

## **From the public consultation process conducted by the Forum in 2009**

### **The aims of the Forum were:**

- To promote a national conversation on dying, death and bereavement
- To ascertain the key issues at end of life
- To explore the views and concerns of the public and varying organisations
- To ensure that a wide range of views are heard
- To report on the issues emerging from the Forum workshops and submissions
- To prepare the ground for a National Coalition to advance the views emerging from the Forum.

### **The issues that emerged as the most important for people were:**

1. Communication
2. Autonomy and dignity
3. End of life care
4. Spiritual and psychological care
5. Support for carers
  - a) Family/informal carers
  - b) Formal carers
6. Administrative issues
7. Respectful care after death

## 1. Communication

*“What is most needed is ... to encourage the kind of flexibility in procedures, institutions and laws that will enable those involved in care for the dying, the process of death and the disposal of the body to listen to the dying person and those close to them about what is most important to them, and to respond effectively to their needs.”*

*“For me the greatest tragedy at this difficult time is the persistent denial by family members (often aided by the medical profession) of the true situation in which they find themselves. This prevents intervention aimed at making life more pleasant for their dying relative/friend.”*

- Better communication with all involved in the end of life journey
- Better communication between individuals and their families and support for families in being able to let go
- Better listening and communication between health care staff and their patients
- The Forum notes that advance care directives are in themselves a form of communication

## 2. Autonomy and dignity

Often the lack of acceptance on the part of medical professionals or family members can lead to unnecessarily uncomfortable and undignified deaths.

*“The lack of acknowledgment of end of life at medical service, family and individual levels lead[s] to systems failure and inappropriate experiences of end of life.”*

*“An elderly lady has several strokes over a period of months; she is admitted to a nursing home for care. In the nursing home, she is taken from her bed each morning, propped up in a chair, and left there until after lunch. Her head nods uncomfortably as she sleeps. She says she wants to die. She is fed, cared for – but not allowed to stay in bed where she would be most comfortable. Eventually, she is allowed to stay in bed. She develops dehydration. She is hospitalised, tube fed and a drip set up. This continuous revolving door from nursing home to hospital is sustained for months and months. The woman is diagnosed with depression, and given medication, because she continuously says she wants to die. Yet nothing - absolutely nothing - is done to relieve her symptoms; to offer therapy; to enhance her life for the time she has it. The focus is on preventing death not enhancing life. Tragic. Her family were not willing to let her go.”*

- Choice regarding place of death
- Inappropriate hospital admissions that go against an individual’s expressed preference should be prevented by allowing people to choose where they are cared for when they are dying, as far as is possible
- There needs to be more individual autonomy at end of life. This can be achieved through the enactment of legislation for a statutory basis framework to underpin advance directives
- People should be allowed to die with dignity and to choose not to be resuscitated if this is their preference

### 3. End of life care

People have a right to appropriate, person-centred end of life care. With the advances in medicine technique and technology there is a danger that the experience of death and dying can become over-medicalised at the expense of the comfort and quality of life of the person that is dying.

*“Medicine and healthcare generally can be seen to have a number of concrete objectives. Among these are the eradication of disease, the relief of pain, the saving of life, and the restoration of health. We must look beneath these objectives for the ultimate purpose of healthcare, which is the well-being of the patient, not just as a body, or as a subject of emotions or of physical sensations, but as a whole person.”*

- The provision of person-centred end of life care to those who are dying needs to be a primary objective of our health and social care services
- End of life care needs to be as tailored to an individual’s wishes as possible
- Inappropriate hospital admissions should be prevented. While it can be appropriate and necessary for people to be cared for in hospital, often this care and its setting is inappropriate and people are transferred from their home or nursing home to hospitals when they are dying due to a lack of confidence or training on the part of their carers
- Adequate pain management is essential to ensure the quality of life of the dying person

### 4. Spiritual and psychological care

*“We would like to ensure hospice staff are aware of patients’ belief systems to avoid distressing them with unwanted visits from chaplains and to be able to provide them with such a service.”*

*“What priority does palliative care give to psychological pain, I’m thinking here of that felt by patients in long term care, in comparison to the pain experienced by patients with more acute illnesses?”*

- Respect for individuals’ beliefs and choices regarding appropriate spiritual or psychological care at end of life
- Psychological distress needs to be addressed as well as the physical symptoms of dying.

