Being part of the change.

Photo: Solace Room, Kilkenny Hospital

The father of medicine, Hippocrates(460-370 B.C) is generally thought to be the first person who viewed disease not as something delivered from the gods but by earthy influences. Hippocrates treated illness seeking to understand his patients as a whole and in their social and natural environment.   This is as relevant today as it was in Hippocrates time. Where we are cared for when we are ill can have an effect on our recovery and our response to treatment - as well as affecting our friends and family who visit and care for us. Our surroundings affect us sometimes in more ways than we can imagine. This is particularly so when we are away from our home environment and even more so if we are dying.

We tend to think of the treatment of the sick today in relation to hospitals. I have never considered the word 'hospital' before, but if we break it down it is very similar to other words such as 'hospitality', 'hotel' 'hostel' 'host'. This similarity is because hospitals did evolve from being places of hospitality for pilgrims. They were somewhere to stay, and somewhere to rest and refresh their weary mind and body. From these simple beginnings

they have evolved into the vast and complex multi-disciplinary buildings with which we are now familiar.

A hospital means different things to different people. For many, it is a place of work. For some of us it a place where we go to get mended, to get tests, to have an operation, to see a consultant or therapist, to accompany or visit our friends and families.

For others, a hospital is a place where they will die.   We know from lots of studies that most of us would not choose to die in hospital. We would prefer to die at home, to be surrounded by those who love and care for us, in calm and familiar surroundings. But sometimes that choice is not available to us. Sometimes the hospital is the most appropriate – or the unavoidable – place for us to die.

Hospitals are busy, clinical, multi-tasking, crowded (sometimes overcrowded), bustling environments. How can they provide end of life care in the "calm and comfortable" place accommodating to the "people we love" that we said we would like when we answered the "Have Your Say" survey?

This is where a ground-breaking project partnership between the HSE and the Irish Hospice Foundation comes in.   Called the Design and Dignity project, its primary aim was to transform the way hospitals are designed and to protect the dignity of patients at end of life and their families.

When the project was starting out, they were conscious that the hospital environment could be a difficult one for patients, families and staff facing or dealing with end of life issues. There was a lack of facilities available for a person at the end of life and for their family. There were very few places to bring people together to carry out private conversations. Sometimes these conversations had to be managed in busy corridors or shared wards, and both the medical staff and the patient and their family recognised it could be better. There was a shortage of single rooms available for patients who were dying and few facilities for their families to stay with them. The personal touches were missing - the things that make a home "homely" such as natural light, personal belongings, plants, nature.

But with the imperative to keep hospitals clean and safe for the many people that use them on a daily basis how do you bring in touches to make them more homely?

To answer this and other questions I spoke with Mary Lovegrove – who leads the Design and Dignity programme for the Irish Hospice Foundation.   What she told me is that Design and Dignity needs many brains, hands and skills for it to work well.   The successful project works with designers, engineers, clinical and non-clinical staff. Together they marry clever design and practical ideas through unity, and teamwork. Of course there is also a little love and a sprinkle of compassion! The result? Changes in the hospital environment which really improve people's experiences.

Like most good ideas Design and Dignity started relatively small. The goal was to trial some shining stars in the hospital settings, to show with it could be done, and to set a standard and have the blueprint for other hospitals to adopt and implement.   The focus on design and dignity was clear to "enhance practice and culture around the end of life" – along with all of the other components of the Hospice Friendly Hospitals programme. In true palliative care fashion the Design and Dignity project not only focused on the patient but their family and friends as well. Rooms were designed with the family at the forefront, with facilities for tea and coffee, charging points for phones, washing facilities. A place where they can take a moment. A place where they can focus on the intensity of what is happening to them. A place to be.

So far over 30 projects have received funding, with 20 projects completed. Every project brings with it overwhelmingly positive feedback and reviews. Design and Dignity is allowing hospital staff to manage and make little changes that they know have a significant impact on their patients and families at such a difficult time. Being able to provide these new facilities leaves them feeling proud of their ideas and their teamwork. It also cements the importance of the Irish Hospice Foundation and the Health Service Executive working in partnership to bring palliative care principles to hospital environments all around Ireland.

Sometimes when projects are put into effect, synergy is created in ways that may not have been anticipated. One such example comes from the new mortuary in Sligo hospital. Since its refurbishment it now hosts the hospital choir practices and is a meeting point for the End of Life committee. The morgue is a place of calm, comfort and hospitality and has been described as one of the most beautiful buildings in the hospital. In the Mater hospital in Dublin, a family room is a haven for long-term, chronically-ill patients families and friends who use it every Tuesday to play cards and get together. The family room gives the illusion they are in someone's home with the benefit of supporting their 'people' at the same time.

Design and Dignity has also managed to effect innovation in care practices. One example is that of St. Luke's hospital who have developed unique appointment cards for bereaved mothers. The mother's appointment card has an image of bluebells from the Design and Dignity Solace Room. When the patient presents her card, she is fast-tracked through the department away from other mothers and their babies. It's a small but beautiful act of compassion.

The real test of any project particularly one which affects those experiencing life's most testing moments is what the users think of it. One of them reflected on the value of a family room as being "space to breathe, to think, to mourn for our mother."
Some simply valued the option of having somewhere to go:
"Thank you for the use of this family room, and it was such a Godsend in our hour of need during John's last four days and nights. It was somewhere we could rest, reflect, cry, be silent, be together as a family, as well as the practical side of being able to lie down and sleep, have a shower and of course have many a cuppa tea or coffee."

Family rooms also take away some stress from the staff. They can relax knowing that the families are being cared for and can take some time to themselves.
"Honestly, I can't describe the benefit of the room. You can see the stress lift from relatives when they come into the room …it has given us all great pride in our work and in our caring for these families" Palliative Care Nurse

So after eight very successful years, I asked Mary what next for Design and Dignity? She explained that through the learnings of the last few years there is a clear vision for the future:

"Our vision is that there will be End of Life Sanctuaries in every adult, paediatric and maternity hospital in Ireland, designed to ensure that death and dying are experienced in surroundings that enhance dignity and respect for patients and their families.
End of Life Sanctuaries include palliative care suites for patients who are dying, family rooms with overnight accommodation, counselling rooms for bereaved families, bereavement suites in emergency departments and family friendly mortuaries."

Have you have had experience of working with or availing of a Design and Dignity facility or project? Let us know what you think. info@hospicefoundation.ie
Do you work in a hospital in Ireland? You might have an idea of how a Design and Dignity grant could enhance the care in your hospital. You can apply for a Design and Dignity grant from the Irish Hospice Foundation and the Health Service Executive. Join us to provide a little sanctuary in every hospital in Ireland.

To find out more about Design and Dignity projects go here.
To apply for a grant go here

The People's Charter on Dying, Death and Bereavement is here

 Hospice Friendly Hospitals programme

CEOL – Compassionate End of Life Care in residential settings

The Irish Hospice Foundation is the only charity dedicated to dying, death and bereavement in Ireland. 80 people die in Ireland every day and the IHF believes everyone has the right to be cared for and to die with dignity and respect in the care setting of their choice. Our mission is to strive for the best end-of-life and bereavement care, for all. The IHF campaigns to make excellence in hospice practices, bereavement and end-of-life care a national priority and to stimulate the conversation about dying, death and bereavement in Ireland. Full details: www.hospicefoundation.ie