

# **Speech to the Committee on Health and Children Public Hearings on End of Life Care**

**24 October 2013**

**By: Patricia Rickard Clarke, on behalf of the National Council of the Forum on  
End of Life in Ireland.**

Patricia is a member of the National Council of the Forum on End of Life in  
Ireland, as well as a solicitor and former Law Reform Commissioner

## Introduction

Ladies and Gentlemen of the Committee, many thanks for inviting me here today to speak on behalf of the Forum on End of Life in Ireland.

The Forum on End of Life is the voice of the people in Ireland on end of life issues surrounding dying, death and bereavement. It is an initiative of the Irish Hospice Foundation and was launched in 2009 by the then President Mary McAleese and is chaired by Mrs Justice Catherine McGuinness. I am going to briefly run through a few areas that the Forum is working on that will enable people to die well in Ireland.

### 1. End of Life Strategy

One of the Forum's key objectives (as contained in its work plan for 2013-2015 which has been submitted to the Committee) has been to advocate for a national End of Life Strategy for Ireland.

Issues arising at End of life are wider than simply healthcare. Any one of us who has had a loved one die knows only too well that there are a myriad of financial, legal, social, cultural, and administrative issues that abound other than those related directly to the person's health care. For this reason, we need a comprehensive inter-departmental Strategy which can address all areas of end of life and ensure that end of life is effectively addressed by government policy, recognising end of life as a natural part of the lifecycle. Government policy addresses the needs of the newborn, the needs of school-going children, and the needs of people up to and post retirement age. So too should it address the needs of those at end of life.

You will read in the Forum's work plan some of the issues which should be addressed by an end of life Strategy to include the regulation of the funeral industry – one of this country's least regulated industries – and the importance of end of life proofing buildings to enable more people to die well in their own homes and communities.

## **2. Changing policy and practice - Recommendation to extend authority to pronounce death to nurses and paramedics**

Our systems need to be flexible to listen to the needs of those at end of life and to change accordingly. Later today I am going to the Forum on End of Life in Dublin Castle. This is a conference that happens every two years. There I will find over 300 members of the public and health professionals who are interested in doing this differently, to making Ireland a good place to die.

One example of a procedure that needs to be adapted is the Forum's recommendation that authority be extended to trained nurses and paramedics to pronounce death. This was raised during the public consultation that the Forum undertook in 2009-2010 as something that needed to happen, both from the perspective of bereaved families, and from the perspective of making effective use of personnel in hospitals and emergency situations.

## **3. Advance care planning**

Ladies and gentlemen, how many of you have an up to date will that reflects your current circumstances and wishes?

If you are anything like the rest of the country, most of you will not have one.

Now, how many of you have thought about where you would like to be cared for at the end of your lives? Whether you would like to be cremated or buried? Have you told anyone close to you about these wishes or kept them to yourself?

Talking about death in Ireland is the last taboo we have to face. People in many other countries make advance directives as a matter of course, in the same breath as taking out a mortgage. We are somewhat behind the times here. But we are catching up.

The Think Ahead project - a major element of the Forum's end of life work programme - is a public awareness initiative and broad advance planning tool designed to guide members of the public in discussing and recording their preference regarding end of life. It is so important that we articulate what we want in preparation for a day where we may not be able to speak for ourselves. Not only is this our right to speak for ourselves, it is also our responsibility to spare our loved ones the burden of having to make decisions on our behalf, not knowing whether they are doing the right thing. The Forum is initiating a culture change through Think Ahead – encouraging people to Think, Talk, Tell. Think about what you would like, talk to your doctor or someone you trust, and then tell someone close to you to make sure they know your wishes.

While advance directives are recognised in Irish law and are legally binding, there has as yet been no legislative framework to give clarity to the public and health care professionals. That is set to change. As you will be aware, Minister Shatter has stated in July 2013 that advance directives will be added to the Assisted Decision making (Capacity) Bill at Committee Stage and this will hopefully help to ensure that people know their rights and can express their preferences.

Think Ahead was launched by An Taoiseach in 2011 and is currently being rolled out nationwide, with the help of community groups and key players, including health professionals, solicitors, accountants, and local politicians.

The Think Ahead project is also part of the move in Ireland towards meeting our international obligations under the Hague Convention on the International Protection of Adults (2000) and the United Nations Convention on the Rights of Persons with Disabilities (2006) to have systems in place to take account of the will and preferences of a person and to ensure the respect and dignity of that person in carrying out their wishes at the end life.

We have an opportunity here to make real changes. Changes that will enable people to die well in Ireland. Let's take it.

Many thanks for your time.