist palliative care providers to only offer support where it is indicated and to work in a way that enhances an individual's own resilience and capacity to cope with loss (Relf et al., 2010; Machin, 2014). Therefore, the outcome of an assessment may suggest that no formal intervention is offered or required, but may allow for an individual to self-refer in the future should needs change. Similarly, the assessment process should respect the individual's capacity to make decisions about the level of support or counselling they require at that time. If an individual declines services, and if they are not deemed to be a risk to themselves or others, this should be respected. Whereas, if an individual is deemed to be at risk, their General Practitioner should be notified (CORU, 2019a).

Different families and individuals will need differing levels of support after a loss (NICE, 2004; Aoun et al., 2015). Given the dynamic nature of grief, needs can also change and evolve over time. It is not expected that all Specialist Palliative Care Services will provide each of the levels of support outlined below. However, each service should be able to support family members 'universal grief needs' "…by acknowledging current or anticipated losses, supporting the expression of emotions and providing information about the grieving process." (HSE & RCPI, 2019: 87). Professionals working within the

service should all have an awareness of the levels of need and of support (Ryan et al, 2014). Each service should develop links with other agencies to facilitate referrals to a range of supports and services, and develop clearly defined pathways for onward referral to more appropriate services in the bereaved person's local community (HSE & RCPI, 2019). Where a specialist palliative care service provides bereavement support services, a social work assessment will determine the response provided based on the level of need identified. Needs will be continually assessed recognising the dynamic nature of grief and the fact that individual or family need can change over time. The different levels or tiers of need are outlined below.

7. Levels of Need

7.1 Level 1: Universal need to have the death acknowledged and for information about grief and bereavement.

It is recommended that as a minimum, specialist palliative care services should provide information about grief and bereavement to those affected by the death of a patient (NICE, 2004; Scottish Government Health Directorates, 2011; Bereavement Services Association/CRUSE, 2014). This information should be made available in a variety of forms:

- Information leaflets or booklets, based on research evidence, made available at the time of death in all settings.
- Signposting towards other resources about bereavement, including the availability of online resources.
- Unless no further contact has been requested, a letter should be sent to the patient's main contact person/relative, subject to GDPR 2016 legislation, within 3 months of the death (Hudson et al, 2017). This should offer written information on bereavement and how to access support, including bereavement events.
- Where resources allow, other events such as a psycho-education information event on bereavement, coordinated by members of the social work team should be provided within 3-6 months of the patient's death. At this event people will be informed about grief, what to reasonably expect for themselves and their families and have their experience of grief normalised. (where appropriate)
- Opportunity for remembrance may be provided to the bereaved as a form of communal support.

7.2 Level 2: Need for support from someone outside of the family or natural support network to review the loss and explore coping strategies. Services at this level may include:

- Offering individual support to review their unique experience of the loss and where appropriate, to normalise their grief reactions or escalate to a higher level of support, if warranted after assessment.
- Offering the opportunity to meet with medical or nursing staff previously involved in the patient's care, if this will help overcome barriers to grieving. The support of the social worker can be important if the person is receiving or is likely to need further bereavement support.
- Services at this level may include peer support which provides an opportunity for bereaved people to meet others who are experiencing a similar loss and to support each other through mutual understanding and sharing of what they are going through.
- Support may be provided by trained bereavement volunteers with level 2 skills and knowledge who receive regular supervision.

7.3 Level 3: More pronounced bereavement support needs than at level 2, requiring a professional response to meet this need. Social workers and others may provide this level of service with appropriate training. The purpose of this intervention is to provide an opportunity for the bereaved person to talk through their experience of loss and to review how they are coping and adjusting to their changed circumstances (Worden, 2003). This may be:

- individual, family and group professional support and counselling:
- An invitation to attend a bereavement support group facilitated by members of the social work team. Volunteers may support this group or help with the delivery of the group, but it will be led by the professional.
- An invitation to engage in up to six sessions of bereavement counselling. A review will be conducted prior to any additional sessions being agreed. The number of sessions allocated to each bereaved person will be based on assessed need and resources available within the service, which will be communicated to the bereaved individual during their initial assessment. Appendix 6 may be used to record contact with bereaved individuals and the agreed outcome/action plan.

