Design & Dignity

How Irish Hospitals are Transforming Spaces for Patients and Families at the End of Life 2017

Susan Parker

Introduction

One of the most difficult jobs of hospital staff is delivering bad news to patients and their loved ones. It can be even harder when that news has to be conveyed in the middle of a busy, noisy corridor. Or when relatives must navigate dank, out-of-the-way hallways to get to an outdated, industrial mortuary to view their family member. But in too many hospitals, such occurrences happen every day.

A programme established by the Irish Hospice Foundation (IHF) and the Health Service Executive (HSE) is providing practical examples of how hospitals can offer quiet and peaceful spaces for family members that help them cope with one of the most trying times in their lives. It highlights the sometimes overlooked importance of the physical environment in providing dignified end-of-life care to patients and their families.

The Design & Dignity Programme has supported 24 demonstration projects in hospitals around Ireland that show what a difference a calm, comfortable, and inviting environment can make. It has funded family rooms where loved ones can find a respite from the chaos and noise of a hospital and make a cup of tea or take a rest. The programme has also supported new mortuaries where family members can say goodbye to their relatives in a space that honours that passage.

This case study describes the experiences of four hospitals as they created new spaces for family members to privately cope with difficult diagnoses and the deaths of relatives. It talks about how staff members found creative ways to carve out spaces in crowded hospitals, used research to choose the right kind of artwork, and dealt with practical issues such as sceptical colleagues to fashion warm, inviting rooms that also met infection-control standards.

The case also discusses common challenges hospitals experience in implementing such projects and learnings for how to overcome them. The hospitals featured in this case provide brief, practical examples of how changing the physical environment can have farreaching effects on the lives of family members and on staff.

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Genesis of the Design & Dignity Programme

In Ireland, 43% of people who die each year will do so in an acute hospital. While end-of-life advocates argue that one of the key jobs of a hospital is to provide support for dying, death, and bereavement, the reality is that the focus of many hospitals is still on curative care. And the reality is that hospitals can be a difficult place to die.

While in recent years there has been new emphasis in providing training on end-of-life care to hospital professionals, relatively little attention has been paid to the impact of the physical environment. But that environment can play a tremendous role in making the end of a relative's life harder or a bit easier, advocates say.

'Our physical environment affects us in subconscious ways', said Ronan Rose-Roberts, an architect. 'If you are sitting in a room with poor finishes and old furniture that looks tatty and worn out, you're not going to feel comfortable or particularly respected in there. At the end of life, these feelings might be buried but you can still feel them and it can add to your sense of distress'.

'Conversely, if you are going to a room that is beautifully appointed and has stylish and luxurious furniture you can feel very relaxed', Mr. Rose-Roberts continued. 'A poor environment is not going to help you feel nourished and cared for while a well-designed environment will help you feel better. It will not take away from the grief, but it won't add to it'.

What is the Hospice Friendly Hospitals Programme?

The Hospice Friendly Hospitals Programme, an initiative of the Irish Hospice Foundation, was the first national end-of-life hospital programme in Europe.

The programme, carried out in partnership with the Health Service Executive that began in 2007, encourages hospitals to see dying and death as a natural and integral part of their work.

The initiative surveyed thousands of staff and relatives to assess the quality of care provided by Irish hospitals during the last week of life.

The programme then developed the European Union's first 'Quality Standards for End-of-Life Care in Hospitals' based on the results of this survey.

The Hospice Friendly Hospitals Programme also created an evidence-based 'Ethical Framework for End-of-Life Care'—unique in the world that provides tools for hospital staff and others to think about difficult problems in end-of-life care. Programme staff trained more than 3,000 healthcare staff to become more comfortable and competent in working with people who are nearing the end of their life as well.

Finally, the programme created the Design & Dignity initiative aimed at enhancing the physical environment of those areas in hospitals that are of particular importance in end-of-life care.

Study Reveals Troubling Findings

Sadly, for too many relatives in Irish hospitals, a poor environment may have only added to their grief. A 2007 <u>study</u> by Tribal Consulting that reviewed the physical environment of 20 Irish hospitals revealed a number of troubling findings including:

- A lack of facilities for hospital staff and patient's family to privately consult.
- Limited or no waiting areas for family members.
- Inadequate numbers of single rooms for dying patients.
- Poor quality of mortuaries.

Too many family members heard devastating news in busy corridors while kitchen staff pushed trolleys of food past and televisions blared from nearby rooms. What also became clear was that poor design not only affected family members, it also had an impact on hospital staff.

