

Speech given by President Mary McAleese at the launch of the Forum on End of Life in Ireland, 11th March 2009.

Tá an-áthas orm bheith anseo libh inniu agus muid ag céiliúradh an ócáid mor seo. Ba mhaith liom bhuíochas a chur in iúl daoibh as an gcuireadh agus as fáilte a bhí caoin, cneasta agus croiúil.

Occasionally I get to launch things that are truly life-changing. This is one of them and ironically its ambition is to be death-changing. The Irish Hospice Foundation's Forum on End of Life in Ireland is about the business of ratcheting up a nationwide debate on dying and death so that, just as we have seen big advances in our quality of life in recent decades, so too we will see big advances in our quality of death. The hospice movement has championed this debate. It has showcased the huge benefits that flow from a much more holistic approach to dying, death and bereavement. It has been the conduit for a whole new and evolving science of palliative care that does not begin and end with medication but begins and ends with the needs of the person and the family as they face death, the one sure part of life, the one we all prefer not to face, yet the one on which we have remarkably strong and clear opinions when we are encouraged to share them. This Forum will help us to open up the worries, fears, desires and ambitions about the end of life that we often keep firmly locked up. Most of us would admit to hoping for a "good" death. How many of us in the past heard our parents and grandparents pray for the gift of a "happy death"? In their day, when the drugs and treatments we take for granted were not available, they knew a silent thing or two about suffering and deaths that were hard on the dying and hard on those left behind. Behind that prayer was a world of dread.

Yeats captures the human condition elegantly and movingly when he says:

"Nor dread nor hope attend
A dying animal;
A man awaits his end
Dreading and hoping all."

Yet we have a wealth of experience to help us illuminate the path to a "good death", a careful death. Many have watched loved ones face serious illness and death. They saw them die in hospitals, in hospices, at home. They know the strengths and weaknesses of institutions, individuals and families when confronted with dying and death. There is a reservoir of experience that tells us what works well and what does not, what hurts and humiliates, what encourages and supports, what exacerbates the dread and what takes it away. From this Forum and the debate it is carrying forward will come the insight necessary to help us face into this great cultural taboo.

Your work will help construct a plan or a series of plans from which will come the tools, the infrastructure and the practices which will reduce our fears, grow our confidence and help us individually and collectively take on dying and death with hope. Death is always going to overcome us but dying does not need to defeat us or overwhelm us. Thanks to the hospice movement more and more people are finding that out. For it has broadened the science surrounding dying far beyond the realm of the medical, vital though that is, and it has put the patient and his or her complex needs, rights and fears at the very centre, not as a person who needs treatment alone but as a person who is entitled to live life to the full, with dignity, comfort and space for joy right to the last breath.

Most people say they would prefer to die at home. It's a very telling ambition. To be among those we love, in the place we feel most comfortable - it's understandable. It is also very telling that most of us will not achieve that ambition. We will die in a busy general hospital among strangers who, with the best will in the world, will have us and a hundred other things to focus on. Our families and loved ones will be unsure of their place there, privacy may be hard to find and all the kindness in the world from medical staff will not dispel the feeling that somehow this was not the way we wanted death to come. Through hospice care, hospice in the home and, more recently, the mainstreaming of hospice culture in general hospitals, a much better range of options is opening up for those who face the dying process. Hospice characterises dying as a sacred space, to be cultivated with enormous care, compassion, sensitivity and focus. In the aftermath of a death, the traditional coping skills go into gear almost automatically and we Irish organise wakes and funerals with a sure-footedness that is commendable and designed to offer support and solidarity to the bereaved. That whole matrix of deep acts of kindness that magically click into place - the making of the sandwiches, the preparing of the house, marking out the local field as a make-shift car park, the arrangements for the funeral, the flowers for the

Church, the digging of the grave – all just seem to materialise without anybody asking, simply out of everybody caring, partly because it is what you do and partly in the knowledge that when your family's turn comes, the same will be done for you. But that is after death. Now we want that same, effective, coping system to snap automatically into place around dying. We have good reason to believe we can do just that.

We are already among the most advanced nations in the world in terms of the development of palliative care yet, even here, this discipline is in its infancy and still has a long road to travel. It is helped by the world of technology and treatments which now help manage the dying process in ways unimaginable a short time ago. But it is underpinned by a care for things that lie beyond the world of tubes and technologies. There is a determination that the dying person is a living person whose life is going to be made as good as it possibly can be until life is extinguished. It carries a commitment to a dying that will be free of needless emotional trauma and physical suffering, that will be sensitive to the opportunity it presents for healing of regrets or resentments, getting affairs in order, for enhancing and growing personal relationships, for laying the foundation for a grieving process that is healthy. We need this Forum and this national debate to get the energy of our hearts and hands behind this culture-changing, life-enhancing, death-enhancing opportunity. We all have a vested interest in getting this right.

When you step out of the daily fray into the calm of a hospice and feel the radiant power of love envelop all who enter that space between fragile life and the certainty of death, there is an immediate reminder that death itself is the constant, the certainty, the one great inevitability. We may not know its mood or mode but we know its outcome. It is mostly treated as an enemy, a superior and ever triumphant enemy. It does not have to be so. It will, in the end, rob us of life, that is true, but as it dances around us it does not have to rob us of hope, dignity, peace, love, ease and comfort. These human things we can get right, we can do better. With the help of The Irish Hospice Foundation, its supporters and friends and this Forum we will. My thanks to Paul Murray for the kind invitation on behalf of the Foundation to be here and my thanks to each of you for being here to invest in this debate and to help bring end-of-life palliative care to a level in Ireland that we can be justifiably proud of – a place of death without dread.

Thank you.