Submission to the Oireachtas Committee on End of Life

As social workers working in hospices and palliative care teams around the country, we have been following, with interest, the presentations to, and deliberations of, the Oireachtas Committee on end of life. We welcome this initiative and commend those involved in spearheading this work. Many excellent speakers have explained the importance of a focus on **living** for those with a serious, life limiting illness; have outlined the potential benefits of a palliative care approach for people with a variety of conditions other than cancer; have argued for a national policy on end of life and bereavement care; and have stressed the value of palliative wherever the person is receiving that care.

As our population ages and treatments extend life span, more people will live longer but with greater levels of frailty. Regardless of place of death, the majority of people currently spend most of the period of illness in the community, usually in their own home, cared for by relatives. This time is the focus of our submission.

- Some years ago, following representations, the minister for health granted a six month *emergency* medical card to persons receiving palliative care and who are coming to end of life. This one intervention has had an extremely positive effect on the experience of those coming to the end of their lives. It has given them access to free G.P. care, medications that were required to optimise their comfort, equipment to make care at home possible and access to the services of members of the wider primary care team such as the public health nurse, occupational therapist, home help and others. It is an essential support in practical and financial terms. Currently, many palliative patients get an emergency medical card for six months with an excellent 'turn around' time on application by staff of the HSE who are to be commended for their prompt response. However, for the small number of patients who live longer than 6 months, the process of renewing this card is much less responsive of, and less sensitive to their needs. They are often renewing the medical card at a time when they are much less well. In order to extend their card, and retain the basic and necessary services needed for them to die at home, a full means test must now take place, which requires an extraordinary level of detail and paperwork, at a time when a patient may be in their final days or weeks of life.
- Other patients of the palliative care services who are unwell but with a longer prognosis can apply for a *discretionary* medical card. These patients complete application forms, submitting financial details and medical information to support the application. Anecdotal evidence suggests that this process often has to be revisited before an application is fully completed in a way that is accepted. Further training may be required for HSE staff assessing such applications as they may not understand the range of issues-social, medical and financial that these families face. The financial burden of a cancer diagnosis has been well documented by the Irish Cancer Society. This has been exacerbated by the current economic downturn, with many families struggling with reduced income, greater levels of household expenditure because of illness and a high debt burden.
- For many of those who require care at home, additional nursing support to supplement the efforts of the family, appears to be available only on an ad hoc basis with considerable inequities between areas. Many of our elderly patients are being cared for by spouses who are elderly and frail themselves. A **priority needs assessment** should be a core part of services in the community for those at end of life. Few families now have the financial resources to supplement care at home.

- For some patients, particularly older patients, care at home may not be possible during the last months of life. They may not need a specialist palliative care bed but need nursing care. In some parts of the country, the provision of intermediate level palliative care beds in long term care facilities for a small patient group has been enabled and supported by the HSE. Patients can be admitted to these beds from the acute hospital, the community or from the specialist in-patient unit. However, this initiative is only available in some areas. In other areas, access to a bed through the Nursing Home Support Scheme is the only care option. This scheme is currently oversubscribed and a waiting list system is not practical for people with a limited prognosis.
- Caring can be a prolonged experience for some families and the financial implications can be considerable. Access to such financial supports as the Carers' Allowance can be difficult as there is no system of prioritisation for applicants in the palliative situation, with many instances of the allowance being granted after the death of the patient. It would be of considerable benefit if the Department of Social Protection could make a 'fast track' application process available to this group of applicants, similar to the approach being taken by the HSE for medical cards.

These areas – access to a medical card; provision of 'hands on' nursing care in the community on a prioritisation basis; and a more responsive application process for financial support for caring, would greatly improve the experience of patients and families . There is also a need for access to nursing care in long term care facilities.

Finally, the presentations made by palliative care colleagues suggest that care be provided wherever the patient is- a 'money should follow the patient' approach. We have emphasised the importance of supporting patients and carers during illness. After the death of the patient, some families will need ongoing support in bereavement for a period of time. The research evidence suggests that we need to continue to support parents and children, and some spouses before and after death. It is important that government continue to support initiatives in hospitals, hospices and in communities that provide information, advice and, in a small number of cases, therapeutic interventions with the bereaved. There is growing evidence that when carers are well supported practically, emotionally and financially before and after death, they have a less complicated course in bereavement. In this way, palliative care is not just life affirming, as our colleagues have suggested to you, but also health promoting.

End of Life care in Ireland Submission 18th November 2013.

Back ground

I'm a member of the public who has recently cared for a loving brother who died on 28th March this year (2013) from Motor Neuron disease at the age of 54 years. The end of his life came sudden having suffered the illness for 3 years. Of the 3 years he was in hospital for 17 days, just one week before he passed away. Seventeen days of hell for him and his family as we looked on at him struggle to get basic care. At home we had routine, lots of hands on care and the comforts of a nice home. He went into hospital fairly well to get a feeding peg inserted just in case one day he could not eat. This should not have taken any more than a couple of days in hospital. He came out 17 days later almost dead, sad and broken hearted. I, as his carer was tired and worn down having been saddened by the poor prognoses I was given and indeed with lack of information as to my brother's true state of health.

Discussion.

I am of the opinion that hospitals are the worst places for terminally ill people. The best place is at home with family members with the help of care teams such as the hospice and public health teams. For over a year my brother got the finest of care in and around his home. He attended day services at a local care centre if he felt up to it and had the support of many health professionals and friends to cared for him with great dignity and understanding.

At home my brother could live to the full, have what he wanted and do more or less what he wished to do. He knew the illness was killing him but it did not stop him from wanting to live. It did not stop him from planning for the future or even dreaming about his life ahead. He loved his family around him, his technology, his view out the window, his quiet surroundings as well as his many visitors who crowded his house many evenings and of course his choice of food. All this was taken from him in hospital. The view was a stone wall, the food was bland and he was not able to entertain visitors. He has no aids that could assist him like he had at home (which were supplied by the central remedial clinic). All he had was a bell that was rarely answered. For the last year of life he had no mobility himself other than the use of on finger where he had a bell strapped onto so that he could alert a need for care.

Little discussion about his end of life came from medical personnel to my brother or his family. We were ill prepared for the end. We were only directed to the hospice team in the last 2 weeks of his life. What a wonderful team with a great understanding for dying patients and their families. This was too late for my brother as he was so unwell at that stage he was not able to benefit from their huge skills. He did get great care from them as did his family.

In this submission I want to point out how important hospice care is and how care in the home is the best for those who wish to choose that way. Choosing this way should be on the discussion agenda with specialist consultants and teams in hospital. These teams seem to be tied up in treatment and training, forgetting all the work patients and relatives do to care for an ill person.

My brother was on a research trial in Beaumont hospital and took a drug for one year which he found out at the end was the real drug and not the placebo. He took part in the trial very diligently in the hope of a cure for motor neuron disease. While a lot of testing was done and I do hope it added to the body of knowledge on motor neuron disease there was a poor out come on the drug. The trial stopped and that was the end of it. My question is;- Why did this research not ask for an organ after my brother’s death? Surely this might be important to research seeing my brother’s illness was so typical of this illness. They knew that he was End of Life while he was in hospital.

Executive summary

This is a personal story about the end of a life of a loved one. The author has gone through the experience and she feels her opinions might be of value to the committee looking at this topic. The author has worked closely with all the carers and professional people during the care of her late brother as well as having many trips to out- patient clinics with him for treatment. It is her opinion that neither the patient nor the relative was prepared for the end of life.

A list of recommendations.

Hospice care is a very valuable care service. This team are the link people with other care teams on behalf of the patient and the family.

Care at home is best where family members can help.

Hospice care teams should be well resourced to be able to provide home care.

Help for relatives on both a practical and emotional level should be build into the package of care for a person who is diagnosed as "End of Life"

Organ and body donation for research should be part of End of Life care if the person and relatives are interested.

There is so much to think about regards End of Life which I fine hard to get on paper. I'm going through a grief process now which does not help when it comes to putting in a submission to a government department. I do hope my few words will help and I would be very happy to do an oral presentation at a later date.

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Submission to the Oireachtas Joint Committee on Health and Children November 2013
on
End of Life Issues
by
Huntington’s Disease Association of Ireland

Huntington’s Disease Association of Ireland (HDAI) welcomes the opportunity to comment on End of Life issues for people with Huntington’s Disease in Ireland.

In the Palliative Care for All document, palliative care has been described as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’. [1]

Introduction

HDAI is a national voluntary organisation providing information and support to those diagnosed with Huntington’s Disease (HD), those at risk, their families and their health and social care teams. HDAI is currently the only specialist support and information provider on Huntington’s Disease in Ireland.

HD is a genetic neurological disorder that causes brain cell degeneration leading to progressive deterioration of the physical, cognitive and emotional self. Each child of a person with HD has a 50/50 chance of inheriting or not inheriting HD. It is multifaceted and can cause a wide variety of symptoms:

- **Physical symptoms** can include involuntary movements, slurred speech, swallowing difficulties, choking, problems with balance and susceptibility to chest infections.
- **Cognitive symptoms** can include changes to organisation, regulation and perception skills. This can affect function including decision making, reasoning, initiative, emotional engagement, mental flexibility, judgment, impulse control, temper control and awareness.
- **Psychiatric changes** are varied with depression being the most common. Other symptoms can include changes in personality and mood such as irritability, anxiety, mania, apathy and disinhibition

The management of HD should involve a multidisciplinary approach which includes:

- Genetic Services
- Neuropsychology
- Neurology
- Neuropsychiatry / Community mental health services
- Speech and language therapy, Nutrition and dietetics, Occupational therapy, Physiotherapy
- Voluntary Organisations
- Social worker
- Specialist nurses
- Home care supports/ Day care / Respite care
- Appropriate Long term Care facilities
- Palliative care

The impact of HD goes beyond the immediate symptoms experienced by the person affected. HD impacts on the whole family: the person(s) living at risk (siblings and / or children), the carer and the symptomatic person.

"As HD progresses it can be associated with high rates of depression and mood changes and these are terribly disabling for many people. Sometimes these changes in emotion and thinking can result in people stopping work or education and falling out with their family. Due to the manner in which the brain changes occur, many people with the disease have little awareness of the severity of their symptoms. This can, of course, be protective for the person themselves but can cause great heartache for family and friends." Dr Niall Pender, Principal Clinical Neuropsychologist, Beaumont Hospital. [2]

Palliative Care Programme

The National Clinical Programme for Palliative Care aims to ensure "that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis." HD is a life limiting disease yet anecdotal evidence suggests that health care professionals do not raise end of life issues with the person with HD or their family unless acute hospital intervention is required. HDAI welcome a more inclusive and accessible palliative care service for all life-limiting conditions. End of life is difficult to diagnose in HD due to the lack of a predictable course and the possibility of sudden death due to choking, injuries from falls, pneumonia or suicide. It is critical that end of life issues are taken into consideration soon after diagnosis.

The four objectives of the programme are:

- Improved planning for palliative care services to ensure optimal resource utilisation.
- Strengthened specialist palliative care services to improve access and quality of care.
- Strengthened generalist palliative care services in order to strengthen access and quality of care.
- Improved partnerships in care to improve continuity and quality of care.

The UK End of Life Care Strategy [3] recognises the need for all health and social care staff to have the knowledge, skills and attitudes to deliver care at the end of life.

Neurological care has been identified by the World Health Organisation as the greatest challenge facing public health systems in developed countries. In Ireland lack of rehabilitation services and shortage of neurological and community support services mean that Irish people with life limiting neurological conditions are been denied the quality of care available in other European countries. The management of neurological conditions in primary care, community services, palliative care and mental health services needs significant improvement.

UK guidelines on the interface between neurology, rehabilitation and palliative care suggest "Neurology, rehabilitation and palliative care services should develop closely co-ordinated working links to support people with long term neurological conditions from diagnosis to death, including:

- Proper flow of communication and information for people and their families
- A designated point of contact for each stage in the pathway
- A needs assessment identifying the patient's individual problems." [4]

Palliative Care Needs for Huntington's Disease

The development of a standard care pathway is critical to the management of Huntington's Disease in order to identify the services and care required by HD patients from initial onset/diagnosis and rehabilitative treatment to end of life care. An integrated service depends on reliable communication between professionals involved ensuring that family carers are consulted and kept informed.

Diagnosis of a life limiting condition

As someone faces the diagnosis and progression of HD many emotional and psychological issues may come to the fore, including fear of the disease, death and implications for the family.Receiving a diagnosis of HD is devastating and can cause feelings of fear, anxiety, anger, sadness and guilt. People may have experienced the impact of HD on other family members and may be fearful of passing the disease to their children. For others it may be the first time HD is diagnosed in the family and the person may be overwhelmed by the myriad of possible symptoms and the genetic implications. Clinicians should be sensitive in delivering this life-limiting diagnosis. Basic principles to consider include:

- Invite the person to bring someone with them when getting test results
- Convey the diagnosis sensitively giving the person time and undivided attention
- Allow time for the information to sink in checking that the person understands what is being said
- Provide information on specific and general support
- Arrange a follow up appointment in the near future
- Discuss referrals to neuropsychology, rehabilitative therapies etc

Family carers require information on HD including tips to assist in managing behavioural, cognitive and physical changes. The person with HD and their family will experience multiple losses over the disease trajectory. Psychological support and counselling is frequently required by the spouse/partner who may have children at risk. Adult children at risk may be impatient to access predictive genetic testing. People who receive an unfavourable result may find it difficult to live a normal life as they await symptom onset. Gene carriers may be unwilling to be closely involved in their loved ones care due to a reluctance to being reminded of their own future.

Cognition Difficulties in HD

A clinical diagnosis of HD relies on motor abnormalities yet by the time of clinical diagnosis the brain's striatal volume is reduced by 50%. [5]

Cognitive symptoms in HD impact on a person's initiative , planning and decision making abilities therefore discussions on Advance care planning (ACP) should commence soon after diagnosis. People with HD should be facilitated and encouraged to consider decisions about their future. A neuropsychological assessment is necessary to determine the level of impairment. Early discussions on ACP, power of attorney and future legal and financial decisions can be difficult. Neuropsychological support is essential in supporting the person with the condition and their family members throughout the complex and prolonged course of their illness.

Behavioural and Emotional changes in HD

Psychiatric symptoms in HD can result in changes in personality and mood with depression being a common symptom. Increased prevalence of suicidal ideation and attempted suicide, of up to 20%, have been reported in HD gene carriers.[6]

Some people with HD will experience severe behavioural changes such as anxiety, mania, paranoia, apathy and disinhibition. Accurate information and training on understanding behaviour in HD will help to maintain the patient's independence for longer.

Physical changes in HD

The physical symptoms of HD can include involuntary movements, slurred speech, swallowing difficulties, choking, problems with balance and susceptibility to chest infections. "Quality of life is greatly dependent upon the ability to communicate and otherwise share with others. Likewise, the ability to feed safely and share meals with others impacts the physical and social well-being of an individual".[7]

Delays in accessing essential rehabilitative therapies will have a direct consequence on a person's length and quality of life. Many HD patients face long waiting lists in accessing essential rehabilitative therapies. Timely access to occupational therapists and physiotherapists can prevent unnecessary head injuries for HD patients with balance problems and involuntary movements. The lack of speech and language therapists and dieticians can have a significant impact on a patients swallowing difficulties and may result in malnutrition or pneumonia. Similarly the lack of accessible neuropsychiatric and neuropsychological services will have an impact on levels of suicidal ideation and the severity of mental health symptoms. The lack of appropriate services places an extra burden on carers and can also impact their physical and psychological health.

Impact on Family Carers

Cognitive difficulties and behavioural changes increase anxiety and stress for family carers who will experience continuous loss over the course of their loved ones illness. Information and support is critical for carers to maintain their own health and well-being. People with HD may live 15-20 years after diagnosis. Caring for a person with HD is physically, psychologically and emotionally challenging. Some HD family carers care for more than one person with HD. Typically carers maintain a central role even when a person with HD needs residential care. Appropriate facilities are difficult to access and this can cause added stress for all involved. Care facilities and healthcare teams should recognise the carer's knowledge of the condition and of their loved one's preferences. Family carers should be included and consulted at each stage of the person's care.

Communication

Sensitive communication is essential for people going through the traumatic impact of HD. For the person with the condition frequent repetition and clear information is necessary. Information on life-prolonging treatments such as feeding tubes and intravenous antibiotics should be discussed while the person is still cognitively capable of agreeing their preferences. Family members should be consulted and included in care plans. Preferences should be recorded and communicated to health care professionals. Referrals to rehabilitative therapists should commence without delay in order to maintain function and assist the person in dealing with the gradual loss of their abilities.

Bereavement Support

Family members should be offered counselling and bereavement support. Family members may feel sad at the loss of the person while feeling relieved that their suffering has ended. Carers may find it difficult to deal with the gap left in their life at the loss of their loved one and by the end of their caring role. Some carers may already be caring for other family members with HD.

Summary

The development of a standard care pathway is critical to the management of HD in order to identify the services and care required by people with HD from initial onset/diagnosis to rehabilitative treatment and on to end of life care.

Conveying a HD diagnosis requires sensitivity and support from the clinician involved. A Neuropsychological assessment following diagnosis is necessary to establish decision making capacity and facilitate advanced care plans and legal and financial decision making. Neuropsychological services are required for people with HD and their families throughout the disease trajectory.

Health and social care professionals working with people impacted by HD should be aware of the genetic impact of HD and the myriad of physical, cognitive and psychiatric symptoms in order to effectively assist in supporting the patient and family.

Combining palliative care with multi- disciplinary care throughout the course of HD will help the patient and family make a successful transition through increasing levels of disability while maintaining independence and dignity.

Care facilities and healthcare teams should recognise the carer's knowledge of the condition and of their loved one's preferences. Family carers should be included and consulted at each stage of the person's care.

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Joint Committee on Health and Children

Public Hearings on End of Life Care

Submission from Prof. Tom Inglis

1 November 2013

We are born as animals and we die as animals. In between we are enveloped in meaning. We are suspended in webs of meaning that have been spun over generations. The meanings of life and death are continually evolving. If the management and control of fertility was one of the major social concerns in the 20th century, this century may well be dominated by debates about the management and control of death. It may well be that the 'right to choose' debate will be extended to when, where and how to die.

Secularisation has become a fact of life in the West. The webs of meaning about death are no longer spun within institutional religious discourses. In Ireland, the Catholic Church has lost its monopoly not just over morality, but over the understanding of what happens when you die. Research findings suggest that the concept of God, of belief in heaven and hell, are becoming more nuanced and varied. In 2008-09,l I conducted an in-depth study of one hundred people across I Ireland: I found many Catholics who did not believe in life after death.

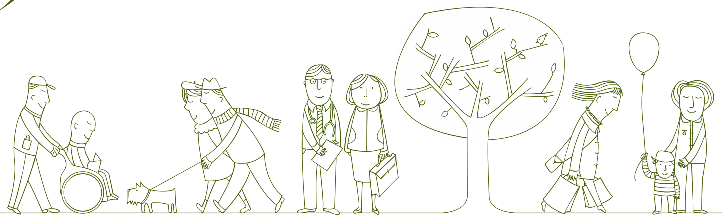
This poses a major problem for the end of life care, particularly when it takes place outside the family home, in an institutional setting. How are carers in institutions to talk and relate to the dying and their family and friends about death? When and how to medically intervene, often relates to people's concept of what happens when you die and what constitutes a good death. Leaving aside medical ethical issues, what are institutional carers to say and do to bring comfort and consolation at a time of major trauma? Saying something religious could be an act of symbolic domination. Saying nothing could be to reduce death to a scientific medical event. How can people die in love and care when they may not speak the same language about the meaning of life and death?

It is difficult to replace or spin new webs about the meaning of life and death. Like many others, I grew up in a very Catholic culture in which the meaning of life and death was taken for granted. Like many others, while I no longer accept the Church's teachings, I have not replaced them with any equally certain beliefs.

My wife Aileen died of breast cancer in 2005. I was deeply in love and devoted to her. The night she died, while she remained silent, I talked about God and heaven, and how I would see her again, soon. I was grasping at lose threads as I fell from the web of meaning of life and death into which I had been born. I thrashed about until the early morning when the hospice night nurse gave Aileen 'something to settle her down'. She died within the next half hour with myself, my son Arron and my daughter Olwen beside her. It was probably as good an end of life as possible given the cultural conditions of our existence.

IAPC

Irish Association For Palliative Care
A Collective Voice for Palliative Care in Ireland



www.palliativecare.ie

Written submission to the Joint Oireachtas Committee on Health and Children, on behalf of the Irish Association for Palliative Care

Author: Dr Margaret Clifford MRCPI, Specialist Registrar in Palliative Medicine
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Introduction:

"You matter because you're you, and you matter to the end of your life. We will do all we can not only to help you to die peacefully, but also to live until you die."
(Dame Cicely Saunders)

This quote from Dame Cicely Saunders, one of the founders of the modern hospice movement, captures the person-centred and life-enabling approach that underpins palliative care. The ultimate aim of palliative care is to enable every person with an illness from which he/she will not be cured, to live as well as possible right up until he/she dies. In its modern sense, this is a relatively new concept, originating in the late 1960s / early 1970s.