'Bad design leads to bad practice', said Michael O'Reilly, board member of the Irish Hospice Foundation. 'It means that people are just not aware. Good design changes everything'.

An Approach to Transforming Hospital Spaces

To help address these shortcomings, in 2010 the Irish Hospice Foundation, together with the HSE, created the Design & Dignity Programme that aims to enhance the physical environment of areas in hospitals that are particularly important in end-of-life care. It grew out of a larger programme, the Hospice Friendly Hospitals Programme, which The Atlantic Philanthropies funded for €5.25 million from 2007 to 2012.

"The Design & Dignity Programme aims to create a physical environment and ambience that is peaceful and respectful and dignified so that people can grieve properly and are protected and looked after in the raw few days after the end of life', Mr. O'Reilly said.

The programme had two main components:

- Funding 24 'exemplar' or demonstration projects beginning in 2011 that would provide examples for future development of facilities related to end-of-life care. Most of the projects focused on improving mortuary facilities and developing family rooms where relatives could have a respite and—if needed—spend the night in comfortable surroundings. The projects also funded gardens, waiting areas, bereavement suites in emergency departments, and maternity bereavement rooms.
- Providing guidance for these projects and others. That included developing <u>Design & Dignity Guidelines</u> in 2008 that provide guidance to design and plan acute hospitals so that the building could support quality end-of-life care and an accompanying <u>Design & Dignity Style Book</u> in 2014 that provided more detailed information on designing spaces. While design guidelines existed for specialist palliative care settings and residential settings for older people, none had existed for acute hospitals where nearly half of people die. The guidelines and stylebook were developed jointly by architects, senior nurses, end-of-life care coordinators, estate managers, palliative care nurses, and healthcare quality experts. They were based on research into the kinds of physical environments that are most soothing to people during times of distress.

Between the practical guidance and the exemplar projects, the Irish Hospice Foundation hoped to catalyse a change in hospitals' approach to their physical environment in addressing quality end-of-life care.

"These projects are trying to change the culture and organisation to provide better care at the end of life', said Sharon Foley, CEO of the Irish Hospice Foundation. "When hospital staff are used to working in a poor physical environment and then they see what a difference these new spaces make it has a real effect. If you have something that touches people along the way it is transformational'.

How the Design & Dignity Programme Works

Under the Design & Dignity Programme, Irish hospitals could apply for funding to create exemplar projects in their institutions. 'From my experience, to make change you have to challenge people's ideas and attitudes toward things', Mr. Rose-Roberts said. 'We were hoping to create exemplar environments that people could say: "This is how it should be like. This is how good it could be for patients and for staff. You can do this, and it doesn't cost the earth''. It's taking hospitals and making them feel more like hotels and that the patients and family members are really important—more important than they have been made to feel'.

The budgets of many of these projects were relatively small, and the aim was that the rooms had to be run and maintained as cost efficiently as possible while also making use of high-quality, durable materials. Initial funding for projects ranged from \leq 30,000 to \leq 376,000. The first two rounds of funding cost of a total of \leq 2.4 million and came from the National Lotteries, the Health Service Executive, and from participating hospitals and the Irish Hospice Foundation.

Successful applicants created a project team that consisted of representatives from the estates (hospital) department and building managers and staff, including nurses, doctors, end-of-life care coordinator, cleaning staff, porters, hospital chaplain, infection control staff, and mortuary staff. Patient and family representatives were also consulted and involved as the project progressed. Ideally the project team would be formed under the auspices of a hospital end-of-life care committee or a member of the senior management team to ensure there would be sufficient support for the project. While each project hired its own architect, the IHF provided a Design and Dignity project manager as well as an architect as a consultant—Ronan Rose-Roberts—to provide overall guidance and consistency.

The initial projects typically took six to 18 months to complete and involved intensive hospital staff engagement throughout. A key emphasis was on making these spaces feel completely different from the rest of the hospital, as if family members have stepped into an oasis of calm. That meant looking for materials that felt homey, like wood-like floors that were still linoleum to meet infection control standards. It also meant finding comfortable, bright, and durable furniture; providing facilities to make tea and get a snack; and carefully choosing colours and artwork that research showed to be soothing.

Projects often ran into challenges including staff resistance and navigating the need to bring the work to completion quickly and economically while not cutting corners on quality of design and furnishings.

The following are the stories of how four hospitals successfully navigated those challenges and what they learned that may be helpful to others embarking on a similar process.