● The individual is made aware that they can avail of bereavement support and counselling at any time in the future should they wish to do so, thus acknowledging that grief is an ongoing process and a person's need for support may change over time.

7.4 Level 4: At any point in the grief trajectory, following assessment, a minority of people may present with complex bereavement needs, such as the risk of suicide/extreme emotional and psychological distress, to prolonged or persistent and intrusive grief symptoms (Maciejewski et al, 2016). All bereavement service personnel, including specialist palliative care social workers, must be aware of the ICD-11 diagnostic criteria (WHO, 2018) and the DSM-5 criteria (APA, 2013) so that they recognise prolonged grief and serious risk to health and well-being arising from the death. This is important as there is emerging evidence that support in the early months after loss for some individuals may reduce the risk of complications in their grief in the longer term (Scottish Government Health Directorates, 2011; Fenger-Gron et al, 2018). Such individuals may access support from staff with specialist training within the agency if available or may require an onward referral to external agencies offering specialist bereavement counselling or specialist teams (e.g. mental health services via the General Practitioner). Systems should be in place to formally capture onward referrals and to manage delays in accessing the relevant specialist services (see appendix 6).

8. Conclusion

This document provides evidence informed guidance to all specialist palliative care social workers who are involved in the delivery of bereavement support to patients and families. While acknowledging that the majority of bereaved individuals manage their grief with good quality information and their informal support networks, a significant minority of bereaved people may require additional supports. The guidance recognises the differing levels of need which may emerge after a significant loss and advocates an appropriately matched response.

While recognising the variation in service structure and resourcing nationally, this guidance strives to ensure a minimum level of standardised practice for specialist

palliative care social workers and how bereavement services could be structured, irrespective of geographical location. The guidance emphasises the social context of the illness and loss, and highlights the importance of continuous bereavement support from the initial point of contact with a specialist palliative care service, right up to, and following, the patient's death (DOHC, 2001; HSE & RCPI, 2019). It also take account of the competencies required by social workers working with bereaved people (National HMSW Forum, 2013; Ryan et al, 2014).

The guidance in underpinned by a number of key principles: Access, Values and diversity, Partnership, Quality Assurance and Governance. It acknowledges the wide range of grief experiences and needs encountered by individuals and families and suggests how palliative care social work services can be structured and delivered using a tiered system of bereavement support (Aoun et al, 2012; Aoun et al 2015).

9. References

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10. Appendices

Appendix 1: Factors influencing risk in bereavement:

Definition:

Risk factors in bereavement are the qualities of individuals and aspects of their situation that may increase the likelihood of vulnerability in coping with a significant loss (Relf et al, 2010:6). A review of the factors that influence grief conclude that those most vulnerable to poor outcome in terms of complicated grief (Lobb, 2010) and post-loss depressive symptoms (Nielsen et al, 2017) are as follows:

- Loss a child (Lobb, 2010)
- Spousal loss at a young age (Nielsen et al, 2017)
- History of previous multiple losses and life struggles (Lobb, 2010; Nielsen et al, 2017)
- Lack of preparedness for the loss (Lobb 2010, Nielsen et al, 2017)
- High levels of care-giver burden pre-death (Nielsen et al, 2017)
- High levels of pre-death distress and depressive symptoms (Nielsen et al, 2017)
- High levels of family conflict (Kissane et al, 2016)
- Financial distress and poverty (Newsome, 2017; Nielsen et al, 2017; Roulston et al, 2016)
- Lower levels of educational attainment (Nielsen et al, 2017).

Neimeyer and Burke (2013) reviewed the clinical literature and summarised categories of factors that may give rise to concerns about an individual's capacity or ability to cope with loss and change and may lead to the development of complicated grief. The categories are as follows:

Background factors
• Close kinship to the dying person (especially spouse or child loss)
• Female gender (especially mothers)
• Minority ethnic status (in the United States)
• Insecure attachment style
• High pre-loss marital dependence

• Religion and spiritual beliefs and practices (for some, religious/spiritual belief results in lower levels of grief and, for others, a stronger faith can lead to more severe experiences of grief)

Treatment-related factors

• Aggressive medical intervention (for example, intensive care, ventilation, resuscitation)
• Ambivalence regarding treatment
• Family conflict regarding treatment
• Economic hardship created by treatment
• Caregiver burden