There has been intense development of palliative care in Ireland over the past 20 years. In 1995 Ireland became the second country in Europe to recognize palliative medicine as a distinct medical specialty. The Irish Association for Palliative Care (IAPC) was established in 1993, bringing together in a membership body the multidisciplinary professionals involved in the delivery of palliative care, and seeking to build capacity in palliative care through education and research, and with a mission to promote patient-centred, equitable and accessible palliative care for all who need it. (www.palliativecare.ie)

The palliative care approach was initially applied to people with cancer, but the last two decades have seen an increasing recognition of the palliative care needs of everyone with a life-limiting illness, irrespective of what that illness is. International literature has demonstrated that patients with many non-

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malignant diseases have the capacity to benefit from palliative care services[1], and have symptom profiles that are comparable to cancer patients[2],[3]). Here in Ireland, the call for "palliative care for all" was made in the mid-2000's (Irish Hospice Foundation and HSE, 2008[4]), and more recently a global petition seeking for palliative care to be recognised as a human right (The Prague Charter, 2013), was launched. This is an ongoing international campaign to raise the profile of access to Palliative Care.

How is palliative care delivered?

Palliative Care is delivered in a variety of ways, all with the aim of bringing the service to the patient rather than vice versa, or, as Dame Barbara Monroe (CEO of St Christopher's Hospice) puts it, "palliative care in the bed you're in". Therefore, Specialist Palliative Care (SPC) services will typically have a presence in acute hospitals, in community hospitals, in nursing homes, and in patient's own homes.

National policy for the provision of palliative care:

- *Report of the National Advisory Committee on Palliative Care (NACPC)* (2001)[5]
- *Palliative Care for Children with Life-Limiting Conditions – a National Policy* (Department of Health and Children, 2010).[6]
- HSE's Palliative Care Services - Five Year Medium Term Development Framework (2009 - 2013).[7]

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The *Report of the National Advisory Committee on Palliative Care (NACPC)* (2001),[8] which was adopted as government policy, recognised that patients with advanced disease have varying levels of need, and therefore require different levels of palliative care expertise. The Report describes three levels of palliative care service provision:

"Level one – Palliative Care Approach: Palliative care principles should be appropriately applied by all health care professionals.

Level two – General Palliative Care: At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care.

Level three – Specialist Palliative Care: SPC services are those services whose core activity is limited to the provisional of palliative care."

The Report recommended that in each region (which at that time constituted a health board area) "all three levels of service provision should be available and all patients should be able to engage easily with the level of expertise most appropriate to their need.

A team approach is at the very core of the delivery of palliative care. Within specialist palliative care, the combination of medical, nursing, social work, pastoral care / chaplaincy, psychology, physiotherapy, occupational therapy, complementary therapies, dietetics and others work together to meet the multiple and complex needs of patients with advanced disease.

In addition, specialist palliative care services aim to work alongside other specialties and primary care teams in a cohesive manner, to ensure that together we are more than the sum of our individual parts.

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Specialist Palliative Care in the Community:

Recommendations of the NACPC report (2001)[9]*:*

- Specialist Palliative Care services should be available (seven days a week) to everyone living in the community, whether at home, in nursing homes or in community hospitals.
- Community Specialist Palliative Care teams should be interdisciplinary, containing a consultant(s), nursing staff, and at least a physiotherapist, occupational therapist and social worker, all of whom must be trained in specialist palliative care.

Current provision of community specialist palliative care services:

There are currently 35 community specialist palliative care services in Ireland.

There has been an annual increase in patients with non-malignant diseases accessing specialist palliative care. National figures for homecare show an increase for these patients from 17% in 2010 to 24% in 2012 (HSE National Minimum Dataset for Palliative Care).

Evidence for the effectiveness of home palliative care:

A Cochrane review, which brought together the results of 23 studies, found that symptom burden amongst patients who received home palliative care services was significantly less than those who did not. In addition, those in receipt of specialist palliative care services at home were more than twice as likely to die in their own homes [10].

Specialist Palliative Care in acute hospitals:

Recommendations of the NACPC report (2001)[11]*:*

- All acute general hospitals should have a specialist palliative care service provided by an inter-disciplinary team, to offer advice and support to other professional health care providers regarding the management of patients with advanced and progressive disease.

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[9] Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

[10] Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ (2013) Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database of Systematic Reviews. 6:CD007760*

[11] Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

- Hospital admission policies should be sensitive to the needs of patients with advanced disease.
- Joint outpatient clinics should be established in some acute hospitals so that the specialist palliative care team can become involved in the care of patients early in illness journey as appropriate.

Current provision of acute hospital specialist palliative care services:

There are currently 39 acute hospital specialist palliative care teams in Ireland, many of which are uni-disciplinary.

Evidence for the effectiveness of specialist palliative care in the acute hospital:

A randomised controlled trial was conducted in the USA comparing the early introduction of a specialist palliative care team (alongside standard cancer care) in patients with newly diagnosed advanced lung cancer, with standard cancer care alone. The results showed that patients who received early palliative care had significantly better quality of life scores, less depression and anxiety, and survived an average of 2 months longer than patients in the group who received standard cancer care alone[12].

Specialist Palliative Care Units / Hospices:

Recommendations of the NACPC report 2001[13]:

- There should be at least 1 specialist palliative care inpatient unit in each health board area.
- Specialist palliative care units should, where possible, be based close to the acute general hospital with the broadest range of specialist services, including radiotherapy and oncology in the area.

Current provision of Specialist Palliative Care Units in Ireland:

There are currently 9 specialist palliative care inpatient units for adults, and 1 children's hospice, in Ireland.

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[12] Temel JS. Greer JA. Muzikansky A. Gallagher ER. Admane S. Jackson VA. Dahlin CM. Blinderman CD. Jacobsen J. Pirl WF. Billings JA. Lynch TJ. (2010) Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine.* 363(8):733-42.

[13] Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

Three areas of the country - the north east, the south east, and the midlands - have no specialist palliative care inpatient unit and no access to ring-fenced specialist palliative care beds.

Children's Palliative Care:

A national palliative care needs assessment for children in 2005 estimated that there were 1,369 children living with life-limiting conditions (set to increase to 1,610 in 2021 based on population projections) but warned that this figure may be much higher, given the lack of a system in place to collect this information.

Recent key developments in children's palliative care in Ireland include the national policy - *Palliative Care for Children with Life-Limiting Conditions – a National Policy* (Department of Health and Children, 2010[14]). The policy aims to build a service that is responsive to the needs of children and families, and equitable across the country. Implementation of the policy is being overseen by the HSE National Development Committee for Children's Palliative Care. Under the policy, Ireland's first Consultant Paediatrician with a special interest in Palliative Medicine, was appointed (2011). As of September 2013, 8 Children's Outreach Nurses are in post, as per the recommendations of the National Policy. The Consultant Paediatrician post, and 5 of the 8 Outreach Nurses posts, are funded by the Irish Hospice Foundation (IHF). Ireland's first children's hospice, LauraLynn House at the Children's Sunshine Home in Dublin, which receives no State funding, officially opened in 2011.

The Consultant Paediatrician with a special interest in Palliative Medicine is based at Our Lady's Children's Hospital, Crumlin (OLCHC). Since her appointment in 2011, there has been a 67% increase in referrals to the specialist palliative care service at OLCHC [15]. In addition, a broader range of other paediatric specialist services are now referring children to the specialist palliative care service. This may reflect the benefit of having an on-site palliative medicine paediatrician, and her role in education /

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[14] Department of Health and Children. Palliative Care for Children with Life-Limiting Conditions in Ireland- A National Policy. Dublin: Stationary Office , 2010

[15] Clifford M, O'Donoghue L, Jennings V, Hurley I, Delaney L, O'Reilly M, Twomey M, Devins M. Review of referral patterns to a children's palliative care service. European Association for Palliative Care Congress abstracts.

empowerment may be responsible for bringing about a greater recognition of the palliative care needs of children with life-limiting illnesses.

Bereavement:

Recommendations of the NACPC report 2001[16]:

- Bereavement support should be available in all settings where specialist palliative care is offered, and should begin early in the disease process, long before the death of the patient.
- All specialist palliative care staff can provide a general level of bereavement support to individuals and families. For those who require extra support, appropriately trained staff such as social workers, psychologists or professionals' counsellors should be available. An appropriate member of staff should act as bereavement service co-ordinator.

Education and Research:

Recommendations of the NACPC report 2001[17]:

- The culture of continuing professional education and development should be promoted among health care professionals in all disciplines that are involved in the delivery of palliative care.
- Academic departments of palliative medicine should be established in each medical faculty to support and develop education and research in all disciplines.
- There should be a major public funding allocation to promote palliative care research in Ireland.

Current role of SPC in Education and Research:

The role of SPC services in education is four-fold: 1. On-going education and continuing professional education of specialist palliative care professionals. 2. Providing or facilitating formal education courses for healthcare professionals involved in delivering palliative care. 3. Education / support / advice to healthcare professionals in primary care and other specialist services, in delivering palliative care to individual patients. 4. Promoting public awareness of palliative care / involvement in "health promoting palliative care" initiatives.

In times of scarce resources, research assumes an even more important role, as it assesses the effectiveness of services and various components of care, which helps guide resource allocation. It is

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[16] Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

[17] Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

essential that interventions, that require both time and funding to implement and maintain, are impacting positively on patient outcomes.

Future need / Changing demographics:

There are challenging times ahead, both for palliative care services and for the healthcare system as a whole. Projected changes in demography over the next 10-15 years present a significant challenge. According to Ireland's Central Statistics Office, the Irish population is gradually ageing with a predicted doubling of numbers for those aged 85 years by 2021[18]. This is predicted to coincide with an increase in disease prevalence between 2007 and 2021 for diseases including cancer as well as chronic conditions such as cardiovascular and respiratory diseases [19]. Such data has great implications on palliative care service provision as estimates show that each year, 1.6 million cancer patients in Europe experience pain related to their disease, one third of them will require complex treatment and a significant number also experience distressing symptoms [20].

Recommendations:

1. Specialist Palliative Care services should be integrated with other healthcare services in each region, so that the service can be brought to where the patient is, and patients and families can access the element of care most appropriate at any given time.
2. Everyone with an illness which cannot be cured should have access to the palliative care approach, which may be delivered by the primary care or other specialist team with ongoing education and support from the SPC team, or directly by the SPC team in the case of more complex patients.
3. The benefit to patients of early referral to Palliative Care needs to be recognised. Patients not only benefit from a better quality of life, but may also survive longer and with a good quality of life.

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[18] Central Statistics Office. Vital statistics: Fourth quarter and yearly summary 2010, http://www.cso.ie/en/newsandevents/pressreleases/2011pressreleases/vitalstatisticsfourthquarter2010/

[19] Layte R, Barry M, Bennett K, et al. Projecting the impact of demographic change on the demand for and delivery of healthcare in Ireland. Report for the Economic and Social Research Institute (ESRI). October 2009

[20] Higginson IJ and Costantini M. Dying with cancer, living well with advanced cancer. Eur J Cancer 2008;44:1414–24

IAPC

Irish Association For Palliative Care
A Collective Voice for Palliative Care in Ireland

www.palliativecare.ie

Submission on behalf of the Irish Association for Palliative Care (IAPC) Pharmacists' Group.

Introduction

The IAPC Pharmacists' Group is a network of fourteen pharmacists working in hospice and palliative care units across Ireland. Currently all member pharmacists are employees of the voluntary hospice sector. The purpose of the Pharmacists' Group is to strive for excellence in the pharmaceutical care provided by palliative care pharmacists so as to improve and enhance the care and quality of life of people with palliative care needs, and to advocate for and promote equality of access to such pharmaceutical care at end-of-life.

Executive Summary

Pharmacists based in the community, in long-stay residential care settings and in hospital and hospice settings across Ireland play an important role in for caring for patients at the end-of-life. There is international evidence to support the positive impact on patients of specialist clinical pharmacist service provision as part of the palliative care team. There is evidence for a broad clinical pharmacist role in palliative care, incorporating but not limited to, the safe and timely supply of essential medicines to medication review and symptom management clinics and to medicines information and education provision. There is great scope for the development of role of the pharmacist in caring for patients with palliative care needs across all healthcare settings in Ireland. Expanding and developing the role of the pharmacist will improve access to medicines and services, improve symptom control and increase the overall quality of life of the patient at the end-of-life. Therefore, the recommendations outlined below focus on the manpower planning, service development, supply and access to medications, cost effective supply of medication, and addressing ethical dilemmas faced by pharmacists caring for patients at the end-of-life.

Recommendations

- The recommendations from the National Advisory Committee on Palliative Care (2001) that "In the acute general hospital setting, the pharmacy department should be sufficiently resourced to enable staff to become involved with the specialist palliative care team." should be implemented.[1] We are currently aware of only one specialist palliative care pharmacist in an acute hospital setting in Ireland. The report also recommends that specialist services should also access to pharmacy services with in full-time, part-time or with regular sessions.[1] Pharmacists should have recognised post-qualification specialist training and clinical experience in palliative care services.[1] We advise that this recommendation should also be implemented across all specialist palliative care units in Ireland.

- A clinical practice model and capacity planning framework for community pharmacy palliative care services in Ireland should be developed. This model should address the skills development needs, information needs, communication needs of community based pharmacists and community pharmacy services development capacity. (Based on the NHS Greater Glasgow and Clyde, Scotland model)
- Medicines outlined in Appendix 1 should be reimbursable on the community drug schemes. The supply of certain licensed and unlicensed medicines to patients in the community can be costly for patients. There should be concise and transparent application procedures implemented to allow palliative care healthcare professionals (including pharmacists, doctors and nurses) to apply to the HSE to make medications used in palliative care available on the community drug schemes. Detrimental delays in accessing medicines can occur due to uncertainty about costs, procurement and reimbursement.
- Schemes for the supply of essential medicines in palliative care (based on the North East Community Pharmacy Palliative Care Network or the NHS Dorset scheme) should be implemented across Ireland.
- The Department of Health and Children and the Pharmaceutical Society of Ireland (PSI) should issue guidance to address ethical dilemmas faced by pharmacists caring for patients with palliative care needs, most notably, where in emergency situations, the absence of a legal prescription directly conflicts with the rights and welfare of the patient to have access to medications.

Evidence Base for Recommendations.

Dying in Hospital

Positive impacts of specialist palliative care pharmacists' involvement in the care of patients were evident in the literature in a variety of care settings. In the inpatient specialist palliative care unit setting, a US study assessing clinical pharmacist activities reported that a pharmacist's recommendations had a 90% acceptance rate.[2] Out of the 172 medication profiles reviews carried out over the twelve week study period, 160 recommendations were made of which 140 were accepted by physicians. The most common interventions of the pharmacist in this setting were pain management, symptom management, medications no longer needed, and medications requiring laboratory monitoring. Drug information requests, bedside visits and medication counselling sessions were also provided. The results highlighted the value of a clinical pharmacist as a hospice team member in inpatient settings. Lee and McPherson concluded from a study of a hospice program-based specialist pharmacist's interventions that patient outcome were positively influenced.[3] There is also evidence in the inpatient palliative care setting of medication safety improvements as a result of medicines reconciliation by a pharmacists.[4]

The international recommendations supporting the role of pharmacists in palliative care are unambiguous. In Ireland, the National Advisory Committee report in 2001 recognised the importance of the both the role of the specialist pharmacist in palliative care and the community pharmacist (Department of Health and Children (Rep. Of Ireland), 2001). Also recommended in this report was that pharmacists working in specialist palliative care units would be available to provide advice regarding medicines to health professionals in the region. This recommendation provides a clear mandate for a medicines information service based in the pharmacy department of a specialist palliative care unit. In the UK, The National Council for Hospice and Specialist Palliative Care Services in the UK has recommended that all specialist palliative care services should have available an essential minimum core of professionally trained staff with recognised post-qualification specialist training and clinical experience in palliative care services, including pharmacists (National Council for Hospice and Specialist Palliative Care, 1995). The UK Department of Health's End of Life Strategy recognises pharmacists as essential to provision of end of life care (UK Department of Health, 2008). In the US, The American Society of Health-System Pharmacists (ASHP) Position Statement on the Pharmacists Role in Hospice and Palliative Care outlines the belief that pharmacists have a pivotal role in the provision of hospice and palliative care and that pharmacists should be integral members of all hospice interdisciplinary teams (American Society of Health-System Pharmacists, 2002). The statement outlines the responsibilities of pharmacists in hospice and palliative care and includes the provision of advice and education on medication to the interdisciplinary team. Based on this information we are recommending that the recommendations from the National Advisory Committee on Palliative Care (2001) that “In the acute general hospital setting, the pharmacy department should be sufficiently resourced to enable staff to become involved with the specialist palliative care team” should be implemented.

Dying at Home

The recommendations outlined above have been made based on the current barriers faced by community pharmacists caring for patients with palliative care needs and the opportunities for the development of the role of the community pharmacists in improving the quality of life and symptom control of patients with palliative care need.

The following barriers were identified by community pharmacists in Ireland;

- **Communication:** Variable communication between health care professionals, and across health care settings, particularly on discharge from hospital or hospice settings. A lack of communication regarding the involvement of homecare teams etc. in the patients care.
- **Education:** A lack of education initiatives on the use of medicines in palliative care. A lack of information support ‘out-of-hours’.
- **Supply of medications:** Medicines commonly used in Palliative Care are not always easily accessible to patients in the community setting. Certain medicines used in palliative care are unlicensed resulting in increased procurement time due to their complex and brittle supply chains (with at least a delivery time of one working day). Wholesalers will not accept returns of ULM's (unlicensed medicines) or medicines subject to 'Cold Chain' storage and only accept other licensed medicines after typically charging an administration charge of 7% and thus significant financial losses are a highly likely. Holding essential medicines required in emergency situations in palliative care can be costly if medications go out-of-date.
- **Cost of medications:** The cost of certain licensed and unlicensed medicines and non-prescription medicines pose problems for patients in the community as they are not always paid for by the government medicines schemes and can be costly for the patient and/or their family members.
- **Ethical decision making:** Pharmacists are obliged to comply with Pharmaceutical Society of Ireland (PSI) Regulations, the Code of Ethics and any applicable Legislation passed into statute by State Institutions. Frequently, pharmacists are

compelled to release "Controlled Drugs" prior to a legal prescription being presented to the Pharmacy in the case of a dying patient whose care is being supervised by the "Local Palliative Care Team". The Pharmacist must uphold the rights and welfare of their patient and not deny that patient any medicine which in the view of that Pharmacist is essential to maintain a state of adequate (or preferably optimal) analgesia. The obligation to serve the patient can directly clash with the requirements of the PSI for Pharmacists and Pharmacies to observe Prescription Regulations and more particularly; the Controlled Drug Regulations.

Role of Community Pharmacists in Palliative Care

In the outpatient setting, an assessment of a pharmacist's input into a palliative care clinic in the UK demonstrated that drug histories, documentation of medication-related problems, prompt supply of medicines, patients' and carers' understanding of their medicines and overall running of the clinic were thought to be much improved with pharmacist input, indicating that the pharmacist has a valuable place as a key member of the multidisciplinary palliative care team.[5] Wilson and colleagues conducted a study in set in an outpatient palliative care clinic in the US which examined the actual clinical outcome of the patient following the pharmacist intervention. They concluded that acceptance of the pharmacist's recommendation is high in the palliative care setting and is significantly associated with and to be the strongest predictor of the patient achieving the desired clinical outcome.[6] A retrospective descriptive study of the impact of multi-disciplinary symptom control and palliative care outpatient clinic in the US which included assessment by a specialist pharmacist reported high levels of patient care recommendations, improved symptoms and high levels of patient satisfaction.[7] A further study in the United States described the success of a pilot programme involving a palliative care pharmacist clinic based in an outpatient pharmacy.[7,8] An Australian community palliative care programme including a pharmacist reported that the inclusion of a specialist pharmacist in a community palliative care team lead to an increase in the medication-related knowledge and skills of its members, improved patients' medication management, and minimised related errors.[9]

Evidence for the role of the community pharmacist was found in a UK study which concluded that when community pharmacists are appropriately trained and included as integrated members of the team, they can intervene effectively to improve pharmaceutical care of palliative care patients.[10] A Japanese study replicated these findings.[11] The final results of a study in Scotland, which developed pharmacist facilitator posts to collect qualitative data on areas for improvement in community pharmacy services in palliative care have yet to be published. Nonetheless, a report on the Palliative Care Greater Glasgow and Clyde website details the outcomes of the project to date, presenting a conceptualised clinical practice model and capacity planning framework for community pharmacy palliative care services (Palliative Care Greater Glasgow and Clyde and Strathclyde, 2012). An Australian study which evaluated the interaction of community pharmacists with patients recruited from a palliative care service from the perspective of the patient found that most patients and caregivers reported that their interaction with, and the value of information provided by the pharmacist, was excellent.[12]

In summary, pharmacists in all healthcare settings have an important role to play in caring for patients with palliative care needs in Ireland. Based on the evidence outlined above, we are submitting several recommendations for consideration that will increase the capacity for pharmacists to care for patients at the end-of-life.