Nenagh Hospital – A Committed Champion Shepherds Through a Family Room

For years, Carmel Sheehy had been concerned at the lack of a proper space where she could bring family members when she had to share difficult news about their loved ones. Working as a clinical specialist in palliative care for more than 16 years, Ms. Sheehy was often the one who worked most closely with patients and their families at the end of life.

The hospital where she worked—University Hospitals Limerick, Nenagh Hospital—is a small, rural hospital where about 50 people die each year. Most of the deaths in recent years have been from end-stage chronic illnesses such as cancer, heart disease, and chronic obstructive pulmonary disease. Many patients and their families who grew up and still lived in the area much preferred to go to their local hospital in Nenagh rather than the larger institution in Limerick, some distance away.

Bringing Awareness to Staff

Ms. Sheehy experienced the same issues as other healthcare staff in hospitals—having to give sad news to family members in settings that were not appropriate.

Ms. Sheehy had actively campaigned in her hospital for years to create a family room where patients' loved ones could receive upsetting news in a dignified manner. Then she happened to read about the Design & Dignity grant the day before the competition closed. Based on her years of thinking, she was able to quickly submit a grant proposal and eventually was awarded €30,600 in funding from the Design and Dignity Grants Scheme to create a family room. The funding and the professional assistance from an architect helped generate interest from the hospital leadership in the project, which started in 2013. Ms. Sheey had also identified a small room that was being used for storage that could be transformed into a family room when a wall was knocked out.

Staff interest in the project was developed by participating in 'Final Journeys'. This is a communication training day that empowers staff to become more competent, confident, and comfortable when communicating with patients and their relatives as they deliver end-of-life care.

All grades of staff attended these training days on site. This was a game changer. These training days were the first opportunity staff had to take time out and talk about death and dying, share their personal experiences, and think how they could change their work practices to improve end-of-life care at Nenagh Hospital. The interest in the family room project grew with many staff offering their opinions and suggestions on it. By the end of a training, many of the staff who thought end-of-life care was not part of their remit realized that it was everyone's business in the hospital.

Adhering to Infection-Control Hospital Policies

One challenge that Ms. Sheehy encountered was to convey her vision of this room and its exact purpose to various staff and designers involved in this project to ensure that the Design & Dignity Guidelines were adhered to, and that health-and-safety and infection-control hospital policies weren't breached. Ms. Sheehy had to continually refer to the Design & Dignity Guidelines and research that delineated what design elements are necessary for such a room to serve its intended purpose.

The eventual room included a number of key features:

- Bright, lively colours to reflect as much light in the room as possible because daylight has a positive effect on people's mood.
- The colour lime green was chosen as an accent because green has a calming effect.
- Artwork that was chosen based on evidence that landscapes provide a sense of peace and with complementary blue and green colours.
- A high-quality sofa in faux leather that is easy to maintain and that can be extended to provide a comfortable sleeping area for relatives staying overnight and storage space for their belongings.
- An oak table and wood-like floors that provide a homey feel.
- A kitchenette and small fridge.

Throughout the process, Ms. Sheehy consulted with staff members such as security and cleaning staff to ensure this room would meet its intended purpose.

Using the Launch of the Family Room to Reinforce its Purpose

The project took 18 months to complete, and when it was ready to launch in March 2014, Ms. Sheehy had one more idea: to celebrate the successful completion of this room and raise the profile of end-of-life care at the hospital. She invited Irish designer Louise Kennedy, whose father had been in palliative care in the hospital and died years earlier, to launch the project. Ms. Kennedy's appearance generated tremendous interest among the staff and local media and provided a positive story in a time of news reports about many health services closing.

"This is someone who has experienced first-hand what it's like not to have a family room', Ms. Sheehy said. 'Having a celebrity and someone who was not a politician was really important. It helped raise the profile of end-of-life care and generated positive conversations'.

Meanwhile, Joe Hoare, an HSE estates manager, who was involved in the development of the family room, took the opportunity to create a family room in another hospital in Ennis, some 90kms away. This room was incorporated within a new development and replicated the Design & Dignity model so it cost one third of the price of the Nenagh room.

After the project in Nenagh was completed, Ms. Sheehy said that she noticed a cultural change in how staff approached end-of-life care at the hospital.

'It has brought the hospice feel to the hospital', she said. 'I can't remember the last time I saw someone being told bad news on a corridor'.

Below are photos depicting the room before and after the renovation:



Before renovation

Family room after renovations





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Mortuary at Limerick Hospital—Enhancing Family Experience

When Catherine Hand, a nurse service manager at the University Hospital Limerick, learned about the Design & Dignity grant programme, she asked nurses which areas needed the most improvement.

