DESIGN & DIGNITY
Transforming End-of-Life Care in Hospitals
...One Room at a Time
Death and dying are facts of life. Our aim in the Irish Hospice Foundation is to make the experience of dying as positive as it can be, both for those going through it and for those left behind.

We believe that no one should face death or bereavement without the care and support they need. Our mission is to achieve dignity, comfort and choice for all people facing their final journey.

Throughout the 27 years of our charity’s history, we have pursued the hospice model of end-of-life care, which looks to relieve pain and distress and helps people to live life as fully as possible to the end.

More recently, our work has expanded to embrace the needs of people who cannot access hospice care, including those who die in hospitals. Today, nearly half of all people in Ireland die in this setting, and while hospital staff do their best, the reality is that with limited resources, hospitals are more focused on clinical care and on cure than on creating a sympathetic environment for those for whom sadly, there is no cure.

Through our Hospice Friendly Hospitals Programme, we are working with hospital managers and staff to improve care at the end of life. We aim to ensure that hospitals apply the principles of hospice care for the dying, the deceased and the bereaved.

And this is where our Design & Dignity project comes in. Recognising how deeply people are affected by their surroundings, we are working to change not just the culture of care but also the physical environment of hospitals for people facing death and for their families.

So, we are renovating shabby storage rooms, turning them into oases of calm where bad news can be broken sensitively or where families can gather and have a cup of tea. We are re-designing viewing rooms where people first see a deceased loved one, with quiet ante-rooms to allow for a catching of breath. We are transforming neglected mortuaries into havens of peace.

The response has been hugely encouraging. These relatively small investments are making a real difference at what is often a traumatic time in people’s lives. But we want to do more, and for that we need funding.

We hope you may consider supporting us in this work.

Sharon Foley
CEO, Irish Hospice Foundation

Gabriel Byrne
Patron, Design & Dignity

‘The great Robert Kennedy once said each of us can work to change a small portion of events. If each one of us can change a small portion of a person’s journey to the end of life in hospital, then together we can make bigger changes’.

- Gabriel Byrne, Patron, Design & Dignity
The *Design & Dignity* project is grounded in the firm belief that the end of life should be recognised as a time of the most intense human feelings, which can include sadness, loss, anxiety and fear. These should not have to be endured, sometimes publicly, in completely inappropriate surroundings: a busy corridor, a waiting room, a ward reception area, where others may be chatting and laughing.

Ground breaking research commissioned by the Irish Hospice Foundation in 2007 found that many hospitals are old and poorly designed. The research identified a lack of:

- facilities for private conversations
- single rooms for patients
- facilities for families
- provision for different religious traditions and beliefs
- attention to external and natural surroundings

It also found that mortuaries are often in poor condition.

In human terms, the impact of all of this can be immense. For the person nearing the end of life, it means being deprived of the space and privacy for intimate encounters with loved ones. For hospital staff, it means having to break bad news in bustling public spaces. For families, it means struggling to put an acceptable face on intensely private emotions, or seeing a deceased family member for the first time in a grim, dilapidated mortuary.

“How can you say goodbye, ask for or give forgiveness, when there are … five other people on the ward, a pile of visitors, the TV on and the staff working away all around?”

*– Gabriel Byrne, Patron, Design & Dignity*

> **Design & Dignity at a glance**

- *Design & Dignity* is an initiative of our Hospice Friendly Hospitals Programme, which is working to enhance end-of-life care in Irish hospitals, where almost half of all deaths occur.

- The aim of *Design & Dignity* is to fund ‘exemplar’ projects in public hospitals, transform the way hospital spaces are designed for people at the end of life and their families, and set the standard for other hospitals to follow.

- Projects include: family suites and gardens, viewing rooms, ward reception areas, waiting areas, mortuaries, and maternity bereavement rooms.

- To complete the first phase of the *Design & Dignity* project, we need to raise $1 million (€750,000). Ireland’s Health Service Executive will match all funds raised.

- Our vision is to roll out the *Design & Dignity* project across Ireland and to embed the Hospice Friendly Hospitals Programme within the health system. To achieve this vision an additional $3.5 million (€2.5 million) is needed.

- To date three projects have been completed and the feedback from patients, families and staff has been overwhelmingly positive.
Our projects

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Embracing the work of international experts from the US, UK and Scandinavia, Design & Dignity wants to:

- help hospitals to build better facilities
- fund exemplar projects and showcase them nationwide
- provide practical architectural support and advice
- assist hospitals to meet the Quality Standards for End-of-Life Care
- influence healthcare policy regarding new builds and refurbishment projects

We have made a start by developing a number of ‘exemplar’ projects in 11 Irish hospitals. These projects — some of which are already complete — are seeing cluttered rooms and dreary facilities transformed into tranquil spaces where families may gather or can be with a deceased relative in appropriate surroundings.