Thank you for the opportunity to present this submission.

Kind regards,

Cliona Hayden.

Date: 19/11/2013.

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12) Hussainy SY, Marriott JL, Marriott JL, Nation RL. Assessing medication knowledge of Australian palliative cancer care patients and caregivers and their interactions with pharmacists. 2009. Journal of Palliative Medicine, 12, 769-769.

Appendix 1: Medicines Commonly Used in Palliative Care which are NOT reimbursable on the DPS or GMS.

Prescription Medicine	Licence Status	Non-Prescription Medicine	License Status
Alfentanil 500microgram/ml INJ	L	Anusol Ointment	L
Alfentanil 5mg/ml INJ	ULM	Anusol Suppositories	L
Amitriptyline 25mg/5ml suspension	ULM	Aveeno cream with menthol	L
Dexamethasone 0.5mg tablet	ULM	BioXtra gel	L
Dexamethasone 2mg/5ml liquid	ULM	Bisacodyl suppositories 10mg (Dulcolax)	L
Dexamethasone 4mg/ml INJ	L	Bisacodyl tablets 5mg	L
Diazepam 10mg/5ml suspension	ULM	Chlorhexidine mouthwash 0.2%	L
Diazepam 2mg/5ml suspension	ULM	Glycerine Suppositories 4g	L
Docusate 100mg cap (Dioctyl)	ULM	Hyoscine hydrobromide 300micrograms (Kwells)	L
Fentanyl 50micrograms/ml INJ	L	Ibuprofen suppositories 60mg	L
Fleet Ready-to Use enema	L	Ibuprofen suspension 100mg/5ml	L
Glycopyrrolate 1mg tablet	ULM	Microlette	L
Hydromorphone 50mg/ml INJ	L	Milpar	L
Ketamine 10mg/ml INJ	ULM	Paracetamol sachets 1g (Panadol Max)	L
Ketamine 50mg/ml INJ	ULM	Paracetamol suspension 250mg/5ml	L
Levomepromazine 6mg tab (Levinan)	ULM	Senna liquid	L
Methadone 10mg/ml INJ	ULM	Senna tablets	L
Metoclopramide 5mg/5ml oral liquid	ULM	Sodium picosulphate liquid 5mg/5ml	L
Midazolam buccal liquid (Epistatus)[#]	ULM	Sodium picosulphate liquid 5mg/5ml	L
Ondansetron 4mg/2ml, 8mg/4ml injection (Zofran®)	L	Sodium picosulphate liquid 5mg/5ml	L
Phenobarbital 15mg/ml, 30mg/ml, 60mg/ml injection	L	Sodium picosulphate liquid 5mg/5ml	L
Phenobarbital injection 200mg/ml	ULM		
Sodium valproate injection 400mg (Epilim®)	L		

Irish Cancer Society

Written Submission to Joint Oireachtas Committee on Health and Children in relation to End of Life Care in Ireland

November 2013

Introduction

The Irish Cancer Society welcomes the opportunity to participate in the discussion on end of life care. Cancer is one of the leading causes of death in Ireland and accounts for a third of all deaths in Ireland (8,684)[1]. Cancer patients are currently the biggest group of specialist palliative care users. This is unlikely to change. There were 33,741 cases of cancer in Ireland in 2010 (NCRI, 2013). The National Cancer Registry (NCRI) predicts that the number of cancer cases will increase to 42,000 a year by 2020[2].

Improvements in cancer detection and treatment mean that cancer survival rates are improving with 65% of cancer patients surviving their illness. New treatments mean that people with cancer are living for longer but many will require end of life care. An ageing population with complex medical needs is likely to further increase demand for palliative care services. This presents a significant challenge for a health system, which is undergoing extensive reform in the face of an increasingly difficult financial situation.

Palliative care is the continuing active total care of patients and their families, at a time when the expected medical outcome is no longer cure. It responds to physical, psychological, social and spiritual needs, and extends to support in bereavement. The goal of palliative care is to ensure the highest possible quality of life for both the patient and their family.

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[1] Central Statistics Office. Vital statistics: Fourth Quarter and Yearly Summary 2011

[2] National Cancer Registry: 2006, Trends in Irish cancer incidence 1994-2002 with predictions to 2020

Summary of recommendations:

- Ensure that further policy development will support integrated palliative care in primary care and the *Money Follows the Patient* model will incorporate end of life care at night-time in the patient's own home
- Bridge the gap in homecare service provision by integrating the Night Nursing service into palliative care and primary care services so that patients have access to 24-hour care if required
- Address the training needs of primary care workers of primary care health professionals so that they can provide the best possible standard of end-of-life care to patients in the community setting
- All patients irrespective of their geographical location would have equal access to specialist services and hours of care
- Grant patients in the advanced stage of their illness a special status that does not require them to be financially assessed to extend medical card beyond the initial 6 month period
- Improve access to the homecare package scheme for those under 65 with cancer
- Introduce a formal protocol so that all patients can access the supports and equipment they need to have end of life care in the home if appropriate
- Provide dedicated psycho-oncology services in each of the designated centres and hospitals where cancer is treated
- Ensure that the psycho-oncologist is part of the multi-disciplinary team and involved in the patient's care from the point of diagnosis

Primary Palliative Care

Palliative care is an approach to caring for people with illnesses that will not be cured and can be delivered in a variety of settings including acute hospitals, community hospitals, nursing homes, hospices, or in the home.

The National Advisory Committee on Palliative Care recommended that palliative care services be structured in three levels of ascending specialisation according to the expertise of the staff providing the service [3].

- Level one – Palliative Care Approach: Palliative care principles should be appropriately applied by all health care professionals.
- Level two – General Palliative Care: At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care. ('generalist')
- Level three – Specialist Palliative Care: Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

Level one and two of care are delivered in the primary care setting and make it possible for people to spend their final days at home where this is appropriate. This is line with the HSE's Palliative Care National Clinical Programme (2010) which aims to:

"Ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs, regardless of care setting or diagnosis".

An Irish Hospice Foundation study in 2004 found that two thirds of people wish to die at home[4]. Data from the Irish Hospice Foundation tell us that nationally, only 26% of people do so[5].

The Irish Cancer Society wants to make it possible for cancer patients to die at home if this is their wish and where this is appropriate. In supporting end of life care for

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[3] Report of the National Advisory Committee on Palliative Care (NACPC, 2001)

[4] Weafer J.A., 2004. Nationwide survey of public attitudes and experiences regarding death and dying, Dublin: The Irish Hospice Foundation.

[5] Access to Specialist Palliative Care Services and Place of Death in Ireland (Irish Hospice Foundation, 2013)

cancer patients in the primary care setting, the Society provides a free night nursing service in the patient's own home. The Society began providing this service in 1986. This is the only national palliative care service available to cancer patients at night in their own home. The Irish Cancer Society receives no state funding towards Night Nursing and is dependent on public donations to operate the service. The service plays a vital role in supporting primary care and integrated palliative care and without it, many patients would have to be readmitted into hospital, as they could not be cared for in their own home.

In 2012, the Irish Cancer Society provided 7,600 nights of care to 2,161 cancer patients. The average cost per night of care is €350. The demand for this service increases annually at a rate of approximately 7%. It cost €2.6 million to deliver the service in 2012. As discussed above, the demand for this service is likely to increase.

Recommendation: The Irish Cancer Society is seeking that further policy development will support integrated palliative care in primary care and the *Money Follows the Patient* model will incorporate end of life care at night-time in the patient's own home.

A gap in the provision of home care exists as night nurses are available to the patient in their home from 11pm-7am. In general, day services are available from 9am-5pm. This means that from 7am-9am and from 5pm-11pm, there is no standardised palliative homecare nursing service available to patients and their families. This can cause considerable distress.

Recommendation: The gap in service provision needs to be bridged by integrating the night nursing service into palliative care and primary care services so that patients have access to 24-hour care if required.

Primary care professionals are the main providers of care to patients with a life limiting condition in the home. A 2010 survey by the Irish Hospice Foundation, in partnership with the Irish College of General Practitioners and the HSE found that primary care healthcare professionals providing end-of-life care identified a need for training in palliative care, in particular symptom control and training in care for imminently dying patients at home.

Recommendation: These training needs should be addressed so that primary care health professionals can provide the best possible standard of end-of-life care to patients in the community setting.

Specialist Palliative Care

Generalist and specialist palliative care play an important role in the effective care of people with life-limiting illnesses. Access to specialist care can vary depending on geographical location.

Recommendation: All patients irrespective of their geographical location would have equal access to specialist services and hours of care.

Access to services

Palliative care patients require timely access to services and care and should be able to access those services in the most efficient and stress free manner possible.

Patients with a terminal illness are entitled to an emergency medical card which is valid for 6 months. A letter from a doctor or consultant stating that the patient has a terminal or life-limiting illness is required in order to obtain the card. Cancer patients with an incurable cancer who survive for longer than 6 months are required to be reassessed on financial grounds. This requires extensive paperwork at a time of considerable distress for the patient and their family. It is estimated that 20% of these discretionary cards require renewal after 6 months.

The Society has heard that doctors and consultants may be reluctant to write 'terminal' or 'life-limiting' on a letter required to obtain a medical card because of the impact which this has on the patient. This is a barrier to patients accessing the services they need.

Recommendation: The Irish Cancer Society recommends that cancer patients in the advanced stage of their illness be granted a special status that does not require them to be financially assessed at a time of significant distress.

The HSE's Home Care Package Scheme (HCP) is an administrative scheme which supports people to return home following a hospital stay or to remain at home longer rather than be admitted to hospital or a nursing home. A home care package enables people to stay in their own home by providing various services might be needed due to illness, disability or after a stay in hospital or rehabilitation in a nursing home. These services include extra home help hours, nursing services and therapy services.

People aged over 65 are the main priority for the scheme although those under 65 may apply for a package. The Irish Cancer Society has heard reports that it is becoming increasingly difficult for patients under 65 to obtain a homecare package. As 27% of malignant cancer deaths occur in people under 65 (CSO, 2011), many in this age group will require the supports provided by a homecare package and should be able to access a package to assist with their end of life care.

Recommendation: Improve access to the homecare package scheme for those under 65 with cancer.

Cancer patients receiving treatment in private hospitals do not have access to a social worker. This means that they are discharged into the care of a GP who may not be able to assist the patent to access the supports that are required for them end their life at home.

Recommendation: Introduce a formal protocol so that all patients can access the supports and equipment they need to have end of life care in the home if appropriate.

Psycho-oncology Services

Forty per cent of people with cancer are known to experience significant distress and anxiety, which requires the intervention of as mental health professional[6]. Psycho-oncology has been proven effective at helping patients and families confront the many issues that arise when facing a life-limiting illness.

The National Strategy for Cancer Control (2006) recommended that:

"Multidisciplinary psycho oncology services need to be provided to identify and manage distress in cancer patients. Structures should be developed in each Managed Cancer Control Network to ensure that each cancer centre has a

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[6] Carlson LE, Bultz BD (2003a) Benefits of psychosocial oncology care: improved quality of life and medical cost offset. Health Qual Life Outcomes 1: 8

dedicated psycho oncology service and is capable of meeting the psychosocial needs of patients and their families"

Currently, dedicated psycho-oncology services are provided 2 of the 8 centres of excellence -St. James's Hospital and Vincent's Hospital. Cancer Care West provide psycho-oncology services in Galway.

Recommendation: The Irish Cancer Society recommends that dedicated psycho-oncology services be delivered in each of the designated centres and hospitals where cancer is treated. The psycho-oncologist should be part of the multi-disciplinary team and be involved in the patient's care from the point of diagnosis

Signed: ______________________________

Donal Buggy
Head of Services
Irish Cancer Society

19th November 2013

The Irish Childhood
Bereavement Network

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

Executive Summary

This submission to the Joint Committee on Health and Children is made by the Irish Childhood Bereavement Network and refers to the nature and consequences of a child's grief. It outlines the nature a significant bereavement can have on a child and highlights the uniqueness of children's grief.

As children grow and develop in the context of the family, the report looks at the family dynamic in relation to grief and how this can impact on the grieving child.

It also describes what bereaved children need to overcome their sadness and loss and grow towards healing. It outlines the services which are available in Ireland to bereaved children and identifies the service gaps that need to be filled.

The report finishes with 4 key recommendations:

1. An agreed framework for community, public, volunteer and professional education with respect to childhood bereavement
2. An agreed research agenda with respect to childhood bereavement – consequences, impact and support
3. Continued support for networking of Irish and European bodies working in child bereavement
4. The development of existing and new services within an agreed framework that includes the development of Standards *for Bereavement Care* for children in Ireland

1.1 Introduction

The Irish Childhood Bereavement Network (ICBN) welcomes the opportunity to address the house. The vision of the ICBN is that by sharing and developing good practice, including training and resources, 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.

The Network is a national organization and represents the views of professionals working with bereaved children across Ireland. It was set-up in 2013 with funding from the Family Support Agency and the Irish Hospice Foundation. The Advisory Panel of the ICBN comprises of representatives of various agencies supporting bereaved children in Ireland, namely Our Lady's Hospice, Dublin; Milford Care Centre, Limerick; , Barnardos;, the Family Support Agency;, Beaumont Hospital, Dublin; Cois Cheim, Cork; Rainbows; Anam Cara; Association of Agency based Counselling in Ireland and the Irish Hospice Foundation.

The **ICBN** is a hub for those working with bereaved children, young people and their families in Ireland. It was established to:

Support professionals to deliver high quality and accessible bereavement support;

Signpost families and carers to a directory of bereavement support services;

Inform the general public regarding issues involved in childhood loss;

Advocate for bereaved children, young people and those supporting them.

Bereavement experiences amongst children are extremely common. There are no definite figures in Ireland as to how many children are bereaved of a significant person in their life but new research by the ESRI (Growing up in Ireland) demonstrates that 2.2% of nine year olds have lost a parent, 1.1% a sibling, 7% an aunt or uncle and 6% a close friend. By the age of nine 28% of Irish children have lost a grandparent.

Based on the 2011 census the Central Statistics Office provided us with information on the number of parents categorised as 'Widow' or 'Widower'. Using these figures we know that 20,889 children and young people under 19 are currently bereaved of a mother or father. (It should be noted that these figures do not account for bereaved children whose parents were not married).

In the UK, estimates indicate 7% of children & young people will be bereaved of a parent by age 18.

1.2 Impact of bereavement on children

Reactions and outcomes to bereavement in childhood differ depending:

- The child's age and personality,
- The child's relationship with the deceased,
- The circumstances surrounding the death,
- The child's social supports,
- The impact the death has on other members of the family/ how the family cope after the death

- The changes the death brings for the child and previous losses experienced.

These factors can mediate or exacerbate the outcome for the child and the death of a person, coupled with the changes it brings to the child's world that can result in behavioural and/or emotional stress reactions (Worden, 1996).

Some significant effects of childhood bereavement include:

- depression (in the short term or in adult hood),
- criminal or disruptive behaviours,
- early sexual activity,
- reduced educational attainment and employment status,
- leaving home early and
- diminished self-concept and self-esteem
- lower employment rates (Ribbens-McCarthy and Jessop, 2005; Ansley-Green et al. 2012. Parsons, 2011)

However, not all the changes that bereavement brings are negative: some parentally bereaved young people report growth in areas such as having a more positive outlook, gratitude, appreciation of life, living life to the full and altruism (Brewer and Sparkes 2011).

1.3 The nature of children's grief

Children who experience the death of a parent (or sibling) are likely to experience a time of disruption in the family which can be both confusing and worrying (Christ 2000; Silverman 2000). Most children oscillate naturally in their grieving as they grieve intermittently, often staying busy with the day-to-day living and facing their grief when a trigger causes them to engage with the loss (e.g. hearing a song or playing a sport that triggers memories of the deceased).

Rando (1991) explains that a child may manifest grief on an intermittent basis for many years in an 'approach–avoidance' cycle in order to manage their painful feelings.

> '*the grief of children is like splashing in puddles while adult grief is like wading through a river*'. Crossley (2000)

Children's grief must be considered in terms of their developmental age and understanding of death as a concept. For example, a 2 year old does not understand that death is forever while a teenager understands that concept and may haven unspoken worries about their own mortality.

A loss during formative years may have a long-term effect. Christ (2000) describes three models which might be useful in terms of representing the impact of grief on children; each of these is discussed briefly below.

The ***'Blunt Trauma'*** model reflects the traditional view of childhood bereavement, whereby parental death is seen as a single event, **a discrete blow** that is *'bounded in time, powerful in impact, and more disruptive for children than adolescents'.* This model focuses on the nature of the event and the developmental stage of the child when the death occurs

The second model, the '***Shock- Aftershock Wave'*** model, emphasises the role of the death and subsequent multiple intervening factors which can continue to impact on a child's development. A parent's death is not seen as a single event that determines later outcome.

It is notable that changes take place within a child as he or she **experiences and re-experiences grief during successive stages of development**. Thus, refer to this process as a series of shocks and aftershocks.

The last model, called the ***'Cascade of Events'*** is based on an expanded view of the long-term developmental effects of a parent's death and how these manifest in the child. The term 'cascade' is designed to help clinicians understand:

- the interactions of the child's developmental stage,
- the meaning of the parent's/siblings death for the child,
- subsequent life stressors,
- the child's vulnerability and resilience.

Depending on the support received these can lead to either a successful or detrimental adaptation to the loss. Thus, the death may trigger a cascade of significant life changes that will influence the child's future development in the immediate and long term.

These models of adaptation have far-reaching implications for the services offered to bereaved children because the support required by children may need to extend over a period of time into adult life. The *Candle Project* in London refers to this as an 'extended warranty' (Kraus and Monroe, 2007). It is also worth noting finding that some negative outcomes do not appear in children until two years after their parent's death, but we do not know whether, and for how long, these outcomes persist.

1.4 Children in the context of family

Children do not exist alone but are in a constant dynamic relationship within their family system. Death can become a major taboo subject in families when they are protecting themselves. This, in turn, can cause difficulties in talking to children about death in the family due to a script of silence that can prevail. However, it has been established that children need a caring adult to make sense of their losses for them in order to mourn (Black, 2002).

The role of the family is key in providing support to bereaved children. Openly expressing thoughts and feelings, tolerating different grieving styles, remaining flexible, and caring and supporting one another, enable a family to live with the change that death inflicts on their lives (Biggs, 2002). Collectively, these findings underline the importance of including parents and caregivers in children's bereavement support provision.

Nadeau (1993) states that children will actively make meaning out of their experiences within the family unit, but this will depend on:

- their age,
- developmental stage,
- life experience, whilst they will also be
- the influence of other family members and how they model grief.

Support to children can be facilitated in the home with family members, in schools and parishes or through a range of supports available through health and social care services, which may be delivered through the statutory or voluntary sectors. Indeed, the first point of bereavement support for children lies in the family context and evidence suggests that children's outcomes correlate strongly with their surviving parent's:

- mental health,
- coping style,
- levels of warmth and
- discipline,
- communication.

The family context offers the optimum opportunity to provide children with continued routine activities, witness normal grief behaviours and engage in opportunities to remember the deceased. However, while parents are grieving themselves, it can be a significant strain to continue routines and remain emotionally and practically available to their children (Aynsley-Green et al., 2012).

Beyond the family, in school and other community contexts, adults and peers may be unsure what to say or how to help the bereaved child and as a result, evidence suggests that many children report having no one to talk to (Ribbens-McCarthy and Jessop, 2005).

1.5 What do bereaved children need?

There is a general consensus that children need:

- information and education on what death means;
- encouragement to talk about how they feel;
- reassurance that they are not to blame for the death;
- an opportunity to understand and express their grief;
- meet others and share experiences, and above all,
- access to support to generate hope for the future (e.g. Worden, 1996, Herbert, 1996).

Children also need inclusion at the time of illness, in the rituals of grief and in the grieving process of the family. They need to be able to let their grief ‘ebb and flow’ and to have understanding from those who support them.

This support is provided in the main not by ‘grief specialists’ but by extended family, teachers, youth workers and other adults in the child’s network.

Further supports must be set in a framework of standards and ‘best practice’.