'What came up repeatedly was that the mortuary facility was really poor', Ms. Hand said. 'It was a very cramped and drab room. It was very Catholic. And when you looked out the window, you see rubbish bins and broken equipment and maintenance tools. It gave you the impression that's where the rubbish goes'.

The University Hospital Limerick has about 600 deaths a year. All of these patients will eventually come to the mortuary. To get to the mortuary, relatives had to walk down a corridor and outside the main hospital through areas filled with equipment, rubbish, and peeling paint. Families had to wait in a corridor crammed with equipment before they went into the mortuary. Instead of a peaceful entrance to see a loved one, a relative's path to say goodbye felt like an afterthought. Hospital staff did not want to bring the relatives to that area, and the mortuary staff continually felt that they had to apologise for the poor facility, Ms. Hand said.

A Proper Environment to Say Goodbye

'We wanted to create an environment that would support better delivery of care and make relatives feel as if the hospital cares about them', Ms. Hand said. 'The memory of that mortuary would be etched in their minds forever. It's such an emotional time. They would never forget the environment where they were when they said goodbye to a loved one'.

In 2011, the hospital received €253,000 from Design & Dignity to renovate the mortuary. Unlike some participants in the Design & Dignity Programme, the University Hospital Limerick had an end-of-life care coordinator who played a key role in this project.

The plan was to create three new spaces: (1) a family room where relatives could wait in comfort with facilities for making hot drinks and a view of an internal garden; (2) a new peaceful and secular viewing area adaptable to the needs of different faiths and cultures; and (3) a new private counselling/interview room available as a quiet space for bereaved family members.

As in all Design & Dignity projects, a team was created to oversee the work. It consisted of key staff including mortuary and technical services staff, the laboratory manager, architect, end-of-life care coordinator, and the nurse service manager.

One challenge of this project was ensuring that all staff working in this area were involved in the development of the new facilities including mortuary staff. However, in retrospect the mortuary staff were not as engaged in the project as much as the project team would have wished due to staffing difficulties.

"The greatest impact of the change was for the mortuary staff. The new project impacted on their work practice, and they seemed comfortable using the older smaller room', Ms. Hand said. 'It's important to acknowledge the people who are being impacted by a change when undertaking a large project such as redesigning their department'.

Denis Casey, the end-of-life care coordinator at the hospital, added that although the mortuary staff were involved from the start, they may not have felt empowered or as much part of the project as they could have. Because they are the front-line staff, their buy-in is critical.

"The most important lesson is to get all stakeholders involved from the outset, to make them fully aware of what is going to be achieved, Mr. Casey said. 'It is their project as well. They will be responsible for it. One of the biggest challenges is to get staff to use the new facilities as much as possible'.

The project took about a year and a half to finish and was launched in October 2015. Among the key features are:

- A new mortuary facility that wraps around an internal tranquil garden that allows family members to reflect and prepare themselves for viewing their loved ones.
- The entrance doors have an end-of-life spiral engraved on the glass that adds a degree of respect and solemnity. The threestrand spiral is inspired by ancient Irish history, is multi-denominational, and represents birth, life, and death.
- The main family room is a bright, airy space with quality, durable, comfortable furniture and includes a kitchenette to make coffee or tea. Those facilities are contained behind sliding doors if not in use or considered appropriate.
- The family room leads to a new secular viewing room that is adaptable to meet the needs of different faiths and cultures.
- A new private counselling/interview room is available as a quiet space for bereaved family members. This can also be used by outside agencies such as the Garda Síochána (police) where they can meet and interview relatives. The room includes contemplative artwork to enhance the feeling of a quiet retreat.
- Designated car parking for relatives next to the mortuary building.

The hospital also secured separate funding from Compassionate Communities, Milford Care Centre, to create a new walkway to the mortuary. The walkway includes a garden, planters, benches, and lights to provide a more peaceful entrance to the mortuary than had been possible in the past.

Below are pictures depicting the old and new mortuary walkway.

Walkway before



Walkway after







Below are pictures depicting the new facilities.

Family waiting area with kitchenette

Internal garden



Multi-faith viewing room



CALLS 1

Counselling/interview room



In addition to the new mortuary facilities, a key outcome of the project is the hospital leadership has agreed that they would apply the Design & Dignity Guidelines to any new building they do. As a result, the hospital's new Emergency Department will have a serenity suite that staff can use for breaking bad news. In addition, the staff on a ward took the initiative, including raising money, to upgrade a room for families where difficult conversations can be held in private.

