Submission to the Oireachtas Committee on Health and Children - Public hearing on End-of-Life Care

Bereavement Care

Briefing Document

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Summary

People's experience of loss is diverse; bereavement is not a singular issue. Approximately 290,000 people are bereaved each year.

Bereavement itself is a risk to health. There are documented mortality links to bereavement, highest in the early period but maintaining over time; and highest for subgroups including widowers and bereaved parents. Physical and psychological illnesses are more common in bereaved than non-bereaved people, and these are accompanied by increased use of health service — including hospitalisations.

A 'public health' approach to bereavement and loss focuses on education and helping to develop an understanding of loss at community and public level. This increases the chances of people being supported, and feeling supported, through loss. It acknowledges people's strength and seeks to promote and preserve their capacity to cope with loss.

A public health approach anticipates and sets out to avoid problems people may face in coping with bereavement. It looks to develop cross-sector policy frameworks to maintain such health promoting practices. The model focuses on what bereaved people need (information about 'normal' grief and coping; practical help, understanding and natural social supports) and seeks to minimize additional stressors (financial hardship and isolation).

We need to identify those who may be at heightened risk, whose coping resources are limited – for example, people who are isolated/alone; who have additional challenges in their bereavement such as financial hardship, other caring responsibilities, other personal or interpersonal difficulties. At times the circumstances of a death may merit extra support for those who are bereaved.

Interagency approaches are a vital part of a public health approach and the Irish Hospice Foundation contends that a national strategy which focuses on end of life and bereavement must address the issue of coordination and liaison between those agencies working only occasionally with loss and bereavement and those dealing day to day with supporting bereaved people.

We believe there are individual and soci-economic costs associated with bereavement. There is little policy guidance on education, service development, funding and standards for bereavement care in Ireland. A common purpose and vision, shared language, agreed practices and training approaches would be a welcome addition to the landscape of bereavement care.

We believe there should be strategically-driven training initiatives in end of life and bereavement care – e.g. address undergraduate education gaps around

bereavement and loss, not only for our health professionals but for teachers, educators, solicitors and others

There are 'levels' of bereavement care- general care, volunteer based support and professional or psychotherapeutic services.

'Level one' bereavement care includes good end of life care. It also requires practical and emotional support.

'Level two' is 'extra supprot' a service usually delivered by trained volunteers who have themselves been bereaved.

'Level three' is professional and therapeutic supprot required by only a minority of bereaved people.

We promote a tiered approach to bereavement care ensuring generic care for all and specialist care for those in need. We believe a National Strategy on End of Life and Bereavement Care could harness the good work being done by many and varied voluntary organisations providing bereavement care; allow for innovative best practice to be nurtured, documented and shared with others involved in bereavement care; - provide clear direction on how voluntary organisations providing Level 2 bereavement care interact with providers at Levels 1 and 3.

Introduction

The Irish Hospice Foundation (IHF) welcomes the opportunity to draw attention to the situation for people bereaved in Ireland. The paper will:

- set out some of the facts about bereavement;
- propose that bereavement can be viewed as a public health issue;
- provide a review of bereavement related policy and services, and
- make recommendations for development of service at three levels from general public approaches, through to voluntary services and specific therapeutic approaches.

Irish Hospice Foundation and the Bereavement Education Resource Centre

A specific part of our work at the Irish Hospice Foundation is to build on the hospice philosophy of care which includes care for bereaved family and those important to the patient. We do this through hosting a Bereavement and Education Resource Centre which has a number of streams – information and education about bereavement; development of service and research.

Bereavement and grief are common denominators in the human experience and the vision of the IHF Bereavement and Education Resource Centre (BERC) is that people experiencing loss and bereavement are met with informed compassion, and with appropriate care regardless of the circumstances of the loss.

Part of our work in the Bereavement Education and Resource Centre is to provide a comprehensive range of training and education on bereavement and loss. We work with professionals and volunteers from all sectors of society – hospitals and health sector, but also with school teachers, work organizations in the public and private sectors, voluntary bereavement groups for adults and children.