Death-related factors

• Bereavement overload (multiple losses in quick succession)
• Low acceptance of impending death
• Violent death (suicide, homicide, accident)
• Finding or viewing the loved one's body after a violent death
• Death in the hospital (rather than home)
• Dissatisfaction with death notification

Appendix 2:

Characteristics that indicate a resilient or vulnerable response in bereavement

Specific indicators of a vulnerable response;

- Avoids facing the issues of impending loss resulting from the illness
- Does not demonstrate coping strategies that make use of inner resources and external sources of support
- Cannot acknowledge the current emotional and social impact of the illness
- Does not feel hopeful that strength or meaning may come from the experience (Relf et al, 2010:16).

Specific indicators of a resilient response:

- Can face the issues of impending loss resulting from the illness
- Demonstrates coping strategies that make use of inner resources and external sources of support
- While acknowledging the current emotional and social impact of the illness, there is hope that strength and meaning may come from the experience (Relf et al, 2010:16).

The elements which characterise **resilience** are:

- Personal resourcefulness: where there are qualities of flexibility, courage and perseverance.
- A positive life perspective: where there is optimism, hope, a capacity to make sense of experience and motivation in setting personal goals.
- Social embeddedness: where support is available and there is the personal capacity to access it (Machin, 2014:32).

Appendix 3

Bereavement Service Evaluation Form

We would be delighted if you could take a few minutes to provide feedback on the bereavement service that you received. Feedback, both positive and negative, informs how we deliver services in the future.

1. Please rate your overall satisfaction with the bereavement service (tick or circle one).

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Unsure	Somewhat satisfied	Very satisfied

Comments:

2. Please rate your satisfaction with the number of appointments provided (tick or circle one).

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Unsure	Somewhat satisfied	Very satisfied

Comments:

3. Please rate your satisfaction with the duration of appointments (tick or circle one).

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Unsure	Somewhat satisfied	Very satisfied

Comments:

4. Please rate your satisfaction with the frequency of appointments (tick or circle one).

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Unsure	Somewhat satisfied	Very satisfied

Comments:

5. Please rate your satisfaction with topics discussed during the sessions (tick or circle one).

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Unsure	Somewhat satisfied	Very satisfied

Comments:

6. Were there any other topics that you would have liked to have discussed during the sessions?
   Yes / No
   Comments:

7. Has accessing the bereavement service helped you to cope better with your bereavement? Yes / No
   Comments:

8. Please rate how likely you are to recommend this bereavement service to a relative or friend.

0	1	2	3	4	5	6	7	8	9	10

Not at all likely ……………………………………………………Extremely likely
   Comments:

9. How could we improve the bereavement service?
   Comments:

10. Any other comments:

Appendix 4

Guidelines for Bereavement Care: Audit Tool

Audit the following components by finding evidence in the organisation to support the statements or by using a selection of staff, volunteers or records (as indicated). Grey areas do not need to be completed as they apply to statements that have only compliance or variation as an option. For other areas a random selection of 10 files or staff should be used.

Compliance should be recorded by a √. Variation should be indicated with X or N/A as appropriate. Please note, it is unlikely that a recording of N/A will be used because the audit will only measure standards that should be implemented and adhered to across agencies. The scores should be calculated at the end of each column, and a summary of findings should be written highlighting relevant points and/or a description to explain findings. An action plan should be agreed and used to inform issues or identify areas of concern.

Bereavement Standard	1	2	3	4	5	6	7	8	9	10	Total Ticks	Total N/A
1: A booklet or information leaflet available after the death of a patient.												
2: All Social Work staff are in receipt of clinical supervision.												
3: All volunteers actively engaged in providing bereavement support receive regular supervision.												
4: Systems are in place to screen individuals being referred to the service, prior to being allocated to a SW, volunteer or group.												
5: Systems are in place to formally capture onward referrals to specialist agencies or teams for complex grief.												
6: Systems are in place to offer psycho-education information events on bereavement, within 3-6 months of the patient's death.												
7: Systems are in place to obtain service user feedback when individuals exit the bereavement support service.												