Given the considerable array of factors that determine the outcome of childhood bereavement, it is clear, and supported by evidence that a range of bereavement supports for children, at different levels, are required to meet the needs of children and their families in a range of proactive and reactive ways (Akerman & Statham, 2011). Such an approach has been advocated by the Childhood Bereavement Network (2007) in the UK as outlined below:

John’s story below illustrates a bereaved child having his needs met and the positive impact this has had on his grieving process:

John aged 12 years was a young man bereaved suddenly of his father who died at work from a heart attack. The family unit was devastated by the loss and John's mother who was five months pregnant at the time was inconsolable. John's grandmother told him he was the *man of the house now. So John decided not to let Mam know how he was feeling about his father’s death and took it upon himself to take care of his little brother Cathal. His teacher noticed John becoming very withdrawn in the class and suggested to his mother that he might attend a child bereavement service in his area. John got on very well with the therapist as they explored his father's death and its meaning for him through play and conversation. John explained that he was worried in case the family would lose all their money as there was TB in some of the farms in a neighbouring county and he was afraid their farm would be next. The therapist told John that this was a heavy burden for a young boy to carry. They drew a back pack on a little boys back and started to unpack all the things John carried in worries and needed to let go. John left the session relieved. That night was the first in 8 months that he spoke with his mother of his father's death. Mam too received the support she required and the family unit became functional again They learned in time to accommodate the loss of their father and husband and John will complete his Leaving Certificate and hopes to go to college in September to follow a career path of his choice.*

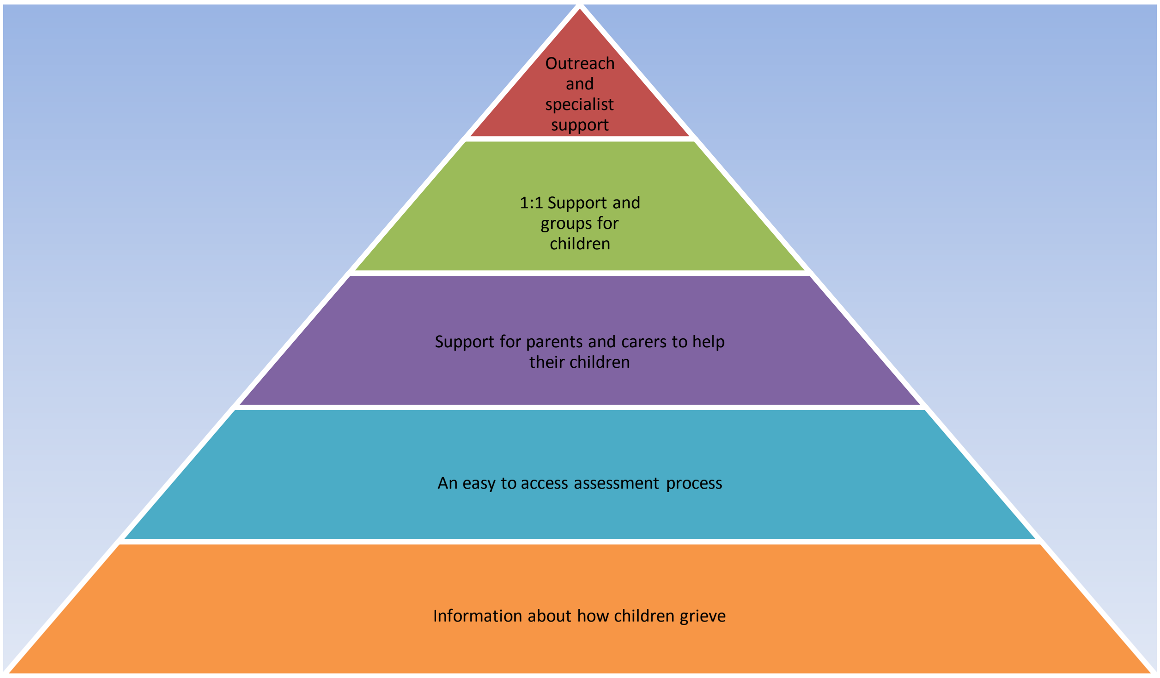

Figure 1: Levels of Bereavement Support for Children. CBN (2007).

1.6 The landscape of bereavement support for children in Ireland

A recent survey of children’s bereavement support services, representing a broad range of voluntary and statutory organisations, indicated that children’s bereavement services are using a diverse range of printed materials, have varying access to training and supervision and do not work to a common set of standards (Carroll, 2010). In addition, the Petrus report (2008) documented the difficulty in identifying up-to-date lists of bereavement service providers, including those serving children, across the country and outlined training and standards targets for bereavement support providers which have not, to date, been operationalised.

The launch by the Department of Health and Children of their *National Policy on Palliative Care for Children with Life-Limiting Conditions in Ireland* (2009) provides hope for future service provision in relation to bereavement care. One of its key recommendations is that:

'Bereavement supports for children's palliative care should be developed according to a bereavement care continuum. Support should be offered at a level appropriate to the service user.' p.35

This policy describes three levels of support and recommends that specific goals and measurable objectives are developed and explicit actions implemented. Reference is also made to the need for appropriately trained professionals and a standard of training and practice required for service delivery. Importantly, this is the first document to recognise the bereavement support needs of children in an Irish context and augurs well for the development of future policy in the area of childhood bereavement within palliative care services, albeit not at a broad community- based level where more traumatic deaths occur and children are exposed to death trough illnesses which are not supported through palliative care as the death was sudden and unexpected.

While many children living in Dublin have access to a range of services there are children living in rural Ireland who have no local professional service to avail of if needed. As part of the scoping study into the feasibility of a Childhood Bereavement Network for Ireland (McLoughlin, 2012), a number of stakeholders working in the voluntary, statutory and private bereavement services were consulted to ascertain the current situation for bereaved children in Ireland.

Stakeholders acknowledged that there were aspects of bereavement support for children in Ireland that were working well but also that significant **gaps in service provision** exist -

1. Lack of a health promoting approach to childhood bereavement in schools and communities to enable the population to recognise death as a part of life and that childhood reactions to death, as experienced by the majority of children are "normal" reactions to a difficult event

2. Need for modules to be developed as part of SPHE focusing on death education for children and in the teacher training curriculum to enable teachers to deal with issues around death effectively

3. The high cost of attending private services for families is a factor we must consider and the lack of low cost/free services for families on low incomes. Whilst hospice's provide excellent services to children these are not accessible to all bereaved by illness in the community

4. Inequity and fragmentation of services nationally – particularly outside Dublin

5. Increase in demand for services alongside annual funding cuts leading to some scaling back in services provided e.g. Barnardos

6. Financial and staffing constraints to future children's bereavement service development and expansion e.g. limited funding to ICBN

7. Lack of continuity and employer support for individuals completing educational programmes Lack of dedicated services/recognition for children experiencing

complicated grief / multiple losses or those requiring 1-1 intervention and those extensive waiting lists for those that exist

8. Limited response by NEPS to bereavement in school situation beyond Critical Incident management and could include post-bereavement support
9. Lack of long term follow up on children who may need their support further into the trajectory of grief
10. Lack of quality/minimum standards / guidelines / regulation for service providers and agreed outcome measures
11. Health and social care staff unable to determine the quality/repute of children's bereavement services available
12. Lack of supervision structures for a small minority who are providing children's bereavement support

1.7 How to improve services for bereaved children

The ICBN believes there should be a multifaceted approach to providing nationwide support to all bereaved children who need it. The list of gaps above are underpinned by the need to develop an integrated and population based approach to providing support for bereaved children. Such an approach should

- Acknowledge the crucial role of family
- Be age-sensitive, proactive and responsive.
- Be guided by the Childhood Bereavement Network model (see figure 1) with activities and investment at five levels.
- Be cross-sectoral and strategic in nature, noting the role of communities, voluntary organisations as well as the education and health sector.
- Be inclusive – for example adult hospitals are often the context for children's bereavement (such as the death of a parent or grandparent) yet children are often excluded
- Demonstrate adequate standard of training for health professionals and volunteers involved in providing bereavement care for children
- Provide adequate funds to services enabling both paid staff and volunteers

1.8 Recommendations

The ICBN makes the following recommendations to improve services for bereaved children in Ireland and those working in them:

> **A) An agreed framework for community, public, volunteer and professional education with respect to childhood bereavement**
>
> **B) An agreed research agenda with respect to childhood bereavement – consequences, impact and support**
>
> **C) Continued support for networking of Irish and European bodies working in child bereavement**
>
> **D) The development of existing and new services within an agreed framework that includes the development of Standards *for Bereavement Care* for children in Ireland**

A) An agreed framework for community, public, volunteer and professional education with respect to childhood bereavement

Education efforts should span from public & community initiatives (developing community awareness of children's grief through media and community education) through to formal professional and volunteer curricula for developing competence to support bereaved children.

The view of the ICBN is that particular emphasis should be focussed on schools. Given that bereavement occurs in a family context, and that the family can be undermined just at the time when it needs to be most supportive to children, school takes on a significant role in providing a predictable, stable and understanding environment.

The ICBN has already begun progressing the development of bereavement education to teachers and during Summer 2013 held Department of Education and Skills' approved teacher's summer school in partnership with IHF and Rainbows Ireland,. The teachers at the school highlighted a desire to develop a language/vocabulary around bereavement, have practical supports and 'teachable moments' and guidance on how to support the child returning to school after a death as key needs in terms of supporting a bereaved child.

The Department of Education should promote a whole school approach to support a bereaved child. This would include incorporating children's grief into professional training and providing accessible continuing professional development. The inclusion of Death Education on the School curriculum in subjects such as Social Personal Health Education should also be considered.

B) An agreed research agenda with respect to childhood bereavement – consequences, impact and support

ICBN would welcome a research agenda to focus our collective efforts on supporting childhood bereavement in Ireland. The shape and consequences of childhood bereavement should be described and understood through longitudinal research. Similarly the most effective interventions at community, voluntary and professional level should be evidence-based. Finally, research represents an opportunity to ensure that children's own views and experiences shape on-going support, policy and decision-making.

C) The development of existing and new services within an agreed framework that includes the development of *Standards for Bereavement Care* for children in Ireland

Children and families should have access to the range of flexible services they require. The gaps identified by those working in bereavement care in Ireland remain outstanding. Continued funding, standards for training and standards for best practice in bereavement care should be a priority.

D) Continued support for networking

Given that children's bereavement support in Ireland is provided by a combination of voluntary, statutory and private agencies at different levels of intervention, there is a value in supporting them in a collective sense. If integrated bereavement care is to become the norm, if shared standards of care, training and resource are to be supported we contend that a network approach is one that will develop capacity across the range of existing services. The allocation of funding to continue the work of the network will help to strengthen the capacity of the sector and to further the recommendations proposed in this submission.

1.9 Conclusion

We have discussed the impact of bereavement on children, the nature of their grief, children's context in the family, what support they need and what is available in Ireland. Our submission has laid out clearly 4 recommendations to the committee that we hope will be considered for implementation.

We believe that a comprehensive approach to children's grief should include a 'three legged stool approach' where the child is the centre and the three supporting 'legs' represent family, school and formal children's bereavement support services.

Our aim is to empower the natural support networks of family and schools to provide the supports bereaved children require through information and education.

For children who require added support due to the fact that the family structure has been devastated by the loss services should be accessible to all.

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Submission from the Irish College of General Practitioners to the Oireachtas Joint Committee on Health and Children on End of Life Issues

Introduction

Established in 1984, The Irish College of General Practitioners (ICGP) is responsible for post graduate specialist medical education, training and research in the specialty of General Practice. The College has a national advisory role in relation to medical standards and interacts regularly with a number of bodies including the Medical Council, Department of Health and Children, the Health Service Executive and the Health Information & Quality Authority amongst others. As a membership organisation the ICGP is responsible for providing continuing professional development (CPD) for established GPs numbering over 3,000 at present.

The mission of the ICGP is to serve the patient, and its members / general practitioners by encouraging and maintaining the highest standards of general medical practice.

The core values of the College are quality, equity, access and service to the patient. The ICGP welcomes the opportunity to make this submission. This Committee is addressing a unique point of care in a person's life where a general practitioner may play a significant role.

Summary of Recommendations

Care of the dying in the community often relies on a multidisciplinary approach particularly interaction between GPs, Public Health Nurses, Community Palliative Care services and Pharmacists. A high standard of care at the end of life requires excellent teamwork / communication (team/patient/family) and forward planning.

Typically the GP has known the patient and their extended family for several years prior to the diagnosis of a life limiting illness. They are often directly involved in the initial investigation and diagnosis at the outset. The news that an illness is life limiting for a patient well known to the GP can of itself be upsetting for the GP on a personal level. In addition the family and those closest to the patient present to the GP for support in adjusting to the diagnosis. The GP will often have a unique insight into family dynamics and context within which palliative care has to be delivered.

The recognition of end-of-life can be a difficult time for patients, carers and doctors. Systems have been developed internationally to aid identification of patients at risk of dying. (For example, Gold Standards Framework or the Supportive and Palliative Care Indicators Tool.). In the UK, additional resources have been made available for GPs to encourage them to use such systems.

The numbers of patients dying in the community cared for by a GP can vary greatly. Many patients will be managed with the support of the local community palliative care service while some are managed solely by the GP. Support services available vary nationally and across urban and rural areas. Regions without inpatient hospice beds rely more on community palliative care teams.

Problems may arise in supporting patients in the context of out of hours and weekends, particularly in the terminal phase of an illness. The majority of out of hours GP care nationally is provided through co-operatives, the duty doctor will obviously be less familiar with a patient than their own GP. To address this some co-ops have notification systems in place where a GP can inform duty doctors in advance of problems that may arise with patients requiring palliative care. The development of a standardised national electronic summary would enhance this process. It is not unusual for GPs to provide their own contact details to a family to prevent any distress for a family in the terminal phase of a patient's illness. It is, however, recognized that many GPs have family and other commitments which means that they cannot be personally available at all times.

Following the death of a patient the GP provides an ongoing role in bereavement support. This may be through assisting with practical family needs in terms of death certification, advice, leave from work etc. The GP also supports the family through the bereavement process providing continuity of care and psychological support. This may continue for several years following the loss. Palliative care delivery by the GP therefore requires a continuum of care across the spectrum and trajectory of a patient's illness.

The ICGP therefore supports any initiative that can bring about improved care for those dying within the community setting. There are a number of specific areas where improvements and initiatives need to be fostered:

1: Developing a structured system for palliative care prescribing in the community:

There is a need to improve and standardise palliative care prescribing systems in the community. At present there is a diverse approach to prescribing and dispensing such medications nationally. Typically a GP is advised by the relevant home care team of suggested medications. The GP remains the principal prescriber in the community. The GP then transcribes these medications onto GMS prescriptions (many require hand written prescriptions as they are controlled drugs).Community retail pharmacists then source and dispense the medications. Most community pharmacies order such medications on as needed per patient basis.

Problems arise at present due to duplication of work, delays in the process and difficulties in accessing the sometimes complex medication in community pharmacy. Additional costs are also potentially incurred due to dispensing of greater amounts of drugs than may be required.

There is scope for improvement in the processes involved. Development of a new national system would aim to address the current shortfalls. A national palliative care medication advice service exists at present but this requires promotion nationally.

2. Palliative Care Education:

The ICGP has a long history of provision of palliative care education. Currently there is a palliative care certificate course available for established GPs and a module devoted to palliative care is included in the core curriculum for GP Training. There is a constant need to update the content and methods of delivery of this education especially in the areas of symptom management, physical and psychosocial care of relevance to primary care. Conversely there is a need to educate palliative care service providers on the role of GPs and the nature of general practice.

3. Enhanced primary secondary care interface

There is a need to enhance communication between GPs and other specialists e.g. palliative care specialists / medicine for the elderly to enhance care for patients in nursing homes and other community settings. This expertise should be available to all patients, not only for those in hospitals/hospices. There is also a need for this expertise to enhance the care of patients dying with conditions such as Cardiac Failure, Chronic Obstructive Airways Disease and Dementia in addition to those with terminal cancer and chronic neurological conditions.

4. Support specifically targeted to primary care:

Dedicated GP liaison staff from within specialist palliative care services should be appointed to allow quick access for GPs to advice and direct access to services, such as bereavement support, occupational therapy and social work to enhance the quality of patient care. Access to these services varies across the country at the present time. These staff could also liaise with GPs in relation to proposed changes in service delivery. GP concerns regarding patients or services could be fed back to services quickly and vice versa to improve patient care.

5. Development of universal discharge processes across palliative care services:

When a patient requiring palliative care is discharged to a community setting their needs are usually complex and typically require coordination of a number of disciplines including GPs. Work is underway in the national clinical programme for palliative care on a pathway for rapid discharge of patients who wish to die at home. Many of the principles outlined in this process can be expanded to develop a universal approach to all palliative care discharges.

Conclusion

General Practitioners have a key role to play in supporting patients and their families to deal with end of life issues. The ICGP welcomes the work of the committee in enhancing end of life care provision for all.

Submitted on behalf of the ICGP by Dr Mary Sheehan Chairman

Submission to the Oireachtas Committee on Health and Children

PUBLIC HEARING ON END-OF-LIFE CARE

Staff Development and Education

Mr Bryan Nolan

Communication and Development Coordinator, Irish Hospice Foundation

14th November 2013

Contents

Introduction

The Irish Hospice Foundation (IHF) welcomes the opportunity to draw attention to the issue of how staff development and education can contribute to good end-of-life care in Ireland.

A specific part of our work at the IHF is to build on awareness of the hospice philosophy of care. We do this through a number of ways including through information and education about end-of-life care and bereavement and through the development of services and research. Our *staff development* and education work is aimed at healthcare professionals (doctors, nurses, physiotherapist, etc.) and staff generally (porters, care assistants, administrators, etc.). Our *education* work is directed towards a number of 'audiences' including healthcare staff and at the general public

There are approximately 95,000 people working in healthcare in Ireland, about half of whom work in acute hospitals and the other half in primary and residential care. End-of-life care is not confined to any part of the health service: people die in acute hospitals (about 43% of the 29,000 people who die each year in Ireland will die in an acute hospital), people die in long-stay residential care settings (about 25% of those who die), in primary care settings (about 26% of people will die at home) and in hospices (about 6%).

End-of-life care is something that is or will be of interest to all of us, sooner or later. Death and dying are part of the human experience. In the IHF, we believe that no-one should die alone, lonely or in pain. Unfortunately, isolation at end-of-life – physical and/or emotional - is too often the reality.

Irish Hospice Foundation and Staff Development and Education

Lack of appropriate education and training in gerontological care and end-of-life care among care staff and medical staff in all care settings can impede good quality care[1]. Part of our work in the IHF is to provide a comprehensive range of training and education on end-of-life care. Our training and education includes the provision of staff development workshops, taught education courses (under-graduate and post-graduate) and web-based e-learning short courses. Our educational work in support of bereavement has been detailed earlier (in a submission made to this Committee by Ms Orla Keegan on 7th November) and so, in this submission, we provide more detail on the staff development aspect of our work.

The IHF has been involved in developing and/or grant-aiding the development of a wide range of initiatives aimed at healthcare staff in the last decade or so. Over the past three years, the IHF has provided (or trained others to provide) staff development workshops to over 5,250 staff in acute hospitals and in residential care settings in Ireland. This number is a testament to the commitment of the managers and staff in the health service, who work hard to release staff, or cover for staff on release for training, or who come in on their day off. It also demonstrates the value of the workshops themselves.

We now have three different staff development workshops, all of which are powerful and which, staff say[2], make a difference to how they provide care to patients and residents at end-of-life. These three workshops are:

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[1] *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland (O'Shea et al., 2007)*

[2] *in two independent evaluations, one by UCD researchers in 2011 and another by TCD researchers in 2013*

FINAL JOURNEYS, a one-day workshop which aims to improve end-of-life care through:

- raising awareness and empowering staff to become more competent, confident and comfortable when dealing with patients and families, and
- enhancing the communication skills of hospital staff so that they are better able to deal with people who are nearing the end of their life.

This course is for **all healthcare staff**. It is a highly interactive course that draws on the experience and stories of participants using discussion, DVDs and opportunities to share examples of good practice.

Over 3,000 healthcare staff from across Ireland and Northern Ireland have completed Final Journeys. An independent evaluation of the course (by researchers at University College Dublin in 2011) showed that the course has been phenomenally successful, with over 99% of participants (of the 625 people covered by the evaluation) saying that the course was very good or excellent, and over 92% saying that it had a positive impact on their ability to communicate with patients and families at end-of-life.

***Final Journeys** has Nursing and Midwifery Board of Ireland Accreditation (7 CEUs) and IASW accreditation (3 CPD points).*

WHAT MATTERS TO ME is a one-day course, specifically designed for staff **working in community hospitals/nursing homes/long-term care settings**. The course is similar to the Final Journeys course (mentioned above), with some adaptation to reflect the longer-term nature of staff-patient/resident relationships within community hospitals/long-term care settings. The aim of the course is to:

- Improve end-of-life care in hospitals/residential care settings by enhancing person-centred care and communication skills, so that staff are better able to engage in discussions with residents, throughout their time in the hospital/care home, about what is really important to them.

This course is being offered to community hospitals/nursing homes in the Dublin, Cork and Limerick areas from 2013. Hospitals/ nursing homes outside of these areas should contact IHF to explore possibilities for support.