Projects completed to date include:

- a family room on a medical ward that can be used to break bad news or as a place of retreat (Mater Hospital, Dublin)
- viewing suites in the Emergency Department, where the bereaved can be with their deceased loved one (St James’s Hospital, Dublin)
- a renovated mortuary (Mercy University Hospital, Cork)

“The very place where death occurs is likely to be imprinted forever in the minds of the witnesses and survivors... This places a tremendous symbolic importance on the quality of this setting, which attains something of the notion of a sacred place.”

Dr Ken Warpole, Design & Dignity Project Adviser; writer on architecture and urban social policy and associate of UK think-tank, DEMOS
Mater Hospital, Dublin
Family room on acute medical ward
$50,000/€40,000/£35,000

Beaumont Hospital, Dublin
Mortuary renovation
$400,000/€300,000/£260,000

St James's Hospital, Dublin
Family and viewing suites
$120,000/€90,000/£80,000

Connolly Hospital, Dublin
Family room & garden in social work department
$90,000/€70,000/£60,000

Our Lady's Hospital, Meath
Family room with kitchenette
$120,000/€90,000/£80,000

Mercy University Hospital, Cork
Mortuary renovation
$180,000/€130,000/£110,000

University Hospital, Limerick
Mortuary renovation
$330,000/€250,000/£220,000

Nenagh Hospital, Tipperary
Mortuary renovation
$40,000/€30,000/£26,000

St Luke's Hospital, Kilkenny
Bereavement room/infant viewing room on maternity ward
$80,000/€60,000/£50,000

Mayo General Hospital, Mayo
Ward reception and waiting area
$150,000/€110,000/£95,000

Sligo General Hospital, Sligo
Extension to mortuary
$510,000/€380,000/£330,000
Small investments for a big impact

All of this costs money. The good news is that Design & Dignity has succeeded in winning the support of the Health Service Executive (the public health service in Ireland), our long-standing partner in the Hospice Friendly Hospitals Programme, without whose leadership and cooperation, the Programme’s successes to date could not have been achieved.

Despite recession and recent severe budget cuts, the HSE has agreed to co-fund Design & Dignity projects on a 50/50 basis. And it has been agreed that all future HSE hospital development and refurbishment projects must comply with the Design & Dignity guidelines developed by the Hospice Friendly Hospitals Programme.

“We are very committed to Design & Dignity in the long-term. This project is a good example of the public sector working in partnership with an innovative charity to improve care for people at end of life.”

- John Browner, Assistant National Director, HSE Estates

As a charity, however, the Irish Hospice Foundation’s own fundraising has been badly affected by the recession. To complete the first phase of the Design & Dignity project, we need to raise $1 million (€750,000). Ireland’s Health Service Executive will match all funds raised.

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The evidence is that this simple but powerful initiative could be a prototype not just for Ireland but for elsewhere in the world.

“In Ireland … why not … be the forerunners of some sort of new cultural link towards living and dying?” – Colum McCann, Writer
Did you know?

- Patients experience less pain when their room has proper exposure to daylight thus requiring less pain medication.
- Views of nature, access to gardens and exposure to art also reduces people’s pain and improves their mood and sense of well-being and therefore reduces care costs.
- Shorter distances to medication storage reduces medication errors.
- Patients in single rooms report higher satisfaction with communication with their doctors and nurses.
- Higher noise levels in neonatal intensive care results in higher blood pressure, heart rate and respiration rate and an increased need for oxygen support in babies.

Prof. Roger Ulrich, US Health Design Academic/Advisor to the Design & Dignity project.
Our Vision

No one should face death or bereavement without the care and support they need

The Irish Hospice Foundation is a national charity dedicated to improving end of life care everywhere by:

✓ Funding Ireland’s only Consultant in Children’s Palliative Care
✓ Funding a team of Children’s Outreach Nurses who support families care for their seriously ill children at home
✓ Funding a Nurses for Night Care Service, for people with illnesses other than cancer which enables more people to fulfil their wish to die at home with dignity
✓ Working with hospitals through our Hospice Friendly Hospitals Programme to bring hospice principles into hospital practice
✓ Developing bereavement resources and providing education to help people cope with their grief