### 5. Support for carers

#### a) Family/informal carers

*“Health care professionals should treat and work with family carers as partners in the provision of end of life care at home. Identify and provide supports to them in a timely manner, including respite care and Home Care Packages, and provide them with training as required”*

- Acknowledgement of the role of family carers
- Support for family carers in caring for a loved one at end of life
- Appropriate bereavement support for family carers

## **b) Formal carers**

*“Professional education and training for all those who care for people at, and following, end of life must be an important focus”*

- Appropriate training in end of life care for formal carers

## **6. Administrative issues**

*“There ought to be a review of the process around the death certification. Currently a person may be buried before a death cert is issued. In reality families are waiting for months in some circumstances before they are able to register a death as they themselves are waiting for the death notification form to be completed in the hospital. This can lead to immense difficulties, particularly financial stresses as the deceased’s accounts cannot be accessed, social welfare payments cannot be processed until a death cert is obtained. Currently there is no pressure on Doctor’s to treat this process as an urgent process as there is no legal obligation for a death certificate to be obtained before the person is buried.”*

- More efficient systems regarding death certification should be developed

## **7. Respectful care after death**

Any treatment of an individual’s body after death must be respectful both of their wishes and of the feelings of their family.

*“While post-mortems are extremely important for medical training and clinical audit, it is essential to balance these issues with the needs of the bereaved family. Post-mortems must take place in an environment that the family can understand”.*

- Legislation needs to be passed to address issues of organ retention and post mortems

These issues could potentially be dealt with through the Human Tissue Bill 2009 which looks at: the regulation of the removal, retention, storage, use and disposal of human tissue from deceased persons, and the use of donated tissue from living persons for the purposes of transplantation and research. Activities covered by the Bill will include hospital post-mortem examinations, transplantation, research, anatomy and education.

## Other quotes

*"Life and death are a natural progression. We assist individuals to come into the world and we need to take a much more serious look as to how we conduct ourselves and services when individuals are leaving the world."*

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*"Suicide prevention is about tackling the root causes of suicide: mental illness, alcohol abuse, educational disadvantage to name but a few. It's also about making health professionals more adept at spotting signs of suicidal intent. It is about removing the stigma - it is in other words, a complex task."*

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*"Bereavement may start long before the time of death and support may be needed from the time of diagnosis ... Although not all families will require professional support, the death of a child is a rare experience and therefore few families will have experienced this form of grief and may not have support to draw on from within the community. In the needs assessment parents spoke of the wish to make contact with other parents in the same situation."*

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*"Unless you've been through it (the loss of a grandchild), you can't realise, that it would be as easy for me to lose my son, as lose my grandson, there is no difference ... to me a grandchild and your own child there is no difference - where do you draw the line?"*

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*"In Ireland today, more and more children and young people are experiencing traumatic grief and loss particularly associated with murder and suicide. It is our strong experience on the ground that there is definitely not sufficient professional services to meet these needs around the country. These losses are beyond the remit of Rainbows and it is a constant struggle to locate suitable professional services for such traumatic losses."*

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*"While there are practical and legal mechanisms that employers can implement in order to manage terminal illness or bereavement in the workplace, often it is the softer issues around communication and accommodations that make the most difference to the experience from an employee perspective."*

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*"It needs to be recognised that the person with Alzheimer's has the same end stage needs as the terminally ill patient with cancer. Therefore the same approach to treatment and care is needed."*

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*"One speaker who lost her mother six months ago described caring for her at home for 10 years with the assistance of her two sisters ... She felt a lot of the supports on offer centred around cancer. When she went looking to see what help she might receive she was told it was nearly unfortunate that her mother didn't have cancer."*