Our training and education includes web-based e-learning such as 'Lost for Words, Words for Loss' and 'Living with Loss' which were developed through a network of voluntary bereavement organizations – including Rainbows, Bethany, Bereavement Counselling Service, Barnardos, Anam Cara and some of the major suicide bereavement organizations including Console, Living Links and Turas Le Cheile.

We work in acute hospitals and in residential care settings. We run an annual workshop programme where topics such as bereavement through suicide, loss for people with intellectual disability, and loss in the family amongst others are

addressed. Finally, we run postgraduate courses in children and loss and in bereavement studies with our partner – the Royal College of Surgeons in Ireland.

As a national organization we play a significant role in supporting and developing the information, support and service options for bereaved people in Ireland. We have a comprehensive Information and resource service, which includes the production and distribution of bereavement information for the public; a public lending library and a professionals' library service linked to our specialist collection. Two special projects – 'Stories of Loss and Hope' and the Bereavement pin have been distributed to tens of thousands of bereaved people across the whole country of Ireland. We host the website www.bereaved.ie

A third aspect of our brief, to develop and model evidence-based bereavement services, has seen the initiation of our programme for complicated grief — a specialist psychological treatment therapy for the smaller proportion of people (between 2 and 5%) who develop serious complications in their grief. New ways of introducing group-based supports have also been piloted and rolled out.

Finally, we maintain our standards through work with international groups (e.g. with our partner in Marymount Hospice, we co-chair the European Association for Palliative Care Bereavement Taskforce). Our work on complicated grief described above, is condcuted with the support of Columbia University. We review and monitor research and hold a vision that the right supports should be available for all at any time in their bereavement.

We believe this variety of work has given us a bird's eye view on bereavement and loss in Ireland. It helps us to identify some of the strengths that characterize our society, but also some of the challenges - social, economic and structural - that need to be addressed if we are to approach our vision.

We will talk about these issues in this submission and make suggestions for how they need to be addressed.

Background facts on bereavement

- 29,000 people die each year each person is surrounded by others who love and care for them. We can estimate that 290,000 people are newly bereaved each year.
- People's experience of loss is diverse; bereavement is not a singular issue.
- These statistics do not take into account 'hidden' losses for example, the loss encountered in miscarriage; the long subjective experience of loss through dementia.
- People die in a range of circumstances expected and sudden, in early and in older-age, through chronic illness, accident and suicide.
- Over 80% of all deaths in 2012 were of people aged 65 years and over leaving older widows, adult children, grandchildren and communities of friends.
- There are also about 350 child deaths from life-limiting conditions each year and a further 140 from other causes.
- In 2010, the CSO recorded 486 deaths by suicide.
- People die in a range of heath settings primarily hospitals and institutions and some (about 1 in 4) at home.
- Bereavement happens in the family context almost one third of nine-yearolds in Ireland have been bereaved of a grandparent and two out of one hundred nine year olds have lost a parent. By the age of 18, up to 7% of children may be bereaved of a parent.
- In Ireland in 2011, a total of 191,059 people were widowed 5.3% of the population.
- The chances of being widowed increase with age almost a certainty for some older women such that "by age 76, women were more likely to be widowed than married whereas for men, married remained the most likely status right up to age 89"
- Bereavement itself is a risk to health. There are documented mortality links to bereavement, highest in the early period but maintaining over time; and highest for subgroups including widowers and bereaved parents.
- Physical and psychological illnesses are more common in bereaved than nonbereaved people, and these are accompanied by increased use of health service – including hospitalisations.
- In our 2011 survey, almost half of bereaved people were surprised by their grief reactions, including by the intensity. (Amarach/IHF, 2011)
- One in five or 20% of people felt they did not get the support they needed during their most recent bereavement. (Amarach/IHF, 2011)

- 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.
- For a small percentage of bereaved people, grief becomes a serious health concern up to 5% of people.

A Caring Society - Public Health approaches to bereavement care

While there are many great voluntary organisations providing bereavement care alongside statutory agencies, there are also large gaps in terms of the availability and distribution of services (Petrus, 2008). However, our submission is not solely about shoring up bereavement support services and bereavement counselling services.

