

Opening statement by Kate Bree, Assistant Director of Nursing

Chair of Hospice Friendly Hospital Network

To the Oireachtas Committee on Health and Children

14th November 2013

Mr Chairman, Deputies and Senators

I am honoured on behalf of the network of Hospice Friendly Hospitals to address you this morning. I plan to explain what we're doing, what we can do better and what needs to happen for our dying patients and their families in our hospitals.

I am one of the senior nurse managers in charge of the hospital and also work weekends in this capacity. My experience to date is that patients do not always die between 9 to 5, Monday to Friday, when all services are in place. Very often you are faced with very profound experiences involving patients and families outside these times.

I was involved with a family that were coming to the hospital to see their adult child who had died tragically. On receiving the news, I contacted the hospital Chaplain and we discussed where would be the best place to take the family. Their adult child had not died in hospital so we would not be involving a ward area but we needed an appropriate space. In difficult sensitive situations like this, you act quickly and make decisions. Time is of the essence.

We were very conscious of where we would take the family because additional news of a distressing nature needed to be broken. We agreed a space, a small office area and met the family when they arrived at the main entrance. We offered our condolences, made tea and were present with the family while tragic news was broken.

In this small room moving for them to comfort each other was difficult. Later, when they were able, we brought them to the Mortuary to see and spend time with their child.

Our viewing area in the Mortuary for families is far from ideal and is outside the main building. Between the Chaplain, the hospital Porter and I, we tried to make it as tolerable and presentable as possible.

We brought the family back to the room and stayed until they were ready to face their difficult journey home. At times like this you become totally absorbed and anxious for the family because you really want to do the right thing for them in their distress. This experience affected us and had a profound effect on me.

I wanted to share this with you this morning as it captures some of the challenges we face on the ground in providing good end-of-life care in our hospitals. Good end-of-life care is everyone's business: the nurse, the chaplain, the porter.... We only get one chance to get it right.

From what I have described, you can sense how important it is that staff have the necessary skills in communication and awareness around end-of-life care.

That all patients and families are treated with dignity, respect and sensitivity.

That we have appropriate spaces with facilities in our hospitals that afford privacy when breaking bad news to the patient and their family.

We need to ensure that our viewing areas in our mortuaries are improved.

Because of the programme some of this work has started and is progressing. The programme invites hospitals to embrace their role in supporting all patients at end-of-life, regardless of diagnosis, whether their death is expected or sudden. It acknowledges that end-of-life care is a core activity in our hospitals.

Can I pose a question to you? Where would you like to die?

- Nearly half of us in this room today will die in a busy acute hospital.
- Nearly half of us will die in a busy ward area as opposed to the privacy of a single room.
- Nearly half of us will not be involved in discussions regarding our care – staff find it easier to talk to relatives than to the patient

We know this based on the results of the National Audit on End-of-Life Care (2008/9) which suggests that there is substantial variation in the quality of care offered to patients and relatives at the end-of-life. The Audit concluded that there are 17 ways to improve dying in hospitals. One way is that the patient is cared for in a single room. We are short of such spaces and have competing priorities such as income generation and infection issues for the same room.

How would you know if a hospital is a hospice friendly hospital? At its simplest it is a hospital that takes end-of-life care seriously and is implementing the Quality Standards for End-of-Life Care in Hospitals (2010). These set out a shared vision for what hospitals should be aiming for and what patients and families should expect.

At its heart, it is a culture change programme. It has introduced numerous practical resources to enhance the culture at end-of-life. I want to bring the End-of-Life Care symbol to your attention this morning. This has been developed to respectfully identify items connected with end-of-life. It is inspired by ancient Irish history and is not associated with any one religion or denomination.

When you see this displayed in the hospital ward it signifies that a person is very close to death or has died. It signals to all staff, other patients and families that an intensely personal and profound

experience is happening to a person and their family in this ward at this time and to be mindful of this.

To recap: Thank you for reading my submission and I would ask that you consider all the recommendations. Of these I would highlight 3 things:

1. We have excellent committed staff in our hospitals and we need to support and invest in them to ensure that they care for our loved ones with competence and compassion.
2. We need to ensure that we have adequate numbers of staff on the ground that can provide compassionate care and be present for patients and their families.
3. We need a National End- of- life and Bereavement Strategy to cover all aspects of dying, death and bereavement in Ireland. We need and can do so much better for our dying patients and their families.

Finally...most of us in this room this morning when pressed will wish to die at home.

My wish for you and myself is that this will happen. But If not, I hope that by the time you die, every hospital in Ireland will be a Hospice Friendly Hospital and offer you patient centred, compassionate care – because you are you and you matter.

I enclose a link to a 5 minute DVD called "A Wish".
<http://irishhospicelibrary.wordpress.com/2012/07/18/a-wish-new-animated-video-from-the-hospice-friendly-hospitals-programme/>

It captures and explores the important role all staff play in providing end -of-life care for those of us who will die in hospital.

A good death in hospital is possible our challenge is to make it happen.