"The Design & Dignity project was an opportunity to raise the awareness of the type of environment that's needed to look after people properly', Ms. Hand said.

Large, Urban Hospital Provides Oasis on Busy Wards

The Mater Misericordiae University Hospital in Dublin is a busy teaching hospital in the heart of the city with 650 acute beds. When Diarmuid Ó Coimín, an end-of-life care coordinator with a background in palliative social work, was looking for where best to create the hospital's first family room using a Design & Dignity grant, he conducted an initial assessment about where the greatest number of deaths occur.

He learned that just 14% of the deaths occur in the emergency department and 66% take place in acute medical wards. It made sense then to build a family room on a ward where staff and family members needed it the most. St. Brigid's Ward, a 31-bed medical ward with an acute stroke unit attached to it, was chosen as the first site.

Demonstrating the Value to Hospital Staff

By placing the first family room built under this grants scheme on a busy ward, Mr. Ó Coimín and the project team not only hoped to demonstrate its value to staff and others but that it could also serve as a real-life example to other wards in the hospital.

"The first step was meeting with the ward staff and talking to them about the possibility of creating a family room and asking them what it should look like', Mr. Ó Coimín said. "There were a mixture of reactions. Some people were unsure as to the need for the family room whereas other staff saw it as important and recognised the valuable contribution it would add to the care of patients and their families on the ward. They were the champions that helped assure those staff who were initially uncertain as to the potential value of the family room on the ward'.

When Mr. Ó Coimín and a team first began meeting to plan the family room in 2011, they immediately ran into some unexpected challenges. While IHF had published Design & Dignity Guidelines, the guidelines did not provide specific answers for some key questions: What are the core elements of a family room? Should it have seating spaces for three people or eight? Is a kitchenette really necessary? Should there be a sofa that converts into a bed so relatives can stay overnight? Would that be a burden on the staff? What do relatives really want? Who has ownership for the project—the ward, the architect, or the end-of-life coordinator?¹

In 2014, the Irish Hospital Foundation published an accompanying Design & Dignity Style Book that provides answers to all of these questions as well as additional specifics on what should be included in family rooms, mortuaries, palliative care suites, and emergency department bereavement suites.

Lacking such specifics, Mr. Ó Coimín researched the literature for models of family rooms in acute care settings and asked staff and family members what they wanted. Mr. Ó Coimín and the project team used that information to work with an architect to develop a plan for the family room. Along the way, the project team members sought input from family members about the design and such details as colour choices for the room.

'We asked some patients and family members on the ward about their views, which was very helpful,' Mr. Ó Coimín said. 'Just the fact that they endorsed what we did and said it was a wonderful idea was important. It was not just the architect and staff involved but the family members who will benefit from this are helping choose colours and design for the room'.

Furniture Shows Wear Quickly

The team overseeing the project also purchased household furniture that met infection-control standards, but those items quickly showed wear and tear from nearly constant use. After six months, the team had to replace sofas and a laminate coffee table with commercial-grade, higher-quality furniture.

'We initially purchased the type of sofa that you would have in your home', Mr. Ó Coimín said. 'But we didn't realise that these sofas would get near constant use, unlike those in someone's home where you might use it just a couple of hours a day. We then bought furniture that was made for commercial use, which were very comfortable but wasn't any more expensive'.

While the team had to spend €4,000 on new furniture, the investment paid off. Two years later, the furniture still looked new, Mr. Ó Coimín said.

Artwork is an important element of a family room as the right pieces can both soothe and engage distraught family members. But the research literature has found that only specific types of art can work in these settings. For example, figurative art and landscapes work better than abstract work, which can challenge and confuse people. In the case of St. Brigid's, no budget was set aside for artwork, and while the paintings were donated from the hospital's small art collection, the architect reported in the Design and Dignity Style Book that the overall look of the artwork was uncoordinated.

Mr. Ó Coimín noted that one of the paintings used was done by a staff member, which was a meaningful addition. But he also noted that obtaining quality artwork is a crucial part of creating the right atmosphere in these rooms.

'Art is vitally important in these rooms', Mr. Ó Coimín said. 'It's the difference in making these rooms feel warm and beautiful and non-clinical. It's very important to set aside a portion of the budget to purchase artwork—in our case at least 10% of the total budget of €40,000 would have been ideal'.

The project took about six months to complete and was opened in April 2012.