Bereavement care should be embedded into the fabric of a caring society. A 'public health' approach to bereavement and loss focuses on education and helping to develop an understanding of loss at community and public level. This increases the chances of people being supported, and feeling supported, through loss. It acknowledges people's strength and seeks to promote and preserve their capacity to cope with loss.

A public health approach anticipates and sets out to avoid problems people may face in coping with bereavement. It looks to develop cross-sector policy frameworks to maintain such health promoting practices. In bereavement and loss, for example, we focus on what bereaved people need (information about 'normal' grief and coping; practical help, understanding and natural social supports) and we seek to minimize additional stressors (financial hardship and isolation).

Research communities have only recently turned their attention to the economic impact of bereavement; we see the costs associated to include funeral expenses; living, medical and therapeutic expenses; and also loss of benefit and household income. Australian researchers noted that lost employment and an increase in medical practitioner and psychological support expenses characterized the experiences of families bereaved of a child. In the UK, widows are shown to be financially disadvantaged relative to pre-death levels of financial functioning and that it takes up to 18months to equalize. (Corden and Hirst, 2013). More than that, the subjective experience of financial hardship is empirically linked by these researchers to psychological distress and poorer quality of life for bereaved people. This is an important point focusing on the *meaning* of money – the security and psychological value for people as much as its fiscal worth. Older carers are deemed to be particularly disadvantaged following bereavement.

It is from this perspective that IHF was disappointed to see the bereavement grant abolished in Budget 2013.

Bereavement is known to have both health (morbidity) and mortality consequences. There is an established risk of mortality associated with bereavement; a range of causes are implicated – suicide, accident and natural causes. The risks are heightened in the immediate aftermath but remain over time. Bereaved parents and widows are identified as specifically at risk. (Boyle et al 2011; Harper et al 2011)

There are physical and emotional health consequences recorded for bereaved people which include self-reported ill health, physical ailments, increased self-medication and use of health services. (Stroebe et al, 2007)

A public health approach identifies those who may be at heightened risk, whose coping resources are limited – for example, people who are isolated/alone; who have additional challenges in their bereavement such as financial hardship, other caring responsibilities, other personal or interpersonal difficulties. At times the circumstances of a death may merit extra support for those who are bereaved.

Such supports (considered in the next section) will vary depending on need – volunteer and listening-based services for some and professional therapeutic services for much a smaller percentage (5 or possible 10%).

A public health approach is consistent with building relationships and developing the capacity of local communities. The Irish Hospice Foundation, with the HSE, piloted and co-funded 'Bereavement Care Liaison Officers' (in the South East during 2003-2005) and in the Midlands (2008-2010). Working across health, voluntary and education sectors these posts sought to clarify pathways. The Officer provided and disseminated information, signposted to training and appropriate services and provided a forum for voluntary and statutory services to share practices and develop common appreciation of standards of care.

Console, one of the national suicide bereavement charities has recently initiated support and liaison posts in HSE West. Provision of information direct to families makes up part of the role but so too, importantly, does the development of strategic approaches and collaboration amongst local agencies.

The Irish Hospice Foundation financially supports (together with the Family Support Agency), and is the host organisation for the Irish Childhood Bereavement Network. Our belief, and the belief of those agencies which make up the network is that by sharing and developing good practice, including training and resource, the care of children and their parents will be improved across Ireland. The ICBN works to a principle of equity – that each child should have the same opportunity for support regardless of where they live.

These interagency approaches are a vital part of a public health approach and the Irish Hospice Foundation contends that a national strategy which focuses on end of life and bereavement must address the issue of coordination and liaison between those agencies working only occasionally with loss and bereavement and those dealing day to day with supporting bereaved people.

The education and support of all front-line professions - not only the health professions but also those working in education and schools, in emergency services, in HR and employee assistance and those in community development - is a second strand of a public health approach. Education about loss should be an explicit topic in the undergraduate training of those who will work with people and families as they face death, dying and loss.

Some work has started with a recent initiative for health professionals, the Palliative Care Competence framework (for ALL health professionals including doctors, nurses, social workers, health care assistants and others) endorsed by the Department of Health and due to be launched shortly. This competence framework includes a dimension 'bereavement and loss' setting out the attributes, knowledge and skill that entry-level professionals should demonstrate.

