Opening Remarks by Sharon Foley
CEO of the Irish Hospice Foundation
To the Oireachtas Committee on Health and Children
24th October 2013

Mr Chairman, Deputies and Senators

I would like to take this opportunity to commend you for your decision to hold a series of hearings into end-of-life care.

You are doing the people of Ireland a great service and I welcome your initiative.

Reviewing the care of the most vulnerable members of our society is worthwhile and essential. Every year 29,000 people in Ireland die. As many as 290,000 people are left bereaved. While €72m goes into specialist palliative care, about €1.3b is actually spent on end-of-life care. But this spending is largely unplanned and uncoordinated.

The elements of a good death are truly personal to each and every one of us. There are many elements which contribute to whether a person has a good death - dignity and respect at end of life, strong services attuned to the needs of the dying, having strong and loving family and social supports, being prepared for death and of course how the dying are

valued in our society. We cannot promise to be able to influence each of these factors – but we do believe that much more can be done by health and social services to ensure **better end of life care, everywhere.**

The key recommendation from the Irish Hospice Foundation today is that **we need a national strategy for end of life and bereavement care to plan for the inevitable and to get end-of-life care right.**

We believe it is possible to secure both high quality care for those facing death which also ensures the best use of resources.

We believe it is the right of every person to die in comfort and dignity.

But we believe you must plan for it.

And as part of any strategy, we can plan to deliver the best care in our hospices, in our hospitals and at home.

1. National Strategy

We need a national strategy to help us to identify how we currently spend, what we estimate is, the €1.3b that goes on end-of-life care and how best to use that money.

This must be a strategy for the entire population – from those who need GP support to those who need specialist

palliative care to manage their pain and other complex symptoms.

We need this strategy to be relevant to all patients – young and old – all over Ireland and for patients with all conditions including dementia.

It also needs to be wider than healthcare. It needs to look at the economic, administrative and legal issues, the funeral industry and bereavement issues.

2. Develop Hospice Care

We need to develop hospice care

We have plenty of strong national policies around specialist palliative care. But we fall down when it comes to putting policy into practice.

And this failing means that citizens are living and dying with an inequitable system where some people have more access to more services and choice of care while as many as 2,500 people can't access an inpatient hospice bed because they don't exist.

We have 155 hospice beds today. We should have 450. We have significant deficits in hospice staff.

The budget for the national specialist service in 2013 was €72m - about one third of the cost of running one Dublin hospital for a year.

We also have three regions of the country with no inpatient hospice unit – the north east, the midlands and the south east - as well as Kerry, Wicklow and Mayo.

Yet look what could be delivered. We know that hospice home care teams – and they're are all over Ireland – help people to fulful their wish to live and die at home. 26% of us die at home. Under the care of a home care team, that number soars to 40%. If you have a hospice in your area, you have fewer deaths in hospital. And hospital care is expensive.

A national end of life and bereavement strategy would help us to plan all services including specialist hospice care.

3. Put hospice principles into hospital practice

Most of us wish to die at home but 43% of us will die in an acute hospital.

We know from a hospital audit we conducted that over 80% of people who died entered the hospital via the Emergency Department. Most patients were not seen by specialist palliative care. On their last admission, patients were in hospital for over three weeks before they died. 44% of people died in a single room. And up to one quarter of patients could have died at home if the community supports were in place.

Our hospitals aim to cure. But they must acknowledge and plan for their role in providing end-of-life care. Because people die every day in hospitals. This is not a failure. This is life.

We need to see hospice principles put into hospital practice so that all deaths in our hospitals are the best they can be – secured in dignity and comfort.

Our Hospice Friendly Hospitals programme has developed a range of recognised quality standards, staff training programmes and practical resources.

It has conducted respected research and is funding projects to physically improve spaces in 11 hospitals countrywide – new mortuaries, better family rooms, comfortable viewing areas etc.

Deaths in hospitals would be considered as part of the national strategy. If this is what a charity can do, can you imagine what could be possible if our services were planned and properly funded.

While we wait for a national strategy, the new hospital groupings that are being set up must take this opportunity to develop comprehensive plans for how they will cope with the people who die in their facilities.

4. Help more people to fulfil their wish to die at home.

Most of us wish to die at home – 67% of us. But in fact, only 26% of us will die at home while another 25% of us will die in long stay settings.

Dying at home is a preference common to all – from elderly people to families who are caring for a child with a life limiting condition.

Already lots of good work is being done through our Primary Palliative Care programme and our work with children where we are funding five out of 8 Children's Outreach Nurses who are supporting families to care for children at home.

Again, we come back to how a national strategy could help us to develop community supports to help people to die at home.

To recap, if there is one thing you take away today, it is that we need a national end of life and bereavement strategy that will help us to plan ahead so that people can die well – wherever they are.

It's worth remembering that we only have one chance to get it right – one chance for good end of life care.

Thank you.