Among the key features of the family room were:

- A space that is warm and welcoming in the heart of a busy, 31-bed medical ward. The room is open and accessible to patients and families at all times.
- High-quality glass artwork at the room's entrance. The commissioned art sign highlights the location of the room from the corridor and gives the space a feeling of quality and welcome.
- The external corridor of the room is green to announce it as a non-clinical space.
- A breakfast bar that creates a familiar feel and separates the kitchen and sitting space.
- Ceiling lighting consisting of spotlighting with different zones, which allows lights to be turned off and on and create different moods.
- A sofa bed with a bright anti-microbial and anti-fungal infection control fabric that can be easily converted into a bed for relatives of seriously ill or dying patients wishing to stay overnight.

Below are before and after pictures of the room on St. Brigid's Ward:



Before renovation the room was used for staff meetings and storage

Family room after renovations



The staff at Mater were so enthusiastic about the first family room that ten more have been opened throughout the hospital since then. Several of those rooms have been funded in part by staff fundraising, Mr. Ó Coimín noted. Learning from the first project, the hospital now has specifications for the layout and content of each room.

'Other ward areas have seen what was created in St. Brigid's Ward, and they wanted to have that space for patients and their families cared for on their wards', Mr. Ó Coimín said. 'We don't need to convince people about the need to have family rooms on acute hospital wards any longer. My concern at the beginning was that staff would use the room as a staff room but it never occurred. The team approach to developing this family room ensured this didn't happen. The staff are very proud of what has been achieved, recognising the benefits the room has bestowed on patients and their families'.

Mortuary at Mercy Hospital—Now a Place of Pride

Mercy University Hospital in Cork prided itself on providing quality end-of-life care to its patients. Except that is, when it came to the mortuary. The hospital has nearly 300 deaths a year, which affect more than 2,000 loved ones. Each one of the patients who die go to the mortuary, both for the families to say goodbye and for the undertaker to transport the body to a funeral home.

But to get to their loved ones, families had to walk past the radiology department, out a back door and past where the refuse bins were stored. Only then would they arrive at the mortuary, which was cold, bleak, and uncomfortable.

"The mortuary was unacceptable', said Michael O'Reilly, board member of the IHF. 'People had to walk past an industrial compactor to get to it. For everyone, staff included, it was simply wrong'.

Margaret McKiernan, the director of nursing who is responsible for end-of-life care, said the hospital had joined the Hospice Friendly Hospitals network and had committed to implement quality standards in end-of-life care. But staff knew that not having the right physical environment impinged on the type of care the hospital could provide for relatives of patients who were dying. Staff were embarrassed by the mortuary and avoided using it, or if required, felt they needed to continually apologise to family members as well as prepare them for the bleak setting.

In 2011, the acute centre city hospital received funding of \leq 126,000 from the Design & Dignity Grants Scheme plus other hospital contributions amounting to \leq 90,000. The project funded a redesigned walkway, new mortuary, an outside garden, and upgraded, wheelchair-accessible toilet facilities.

'We needed to create a place of calm and peace for patients and their families', Ms. McKiernan said. 'We want to make sure that their last memory of the hospital is a good one for the family members'.

The project team had to spend a lot of time in the beginning meeting with staff who would be affected by the renovation to get their input and support—a common theme for Design & Dignity projects. These projects required an investment of effort in bringing all staff on board to ensure the final design was met and included all needs.

Engaging With All Stakeholders

'We engaged with people throughout the hospital from the CEO and chief financial officer to those who play a vital role in transporting patients such as the front hall porter, ward managers as well as liaising with staff off site where coroners' post mortems are conducted', Ms. McKiernan said. 'That all took a few months. What we were promoting was our vision for the end product—a place where we could bring people to that we were proud of and would be of benefit to the hospital and the patients and families we serve'.

In creating a new space that would be beautiful, the hospital team also had to focus on practical matters, which sometimes collided with their architect's vision, Ms. McKiernan noted. For example, because the hospital is a vascular centre, there needed to be a large refrigerator at the mortuary to store limbs.

'It was a very practical concern', McKiernan said. 'It was really important that we have a refrigerator and that it was the right size to store limbs in a respectful manner'.

The project team also needed to ensure that they had flooring that was not only inviting but could be easily cleaned. In addition, the mortuary needed a space to hang heavy drapes that are placed over the mortuary trolley so they would remain crisp and a utility area to store linen that needed to be washed.

The team also wanted to bring a beautiful stained-glass window depicting St. Michael from the old mortuary to the new one. The window was an important link to the hospital's history and the stained glass featuring St. Michael is a shared image across many religions.