ACTIONS

Support interagency working through a national strategy focusing on end of life and including bereavement care.

Implement the Palliative Care Competence framework for all health professionals – this framework includes a dimension on bereavement and loss and any resultant training and education recommendations.

Support the development of communities and natural networks to meet the needs of bereaved people.

Bereavement-related policy and strategy

Our policy resources in Ireland are poor when it comes to bereavement and loss – what we have by way of mandate or direction is rooted in specialised areas (e.g. Report of the National Advisory Committee on Palliative Care, 2001) or in response to crisis (e.g. both the Madden, 2006, and the Willis, 2009, reports call for mandatory training of hospitals staff who deal in particular with post-mortem examinations). The primary care strategy shifts responsibility to the poorly-

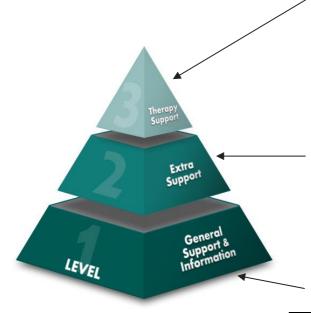
resourced mental health sector while 'A Vision for Change' focuses again primarily on crisis - the case of suicide.

On the positive side, the National Office for Suicide Prevention commissioned a general bereavement service review published in 2008 and this report is the nearest we have to a map which could direct information, training and service provision in a comprehensive way in Ireland. The review document (informally known as the Petrus Report) describes an ascending level of support for bereaved people and distinguishes between various levels of intervention ranging from the provision of information and support to psychotherapy services. This is an evidence-based approach rooted in National Institute for Clinical Excellence guidance in the UK and is also one adopted by the Irish Hospice Foundation in our bereavement work. This layered approach is also consistent with a population or public health approach. The figure below summarizes the approach. The Petrus report's final conclusion calls for investment in core generic support:

'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.'

People who are bereaved can need different types of support. These can be divided in to three levels as in the National Institute for Clinical Excellence (2004)¹ Guidelines.

What types of bereavement support do people need?



Level 3 Therapy Support is

specialised support provided by professionals (psychologists, psychotherapists, counsellors and doctors) and is appropriate for people who develop complications or become stuck in their grieving process (up to 5% of people may develop a grief disorder)

Level 2 Extra Support is a service usually delivered by trained volunteers who have themselves been bereaved. It may also be provided through a hospital or hospice.

(Approximately 25% of people who are bereaved may require Level 2 support)

Level 1 General Support applies to the majority of people who are grieving and involves providing information on the grieving process, practical help with tasks and social support. Family, friends and colleagues will provide much of this support. (Every bereaved person requires Level 1 support)

Our neighbors in Scotland have adopted a bereavement framework 'Shaping Bereavement Care – a framework for action' which is now being implemented through the Scottish NHS. It details training, intervention and structural frameworks based on ascending level of need; responsibilities are mandated across the heath board areas and specific recommendations are made in the following areas:

- Leadership and co-ordination (including linkage to the community, to funeral direction to voluntary support agencies)
- Policies, procedures and information
- Awareness, training and education
- Staff support structures
- Implementation and support.

This type of framework is evidence-based and maximizes benefit for those cared for through the health system and for the staff employed there. At the Irish Hospice Foundation we believe policy must *not* be restricted to the health sector – we call for a strategy which incorporates a wide view perspective. Education, Finance, Social Protection, Environment and Local Government, Transport all have roles in developing a compassionate society.

Finally there is benefit in promoting evidence-based policy making through supporting research, including longitudinal research on the 'natural' course of grief, and on important determinants of coping. National studies such as The Irish Longitudinal Study on Ageing (TILDA) and Growing up in Ireland are well placed to begin this process.

We believe that a strategic approach to be eavement and loss will foster a comprehensive approach to building strength, promoting care and understanding and supporting services responsive to be reaved people's need, including for the smaller number who need professional therapeutic support.

ACTIONS

Adopt an end of life and bereavement strategy which goes beyond health issues and which takes on a community development and public health approach.