***What Matters to Me** has Nursing and Midwifery Board of Ireland Accreditation Category 1 Accreditation (7 CEUs) and IASW accreditation (3 CPD points).*

DEALING WITH BAD NEWS is a four-hour workshop which aims to:

- improve communication skills (confidence and competence) for healthcare staff who are dealing with or breaking bad news to patients and families.

This course is particularly suitable for **multidisciplinary teams and other staff**, including doctors, who have a role in dealing with or breaking bad news. It is an interactive course using discussion, group sessions and practice opportunities.

This workshop has Nursing and Midwifery Board of Ireland Accreditation Category 1 Accreditation (5.5 CEUs). It is also being offered in the Royal College of Physicians and participants are awarded 4 CPD points.

Staff Development Workshops in more detail

The focus in all three of our staff development workshops is very much on the person who is nearing or wanting to prepare for end-of-life. The vast majority of the time spent in the workshops focuses on this person (the patient, the service user, the resident) and the remaining balance of the time is on the staff members themselves and ensuring their self-care.

A recent published systematic review (Pulsford et al, 2013[3]) addressed the question: "*What can be gleaned regarding the most effective educational strategies for enhancing professional end-of-life care*?" This review concluded that the impact of education was mediated by the prior experience of the learners, and, importantly, by practice experience and reflection on practice – and that education needs to be reinforced in the care settings. Our work on staff development has shown us that people (staff) respond to reflective, experience-based, developmental education and training which maintains both resident/patient and staff dignity. The three staff development programmes developed to date and mentioned above have the following features:

- Experiential exercises designed to identify core principles of person-centred care
- Exercises designed to question assumptions
- Role play to promote empathy, develop and test skills
- Information to provide language and concepts for end-of-life care
- Activities demonstrating the core and central role of communication.

The aim of the IHF staff development workshops is that, through participation in a workshop, staff would feel able and confident in their relationships with the people they care for, able to see them as people (not just 'work') and confident enough to be able to talk to them about what really matters to them. In this sense, our workshops are very focused on person-to-person communication as we know that communication is central to palliative and end-of-life care. The workshops also remind staff that good end-of-life care is about respect. In this regard, we invite staff to have conversations with residents in the belief that there is possibly no better way to show respect to someone than to talk and listen and be with them at a time of possible loneliness and/or distress. There is also no better way in which to care than to give someone whole-hearted attention, encouraging them to express their concerns and doing our best to facilitate their preferences. A frequent outcome of participation in our workshops is that staff discover that they can become more relationship-focussed within the course of the normal working day (that is, without extra resources) – simply by letting themselves 'see the person' rather than busying themselves around the person.

Hearts and Minds

The IHF's staff development workshops are largely about helping staff to communicate better with people near and about end-of-life. We deliberately adopt a 'hearts and minds' approach - we educate the **minds** by giving staff good practice tools and theories about how to talk to people about their concerns, preferences, about how to break bad news and help them be with people when they are

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[3] *Classroom-based and distance learning education and training courses in end-of-life care for health and social care staff: A systematic review, Palliat Med March 2013 vol. 27 no. 3221-235*

receiving bad news, and about how to initiate difficult conversations and respond to difficult questions.

And we also put a lot of emphasis on communication being about **heart**, about *connection*, not just about technique. Death and end-of-life care are intimate issues. We work to help staff become comfortable with this intimacy because this level of connection affects them as well as those they care for. This work is emotional and good carers know this. Relationships matter, especially when we are vulnerable, and relationships between staff and patients/residents are often particularly important in so far as staff are often the brokers, advocates and mediators between patients/residents and their family and between patients/residents and other professionals. As I know you have heard in earlier presentations to this Committee (Mr Paul D'Alton, 7th November), relationships are what keep people well and relationships help when we are not well.

Human Challenges

You have also heard that the challenges to staff working in end-of-life care are more human than technical, and this is true of staff working in all health settings. Much of the focus of our work with staff is about reminding them of their own humanity and, of course, of the humanity of those for whom they are caring. In a busy hospital or when work becomes routine, humanity tends to be forgotten. Our starting point in our workshops is that is best to assume nothing about the person being cared for, and we encourage staff to care by really seeing the individual and finding out what matters to them.

Some years ago, an IHF audit of end-of-life practice in Irish hospitals found that staff were much happier talking *about* patients when they were dying than talking *to* patients when they were dying – our aim is to change this. We disenfranchise those near end-of-life when we don't acknowledge them and their experience.

Challenging Staff Fears

In order to help staff talk to people about what really matters to them at end-of-life, we need to help staff overcome their own fears about dying and end-of-life, overcome the 'tyranny of the positive' and inappropriate reassurance in place of real conversation. We also support them to find the words, the compassion, and the emotional maturity to be present to patients or residents when they are worried about any aspect of end-of-life.

We know that communication, connection and relationship are not a panacea. They cannot make people younger or less sick. They can neither alleviate physical pain, nor turn back time. But they can make a huge difference to how people die – they can make for a good death. And we know that a good death makes for better bereavement for those who remain.

Everyone's Business

End-of-life care is part or all of everybody's business in healthcare, and especially the business of those with whom patients/residents have day-to-day interaction. The cleaner and the care attendant can be just as important to the patient/resident as the medical consultant and, indeed, the patient/resident will often have a stronger relationship with the staff member who brings her her tea than with the person who diagnoses her condition. Therefore, all staff need training and development to ensure that they can deliver true person-centred end-of-life care.

Palliative Care Competency

The IHF is not alone in providing good, well-founded education and development programmes for staff working with people at end of life. Many of the higher education institutes and the Hospice Centres of Education are key players and partners in working to raise awareness amongst health care professionals of end of life care.

The IHF welcomes and is fully supportive of the emerging Palliative Care Competency Framework which sets out the requirement for foundational, mid-level and specialist skills in palliative/end-of-life care. This Framework is being developed by the All-Ireland Institute for Hospice and Palliative Care (AIIHPC). This Framework sets out competences but, in this phase of the work, does not identify curricula, learning approaches and materials to support them. An upcoming education needs analysis (AIIHPC) suggests that managers feel their staff's palliative care education needs are not being met. This is certainly a priority for strategic action.

The staff development workshops which have been described above are wholly consistent with this Competency Framework (they are foundational courses in this Framework, that is, they cover the generalist end-of-life skills that all staff should possess) and they can contribute towards building a system-wide culture of good end-of-life care.

Challenges in Delivering Staff Development

Scale and Mainstreaming

In 2007, a report from the Irish Centre for Social Gerontology noted that “education and training for all staff dealing with patients at the end-of-life is desirable, given the range of staff and potential interactions within acute hospitals and long-stay settings.”[4] In our experience and, it is emerging, in the view of health service managers[5], the needs of staff with regard to palliative care education and training are still not being fully met. If all healthcare staff (an estimated 95,000 people) are to receive training and development in end-of-life care, ‘the system’ needs to take ownership of this training and development so that is properly mainstreamed and so that it can be scaled up to the level where all staff have had some training, either at undergraduate or postgraduate level, in good end-of-life care. **The IHF recommends that the health service takes responsibility for delivering end-of-life care training and development**. At the time of writing, it is unclear what the future holds for the HSE with regard to its corporate planning of education and training. If the Department of Health is assuming oversight of all education and training of health service professionals and staff, we would be happy to work closely with the Department and/or the HSE to help plan for the delivery of developmental activities to ensure good end-of-life care.

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[4] *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland (O’Shea et al., 2007)*

[5] *Preliminary data from AIIHPC needs analysis re: palliative care education and training*

Private Contractors and Providers Must be Involved Too

Good end-of-life care requires training and development of independent contractors and the private sector as well as of those in the statutory health system. In particular, GPs and private nursing homes are pivotal players in ensuring good end-of-life care and any national strategy on end-of-life care should address how these **non-statutory stakeholders might be encouraged to attend to their end-of-life care skills and development too**. The HIQA standards for residential care settings have ensured a focus, for the moment, on end-of-life care and we are seeing a lot of interest from private nursing homes for end-of-life care training as a result. **Facilitating GPs to engage in end-of-life care training**, especially end-of-life care training that is focused on initiating discussions with people about their end-of-life care preferences or breaking bad news to people with compassion and care, is a real challenge for the system. The IHF is happy to work with any stakeholders in healthcare to try to address this issue – for example, we know that the ICGP has developed some good educational inputs for GPs on breaking bad news. Good end-of-life care needs to reflect the typical patient journey: it needs to start in the community (primary care and GPs), it needs to include acute care providers, and it needs to be available to all providers of long-stay care, whether public or private. Therefore, all providers need to be afforded opportunities to partake in end-of-life care training and development. We recommend that the **Department of Health would establish a small working group with key stakeholders to address the issue of training for all healthcare professionals/staff in advance care discussions and end-of-life care** so as to ensure that good end of life care happens across the patient journey.

Staff Support

"The heart must first pump blood to itself"[6]. In order to look after others, we must attend to ourselves. We cannot expect staff to continue to work well in end-of-life care if they are not receiving some here-and-now support. As we mentioned earlier, to allow ourselves to connect to others at end-of-life means we must be somewhat open ourselves to being affected by it, touched by the other person. **Support does not have to be expensive or resource-intensive**, it does not necessarily mean having to build new centres or employ more people. It can often be enough for managers and colleagues to acknowledge that the work can be difficult, and to offer a little care to colleagues in the form of a short break, or time to review and debrief if it has been a particularly demanding patient/resident death. Managers, in their roles as quality assurers, should also be encouraged to coach staff so that staff are reviewing and reflecting on their own end-of-life care practice too.

RECOMMENDATIONS / ACTIONS

- Ensure that a national strategy on bereavement and end-of-life care recognises the importance of mainstreaming end-of-life care staff development for all healthcare staff.
- Ensure that training and development in end-of-life care and bereavement is offered to all health care staff and professionals, whether part of the statutory service provision system or independent/private sector providers.

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[6] *Shapiro SL, The Art and Science of Meditation, 2008*

- Engage with key stakeholders to agree an approach to facilitating GPs to take part in end-of-life care training and development.
- Endorse and support the Palliative Care Competence framework for all health professionals – this framework includes foundational training for all staff in end-of-life care.
- Encourage care and support for staff too, by encouraging health service workers to seek support and provide care to colleagues. Managers should be encouraged to acknowledge the challenges inherent in end-of-life care, and to value “emotional labour” (psychological support to the dying person), and to coach and support staff in their provision of end of life care.

Thank you.

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

Bereavement Care

Briefing Document

Orla Keegan, Bereavement Education & Resource Centre, Irish Hospice Foundation

November 7th 2013

THE IRISH
HOSPICE
FOUNDATION

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-year-olds 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 non-bereaved 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

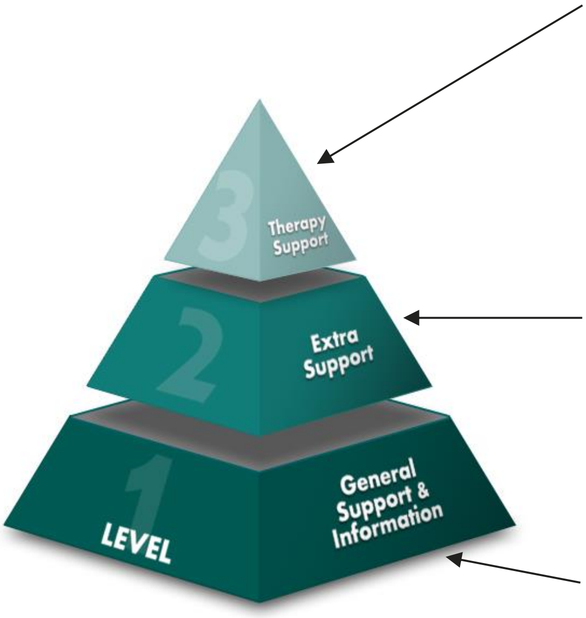
Our policy resources in Ireland are poor when it comes to bereavement and loss – what we have by way of mandate or direction is rooted in specialised areas (e.g. Report of the National Advisory Committee on Palliative Care, 2001) or in response to crisis (e.g. both the Madden, 2006, and the Willis, 2009, 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 bereavement and loss will foster a comprehensive approach to building strength, promoting care and understanding and supporting services responsive to bereaved 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 bereavement 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 educaiton 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 bereaved 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 bereavement 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

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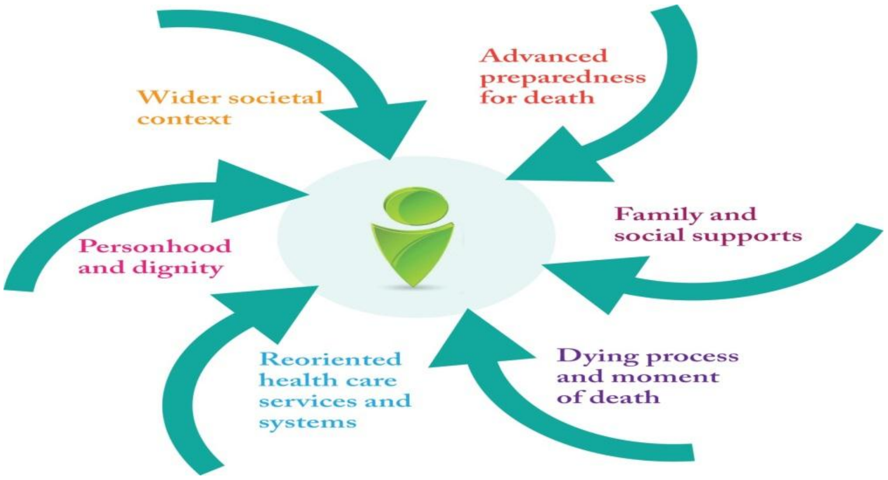

Sharon Foley, Chief Executive Officer,
The Irish Hospice Foundation
24th October 2013

"Life and death are one. Though life comes before death, and though death is the threshold of a new life for some, the progression from life to death is unique to each of us; it can happen at any age, at any time, in any place. It is not as amenable to control as we might wish. Good management of death – our own and others – therefore requires that we all stand ready for it at all times. It implicates everyone in society, as the sum and breadth of the contributions to the Forum make clear. Fewer than a quarter of people are likely to die between 9 and 5, Monday to Friday. Likewise, dying, death and bereavement cannot be left to any particular sector or service on its own: to the emergency services, to hospitals, to nursing, to the gardai, to hospice or to palliative care services, to gerontological services, to funeral directors or bereavement services. But all must play their part. All members and sectors of society must be ready to recognise and uphold the uniqueness and therefore the dignity of each of its citizens at end of life and in death. To do otherwise is both to bury our heads in the sand and to betray our common humanity. The development of high quality end-of-life care is a public health, population-wide endeavour; it is not a specialism, nor is it restricted to any condition or to any group of people. It is preventive rather than a curative in approach, seeking to minimise and even prevent physical, emotional, social and spiritual pain and to maximise the quality of life of those at end of life."

Forum on End of Life in Ireland – National consultation report[1]

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[1] Perspectives on End of Life: report of the Forum 2009; Forum on End of Life in Ireland.

Introduction

What is the hospice/palliative approach to care?
We believe that good end-of-life care is embodied by the hospice approach, which prioritises dignity and respect; seeks to relieve pain and distress; cares for the person and those who are important to them; and is mindful of the role played by the physical environment in providing for the needs of those facing the end of life. The hospice approach allows people to live life as fully as possible to the end.

The Irish Hospice Foundation (IHF) is a national charity dedicated to all matters relating to dying, death and bereavement in Ireland.

Our vision is that no one should face death or bereavement without the care and support they need.

Our mission is to achieve dignity, comfort and choice for all people facing end of life. We do this by addressing with our partners and the public, critical matters relating to dying, death and bereavement in Ireland.

Our work centres on development, aimed at:

- improving access to hospice services
- ensuring the continuous development of high-quality care for people with life-limiting illness and their families, from initial diagnosis through to bereavement
- building support for the hospice philosophy in all care settings.

Established in 1986 in response to a need to develop and fund specific hospice services, the IHF has endeavoured from the start to be innovative and pioneering.

We believe that good end-of-life care is embodied by the hospice approach, which prioritises dignity and respect, seeks to relieve pain and distress, and is mindful of the role played by the physical environment in providing for the needs of those facing the end of life. **The hospice approach allows people to live life as fully as possible to the end.**

Over time, the IHF's work has expanded to embrace the needs of people dying in hospitals, at home and in other institutions, as well as those who traditionally could not easily access hospice care because of the nature of their illness.

Where service gaps appear, we work to see them closed by engaging in a variety of initiatives and partnerships. In addition, we actively promote discussion of a broad range of issues related to dying, death and bereavement in order to identify what matters most to Irish people at the end of life and how best to address their concerns.

Governed by a Board of Directors, the IHF is funded through its own fundraising and the generosity of supporters, and receives no core funding from the State.

The Joint Oireachtas Committee on Health & Children posed the question as to why it is important to pay attention to end-of-life care, establishing what needs to happen to ensure that people die well in Ireland. This paper will answer that question, drawing on the experience of the IHF.

The IHF would like to take this opportunity to recognise the momentous opportunity presented by these hearings to highlight the key issues facing people nearing the end of life, along with the many initiatives that are already happening and which should be mainstreamed in order to ensure the delivery of the best end-of-life care. We commend the Committee, chaired by Deputy Jerry Buttimer, for deciding to raise this issue.

IHF – FACTS AT A GLANCE

Area	**IHF programmes (not exhaustive)**
Children with Life-limiting conditions	• Investing €2.5m in implementation of 2010 National Policy for Children with life-limiting conditions • Funding Ireland's first (and only) Consultant Paediatrician with a special interest in palliative care • Funding 5 out of 8 Children's Outreach Nurse posts nationwide • Funded the training of over 1,500 healthcare professionals
People who die in hospital	• The award-winning Hospice Friendly Hospitals Programme, which involves development of resources, staff training, research, and development of an audit system.
Home deaths	• Primary Palliative Care programme supporting GPs to identify patients with palliative care needs in the community. A GP handover form is also being developed to notify out of hours GP services of palliative care needs of patients.
Care for patients with illness other than cancer	• The IHF's Palliative Care for All Programme has funded action research projects to extend palliative care to people with Chronic Obstructive Pulmonary Disorder, heart failure and dementia • A free *Nurses for Night Care* service for patients with illnesses other than cancer to support them to die at home • *Changing Minds* Programme to promote excellence in end-of-life care for people living with dementia
Development of specialist palliative care	• Advocates for the development of specialist palliative care services • Provides grants for the development of services • Organises the two main national fundraising events of the year for local hospice services
Bereavement	• Education courses for healthcare professionals in bereavement and on 'children and loss'. • Training in bereavement support for community, education, health and private organisations • Advising companies and organisations in developing workplace bereavement policies • Developing resources for the bereaved.

Summary

End-of-Life Care - Why it matters

Death is both a universal and inevitable experience. A fact of life. While most people will experience 'death denial', it is not appropriate that the State should adopt the same attitude. With over 300,000 people dying or newly bereaved each year (29,000 deaths and 290,000 people bereaved in 2012), and with about 10% (€1.3bn) of the national healthcare budget being invested in end-of-life care, it is essential that the State meets the needs of its people and ensures that everyone gets equal access to good care.

We need to plan to ensure that we deliver the best possible care to all of our citizens on their final journey. And by careful planning, we can make the best use of the funds that we directly and indirectly invest in the care of the dying.

We know what works

Hospice care works. Many international studies indicate savings when patients access hospice programmes. They also show improved length of life, better symptom control and a better patient and carer experience[2].

Hospice services can meet the needs of patients and provide real savings to the healthcare system. Ensuring that patients with life-limiting conditions are cared for in the most appropriate setting for their needs is a better use of health resources and could potentially reduce unnecessary admissions to hospital as well as waiting times in emergency medicine departments.

We know that a hospice approach to care across all settings (including excellent communications, planning, comfort and access to specialist services) has a positive impact on patients and on their families. Moreover, it is the type of care that people want.

Context

A growing need

About 29,000 people die in Ireland every year. Over 80% of all deaths in 2012 were of people aged 65 years and over – but there are also about 350 child deaths from life-limiting conditions each year.

While IHF research from 2004 found that 67% of people wish to die at home, seven out of 10 of us will die outside our own homes – 43% in a busy acute hospital[3].

Ireland's population is both growing and ageing. We currently have one of the youngest populations and the lowest proportion of people aged over 65 in the European Union. But this is changing.

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[2] Prospectus Consulting, Acute Hospital Bed Capacity Review, 2007

[3] Weafer, J.A., A Qualitative Study of Public Perceptions of End-of-Life Issues, IHF**,** September 2009

Irish people are living longer today than in previous generations. In 2011, there were over half a million people aged over 65. Thirty years on, it is estimated that that number will reach 1.4 million. So there will be more of us, living longer and living with chronic illnesses such as dementia, cancer and heart failure. It is estimated that up to 13,000 patients will require access to hospice and specialist palliative care in 2016.

