Quality care at the end of life

The Hospice friendly Hospital programme aims to ensure that a ‘good death’ is available to all those who are dying writes Paul Murray

ALMOST 30,000 people die each year in Ireland; over 60% of them in an acute or community hospital. The irony, however, is that most people want to die in their own home. They want to die away from crowded wards with televisions blaring. They want privacy and they want their dignity respected. Most importantly, they want their dying and their death to be treated in a caring, careful way.

These words, caring and careful, were used by President Mary McAleese when she launched the nationwide Hospice friendly Hospitals programme at St Mary’s Hospital, Dublin in May last year. The programme, which is unique in Europe, will cost €10 million over the period 2007-2012.

Challenge

The five-year programme currently involves 40 acute and community hospitals throughout the country.

A team of development co-ordinators employed through the programme is working with hospital staff to assist them in addressing a wide range of issues relating to end-of-life care and prepare for the introduction of a framework of standards in 2010 which will be supported by the HIQA.

Nurses are crucial to the success of the programme and the process of improving the culture of care regarding dying, death and bereavement for everyone. The programme doesn’t only focus on people who are dying and their relatives. It also focuses on the needs of all hospital staff.

Four main themes

The programme is organised around four main themes. These are:

- Integrated care
- Communications
- Design and dignity
- Patient autonomy.

If we address these themes, we will go a long way to ensuring that no one in Ireland dies alone, frightened and in pain. As George Hook has put it, ‘we must strive to ensure that each death is the best ever departure from this planet’.

Bono says that how we treat the dying is a measure of our humanity. Too often we are so intent on cure, on the belief that death is a failure of clinical care, that we forget the centrality of death in life. We forget that our going out is as important as our coming in, deserving of equal respect and attention.

The key issue of sustainability is being addressed through broadly based standing committees on dying, death and bereavement. They will co-ordinate development activities related to improvements in the physical environment and communications skills training. They will explore patients’ and relatives’ experiences and how the various care and service providers respond to need. They will examine staff support and education and audit services to ensure ongoing review and learning.

Challenge of partnership

The pilot project, at Our Lady of Lourdes Hospital in Drogheda, was strongly supported by the Health Services National Partnership Forum. It was one of three winners of Public Service Excellence Awards to represent Ireland at European level in 2006.

One of the most significant actions of the pilot was the organisation of a series of focus groups which involved consultants, cleaners, porters, nurses, healthcare assistants, allied health professionals and
hospital management. The resulting report *Death and Dying in an Acute Hospital* raised issues that are probably common:

- Staff availability for dying patients and their families
- The dying state not acknowledged as a legitimate diagnosis
- Insensitivity in planning for dying and death
- Poor physical environment, lack of privacy and dignity.

**Gate to grave**

What issues are hospital staff, supported by the Hospice Friendly Hospitals (HfH) development co-ordinators, tackling? Put simply, everything that affects the dying and their families from the gate of the hospital, to the mortuary and beyond.

Imagine a scenario: your father is dying and you get a call from the hospital to come immediately. What happens when you arrive?

- Is there some where for you to park – has the parking attendant been asked to set aside a space for you? Who greets you in A&E? What is said to you, and in what way? Is there a place to sit? Does a senior medical person explain what is being done? Does this happen in privacy?
- Are you offered tea or coffee? Do staff members keep you abreast of developments? Are you asked about your father’s wishes in regard to continuation of treatment?
- If your father dies, is what has been done explained clearly? Is it done in a professional, caring way? Is it done in a private comfortable, room? Are you approached by members of the staff, such as chaplains? Is what is going to happen explained properly, particularly if a post mortem examination is required?
- Are you left alone for too long? Are there facilities to phone relatives? If your father is being taken to the mortuary, what is the route and the manner of transport? How is the trolley or bed covered? Is it a dignified journey, away from excessive noise, and undue public notice? Who accompanies you on this journey?
- Is the mortuary dreary, cold and unwelcoming? Are there coffee/tea facilities, somewhere to sit comfortably and a telephone? How long will the mortuary staff allow you stay? Is there a chaplain of your religious background? Is the mortuary adaptable to your father’s beliefs? Are the family being pressured to have the body embalmed?
- Afterwards, are you and the family offered support such as bereavement counselling, if required? Are you invited to return to the hospital to talk with the relevant consultant?
- Most important, what happens to your father when he is dying? Is the service given to him patient centred, and attuned to his wishes?

**Communications**

Poor communication is often a major defect. Sometimes people are not told what is happening, or the communication channels are poor. At other times there is varying quality in how bad news is communicated to patients and their families.

To help deal with this, the HfH programme is currently piloting *Train the Trainers* courses in communicating in difficult circumstances related to end of life issues.

In an increasingly multi-cultural society, communication between staff and patients, and indeed between staff themselves, can sometimes be complex with increased opportunity for misunderstanding. In some hospitals signage is being reformed, relevant literature available to patients, relatives and staff is being rewritten (sometimes in foreign languages), and the use of the internet and intranet to improve communications is being examined.

**Integrated care**

An integrated approach to the process of caring for people dying in hospitals and their relatives is needed if services and supports are to be organised from the point of view of the service user rather than the service provider.

Parking, pastoral care, paint, pain control, pathways and processes all play a role in an integrated approach to care. An inability to provide an adequate supply of ‘family handover bags’, instead of plastic refuse sacks, to contain the last possessions of a deceased patient is just one simple indicator of a need for integrated care and systems thinking.

**Dignity and design**

The physical environment has a major impact on the quality of care that can be delivered to patients and families. The HfH programme has undertaken a baseline review of participant hospitals to make the case for significantly improving the physical environment.

The programme will continue to highlight:

- Utterly inadequate numbers of single rooms and the priority usually given to infection control in the use of those that do exist
- Lack of family rooms
- Lack of easily accessible multi-functional rooms to facilitate short private conversations
- Lack of dedicated staff space to allow emotional recovery
- Poor quality of facilities in mortuaries and chapels.

So serious are these issues that the first task of the Standards Development Team working with the programme was to develop *Design & Dignity Guidelines* which are currently being finalised following public consultation.

**Patient autonomy**

The concept of ‘a good death’ is now widely recognised. There is increasing awareness that the needs and wishes of the dying person, and not just of their family need, to be taken into account.

The patient’s right to choose how and where they are treated is likely to become more of an issue.

Paul Murray is a development co-ordinator with the Hospice Friendly Hospitals (HfH) programme. He was formerly head of communications with Age Action Ireland

- The HfH programme is overseen by a National Steering Committee, chaired by Prof Cillian Twomey. Sheila Dickson, first vice president of the INO currently sits on this committee, which includes a wide range of stakeholder interests
- The HfH programme was initiated by the Irish Hospice Foundation, in partnership with the HSE, and with the support of the Health Services National Partnership Forum, Atlantic Philanthropies and the Dormant Accounts Fund

**Design & Dignity – the case for renewing our hospitals**

**Public Lecture**

Professor Roger Ulrich
Director of the Center for Health Systems and Design and the Department of Architecture, Texas A&M University

Thursday, June 19, 7pm
St Ann’s Church
Dawson Street, Dublin 2

ALL WELCOME

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