Promote a tiered approach to be reavement care ensuring generic care for all and specialist care for those in need.

Promote research to trace the course of bereavement, determinants of coping and effectiveness of interventions.

Bereavement service in Ireland

Specialist and therapeutic bereavement support is varied – e.g. in Ireland, there is no such occupation as 'bereavement counsellor'; while individual counsellors may be listed as having a special interest in bereavement and loss, this is not necessarily underpinned by additional training.

Hospitals, primary care teams and community mental health teams provide varied inputs into the care of bereaved people. Anecdotally, the approaches are inconsistent, ranging from comprehensive (e.g. Beaumont Hospital, Dublin) to sparse, due to lack of resource, staffing and training. The 2009 Willis report on organ retention draws the same conclusion. Specialist services such as maternity services also vary in the bereavement care they can provide (Mulvihill and Walsh 2013). A national network of maternity hospitals has recently convened to share good practice.

There are a large number of voluntary and state-supported organizations providing bereavement support in a voluntary capacity in Ireland. These groups are dispersed through our communities. The 2008 Petrus report identified 277 organizations to survey; the FSA sponsors 107 family resource centres, and further grant funds organizations to provide bereavement support or counselling. While many have individual and explicit codes of practices, there is no national agreed statement of what should be expected from a bereavement service. The Petrus review identified a variable range and standard of printed information and also of training input across the sector. It also made recommendations for the training, support and supervision of staff working in bereavement.

A common purpose and vision, shared language, agreed practices and training approaches would be a welcome addition to the landscape of bereavement care. To some extent this common purpose has been mapped out in the 2007/8 review of bereavement services commissioned by the National Office for Suicide Prevention (NOSP) and published in the Petrus report. In a later development, the NOSP with Console and Turas le Cheile developed a *National Quality Standards for the Provision of Suicide Bereavement Services*.

The development of networks and cooperatives which foster common goals, support advocacy and allow for the pooling of resources could represent an important benefit for the development of bereavement care in Ireland.

It is our belief that clear bereavement-related national policy and strategy could provide a clarity and support for organizations working in this area.

ACTION

Promote clarity in the provision of bereavement care by private, statutory and voluntary agencies through development of a national framework.

For the remainder of this submission we will discuss bereavement care relative to gaps and required developments in each of the evidence-based levels of care identified in the pyramid above.

Bereavement Care at Level One

The most basic and immediate needs of bereaved people are for comfort, information and practical help. The foundations of good bereavement care are firmly rooted in family, community, society and well-trained, empathic professionals.

Good bereavement care begins with good end of life care

We believe that good bereavement care begins with good end of life care. This implicates all of those who can make a difference to the care of a patient towards the end of his or her life. At a recent conference a bereaved partner stated simply 'Because my partner died well, I can live well, and my children can live well'.

Evidence tells us that open communication; preparing families for death – both emotionally and practically; and providing social support before as well as after a death all help in preventing complications. While a complex range of personal and social factors put people at risk of what psychology professionals describe as 'complicated grief', some risk factors are connected with the care and circumstances of the death. These include:

- Poor relationships with medical providers (feeling abandoned, lack of trust due to negative past experience, fear of discrimination)
- Circumstances of the illness/death (recent diagnosis with short prognosis, sudden and unexpected death despite diagnosis, perception that more could have been done).

The IHF endorses and supports the work of the Hospice and Palliative Care Social Workers as a key network of bereavement care providers in palliative care. These professionals, together with volunteers, build relationships with families from point of contact with the service. Their work involves integrated care - practical help, communicating, accompanying and the ability to provide appropriate follow-up information and resource to those in need.

The majority of people in Ireland (about three out of four) die in acute hospital settings or residential care settings; consequently the care provided here should also be viewed as family and bereavement care.

Initiatives seeking to incorporate palliative care principles and shape the culture of end of life care in all settings should be supported.

Training, education and staff support which acknowledges and values the impact that **all** staff can make through good communication, signposting and empathy is a high priority. A comprehensive approach to education will include not only undergraduate education, but the preservation of staff release for continuing education of staff in hospitals and other settings.