While the focus of the healthcare system is on cure, we are spending a significant amount of our time and resources on caring for people at the end of life – but much of that time and spending is unplanned. Our national policies on palliative care date back over 10 years, and most of the recommendations are unfulfilled. While worthy documents, they should at this point be reviewed.

A study[4] commissioned by the Health Service Executive (HSE) found that 40% of patients being cared for in hospitals could be more appropriately cared for elsewhere. More can be done within the health service to coordinate and deliver high quality end-of-life care.

The hospice approach

The principles of palliative care[5] include ensuring a good quality of life, minimising pain, achieving good symptom control, communicating clearly with patients and showing caring support to families. Care informed by these principles is a vital and integral part of all clinical practice in all care settings, whatever the patient's disease or its stage. Palliative care is frequently a component of routine care provided by healthcare professionals to patients, but it is not always described as such.

Understanding of the contemporary meaning of 'hospice' is growing, along with appreciation of the benefits of hospice care – also referred to as specialist palliative care. Among other things, its role in the care of people with *any* life-limiting condition – and not just cancer – is increasingly being recognised. Furthermore, it has strong roots in the community and voluntary sector, which contributes – and is willing to contribute further – both financially and in terms of experience, to service planning and development.

The care provided by specialist palliative care services draws on the expertise of multidisciplinary teams skilled in the management of pain and other complex and demanding symptoms, working in specialist in-patient units (hospices), in the community and in acute hospitals. These professionals also have a key role to play in advising and supporting colleagues in other disciplines and care settings; and are increasingly involved in education, research and community development.

Thankfully, most of us will not require 'specialist' palliative care, but will hopefully have our palliative and end-of-life care needs met by our GP or other clinician. But for those of us who do require specialist services, our level of access to them is currently determined by where we live.

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[4] Prospectus Consulting, Acute Hospital Bed Capacity Review, 2007

[5] Palliative care is defined by the World Health Organisation as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It affirms life and regards dying as a normal process and intends neither to hasten nor postpone death."

Spending on end-of-life care

The specialist palliative care budget in 2013 was €72m. This was the budget to run a national service for patients with the most complex needs, requiring specialist support to control their pain and other symptoms.

With this relatively small budget, in 2012, some 8,066 new patients[6] benefited from specialist palliative care provided by home care teams, with on average 2,978 people[7] cared for each month. In the same year, 4,274 people[8], including 2,203 new patients[9], availed of specialist inpatient care.

International research shows, however, that **10-15% of a national healthcare budget is actually spent on end-of-life care.** In Ireland, this would be about €1.3 billion.

Why an end-of-life strategy?

Any element of a national healthcare system that cares for a significant proportion of the population, expects client numbers to continue to grow, and commands a significant direct and indirect budget, must plan effectively for the future delivery of services. This is particularly the case with palliative and end-of-life care.

The management of our approach to dying, death and bereavement within our health service matters – not only to patients and the health system, but to the whole of society.

Our primary recommendation is that the state should develop an end-of-life and bereavement strategy to cover all aspects of dying, death and bereavement in Ireland.

A truly strategic approach to the care of people facing the end of life makes sense because:

- Death is a natural life experience which **affects a significant proportion of the population** every year.
- **Demand for palliative care is growing**, as more people are living longer with life-limiting conditions and will therefore have increasing palliative care needs.
- Anticipating and planning for people's palliative care needs will ensure that they have a **better quality of life**, and will increase the chance of each person dying in the care setting of their choice.
- Up to **€1.3 billion is actually being spent on end-of-life care** – but this expenditure is largely unplanned. With careful attention, better patient and service outcomes can be achieved for this amount.

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[6] Figure received from HSE 12th June 2013

[7] Ibid

[8] Parliamentary Question reply 2nd May 2013 (PQ number 20437/13) and Adjournment Debate in the Seanad, 27th June 2013.

[9] Figure received from HSE 12th June 2013

- Developing a strategy for the palliative care needs of the population will allow the government **to fulfil many of the welcome and ambitious commitments made in the Programme for Government.**

- Anticipating needs and planning for palliative care can assist in **preventing inappropriate emergency admissions** to expensive care settings such as acute hospitals, and can **facilitate discharge and the provision of care closer to home, in line with patient preferences**

- **Public interest**[10] in end-of-life issues is increasing and is likely to result in more public demand that everyone should be able to have a 'good death'.

- A **public health approach** to end of life care can enable specialist palliative care services to share their expertise with the community and encourage them to discuss end-of-life issues and engage in social models of care that may **reduce healthcare costs** and increase a person's likelihood of being cared for within their own community.

- **A significant resource is available in the form of the voluntary sector**, which is currently pioneering important developments in the area of care at the end of life, and is committed to innovation.

- Specialist palliative care services play a critical role in the development and provision of care for people with life-limiting illnesses **in all care settings,** which makes it an **important component of the overall health service.**

The current restructuring of the health service offers a strategic opportunity to focus on end-of-life care and ensure that people can 'die well' in Ireland.

However, to achieve better care for people with palliative and end-of-life care needs will require development at a number of levels, and any new directions or structures for specialist palliative care will need to be underpinned by clear principles:

- **Strategic leadership** at the highest level of the health service – this will be essential to drive the development of comprehensive palliative care services as a core government commitment.
- The **integrated provision of palliative care** to all patients in every healthcare setting, including – where clinically feasible and in keeping with the patient's wishes – in the home.
- To ensure the **seamless delivery of services** across all six of the new HSE Directorates, a **mechanism for coordinating responsibility for palliative and end-of-life care**.
- The adoption of a **public/population health approach** to palliative and end-of-life care.

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[10] The Irish Hospice Foundation's *Forum on End of Life in Ireland* enjoyed significant public engagement during its period of public consultation in 2009-2010

Current challenges

As a society we are faced by numerous challenges concerning the care of those who are dying and those left bereaved. These include:

- the need for protracted end-of-life care as people live longer with chronic diseases, including dementia, cancer and heart failure
- the economic realities facing our country and our health care services
- the current regional inequity in the provision of hospice in-patient services
- the changes under way in the health service and in how services will be delivered
- the ongoing need for bereavement care.

RECOMMENDATIONS:

PRIMARY RECOMMENDATION:

THAT THE STATE SHOULD DEVELOP AN END-OF-LIFE AND BEREAVEMENT STRATEGY TO COVER ALL ASPECTS OF DYING, DEATH AND BEREAVEMENT IN IRELAND

Medium-term recommendations:

- The specialist palliative care budget should not be allowed to fall below current (2013) levels.
- More practical funding methods should be explored for specialist palliative care; the 44 existing (but unopened) additional beds should be brought into commission as soon as possible; and the HSE should move to pre-planning stage for those areas of the country which currently have no in-patient unit.
- Within the HSE's Clinical Care Programmes for chronic illnesses, work-streams should be developed to include palliative/end-of-life care, including bereavement care.
- A formal framework should be developed to provide guidance, support and resourcing for GPs and primary care teams caring for patients who are dying at home, as part of a national integrated care plan linking primary care, hospice care and hospital care.
- The legality of advance care directives should be underpinned by the provisions of the Assisted Decision-Making (Capacity) Bill 2013 and this should be brought into effect as soon as possible.
- The current provision for medical cards for people with terminal illness should be sustained and underpinned by clear criteria for renewal without means test should this be required.
- Each of the new hospital groups being developed by the HSE should have an end-of-life care plan.
- Sustainable funding and implementation of the National Policy on Children's Palliative Care should be planned for.

END OF LIFE CARE IN IRELAND

We need to plan to ensure that we deliver the best possible care to all of our citizens on their final journey. And by careful planning, we can make the best use of the funds that we directly and indirectly invest in the care of the dying.

Cost of caring for the dying – ethical economics

International studies have shown that more than one quarter of a person's lifetime health expenditure will occur in the last year of life. International studies have also found that where health services invest in hospice care, medical costs can be reduced by up to 25% because most people are cared for at home (70% of people who use hospice services are cared for in the home); there are fewer acute hospital admissions, shorter stays and less intensive care procedures. Hospice patients also live longer and in greater comfort and dignity.

The following is a summary of some of the relevant international evidence:

- The healthcare budgets of most countries are skewed towards spending on care in the last year of life. Although less than 1% of a country's population die every year, it is estimated that up to 30% of all hospital expenditure goes towards caring for people in the last year of life[11].

- Working with an estimate that between 10% and 12% of the total healthcare budget is spent on caring for people in the last year of life[12], this would amount to more than €1.3 billion of Ireland's current total health budget of over €13 billion.

- Spending on the last month of life is the highest. Between 25% and 33% of the average person's lifetime health services consumption occurs in the last year of life. This can be roughly estimated at €70,000, out of a lifetime average spend of €300,000. About 40% (€28,000) of this 'last-year' expenditure happens in the last month of life.[13]

- All of the studies show that proximity to death, rather than age, results in very high use of health service resources.[14]

- The cost of dying in an acute hospital is far greater than in other healthcare settings. For example, in one study which examined 30,000 elderly patients with heart failure who died between 2000 and 2006 in Alberta, researchers found that when heart failure patients die in an acute hospital the cost is more than double that than when they die elsewhere, such as at home or in a palliative care facility. This finding is not surprising – acute hospitals are designed to cater for patients with acute medical needs, and such medical interventions are likely to be cost intensive.[15]

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[11] Gray, A. 2004. Estimating the impact of ageing populations on future health expenditures.

[12] Polder et al, 2006. Healthcare costs in the last year of life: the Dutch Experience.

[13] Ezekiel E et al, 2002: Managed care, hospice use, site of death and medical expenditures in the last year of life.

[14] Raitano, M., 2006: The impact of death-related costs on health-care expenditure: A survey. ENEPRI research report No 17.

[15] Kaul, P. et al, 2011; Resource use in the last six months of life among patients with heart failure in Canada. Archive of Internal Medicine.

We have no reason to believe that the situation in Ireland is any different to that of other countries. It is estimated that the **total** average cost per patient receiving specialist palliative home care support is €686. The average length of stay in home care in the Mid-West hospice service was almost six months[16]. A bed in an acute hospital costs about €1,000 a day. The average length of stay for a dying patient's final admission to hospital is 22.5 days. That comes to about €22,500.

Because specialist palliative care teams offer integrated care across all care settings, patients referred to palliative care teams in hospitals have a clear discharge pathway out of hospital where community supports are in place to meet their needs. Lack of available community services other than specialist palliative care can militate against discharge home

Elements of a good death

We have established why end-of-life care matters. We believe that no one should face death or bereavement without the care and support they need. We recognise that the concept of a good death is deeply personal, and that we differ in what each of us wants, for ourselves or for our loved ones. However, it is possible to identify some elements which may facilitate 'dying well'.

What we present below is the outcome of Irish and international research with dying persons, bereaved relatives and those providing end-of-life care.

The diagram overleaf illustrates some of the factors which influence a good death. Some, such as family relationships and mental health, are deeply personal – but many rely in at least some part on the actions of society, state services and communities. And what is fundamental in this diagram is that the person is truly at the centre of the informal and formal care provided, and of wider policy and infrastructural decisions.

In short, we believe that there is much which can be done by the State, by voluntary services and by society itself to ensure that people are facilitated to die as well as possible in Ireland.

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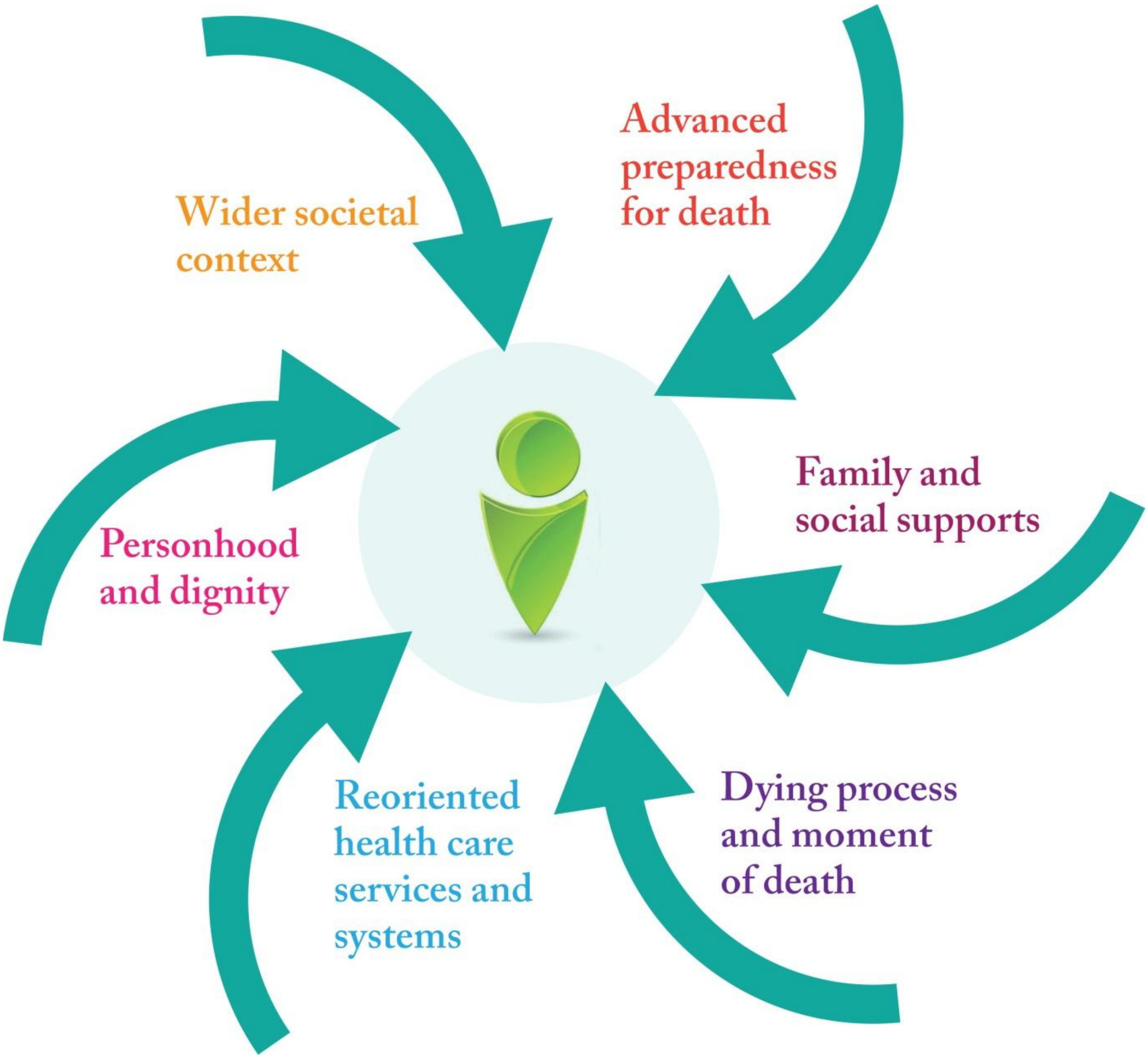
[16] Irish Hospice Foundation 2013: Access to Specialist Palliative Care services and Place of death in Ireland – What the data tells us.

Figure 1: **Factors influencing the 'quality' of dying/death** *(IHF, 2013)*



1. Personhood and dignity

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."
Dame Cicely Saunders, nurse, physician and writer; and founder of the modern hospice movement (1918-2005).

Being treated with respect and recognised as a person are basic expectations of any care system, and being able to retain this sense of **personhood and dignity** is a need expressed frequently by those facing the end of life. For the person who is dying, this translates into being allowed to participate in care decisions, feeling that one's wishes are considered and upheld, feeling respected by staff and knowing that one 'matters', right to the end.

Sadly, the recent review of the Mid-Staffordshire Foundation NHS Trust[17] in the UK has shown how easy it is for the necessary 'culture of care' for those nearing end of life to become lost. Hospital systems, procedures and processes allowed this negative drift to develop gradually over time. There are a number of areas which need to be given careful attention in order to stop this happening.

Staff Training and Development: On-going staff training and development is one of the areas which can help redress the balance. The IHF offers a suite of staff development workshops that have grown out of our Hospice Friendly Hospitals Programme and are relevant for staff right across the health sector. Focusing on competence and compassion, they are variously entitled, *Final Journeys* (primarily aimed at acute hospital staff); *What Matters to Me* (for staff in residential settings) and *Dealing with Bad News* (for staff working in a range of care settings, including doctors). The focus of these workshops is on putting the person (the patient) at the centre of end-of-life care by looking at culture (*'the way we do things around here'*) and communications. Over 4,000 staff have taken part in these programmes and feedback from participants has been overwhelmingly positive.

This type of training needs to be mainstreamed and supported by a commitment within our health services to supporting such staff development initiatives and underpinning them by staff release.

Competence Framework: The IHF is also involved in and is actively promoting the HSE's National Palliative Care Competence Framework. This will guide all healthcare professionals working in all healthcare settings by setting out their responsibilities and expected practice across six domains: the principles of palliative care; communications; optimising comfort and quality of life; care planning and collaborative practice; loss, grief and bereavement; and professional and ethical practice.

This framework will enhance the care of people with life-limiting illness by setting out the knowledge, skills, attitudes and behaviours required of doctors, nurses, midwives, healthcare assistants and a range of allied health professionals. One of the framework's major contributions is clarifying that care at the end of life of part of the responsibility of all staff.

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[17] Inquiry into the operation of the commissioning, supervisory and regulatory bodies in relation to their monitoring role at Mid Staffordshire NHS Foundation Trust. Final report, February 2012

Advance care planning: Advance care planning allows a person to think about and make decisions on their future care – for many it is a way of ensuring a level of autonomy and control at end of life. However, it needs to be underpinned by legislation. Advance planning and advance care directives are recognised in common law. There has been a commitment by Government that this will be added to the recently published Assisted Decision Making (Capacity) Bill 2013 at Committee Stage. There is an emerging evidence base regarding the role that advance care planning can play in improving the quality of care that can be delivered by health professionals. Facilitating advance care planning is also consistent with national policy to promote the expert patient.

Main Action Points

- Include staff training and development in communications and end of life care (such as *Final Journeys*) into all continual professional development
- Facilitate staff release for training
- Implement the Palliative Care Competence Framework
- Facilitate advance care planning and legislate for advance care directives

2. Dying process and the moment of death.

Regardless of the plans we put in place throughout our lives, the very nature of the cause of our death will impact on whether it is a 'good death' or not. Many of us would like to 'slip away in our sleep at a ripe old age'[18], but this is not the reality for everyone. However, much can be done to ensure that the dying process is as peaceful as possible.

Access to pain and symptom control: Central to good end-of-life care is access to adequate pain relief and symptom control when needed. In Ireland, there has been considerable investment in specialist palliative care, but unfortunately that investment has not resulted in equitable access to palliative care for people with life-limiting conditions other than cancer – e.g. advanced kidney disease, neurological disease, heart failure, respiratory illnesses, etc. – who may also have a heavy and complex symptom burden.

Night nursing: While most people would prefer to die at home, the responsibility and burden of care that may fall on families as the end approaches can be daunting. With the right supports in place, however, unnecessary hospitalisations can be avoided. The IHF funds a service known as *Nurses for Night Care*, which aims to support people with diseases other than cancer to die at home. Delivered in association with the Irish Cancer Society – which funds night nursing itself for its own patient group – this service reached over 300 families in 2012.

Medical card for people with terminal Illness: The current provision of a medical card without means testing to terminally ill persons approaching end of life can be an important factor in facilitating good end-of-life care. It not only relieves some of the financial burden of the medical interventions and medication that terminal illnesses can entail, but perhaps more importantly, it

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[18] A Qualitative Study of Public Perceptions of End-of-Life Issues; John A. Weafer; IHF**;** September 2009

allows access to a range of community supports that would not otherwise be routinely available to the person. It is important, in the event that such cards need to be renewed after six months, that the HSE ensures that the system responds swiftly and sympathetically to the variety of circumstances and complexities faced by individuals in these circumstances.

Support for spiritual care: The hospice approach to care promotes holistic care for the dying person and those who care for them – including their spiritual care. Loss is personal and can bring us face to face with the 'big questions' in life. Spirituality is hard to define in a way that appeals to everyone – it means different things to different people – and perhaps for that reason, people today often find it difficult to find expression for their spirituality. Part of palliative and end-of-life care is to ensure that the space is there to meet and engage with a person on their own terms, and this includes their spiritual side.

Main Action Points

- Support and mainstream initiatives such as Nurses for Night Care
- Protect the medical card for people with a terminal illness.
- Promote the hospice approach to care to ensure all care needs are met.

3. Family and social support

In many ways, a good death draws on aspects of the life that preceded it, and positive relationships and the support of family and community have a significant bearing on how people die. Some of these things are highly personal, but much can be done at the level of the community and the wider society to positively impact the experience of those facing the end of life.