The renovation of the mortuary began with the corridor where family members would be escorted to the mortuary. Rather than the stark, bare hallway that took family members past a clearly marked radiology department, the renovated hallway featured black-and-white photos of cityscapes of Cork. The scanning rooms were closed off so it wasn't apparent that family members were walking by them.

A Garden to Reflect

Then family members entered a new enclosed walkway with bench, shrubbery, and a water fountain where they could take a rest and reflect. All of the rubbish and the compactor had been moved to a different location. The entrance to the mortuary was through a glass door with the spiral end-of-life symbol frosted on it. It was a clear indicator of the transition between the hospital and new mortuary.

The new mortuary, which included the existing stained glass, is a multi-faith and multi-cultural space where families can sit with their loved ones in peace. There is also a second viewing area, which can also function as a waiting room for families.

The mortuary, which opened in 2013, also has the following features:

- Recessed shelves for candles and plants.
- Hospital-grade carpet finish that creates a warm, familiar feel and helps sound absorption.
- Soft lighting that is enhanced by electrical candles.
- Religious icons and symbols for all faiths that can be displayed if required.
- Discreet storage facilities for a coffin and trolley.

Below are before and after pictures:



Previous outside entrance to mortuary

New mortuary entrance



New mortuary



J.A. 1.

In addition to the physical renovations, the hospital uses a number of Hospice Friendly Hospital resources to promote respect and dignity at the end of life. These include a framed end-of-life symbol, a family handover bag for patient property, and mortuary trolley drapes. A staff development programme is mandatory. Its purpose is to improve end-of-life care through promoting a culture awareness and supporting the development of good communication skills in those hospital staff who have direct contact with patients at the end of life and their families.

'We have up to 280 deaths a year here', Ms. McKiernan said. 'All of these patients are brought to the mortuary. It's a really important part of what we do. We only have one chance to get it right for people at the end of life. What we do can have such impact—for good or for bad'.

Lessons Learned

Those who coordinated Design & Dignity projects as well as those who oversaw them for the Irish Hospice Foundation offered the following learnings for others who may wish to undertake this work:

- Find a key champion and enlist senior management support. Simply securing funding for a project does not mean it will be easy to bring to completion. Most hospitals carrying out a Design & Dignity project met with staff resistance at some point, in part because it required them to change the way they worked. Having a champion on the inside who continually pushes this work forward is crucial, as is senior management who can provide the necessary leadership when a project may get stalled. It is also vital that one person be given the authority to make final decisions when there is a conflict.
- Hire an experienced architect who understands the purpose of this work. Simply because someone is a qualified architect does not mean that he or she will understand the purpose of this particular work. Architects are being asked to create an 'exemplar' project that is different from other hospital spaces and can be used as an example for other wings and hospitals and not just do a retrofit. Scrutinise their drawings to make sure they 'get it'. Make sure that this project is not handed off to a junior architect who may not have the experience to carry it out.
- Ensure that the project has a sufficient budget to purchase quality furnishings and art. The success of such a project depends on creating a space that feels homey, separate from the hospital, has comfortable and well-designed furnishings, and conforms to the Design & Dignity Guidelines. While these projects do not have to be expensive, they do need to include a budget that is sufficient to cover the cost of purchasing the type of furnishings that will last a long time and make families feel cared for. At least 1% of the overall budget should be dedicated to artwork.
- Bring the staff into decision-making. The hospital staff are the ones who will ultimately ensure that these new physical environments are used the way they are intended. They need to be involved from the beginning so they understand why this project is taking place, how it will help them do a better job, and what the important details are to ensure these rooms provide the soothing environment that they are intended for. Staff must be consulted about what would make these places work for patients—and for staff. To get buy-in and ensure a lasting impact, ask for and listen to their opinions on details such as colour selection.
- **Involve the infection control team from the beginning.** Because of its remit, this department can seem to be programmed to automatically say no to everything. At times, saying the wrong words can make that issue worse. For example, saying that the room will have a kitchenette can raise alarm bells with infection-control staff who picture a refrigerator with mould. But talking about a tea station with a kettle and sachets of milk is a much easier sell.
- Expect delays and build in processes for sign-off at every stage of the project to ensure quality at the end. Coordinating and getting input from a variety of staff members, leadership, and an architect is time consuming; most Design & Dignity projects took much longer than originally planned as a result. Because of that, at times there was a tendency to cut corners at the end. Quick decisions can be made out of exhaustion that diminish the project. For example, some projects toward the end did not follow the Design & Dignity Guidelines on such areas as purchasing high-quality furniture or appropriate artwork, which undid much of the good that the project set out to achieve. It is crucial to have a process that builds in sign-off at each stage so the project does not get derailed.
- Set up a way to maintain rooms for their intended use. Some Design & Dignity hospitals ran into issues with staff trying to use the family rooms for meetings or breaks. One hospital, for example, began holding staff meetings in the room and put up a sign on the room that said, 'Meeting in progress'. The Design & Dignity team had to intervene and say that is not what the space was intended for. It is also important that the room be kept open and accessible at all times for family members, rather than have locks placed on them.