Practical support and information

Information is a key resource to bereaved people. It includes resources on entitlements available through Citizens Information Centres, the Department of Social Protection and others, but extends to information about the impact of bereavement – its emotional, physical and other consequences; as well as material containing resources for coping. Above all, information for bereaved people should be:

- Accessible
- Age appropriate and addressing a range of literacy levels
- Varied (i.e. not always in written form)
- Accurate and evidence-based.

In the 2008 national review of bereavement services (Petrus, 2008) the range and quality of information available to be eaved people was of variable quality.

Bereavement is a stressful time in a person's life and at a vulnerable time protection is an appropriate societal response. An important element of practical support is to protect bereaved people from financial hardship which may be associated with bereavement (Neimeyer and Burke, 2012). There are not only individual costs but economic and societal costs associated with bereavement, for example through lost work days, potential productivity impact, cost to the health service – more research on this is required.

Bereavement is a normal life event; we promote resilience and natural coping by focusing on schools, workplaces and every-day environments. The Irish Hospice Foundation has developed a comprehensive 'Grief at Work' programme. To be compassionate, work organisations need to be informed and equipped from both

practical and legislative perspectives. We believe equitable support for bereaved workers should be upheld through two mechanisms

- A workplace bereavement policy outlining support, training and responses for grief at work
- A minimum leave entitlement following bereavement.

The health sector in Ireland is a major employer, and we call on the Oireachtas Joint Committee to support grief at work initiatives as part of a broader approach to building compassionate communities.

ACTIONS

Promote end of life care initiatives across health settings acknowledging bereavement care begins with end of life care.

Implement the upcoming palliative care competence framework which describes how entry level nurses, doctors, social workers, health care assistants and others should possess an understanding of how loss and bereavement impact on patients, on families and on staff.

Ensure staff release is facilitated for continuing professional development and access to training in communication, end of life and bereavement care.

Support strategically-driven training initiatives in end of life and bereavement care – e.g. address undergraduate education gaps around bereavement and loss, not only for our health professionals but for teachers, educators, solicitors and others.

Ensure quality information and resource provision is incorporated into a national strategic approach for bereavement and loss.

Support grief at work initiatives in the health service.

Bereavement Care at Level Two

The Petrus report (2008) highlighted the key role played by voluntary and community organizations in providing Level 2 bereavement care. Many of these have been set up to address particular bereavement needs (e.g. loss through cancer, death of a child, suicide, etc.).

They are staffed in the main by trained volunteers who themselves have had some experience of the loss involved. They provide vital bereavement care services in the community which otherwise would not exist and could be an important part of an overall bereavement care strategy. However, they are limited in the services that they can provide, and cannot meet all of the bereavement care needs that they are

presented with. The Petrus report identified over 90 voluntary community support or self-help groups providing bereavement care.

The very existence of these organizations is evidence of how individuals and groups can mobilise and respond to situations of need in their communities. In some cases, the necessity of the bereavement situation has given rise to innovative responses and developments in practice (e.g. family days for widows (Widow.ie), online support forums for parents whose child has died (Anam Cara)).

While recognizing the work being done by these voluntary groups, the Petrus report also highlighted that many are not linked together and further, that there is a need for standardised training for those providing bereavement care.

In response to this identified need in 2008, a number of voluntary organisations (Irish Hospice Foundation, Console, Rainbows, Barnardos, Anam Cara, Bereavement Counselling Service, Turas Le Cheile, Living Links, Hospices, Family Centre Castlebar) came together and developed core bereavement support training modules in E Learning formats (Irish Hospice Foundation E Learning) – with over 1,000 people trained to date. This collaborative initiative shows what is possible in terms of working together to share the wisdom, resources and best practice of the individual organisations. However, there is a need for this type of collaboration to sit within the larger context of bereavement care provision in Ireland.

Without a National End of Life Strategy incorporating bereavement care, there is a danger that such initiatives will simply become isolated pockets of practice, whose benefit will wither over time, due to an absence of an overall strategic approach.