Community relations: There are many ways in which communities can be encouraged to support those who are dying and those who are bereaved. An example is the *Compassionate Communities* project initiated by Milford Care Centre in Limerick in 2011, which is now being piloted in Limerick City and Newcastlewest. This project recognises that dying, death, loss and care affect us all, and are not just the responsibility of health and social care professionals. Most people who are living with advanced life-limiting illness spend their time at home in their neighbourhoods and communities. The *Compassionate Communities* project seeks to work in partnership with individuals, groups and communities to enhance the social, emotional and practical support available to those living with serious life-threatening illness; those facing loss; and those experiencing bereavement.

This type of managed project can build on the existing goodwill and effort of communities across Ireland – such as local hospice support/fundraising groups; other volunteer-based support groups, parish support groups in (for example) such areas as suicide, childhood bereavement and so on.

Carers: It is important that the special needs of carers caring for a loved one at end of life are recognised and supported by the healthcare system and the wider society. In addition to the night nursing service referred to in the previous section, the IHF helps to link carers to additional sources of support and information on a range of issues of relevance to them via the website, www.carers.ie

Bereavement care: The care provided to the person who has died lives on forever in the lives of their family and friends. In this sense, care of the patient is also bereavement care. 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).

As regards caring for bereaved people, our intuition often tells us that just 'being there', providing practical help, giving of our time and a listening ear is what most people need most. Accurate information on what is known about bereavement can also help people to travel through uncharted territory.

Nevertheless, in our 2011 survey, more the one in five people said they did *not* receive the support they thought they needed. The IHF seeks to promote people's comfort in talking about loss and in supporting others. We host a wide information resource in the area of bereavement, distributing tens of thousands of information leaflets every year and developing videos, books and other information materials.

From research we know that formal help includes a range of appropriate interventions, from volunteer-based listening services through to psychological therapies. 'Complicated grief', characterised by significant impairment and a sustained inability to engage with day-to-day life, may be experienced by 10-15% of people. This is a problem requiring professional help.

Main Action Points

- Support community initiatives such as *Compassionate Communities* and other innovative projects which aim to stimulate debate and provide more support for those facing death or bereavement.
- A national bereavement strategy should be part of a national strategy on end of life in Ireland

4. Reoriented health and social care services and systems

The health service is facing particular challenges concerning end-of-life care. At present, about 29,000 people die in Ireland every year. However, projections indicate that the population aged over 65 will increase significantly over the next few decades.

While many people will maintain good health into old age, this is likely to give rise to a significant increase in the number of people with chronic life-limiting diseases, requiring care over longer periods. It will be a challenge to ensure that high-quality end-of-life care is available to people with all life-limiting illnesses, in all care settings.

The medicalisation of dying: Ensuring a good death for our loved ones is largely about culture change and will take time. Traditionally, end-of-life care was not seen as a core activity of hospitals, for example. Deaths were not included in service plans or adequately reflected in hospital cultures, systems and structures. To this day, basic data on deaths in each hospital is not routinely published.

All too often medical training is focused exclusively on treatment and cure, but sometimes death is simply part of the natural life cycle rather than a 'failure' to cure. Recognising this fact can enable care plans to be adjusted to focus more on quality of life.

Chronic conditions and end-of-life care: Of particular concern today is the projected increase in chronic conditions such as advanced respiratory disease and dementia.

Diseases of the respiratory system are the cause of one in five deaths in Ireland (almost double the EU average), and people with advanced respiratory disease such as COPD may have a higher disease burden than those with lung cancer, with less access to specialist medical care to relieve the distressing symptoms they face at end of life.

Dementia is a poorly understood and highly stigmatised condition, affecting about 41,000 people. In the next 30 years, the number of people living with this condition is expected to reach nearly 141,000.

About 34% of Irish people with dementia currently live in residential care, and almost one in five acute medical beds are occupied by people with dementia. Just under two-thirds of residents in residential care settings have been diagnosed with the condition. The challenge we face is ensuring that our citizens with dementia receive excellent care at the end of their lives.

The National Audit of End-of-Life Care conducted by our Hospice Friendly Hospitals (HFH) Programme in 2009 assessed the quality of care provided by Irish acute and community hospitals to 1,000 patients in the last week of life. The data was gathered from nurses, doctors and relatives who spent most time with the patient during their last week of life.

The points which follow relate to the audit's findings about people with dementia at end of life.

- The audit revealed that a hierarchy exists in the quality of dying in Irish hospitals, based on the patient's disease. The range from best to worst is cancer, circulatory diseases, respiratory diseases, dementia/frailty.
- People with dementia had the longest stay in acute or community hospitals following admission (55 days average).

- Staff were more likely to discuss the diagnosis/prognosis, etc. with relatives than with the person with dementia. 26% of staff reported no discussion with the patient because of dementia.
- Input from specialist palliative care was lowest for people with dementia, compared to those with cancer/circulatory/respiratory diagnoses.
- People with dementia were perceived by nurses and doctors to be least likely to experience anxiety.
- People with dementia were more likely to die in multi-occupancy rooms, where there is less (and poorer) communication and where relatives are less likely to be present at the moment of death.

The IHF's Palliative Care for All Programme was set up to develop the palliative care skills of staff caring for people with chronic life-limiting diseases in all care settings – nursing homes, hospitals and the community. The aim was to ensure that **all** patients living with life-limiting conditions could access the appropriate care they needed to live a quality life. It involves engaging staff from disease-specific and older persons' services with their colleagues in specialist palliative care in acute and community settings.

It is vital that the learning and practices emerging from initiatives such as our Palliative Care for All Programme and our recently launched *Changing Minds* Programme[19] – Promoting Excellence in End-of-Life Care for People Living with Dementia – is not lost, but where appropriate, shared and mainstreamed.

Health service reform and reorganisation: The health service is currently undergoing major transformation, which, underpinned by the HSE's new Clinical Care Programmes, will result in changes in the way services are delivered.

It is clear there are changes required to ensure that our health care services are fit for purpose in delivering the best end-of-life care across every setting.

Each of the HSE's new hospital groups should be required to have a comprehensive end-of-life care plan. A process for reviewing the quality of end-of-life care should be integrated in its delivery, and key performance indicators should be developed to provide insight into performance in both the acute and primary/community care sectors.

All health facilities in acute and community hospitals and nursing homes should be required to publish the number of deaths that have occurred in the past year as part of their annual report of activities and outcomes, demonstrating that they have a system for review and audit of deaths in place. This would acknowledge their role in end-of-life care.

At a local level, we must preserve staff release for training, as there is a need for a technically and socially competent workforce to help meet patient need in a range of remits and care settings. Projects piloted in healthcare sites which prove effective should be mainstreamed.

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[19] The *Changing Minds* Programme is co-funded by the Irish Hospice Foundation and Atlantic Philanthropies

On a strategic level, the IHF recommended a number of actions in the first paper in our *Perspectives* series, entitled *The Strategic Importance of Palliative Care within the Irish Health Service: Perspectives on Future Service Delivery*.

The paper recommended that a senior official of the Department of Health should be assigned responsibility for overseeing the entire palliative care budget. The services should be managed as a single entity to avoid fragmentation and should have a dedicated, trackable budget under the annual health budget (details are in Appendix 1).

Social care supports

Bereavement grant: The IHF believes the Government should reverse its decision to abolish the bereavement grant in its entirety. Bereavement support begins with practical help and sound information in the aftermath of a death and at the time of the funeral. Any systematic societal approach to bereavement care must begin with such support, including financial aid. This cut also represents a burden on older people and on their psychological security concerning funeral arrangements and peace of mind.

Main Action Points:

- Challenge the medicalisation of death
- Ensure the extension of palliative care to people with all chronic illness
- Ensure that the end-of-life care needs of people with dementia and their families are considered in the National Dementia Strategy
- End-of-life care plans drawn up for each hospital group
- Implement the recommendations of the *The Strategic Importance of Palliative Care within the Irish Health Service: Perspectives on Future Service Delivery*
- Reverse the decision to abolish Bereavement Grants in their entirety.

5. Advance preparedness for death

We have all heard of or have had personal experiences of the disruption that follows when a family member dies without leaving his or her affairs in order. Often, those who are left behind have to deal with sadness and grief while also trying to guess what a loved one or friend might have wanted if they could have spoken for themselves.

Some facts to consider:

- Seven of 10 Irish adults do not have a will
- Half (48%) of married couples or those living together have not updated their will in the last 2-5 years
- More than half (53%) of those with children do not have a will.

We know from an IHF study in 2004 that it is the wish of most of us to be able to die peacefully, conscious, and capable of communicating with our loved ones to the very end. Unfortunately, death does not always occur in this way, and there may be times when we will want others to know our wishes in advance.

Planning ahead for end of life is an aspect of preparation for the future which is difficult for us all. Yet increasingly, there is a demand for more support and recognition for advance planning. The easiest example is a will; others include advance care planning for situations where a person may be incapacitated.

The IHF knows that thinking about dying is challenging, and talking meaningfully with those who are close to us about the prospect of serious illness, dying and death can be difficult. We have developed *Think Ahead* as a citizen-led tool to encourage members of the public to start this process at an early stage, beginning with helping them to reflect on their personal values, beliefs and understanding about end of life. *Think Ahead* aims to guide people in discussing and recording their care preferences in the event of an accident or other emergency, serious illness or death, when they may be unable to speak for themselves. It comprises a detailed form divided into six sections: (1) Key Information; (2) Care Preferences; (3) Legal Matters; (4) Financial Matters; (5) When I Die; and (6) Sharing Information. An initiative of the Forum on End of Life in Ireland, *Think Ahead* was launched by the Taoiseach, Enda Kenny, at the Forum's national conference in October 2011. Having been piloted with a number of groups and in two counties, it is currently being rolled out nationwide.

As previously stated, it is vitally important that advance care directives – while currently legal – have a legislative framework. We welcome the government commitment to rectifying this situation in the Assisted Decision Making (Capacity) Bill 2013 at Committee Stage

To ensure that people's preferences for care are respected, an education programme for healthcare staff must be put in place. Protocols, training and documentation must also be developed. The HSE is coordinating this process and the IHF is pleased to support this development.

Main Action Points:

- Advance directives must be added to the Assisted Decision making (Capacity) Bill 2013 at Committee Stage and this provision enacted as soon as possible.
- The HSE must develop an advance care planning policy, documentation and staff training
- Initiatives such as Think Ahead – a citizens' tool - should be encouraged

6. Wider societal context

The hospice philosophy is a positive one which emphasises quality of life and looks to relieve suffering, whether physical, emotional, psychosocial, social or spiritual.

For many people, however, death and dying are difficult subjects, raising questions they may be reluctant to think or talk about, even though these are fundamentally important to everyone. The hospice movement has worked hard to convey the life-enhancing aspects of hospice and the benefits of referral to specialist palliative care early in the course of illness, but fears often persist, sometimes to a point where such care is refused.

Promote a national dialogue on end of life: There is a challenge to educate and inform the public, and to encourage more open dialogue about all the issues relating to dying, death and bereavement.

An end-of-life and bereavement strategy would take into account the need for education and more public dialogue on matters concerning dying well and care of the dying. One of the IHF’s strategic goals is to inform, educate and empower about key issues at end of life, including bereavement. We will do this by promoting and addressing with our partners and the public, critical matters relating to dying, death and bereavement in Ireland.

Main Action Points

- An end-of-life and bereavement strategy should be developed which would include a public education element.

Meeting Current and Future Needs

Specialist palliative care

Policy documents produced by the Department of Health and the HSE have clearly identified what is required to provide good, equitable palliative care services in Ireland. However, significant gaps remain, and as already noted, there are still geographical regions without an inpatient hospice to serve as the hub around which comprehensive community services can develop.

National policy on hospice/palliative care

Explicit commitments to address inequality in hospice/palliative care contained in a number of Government policies including:

1. Report of the National Advisory Committee on Palliative care, 2001
2. Towards 2016: Ten-Year Framework Social Partnership Agreement 2006-2015
3. A Strategy for Cancer Control in Ireland (National Cancer Forum, 2006)
4. National Development Plan 2007-2013 Transforming Ireland – A Better Quality of Life for All
5. The Joint Programme for Government 2007 and 2009
6. Palliative Care Services – Five Year Development Framework (2009-2013), HSE 2009
7. Palliative Care for Children with Life-Limiting Conditions in Ireland, a National Policy, 2009
8. National Positive Ageing Strategy (2012)
9. Future Health, 2012

People with life-limiting conditions and complex symptoms require specialist hospice/palliative care. International evidence shows that hospice patients live longer and in greater comfort than patients who opt for ‘usual care’. They spend less time in hospital and use fewer drugs and treatments.

The availability of specialist palliative care also has a significant impact on where people die, and thus on hospital bed usage.

In June 2013 the IHF published the report, *Access to Specialist Palliative Care Services and Place of Death in Ireland – what the Data Tells Us.* This report was based on an analysis of information over two years from a number of sources: the National Cancer Registry and the Hospital Inpatient Enquiry from 2010, and the HSE’s Minimum Data Set for Palliative Care and national and regional population statistics from 2011.

There are nine hospice inpatient units in Ireland. Using the ‘old’ Health Board regions as the basis for comparison, the report noted that the Mid-West (comprising Limerick, Clare and North Tipperary) and the North-West (Donegal, Sligo and Leitrim) are the only two regions of the country which come close to providing one bed per 10,000 of the population, as prescribed by the *Report of the National Advisory Committee on Palliative Care,* adopted as national policy in 2011. It estimated that 2,500 patients each year are denied access to the hospice inpatient care they need because of the failure to develop hospice services countrywide.

Most significantly, the report showed that **in those areas of the country with access to a hospice inpatient unit, the number of deaths occurring in acute hospitals is significantly reduced.** Most hospice patients die either at home (with the support of the hospice home care team) or in the hospice itself.

The key findings were:

- 26% of people die at home each year, but 40% of those cared for by hospice home care teams die at home.
- The percentage of all deaths taking place in hospitals was estimated at 43%, but hospice home care reduces this to 21%.
- Only 7% of home care patients in the better-resourced hospice services of the Mid West die in acute hospitals , in contrast with 32% in the North East
- Of all deaths that occur in hospital, the percentage due to cancer is generally lower in regions where spending on palliative care is in line with national policy
- The 2010 National Cancer Register shows that just 21% of all cancer deaths in the Mid-West occurred in an acute hospital, compared to 52% in the North East, 41% in the South East and 37% in the Midlands
- The 2010 Hospital Inpatient Enquiry data shows that cancer accounts for just 16% of all deaths in hospitals in the Mid-West compared to 29% in similar hospitals in the South East and North East.

Hospice services already rely heavily on local voluntary fundraising to meet the shortfall in funding from the State each year. The ratio of State to voluntary funding used to be approximately 85:15. Today, in one HSE area, it is closer to 75:25. Members of the public are very loyal to their local hospice service but there is a real concern that any further erosion of an already small budget will de-stabilise what is a fragile and underdeveloped sector. To run a national service, the palliative care budget has decreased from €76 million in 2010 to €72 million in 2013. In difficult economic times, it is unlikely that the voluntary sector will again be able to bridge the gap.

Service deficits

There are serious staff and bed deficits in specialist palliative care services countrywide, and three regions where residents have no access to a hospice at all.

Going by current population figures, there should be 450 hospice beds in the country – one hospice bed for every 10,000 people, as per national policy. Today, there are only 155 hospice beds available, with another 44 ready (in Marymount Hospice, Cork, and Blanchardstown, North Dublin), but not yet operational.

Three regions of the country – the North East, Midlands and South East – have **no** hospice inpatient unit. As of December 2007, there was a national staff deficit of 610.

The national policy which is being implemented is now more than a decade old. The HSE's five-year 'framework' developed to overcome deficits and launched in 2009 remains largely unfulfilled, and its implementation period runs out at the end of this year.

It is clear that not having access to inpatient hospice beds has a critical impact on whether a patient dies in an acute hospital or not. The IHF believes that by managing national health resources more effectively, many more people could be facilitated to be cared for and to die outside of acute hospitals and in their preferred place of care. It would also reduce the inappropriate usage of hospital beds.

Need to protect home care

It is essential that we safeguard those developments in hospice care that *have* been achieved. Hospice home care, which is available all over the country and is shown to be highly effective, must be protected.

Our June 2013 report found that home care services in areas where palliative care is under-resourced actually compared very favourably with the better-resourced areas. The number of home care nurses relative to the patient population in the North East, the Midlands and the South East is generally higher than the national average. There is above average access to home care in these regions – in the number of patients seen, the percentage of patients with conditions other than cancer, access waiting times, care visits per patent, visits per nurse and the number of patients seen per nurse.

The report highlighted the cost savings to the Irish healthcare system from investing in specialist palliative care. It is estimated that the total average cost per patient receiving specialist palliative home care support is €686. The average length of stay in home care in the Mid-West's hospice service was almost six months.

In relation to funding for specialist palliative care, the report stated that the commitment in the government's recently published document, *Future Health – a Strategic Framework for Reform of the Health Services* (DoH, 2012) offers a potential solution in proposing a 'prospective funding' model, whereby 'the money follows the patient'.

It is clear that the 2001 national policy on palliative care and the HSE's related 2009 framework are both valid policy tools. But they need to be updated to address new challenges and develop new ways to deliver services.

We believe that **by managing existing resources more effectively**, **many more people could be facilitated to be cared for and to die outside of acute hospitals and in their preferred place of care**.

Extending the reach of palliative care

Specialist palliative care professionals are experts at pain and symptom control. This expertise is relevant to anyone with a life-limiting illness, whatever its nature and throughout the disease trajectory – in other words, not just cancer, and not just at the end of life.

Because hospice services have evolved mainly around the needs of people dying of cancer, they are not yet routinely available to those with other illnesses. And yet, while 29% of deaths in 2010 were cancer-related, diseases of the circulatory system accounted for over one-third of all deaths. This challenges the healthcare system to respond to the needs of *all* people with a life-limiting illness. It is vital that the specialist palliative care community reach out to their clinical colleagues in other disease areas to support the delivery of good palliative care to everyone who may need it, and to act as a resource for healthcare professionals caring for patients in the community.

Under our *Palliative Care for All* Programme, the IHF is leading out on hospital and community-based quality improvement projects to address the palliative care needs of people with advanced respiratory disease, heart disease and dementia. We are also working with other voluntary agencies to initiate discussion and explore ways to develop appropriate levels of palliative care for specific conditions, such as advancing neurological disease and end-stage kidney disease

In addition, there are vulnerable sections of our society whose health needs can present specific challenges, and whose palliative care needs can be particularly complex to identify and respond to. Such groups might include people with mental health issues, those who have learning difficulties and the homeless.

More can be done to allow people die at home

There has been an overwhelming shift over the last century towards dying in institutional care.

In 2004, 67% of ‘well’ Irish people who were surveyed indicated that their wish would be to be cared for and if possible to die at home. The reality, however, is that most people die in healthcare settings, with only 26% dying at home. Even allowing for the fact that some people may change their mind as death approaches or their care needs become more complex, this strongly suggests that the wishes of many are not being fulfilled.

Today, almost half of all deaths occur in busy hospitals, and while the IHF’s Hospice Friendly Hospitals Programme is working for change, hospitals are often poorly equipped to provide the care culture and environment that are conducive to a ‘good death’.

There is a challenge to provide people with greater choice as regards where they are cared for and where they ultimately die, and in particular, to facilitate their wish – where it exists and is feasible – to remain at home. More needs to be done, through a planned approach to the delivery of health and social care, to shift the focus of care back into the community.

We acknowledge that the current economic crisis is putting severe pressure on public health and social care services and on voluntary bodies. International research suggests, however, that most of a person’s healthcare costs occur in the last year of life. There is, therefore, an increasing challenge to ensure that this care is cost effective, while also retaining the high quality exemplified by the hospice approach. With comprehensive specialist palliative care and primary care services in place, more end-of-life care could be provided at home, delivered by GPs and home care teams, with the back-up of the specialist services. This could provide a very cost-effective model of care – although a sound evidence base is needed to underpin the economic arguments in an Irish context, particularly in light of our evolving healthcare structures. The IHF's Primary Palliative Care Programme is developing frameworks to support the delivery of palliative care in community settings.

Emerging models of 'compassionate communities' in the UK are also highlighting how, with the addition of a social model of care that mobilises community support, more people can die at home, with fewer visits to healthcare providers.

Dying in an acute hospital

IHF research in 2004 found that only 10% of people would choose to die in a hospital. Most also believed that hospital care at end of life needed to improve.

An audit conducted by our Hospice Friendly Hospitals programme in 2008/2009 found that seven out of 10 people die outside their own homes. Some 43% die in busy acute hospitals. Of these deaths, 12% take place in an emergency room, and only 40% of those who die in hospitals die in a single room (just 14% of hospital beds are in single room). The audit also found that one in four of these deaths could have taken place in the community if the necessary supports were in place.

Quality Standards for End-of-life Care in hospitals[20] were developed as part of the IHF's Hospice Friendly Hospitals (HFH) programme and are being implemented in hospitals countrywide on a voluntary basis. The National Economic and Social Council[21] suggested that the Department of Health could support these standards by underpinning them with legislation. In its conclusions, the NESC report said that such a legislative underpinning by the Department of Health could ensure that non-participating hospitals became involved or that more of the standards were successfully implemented.

