

## Opening Remarks by Orla Keegan

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To the Oireachtas Committee on Health and Children

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Mr Chairman, Deputies and Senators,

We welcome this opportunity to talk to the committee about bereavement in Ireland. It explicitly acknowledges that every death has a legacy.

Today alone 80 people may die in Ireland, 80 people died yesterday and 80 will die tomorrow.... Since October 24<sup>th</sup> when you as a Joint Committee met to begin these sessions, 1,200 people have died in Ireland. This makes for many bereaved families, parents, wives, husbands, brothers, sisters, many bereaved children, grandchildren and friends. It makes for a lot of sorrow.

We estimate that if ten people are impacted by a single death then 290,000 people are bereaved each year.

These past weeks in the hearings you have heard from those involved in palliative care as a speciality and from those working in hospital and primary care settings, you have also heard about children with life limiting illness and the best care needed for these families. Some deaths occur in situations where there has been a chance to provide care before a death – others are more sudden deaths including accidental death, death from suicide. Any focus on bereavement must take all of this variety into account.

The vision of our bereavement work at the Irish Hospice Foundation is:

*'that people experiencing loss and bereavement are met with informed compassion, and with appropriate care regardless of the circumstances of the loss.'*

In this presentation I will make a number of simple points further backed up in the written submission.

1. The first is that good bereavement care begins with good end of life care, good palliative care, good communication.
2. The second is that bereavement may be considered in a public health context if we turn our attention to building communities of caring.
3. The third point is that we would benefit from setting out a strategic framework, as part of an end of life strategy which could guide our response to and support of bereaved people.

#### 1. Good end of life care is good bereavement care

Research confirms this, but people's experience communicates it very clearly – for example in October a widow commented from the audience at a conference *'because my partner died well, I can live well and my children can live well'*. It was an eloquent tribute to the impact of full, empathic care. It precisely made the point that care for a patient is also family care with a long term legacy. We need to do to make sure this is more people's experience, in fact the usual experience in Ireland.

#### **We call for education & training about end of life, about understanding loss and bereavement – at undergraduate level, and on a continuing basis for people in practice.**

The focus of this education would be on care and on communication, on keeping people informed and comforted; ensuring that everything that can be done is being done. We note this is not the first time in these sessions you are hearing a call for education. We note also that this is a cross sectoral issue – not all deaths are expected, therefore education is required for police, paramedics and others involved in breaking difficult news, in being the first responder to emergencies; indeed in helping them to deal with death day in, day out.

In addition, we need to maintain, support and maximise the efforts our hospitals are making to ensure that dying is an integrated, expected and legitimate part of the care that is provided there. **Investment in education has to be paired with investment into the care systems professionals return to** – thinking of the physical facilities of our hospitals and our residential care settings but also the work practices there. Through the hearings you have heard about models of hospice & palliative care, and also about the Hospice Friendly Hospice initiatives. **The principles & practices of these movements should be applied in all settings and they represent the beginnings of good bereavement care.**

## 2. Building communities of care/public health

We say that bereavement is not an illness – although it has health consequences, particularly in the short term and although it is disruptive, and both psychologically and socially painful. For a small proportion it is debilitating and will require expert professional help. Bereavement has socio-economic dimensions which are not always considered. We believe we should adopt a public health approach focusing on building strengths, on supporting the voluntary bereavement services and on the development of professional therapy as appropriate.

### *General*

A strong and supportive community has an understanding of loss and bereavement. These are the communities where people do not ‘*cross the road*’. We may look to public awareness initiatives reminding people to simply ‘be there’ for others – a life skills approach. Workplace initiatives, and compassionate communities projects, for example the one in Limerick convened through Milfrod Hospice, are welcome developments here.

It is important to think also of people whose bereavement may not be recognised and therefore may go unsupported – for example gay and lesbian relationships. Some losses such as miscarriage which have not been visible or shared also go unsupported and others for example abortion isolate a person even further;. All of this sort of thinking builds on people’s strengths, and supplements coping with information, practical support and understanding.

### *Volunteer support*

Access to well organised volunteer bereavement services or befriending services, many already available in our communities, is an important part of structured bereavement care which provides social support and help. These services are staffed in the main by trained volunteers who themselves have had some experience of the losses involved. They provide vital bereavement care services in the community – you will recognise some of their names a selection include Console, Rainbows, Barnardos, Anam Cara, Bethany.

While recognizing the work being done by hundreds of bereavement services across Ireland, a 2008 report commissioned by the National Office for Suicide Prevention (on all bereavement services, not solely those supporting suicide bereaved), highlighted that many services are not linked together and further, that there is a need for standardized training for those providing bereavement care and a means of rolling out good practice. One organization, Console, has developed quality standards for the provision of suicide bereavement support services.

Many of the voluntary groups rely on small grants and are concerned that these are under threat, and also the year to year nature of the grants makes planning difficult. **There is scope to further harness the good work being done by these organizations and to develop consistent good practice.**

### *Professional support*

Bereavement represents a serious mental health problem for between 3,500 to 7,000 people each year. A means of identifying and responding to those who need such professional help and investing to ensure that such help is there is vital. **Support for development and resourcing of bereavement therapy in mental health, psychology, primary care and private practice is required.**

In order for each of these community, voluntary and professional needs to be met there is an imperative for both coordination and education. For people to be able to access what they need – and remember it is not always a service - responsibility does not rest in the health sector alone. This leads to our third point the need for a national strategy.

### 3. National agreed frameworks

We would like to see a national strategy on end of life which would include bereavement. We believe such a strategy would promote clarity in the provision of bereavement care by private, statutory and voluntary agencies. It would promote and clarify the role of education – in a lifelong context. Bereavement is a predictable and unavoidable experience which for all of that, is not as well understood on an individual and societal basis as it might be. A strategy is a starting point to developing informed responses to bigger questions and could include a research agenda- What are the socio-economic costs associated with bereavement in this country (health, lost work days)?; How can the contribution of voluntary bereavement organisations be best acknowledged and supported? and ultimately, how can our social and professional structures best serve our needs?

Thank you for listening.