One attempt to address this need for a strategic approach to be reavement care provision is the development of The National Quality Standards for the Provision of Suicide Bereavement Services (2012) which outline standards that are relevant for voluntary organisations providing bereavement care. These deal with key aspects such as ensuring:

- the person accessing the service is supported appropriately,
- that volunteers providing the service have adequate training and support
- that there are organisational policies and procedures in place.

While these standards are a welcome development, and provide a framework to which voluntary organisations can aspire to – there is no coherent plan for helping organisations to implement these standards or to address any difficulties or gaps that may exist between present practice and the ideal.

ACTION

Therefore the Irish Hospice Foundation is calling for a National Strategy on End of Life and Bereavement Care which could

- harness the good work being done by many and varied voluntary organisations providing bereavement care;
- allow for innovative best practice to be nurtured, documented and shared with others involved in bereavement care;
- provide clear direction on how voluntary organisations providing Level 2 bereavement care interact with providers at Levels 1 and 3;
- provide direction on the implementation of National Quality Standards in Bereavement Care, and
- provide direction for linking and coordinating various bereavement care providers at Levels 1, 2 and 3.

Bereavement support at Level Three and Complicated Grief

There is an established health, indeed mortality, effect in bereavement for widowed people (e.g. Boyle et al 2011) and for bereaved parents (Harper et al, 2011). Bereaved individuals have higher rates of disability and medication use than their non-bereaved counterparts and pose a heightened risk of death and suicidal ideation.

For a small percentage of bereaved people, grief becomes a serious health concern as their acute grief fails to integrate. This unremitting grief is distressing and debilitating, and many researchers in the area believe it meets criteria as a distinct mental disorder. The diagnostic manual used in psychiatry (the 'DSM-5') describes this as Persistent Complex Grief Disorder with a prevalence of 2.4%-4.8%.

In the Irish context, 29,000 people die every year. If we say, conservatively, that five people are impacted by each death, we estimate that between 3,500 to 7,000 people will develop symptoms of complicated grief each year.

These people may present at GPs' offices and voluntary bereavement support services but are often undiagnosed or misdiagnosed, leading to frustration for both service users and service providers when no improvement occurs.

New assessment instruments have been developed to diagnose complicated grief (Prigerson et al, 1996) and at least one evidence-based treatment protocol has been

developed to treat this condition (Shear et al, 2005). Rigorous research has indicated that an innovative treatment approach, incorporating aspects of trauma work and cognitive-behavioural therapy, shows improved outcome when compared to traditional psychotherapy, and that patients who have undergone this treatment report improved levels of mental health and general functioning.

As a health issue, it is important that the statutory service providers develop an understanding of complicated grief; how to recognise it, diagnose it and treat it. This treatment should be available to all service users, irrespective of where they live or their ability to pay. With limited resources, the already-overstretched volunteer sector is not equipped to meet the needs of this population; a more formal level of intervention is required.

The Irish Hospice Foundation has taken a lead in up-skilling both the statutory and the voluntary sector in complicated grief.

ACTION

These developments in diagnosing and treating complicated grief should be incorporated into primary care, mental health services, palliative care and the private and voluntary services who provide therapeutic care.

A national end of life and bereavement strategy should endorse pathways for bereaved people - from assessment to treatment

REFERENCES

Boelen, P., Van den Bout, J. (2008) 'Complicated grief and uncomplicated grief are distinguishable constructs' *Psychiatry Research* Vol. 157 (1) pp. 311–314

Boyle, P., Feng, Z. & Raab, G. (2011) 'Does widowhood increase mortality risk? Comparing different causes of spousal death to test for selection effects' *Epidemiology* Vol. 22 (1) pp. 1-5

Bradbeer, M., Helme, R., Yong, H., Kendig, H. & Gibson, S. (2003) 'Widowhood and other demographic associations of pain in independent older people' *The Clinical Journal of Pain* Vol. 19 (4) pp. 247–254

Central Statistics Office (2012) 'Census 2011, Profile 5; Households and families' Dublin : The Stationary Office