When people end up spending their last days or hours in hospitals, or are brought into hospital already deceased, we must ensure that the staff – both clinical and non-clinical – are trained to provide the best possible care to these patients and their families, and that hospital routines are flexible enough to meet the needs of the families. The environment in which the person dies also needs to be designed to meet relevant standards and promote dignity and respect.

Caring for our children

There are an estimated 1,400 children living with life-limiting illness in Ireland. Some 350 of these children die each year, most of them in the first year of life.

In 2005 the IHF in association with the Department of Health & Children published *A Palliative Care Needs Assessment for Children*. Following this, a national policy on palliative care for children with life-limiting conditions was launched in 2010. The IHF has committed to investing €2.5m in the implementation of this policy. It is essential that there is planning for sustainability and that we see the full implementation of this strategy.

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[20] Quality Standards for End-of-Life Care in Hospitals: Making end-of-life care central to hospital care. Hospice Friendly Hospitals Programme of the Irish Hospice Foundation (IHF); IHF, HSE 2010.

[21] NESC Council Reports 130: Quality and Standards in Human Services in Ireland: Home Care for Older People, and Quality and Standards in Human Services in Ireland: End-of-Life Care in Hospitals; 16 October 2012

Our current work in relation to children spans a number of our programmes. It includes funding Ireland's first Consultant Paediatrician with a Special Interest in Paediatric Palliative Care, along with five Children's Outreach Nurses, working at different locations around the country. We also fund a post (Clinical Nurse Specialist in Haematology/Oncology) at Our Lady's Children's Hospital in Crumlin; as well as a free night nursing service, which helps families to keep a loved one in the final stage of illness (an adult or a child) at home to the end. We also run staff development workshops for staff working in paediatric hospitals and maternity services, which aim to enhance end-of-life care, raise awareness and improve communication skills.

While there are no official figures for childhood bereavement, it is estimated that between 36,000 and 60,000 children in Ireland may have experienced a significant bereavement. The IHF offers a number of education/training programmes for professionals working with grieving children and families. We are also currently hosting the Irish Childhood Bereavement Network – a hub for those working with bereaved children, which aims to facilitate access to information, guidance and support – and employ a half-time Coordinator to help lead and develop its work.

Bereavement care

At any one time in Ireland up to 290,000 individuals are coming to terms with the recent loss of a loved one. Bereavement has a personal impact, but its effects are also seen at work and in society as a whole. Bereavement care should be a core element of any national end-of-life strategy.

In the IHF's public survey on bereavement conducted in December 2011, a majority of people (84%) had experienced bereavement at some point in their lifetime, and 42% (which equates to almost 1.5 million of the adults in Ireland) had experienced the death of 'someone close' over the previous two years.

In relation to childhood bereavement (from the *Growing up in Ireland* longitudinal study, 2013), two out of 100 nine-year olds have experienced the death of a parent, while 28 out of 100 of the same age cohort have experienced the death of a grandparent. UK figures tell us that 4-7% of children will be bereaved of a parent before the age of 18.

Support in bereavement

If Ireland is to develop the best system possible for meeting its bereavement care needs, three levels of care must be considered:

1. People in the neighbourhood, family, schools and health/community services locally need to be understanding, available and compassionate, as well as having access to accurate information about grieving and about support.
2. Volunteer and peer support groups should be funded, trained and promoted to be available to those in need.
3. Counselling, psychology and psychiatric services need to be up to date on developments and available for the small proportion of people who need them (10-20%)

The IHF has begun a national programme for complicated grief[22] which pilots complicated grief therapy and teaches methods of assessment and treatment to psychologists, psychiatrists and socials workers.

We also run a national Bereavement Education and Resource Centre (BERC), which provides a suite of educational courses, training and resources aimed at helping people to provide good bereavement care

Recommendations:

PRIMARY recommendation

Develop a comprehensive end-of-life and bereavement strategy for Ireland.

The IHF is advocating the development of an end-of-life and bereavement strategy. While we want it to include a strong focus on health, it must also reflect a wider perspective. We will be looking for a public health approach, which in essence means:

- Looking at the needs of all the population, across all care settings and locations
- Using a multi-lens focus to capture all the elements, one that can promote optimal health and make ‘living well to the end’ a reality.
- Adopting a health focus which achieves health service quality improvement concerning end of life and ensures, in so far as possible a ‘good death.

MEDIUM TERM recommendations

1. Protect Specialist Palliative Care

The specialist palliative care budget should not be allowed to fall below current (2013) levels

The €72m budget for specialist palliative care in 2013 funds not only the nine specialist in-patient units (hospices) but also the vital home care teams that operate in each of the 26 counties. This budget has had a direct cut of over 3% in each of the last two years, amounting to a direct cut of 14% in five years. In addition, there have been indirect budget cuts of an estimated 1.5% each year, arising from non-pay inflation and the withdrawal of payment to the voluntary hospices for increments.

Despite this, the number of people accessing both home care and in-patient care has increased, with over 8,000 people in home care and 2,203 new patients in inpatient care in 2012.

Cost reduction measures, efficiencies and increased support from charitable and other sources have been successful to date in maintaining and even increasing services, but the sector is now reaching a situation where there is little or no potential to achieve further cost reductions.

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[22] Complicated grief may be experienced by 10-15% of people and is characterised by significant impairment and a sustained inability to engage with day-to-day life. It is a problem which requires professional help.

In particular, the service provided by hospice home care teams allows people to die at home and keeps many people out of acute hospitals. This service must be protected, as it is the only palliative care service available nationwide and is absolutely critical in the three regions of the country which have no hospice inpatient unit. If the budget is further reduced, it is hard to see how cuts to and further fragmentation of this vital service can be avoided.

2. Invest in specialist palliative care infrastructure:

- **Explore more practical funding methods**
- **Existing additional beds must be brought into commission as soon as possible**
- **HSE move to pre-planning stage for areas of the country which currently have no inpatient unit**

Three regions of the country – the North-East, the Midlands and the South-East – currently have no specialist hospice inpatient unit. This leads to significant health inequities for people at the end of their life.

The IHF welcomes the HSE's plans for the development of a 20-bed unit in Waterford, a satellite unit in Kerry and the opening of the 20 additional beds in Marymount Hospice, Cork. A 24-bedded unit at St. Francis Hospice in Blanchardstown, built exclusively by public subscription, remains unopened.

Over 80% of capital funding for hospice development comes from voluntary fundraising. Waterford hospice groups have committed €2.5m toward capital costs, but have been asked to increase this to €6m to support the building costs. This sum was requested in addition to the €400,000 the Waterford hospice groups already contribute annually to support their specialist palliative care homecare teams in the county. This is a huge burden for the voluntary sector.

3. Use specialist palliative care to support other patients and support the wider communities to engage in issues relating to dying, death, loss and care.

Within the chronic illness clinical care programme, develop work streams to include palliative/end of life care including bereavement care

Specialist palliative care services have traditionally developed to respond to the needs of people with cancer. Extending access to palliative care to patients with conditions other than cancer was a key recommendation of the 2001 national policy, as outlined in the *Report of the National Advisory Committee of Palliative Care*.

The IHF's *Palliative Care for All* Programme supports the development of palliative interventions for people with advancing life-limiting diseases other than cancer. At the time of the launch in 2008 of the joint HSE/IHF report *Palliative Care for All – Integrating Palliative Care into Disease Management Frameworks*, 95% of the 6,000 people who accessed hospice/palliative care services in Ireland each year were cancer patients. Today that figure is about 80%.

The report recommended, in line with international practice, that collaboration between disease-specific specialists and specialist palliative care professionals was the most effective way to deliver palliative care for non-cancer patients. For example, this would mean that cardiologists would deliver 'non-specialist' palliative care support to patients they are treating over a long time. They would draw on the advice of their colleagues in palliative care, and only in a minority of cases would the palliative care specialists take over the direct care of the patient. Following publication of the 2008 report, the IHF rolled out three action research projects in heart failure, dementia and COPD, which demonstrated how disease-specific services could include palliative care in their service delivery. We are currently linking up with other disease groups.

The HSE's Clinical Care Programmes provide an opportunity and a means of integrating end-of-life care into the work under way in relation to all chronic illnesses.

4. Support people to die in their own homes – Wherever that is

- **Develop a formal framework which provides guidance, support and resourcing for GPs and primary care teams caring for patients who are dying at home as part of a national integrated care plan linking primary care, hospice care and hospital care.**

Only 10% of the 29,000 deaths each year are sudden and unexpected, and 90% of care in the last year of life is provided by the GP and primary care team including community nurses.

The average fulltime GP will manage the medical care of 12 people who die each year – one a month. Nearly half of these deaths will occur either at home (26%) or in another community setting, e.g. a nursing home (20%). Specialist palliative care services play a significant role in supporting those patients with complex needs, but recent figures indicate that they provide support in relation to less than 40% of those deaths that take place at home. The remainder of the patients concerned are solely under the care of the GP and other members of the primary care team

The IHF, in partnership with the Irish College of General Practitioners and the HSE, set up the Primary Palliative Care Programme in 2010 to identify palliative care initiatives in primary care settings that could support the management of people with progressive life-limiting disease who are expected to die within 12 months. The report *Primary Palliative Care in Ireland*: *Identifying Improvements in Primary Care to Support the Care of Those in Their Last Year of Life*, was launched in November 2011.

With an ageing population, it is essential that we look now to see how we can enhance the end-of-life service being offered to patients and their families through primary care.

Unlike some other countries, Ireland has no formal framework to support the delivery of palliative care by primary care teams.

5. Encourage advance care planning

- **The legality of Advance Care Directives must be underpinned by the provisions of the Assisted Decision Making (Capacity) Bill 2013 and that this section be brought into effect as soon as possible.**

While there is currently no specific legislation in Ireland governing advance care directives, these *are* in fact legally binding, according to both Irish law and international law to which Ireland is bound. The decision of the Irish Supreme Court in *Re a Ward of Court (No 2)* [1996] 2 IR 79, says that advance care directives are recognised by Irish law, provided that the author was competent and that the directive was specific to the patient's current situation.

There have been several policy statements supporting the concept of advance care planning. A goal of the HSE's Strategic Plan for 2008-13 is: '*to develop the role of the "expert patient", especially those with long-term illnesses, in developing their own care plan and in looking after their own condition'* (p.14).

Related actions to achieve this goal are as follows (see *National Strategy for Service User Involvement in the Irish Health Service 2008-13: 14*)

a) the promotion of patients as 'partners with health professionals', and
b) the education of staff on the 'importance of patient involvement in their care'

The Department of Health's *Future Health: A Strategic Framework for Reform of the Health Service 2012-2015* commits to:

- A focus on the rights and dignity of the person concerned, with care guided by the person's own views and wishes
- A strengths-based approach to needs assessment, i.e. a focus on supporting and enhancing ability to enable active community living;
- Individual care plans with a focus on personal goals and outcomes;

HIQA Standard 16 calls for nursing homes to engage with residents in relation to planning their end-of-life care and preferences.[23] It is important to note that there is no specific guidance in the standards for residential care settings for the timing of discussions and for any consequent documentation regarding residents' wishes and choices regarding end-of-life care. This is leading to the development of inconsistent approaches.

The IHF's *Think Ahead* project comes in the context of the Law Reform Commission's Report, *Bioethics: Advance Care Directives*, published in September 2009, which recommended legislation to provide for advance care directives in the wider context of advance care planning, stressing that advance care directives are not limited to wishes made in a healthcare setting, but encompass wider

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[23] HIQA Standard 16: The resident's wishes and choices regarding end-of-life care are discussed and documented, and, in as far as possible, implemented and reviewed regularly with the resident. This includes his/her preferred religious, spiritual and cultural practices and the extent to which his/her family are involved in the decision making process. Where the resident can no longer make decisions on such matters, due to an absence of capacity, his/her representative is consulted

care settings as well. *Think Ahead* is a tool designed, among other things, to ensure that people have an understanding of their legal right to refuse care and to express their preferences.

In March 2013, a commitment was made by Government that provision for advance directives would be included in the Assisted Decision Making (Capacity) Bill at committee stage. The enactment of this legislation and its inclusion of provision for advance care directives would go toward fulfilling Ireland's obligations under the 2006 UN Convention on the Rights of Persons with Disabilities.

6. Maintain access to medical cards

The current provision for medical cards for people with terminal illness should be sustained and underpinned by clear criteria for renewal without means test should this be required.

The IHF believes that people who are living with advanced incurable illnesses should have a statutory entitlement to a medical card that will allow them access to a full range of free medical and health services, including basic supports at home such as oxygen supplies, a hospital bed in the home and access to the services offered by a community-based, multidisciplinary team.

People with a terminal illness and approaching end of life currently have the right to a medical card without means test for a period of six months when their condition is verified by a GP or hospital consultant. This is a valuable and welcome development. IHF has found that this process works well where there is a medical social worker, SPC or other healthcare professional involved, but may be more difficult for people who do not have this support. We have also heard of difficulties arising where the card needs to be renewed. People whose condition will have deteriorated over the six month provision of the card may then be required to provide full means test information.

Appendix 1:

SUMMARY OF KEY RECOMMENDATIONS FOR PALLIATIVE CARE INFRASTRUCTURE[24]

THEMES	**SUMMARY OF KEY RECOMMENDATIONS**
Strategic and structural support	- The palliative care service strategy should be managed by a senior official of the Department of Health with responsibility for overseeing the entire palliative care budget. - Strategic mechanisms should be developed to allow the HSE's Palliative Care Clinical Care Programme to work logically across the Department of Health and the HSE's six new health Directorates. - The government's 2001 palliative care policy should be updated to take account of more recent developments and research findings. - An updated five-year development plan for palliative care services should be drawn up and implemented, with the aim of addressing inequities in services and facilities, and providing both specialist and generalist palliative care across all care settings and for all patient diagnoses. - Clear mechanisms should be developed for the inclusion of the voluntary sector in the planning process, given that it leads and delivers most of the country's inpatient specialist palliative care services. - The national strategy should address public education needs in order to promote a greater understanding of palliative care and more discussion of dying, death and bereavement in Irish society.
Strengthened financial support	- To support high-quality patient-focused services, there should be a dedicated, trackable budget for palliative care under the annual health budget. - The palliative care budget should be viewed in context. This is an evolving area which needs championing and protection – further cuts will have a direct impact on service delivery. - Within each of the new HSE Directorates, an annual core budget should clearly establish the resources allocated to palliative care, and should allow for tracking and monitoring of expenditure. - The Department of Health's commitment to complete a prospective funding model for palliative care in 2013 should take account of these recommendations
Planned service delivery	- Palliative care services should be managed as a single entity in order to avoid fragmentation. - Palliative care services should be available in the full range of care settings in which people die. While overall responsibility may be retained within one Directorate, the remit should extend to palliative care services provided in other areas of the healthcare system, such as primary care. This will mirror structures at the level of government departments. - A mechanism should be identified to coordinate and direct all organisational and developmental responsibilities for palliative care across all Directorates. This should include regional service managers with responsibility for the development of palliative care.

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[24] IHF: Perspectives series: Number 1: The strategic Importance of Palliative Care within the Irish health services: Perspectives on Future Service delivery.

	- Existing levels of service should be maintained and sustained as a matter of utmost priority – any deterioration in the level of services available to patients who are dying would be unacceptable. - To facilitate the effective delivery of service plans for palliative care across all care settings so that there is equitable access to palliative care, a senior official, supported by a professional staff, should be assigned responsibility for the operational delivery of palliative care. - Each hospital group should be required to develop a strategic plan for end-of-life care within each of its hospitals. The Hospice Friendly Hospitals Programme – an Irish Hospice Foundation (IHF) initiative – can assist in the development of these plans. The HSE's Palliative Care Clinical Care Programme will provide leadership in as regards clinical care pathways. - The systematic gathering and sharing of information on end-of-life and palliative care issues is needed throughout the health service in order to support the development and adoption of minimum data sets for palliative care in all care settings. This will inform and strengthen service delivery.
Building capacity through the HSE's Clinical Care Programmes	- Support is required for the HSE's Palliative Care Clinical Care programme to continue to develop service-wide policies and approaches. - Interdisciplinary models of integrated care for palliative care patients should be developed by the Palliative Care Programme as a matter of urgency. - A work stream under the direction of the Palliative Care Programme should be established to develop a commissioning model for palliative care. Building on the work currently under way in Trinity College under Prof. Charles Normand, this should be capable of being implemented across all of the new HSE Directorates. - All of the Clinical Care Programmes should be directed to include a work stream on palliative care. This will ensure that palliative care approaches are embedded in the care of all patients with life-limiting illnesses, whatever their diagnosis. - Membership of the HSE's national Palliative Care Working Group should be extended to include the representation of those voluntary agencies which are contributing significantly to policy and service development.
Support for staff development and training	- A system of education for health and social care professionals should be developed in partnership with training bodies and health service training structures, to include the facilitation of competency and practice development and continuing professional development. - To supplement the education of individuals, training and staff development initiatives should be developed for teams, units and organisations. Voluntary agencies, such as the voluntary hospices and the Irish Hospice Foundation, can assist. - Staff release for training must be preserved, as there is a need for a technically and socially competent workforce which can meet patient needs within a range of role remits and care settings.

Additional Written Submission from the Irish Hospice Foundation[1] to the Oireachtas Committee on Health and Children on Children's Palliative Care.

Introduction:

In the course of its hearings on end-of-life issues, the Oireachtas Committee has heard that there are an estimated 1,400 children with life-limiting conditions in Ireland, some 350 of whom die each year, most of them in the first year of life.

In 2005, the Irish Hospice Foundation (IHF) in association with the Department of Health & Children published the results of a nationwide study under the title, *A Palliative Care Needs Assessment for Children*. A key finding of this study was that what most families want for their seriously ill child is that he/she should be able to be cared for and to die at home in a familiar environment, surrounded by their loved ones, cherished pets and favourite toys. Currently only 11% of such children die at home.

The special end-of-life and palliative care needs of children have been recognised in government policy since 2010[2] when the formal government policy on paediatric palliative care *Palliative Care for Children with life-Limiting Illness in Ireland – a National Policy* was launched. These needs were reiterated in the Committee's hearings.[3]

Recommendations:

In response to the needs assessment and national policy, the IHF worked closely with the Department of Health to develop the *Hospice Home Care for Children* programme. At present, we estimate that 85% of the staffing costs of that programme is currently met by the IHF and this is clearly unsustainable. The programme has four key strands:

- The appointment of a **Consultant Paediatrician with a Special Interest in Paediatric Palliative Care**, to give clinical leadership and direction for children's hospice/palliative care services. In 2011, Dr Mary Devins was appointed to this post, which is currently fully funded by the IHF.
  <u>Key recommendation</u>: That the HSE plans for the on-going and sustainable funding for this important post.

- A national network of **Children's Outreach Nurses** (8 initially) to provide advice and support to parents and to other professionals involved in the care of very sick children in the home. Five of these posts are currently being funded by the IHF; the remaining three by the HSE. The Children's Outreach Nurses coordinate the care needs of children and their families hand have been recognised as a vital support to healthcare professionals providing care to children with life-limiting illness at home and as a liaison between hospital and home.[4] The appointment of the 8 outreach nurses was considered to be an interim step and further such nurses will be required to fully meet current and future needs.[5]

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[1] The Irish Hospice Foundation is a national charity dedicated to all matters relating to dying, death and bereavement in Ireland. Our vision is that no one should face death or bereavement without the care and support they need.

[2] *Palliative Care for Children with life-Limiting Illness in Ireland – a National Policy 2010, Department of Health and Children and Irish Hospice Foundation*

[3] Dr. Maeve O'Reilly, Committee hearing Session 4, 7th November 2013

[4] Ms. Sinead Moran, Jack and Jill Foundation and Dr. Maeve O'Reilly, Committee hearing Session 4, 7th November 2013

[5] *Palliative Care for Children with life-Limiting Illness in Ireland – a National Policy 2010, Department of Health and Children and Irish Hospice Foundation*

Key recommendation: That the HSE plans for and provides the funding for the 8 outreach nurses, including the 5 nurses currently funded by the IHF, and immediately begin planning for the expansion of this service to allow for coordinated care for children with life-limiting illness throughout the country.

- **Education/training in children's palliative care** for healthcare professionals such as public health nurses, via an education programme developed in association with Crumlin children's hospital. With IHF funding, this training was delivered initially to more than 1,500 health professionals. The HSE has since taken over the funding; the IHF retains some administrative involvement.
  Key recommendation: That staff release for and the provision of funding for training in children's palliative care for healthcare professionals is sustained.

- The **standardised collection of data on children with life-limiting illnesses** in Ireland. A lack of accurate data has been a problem in the planning and development of services for children with life-limiting conditions. The IHF is contributing to current HSE work in this area.
  Key recommendation: That standardised data collection systems are developed to allow for the efficient planning and roll out of appropriate, evidence-based services for children.