Resources for Next Steps

The Design & Dignity Programme has put together a number of resources for hospitals that wish to embark on the process of addressing their physical environment to better meet the needs of patients and families at their end of life.

The Design & Dignity Guidelines provide guidance to design and plan acute hospitals so that the building can support quality endof-life care.

The <u>Design & Dignity Style Book</u> provides more detailed information on designing specific spaces including family rooms, mortuaries, hospital emergency department bereavement suites, and palliative care suites. It is a practical guide for hospital staff, designers, and architects involved in building projects. In addition to the Guidelines, it provides information about furniture, finishes, and art work, and photographs and details of completed projects. It also includes a range of tools to assess existing facilities against the Guidelines. The Style book is available in hardcopy as well as online and is updated as new facilities are completed.

Videos provide both an overview of the purpose of Design & Dignity and specific case studies of individual projects.

Hospitals can also take other steps to enhance a family and patient's end-of-life experiences, which are described in Appendix 1. For additional information, hospitals can contact Mary Lovegrove, Design & Dignity Project Manager at the Irish Hospice Foundation (marylovegrove@hospicefoundation.ie) or visit www.designanddignity.com.

Conclusion

The Irish Hospice Foundation's Design & Dignity Programme was among the first to recognise the importance of the physical environment in hospitals in creating quality end-of-life care. Its demonstration projects throughout Ireland have not only improved the lives of relatives, patients, and staff, the work has provided real-life examples of what can be done.

A key take-home message is that starting with one relatively small project can lead to positive ripple effects throughout a hospital. Once staff and family members experience the impact of a soothing, quiet, and reflective space, that often seems to usher in a new appreciation and consciousness of the importance of honouring patients and their families at the end of life.

As result of these exemplar projects, the Health Service Executive in Ireland continues to support the additional rounds of projects through the Design & Dignity Scheme and is requiring that all new building of public hospitals incorporate the Design & Dignity Guidelines into their plans.

Lovegrove said that the success of the project was the result of the strong relationship the Irish Hospice Foundation has with the HSE. 'The Irish Hospice Foundation, through its dedicated administrative function and design expertise, has enabled this work to be prioritised but the HSE through its leadership and funding commitment enabled the projects to happen,' Lovegrove said.

An independent evaluation is being undertaken to evaluate the impact of the Design & Dignity projects from patient, family, and staff perspectives. It is scheduled to be completed by the end of 2017.

The experiences and learnings of the hospitals featured in this case study, as well as the additional resources developed by the Design & Dignity Programme, can be a starting point for hospitals to begin their own work to improve the physical environment for staff, relatives, and patients during end-of-life care.

"These projects make staff more comfortable that they can deal with end-of-life situations and family', said John Browner, Assistant National Director at the Health Service Executive for capital and property, estates directorate. 'When they have facilities like family rooms, staff can take more ownership in the rituals of the last days. They have something they take pride in'.

Appendix 1: Additional Resources

In addition to providing information about designing individual spaces, the Design & Dignity Guidelines and Style Book provide direction about other practical steps that hospitals can take to help relatives at the end of life.

For example, one is to place an end of life symbol at a nurse's station, patient's door, or entrance to a ward to signal to staff that a patient is dying or has died (see Box 1). The purpose is that when staff see the symbol, they will create an atmosphere of quiet, avoid using their mobile phones, and be prepared to meet people who are grieving.

Another step that the guidance suggests is that hospitals have high-quality bags to return a deceased patient's belongings rather than handing them over in a hospital plastic bag (see Box 2). The principle of the family handover bag is to promote a dignified and sensitive way of returning these belongings to the family.

Hospitals can also use purple drapes on mortuary trolleys when transporting the body of a deceased person through the hospital (see Box 3). The drape can also be used within the mortuary itself for viewing the deceased.

More information on these products can be found at the Irish Hospice Foundation's <u>Resources for End of Life Care</u>.



Box 3

Box 2