8: All staff who have contact with family members during the illness trajectory and with bereaved individuals received bereavement awareness training from the Social Work team. *Ask 10 staff confirm this.*		32										
9: Following the death of a patient, the MDT reviewed the circumstances of the death and the family's perceived capacity to cope. *Ask 10 staff for evidence to support this OR Examine 10 sets of records for evidence to support this.*												
10: Contact was made within 10 working days of a referral or the patient's death where an individual was deemed to be vulnerable (e.g. mental health history, multiple losses, multiple stressors, limited social support, addiction or financial issues). *10 sets of patient records for evidence to support this.*												
11: An initial assessment of bereavement support was conducted. *Examine 10 sets of records for evidence to support this.*												
12: There is evidence that consent was obtained prior to onward referral to another agency/professional. *Examine 10 sets of records for evidence to support this.*												
13: There is a written action plan completed for each patient/client who accesses the service. *Examine 10 sets of patient records for evidence to support this.*												

14: Patient's main contact person/relative was contacted within 3 months, unless they requested no follow up. *Examine 10 sets of records for evidence to support this.*													
15: The need for ongoing support is reviewed after 4 – 6 sessions of bereavement support. *Examine 10 sets of patient records for evidence to support this.*													

Additional Comments from Auditors

Auditor's details:

Name / Job Title

……………………………./ ……………..………………………

Signature (Date)

………………………………………………………….(_ _ / _ _ / _ _ _ _)

Action Plan:

Appendix 5

**Irish Childhood Bereavement Network (ICBN) 'Standards for Supporting
Bereaved Children & Young People – A Framework for Development' 2017.
Appendix C: Self-assessment tool for bereavement services**

	Criteria met
Supports and services have clear, accurate and up to date written information outlining the range of their services and which identifies the level of specific need it can meet.	
A clearly documented model of care.	
All services providing support to bereaved children should have knowledge of contemporary understanding of children's grief and appropriate interventions.	
Services provide information on children's bereavement through leaflets, useful links, websites, information on further reading materials.	
Accessibility of all service levels to all children and families who have experienced bereavement.	
Clearly identified referral pathways at all levels of service provision.	
Use of written consent of parents or guardians for children to access services, and verbal assent from the child who is availing of support.	
Transparent assessment is required to ensure that the service being offered to the child is the most appropriate at that time.	
An assessment procedure that ensures that the child's bereavement needs can be met by the organisation.	
A governance structure that clarifies ongoing referral pathway, if the organization find that the child's needs do not fit with the service being provided.	
Evaluation and feedback procedures and policies for all service stakeholders.	
Records are maintained in accordance with the Data Protection Act 1988 and the Data Protection (Amendment) Act 2003.	
Information obtained by the service pertaining to service users shall be kept confidential.	
A safe process of Recruitment, Selection and probationary period for service personnel.	
Adheres to the National Vetting Bureau (Children and Vulnerable Persons) Acts 2012 to 2016.	
Adheres to Children First Act 2015 and national Child Protection Guidelines.	
Training and support of all staff and volunteers to underpin the service level provided.	
Individuals involved in supporting bereaved children shall engage in regular professional supervision, Continuous Professional Development and self-care activities.	
Persons providing support services shall do so in an ethical manner, in accordance with the Code of Ethics pertaining to their particular profession.	
Agencies shall seek and create opportunities to work collaboratively with other organisations providing support to children and families who experience bereavement	
Organisations shall ensure that all necessary governance procedures are in place to guarantee a transparent service which is run to the highest standards (as set out in 'Your guide to the governance code for community, voluntary and charitable organisations, published by the Department of Education and Skills).	

> # BEREAVEMENT SUPPORT
> # CONFIDENTIAL WORKING AGREEMENT
> ### (*Refer to National Data Set Requirements on last 2 pages)

Name: _____

Address: _____ **Postcode:** _____

Telephone: (H) _____ **(W)** _____ **(M)** _____

Age*(DOB): _____ **Gender*:** **Male / Female /Other**

_____

Emergency Contact Person: _____

Telephone: _____

Address: _____

Name of deceased: _____

      Relationship*: _____

Place of death: _____ **Date:** _____

Diagnosis*: _____

Confidentiality explained   Yes ☐   No ☐

GP details:

_____

Permission to Contact GP if necessary   Yes ☐   No ☐

Other Professional Support Received. Please Specify:

_____
_____

Initial Assessment:

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Key Issues:

_____

_____

_____

_____

_____

Action Plan:

_____

_____

_____

_____

_____

_____

_____

_____

Contact Arrangements:

_____

_____

_____

Any other issues:

_____

_____

_____

Signature: (Service user) _____

Signature: (Staff member) _____ (Designation) _____

Date: _____

Summary of contact

Session 1:   Date: _____   Duration: _____

Mode of Contact: Telephone contact ☐

Face to Face: Individual ☐ Family ☐ Group ☐ Office ☐ Hospice ☐ Home visit ☐

Session 2:   Date: _____   Duration: _____

Mode of Contact: Telephone contact ☐

Face to Face: Individual ☐ Family ☐ Group ☐ Office ☐ Hospice ☐ Home visit ☐

Session 3: Date: _____ Duration: _____

Mode of Contact: Telephone contact ☐

Face to Face: Individual ☐ Family ☐ Group ☐ Office ☐ Hospice ☐ Home visit ☐

Session 4: Date: _____ Duration: _____

Mode of Contact: Telephone contact ☐

Face to Face: Individual ☐ Family ☐ Group ☐ Office ☐ Hospice ☐ Home visit ☐

Review: Date: _____   Duration: _____

Mode of Contact: Telephone contact ☐

Face to Face: Individual ☐ Family ☐ Group ☐ Office ☐ Hospice ☐ Home visit ☐

Further Sessions Agreed:

Referral to other agency:

Signature: (Service user)_____

Signature: (Staff member)_____
Designation*:_____

Date: _____

Date of final session: _____

Length of support*: _____

Evaluation form issued: Yes   /   No

Date: _____

Evaluation form returned: Yes   /   No   /   Not Known

Additional contacts
Session: Date: _____   Duration: _____

Mode of Contact: Telephone contact ☐

Face to Face: Individual ☐ Family ☐ Group ☐ Office ☐ Hospice ☐ Home visit ☐

Session: Date: _____   Duration: _____

Mode of Contact: Telephone contact ☐

Face to Face: Individual ☐ Family ☐ Group ☐ Office ☐ Hospice ☐ Home visit ☐

Minimum Data Set Requirements

Gender   -   Male
                -     Female
                -     Other   *use standard HSE descriptor*

Service user analysis – Age

    0-17   From birth up to and including 17 years and 364 days old (Child)*

    18+   From day of 18th birthday onwards (Adult)

*indicates a person under the age of 18 years. A 'child' is defined under the Child Care Act 1991 as anyone under the age of 18 years who is not married. In rare situations, a person aged 16 or 17 who is married may present, but for the purposed of this metric, they are counted by their age.

Number of contacts
No. of individual (new):
No. of individual (ongoing):
Family group contacts

Contact Type
Post Death Visit Post death Phone call Therapeutic telephone call
Trained bereavement volunteer support
Professional Support (face to face)
Psycho educational group Therapeutic Group

Designation of staff member (Record the professional group of the member of staff or volunteer providing the bereavement support)
Contact Person
Staff member
Volunteer

1. **Wait times:**
   a) Time from **point of referral** (day 1) to **point of assessment** of bereavement need by a professional. The initial assessment may be face to face or by therapeutic phone call.
      i) No. of referrals who received an assessment by a bereavement professional **within 10 working days**
      ii) No. of referrals who waited for an assessment by a bereavement professional **over 10 working days**

   b) Time from **point of assessment** (i.e.: identified need) to **service delivery** – which could be volunteer appointment; professional appointment; discharge from service or formal referral to GP/a mental health service or to another service.

i) No. of referrals with assessed bereavement need who received a bereavement service by a bereavement professional **within 10 working days**
ii) No. of referrals with assessed bereavement need who waited for a bereavement service **over 10 working days**

2. **Discharges:**

   Planned: Where there is an agreed plan for the service to finish. Often a collaborative decision between the service and the client. Can include, for example appropriate ending of sessions; recommendation or advice about another service etc.

   Unplanned: Abrupt ending, for example client DNA's appointments, doesn't respond to messages/contact

   Formal referral to GP/a mental health service: Where a professional in the service makes formal contact and referral to GP and/or a mental health service.