[Online] Available at

http://www.cso.ie/en/media/csoie/census/documents/census2011profile5/Profile%205%20 Households%20and%20Families%20full%20doc%20sig%20amended.pdf Accessed October 31 2013 Console, National Office for Suicide Prevention & Turas Le Cheile (2012) *National quality standards for the provision of suicide bereavement services*. Dublin: National Office for Suicide Prevention

[online] Available at http://www.nosp.ie/quality_standards.pdf
Accessed October 31 2013

Corden, A., & Hirst, M (2013) 'Economic components of grief' *Death Studies* Vol. 37 (8) pp. 725-749

Department of Health and Children (2001) *Report of the National Advisory Committee on Palliative Care*. Dublin: Department of Health and Children [Online] Available at http://www.lenus.ie/hse/bitstream/10147/42522/1/1890.pdf Accessed on 31 October 2013

Harper, M., O'Connor, R. & O'Carroll, R. (2011) 'Increased mortality in parents bereaved in the first year of their child's life' *BMJ Supportive and Palliative Care* Vol. 1 (3) pp. 306-309

Health Service Executive (HSE) *Retained organs audit and carter report 2009* [online] Available at;

http://www.hse.ie/eng/services/Publications/services/Hospitals/williscarter.html Accessed October 31 2013

Madden, Deirdre (2006) Report of Dr. Deirdre Madden on Post Mortem Practice and Procedures. Dublin: The Stationary Office [Online] Available at http://www.dohc.ie/publications/pdf/madden.pdf?direct=1 Accessed on October 31 2013

Mulvihill, A., & Walsh T (2013) 'Pregnancy loss in rural Ireland: an experience of disenfranchised grief' *British Journal of Social Work*May 3 2013 DOI: 10.1093/bjsw/bct078

National Institute for Clinical Excellence (NICE) (2004). *Services for families and carers. Improving supportive and palliative care for adults with cancer; The Manual.* London: National Institute for Clinical Excellence

[online] Available at http://www.nice.org.uk/nicemedia/live/10893/28816/28816.pdf
Accessed October 31 2013

Neimeyer, R., & Burke L (2012) 'Complicated grief and the end-of-life: risk factors and treatment considerations'. In: Werth, J (2012) *Counseling clients near the end of life*. New York: Springer

Petrus Consulting, Bates, U., Jordan, N., Malone, K., Monahan, 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. [online] Available at http://www.nosp.ie/review_of_bereavement_support_services-1.pdf Accessed on October 31 2013

Prigerson H., Bierhals A., Kasl S., Reynolds C., Shear M., Newsome, J & Jacobs, S (1996) 'Complicated grief as a disorder distinct from bereavement-related depression and anxiety a replication study.' *American Journal of Psychiatry* Vol. 153 (11) pp. 1484–1486

Prigerson H, Horowitz M, Jacobs S, Parkes C, Aslan M, Goodkin, K., Raphael, B., Marwit, S., Wortman, C., Neimeyer, R., Bonanno, G., Block, S., Kissane, D., Boelen, P., Maercker, A., Litz, B., Johnson, J., First, M., Maciejewski, P. (2009) 'Prolonged Grief Disorder: psychometric validation of criteria proposed for DSMV and ICD-11. *PLoS Medicine* Vol. 6 (8) [Online] Available at

http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000121 Accessed October 31 2013

Scottish Government Health Directories (2011) Shaping Bereavement Care; A framework for action for Bereavement Care in NHSScotland. Edinburgh: Scottish Government [Online] Available at http://www.sehd.scot.nhs.uk/mels/CEL2011 09.pdf
Accessed October 31 2013

Shahar D., Schultz, R, Shahar, A. & Wing, R. (2001) 'The effect of widowhood on weight change, dietary intake and eating behavior in the elderly population' *Journal of Aging and Health* Vol. 13 (2) pp. 189–199

Shear, M., Houck, F. & Reynolds, P. (2005) 'Treatment of complicated grief: a randomized controlled trial' *JAMA*; *Journal of the American Medical Association* Vol. 293 (21) pp. 2601–2659.

Stroebe, M., Schut, H. & Stroebe, W. (2007) 'Health outcomes of bereavement' *The Lancet* Vol. 370 (9603) pp. 1960–1973