HOSPICE FRIENDLY HOSPITALS

The case for continued investment

THE IRISH HOSPICE FOUNDATION

The Hospice Friendly Hospitals Programme is an initiative of the Irish Hospice Foundation in partnership with the Health Service Executive.

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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THE IRISH
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“HOW WE CARE FOR THE SICK AND DYING IS SURELY A TEST OF OUR HUMANITY... JUST AS WE FIGHT FOR EQUALITY IN LIFE, WE SHOULD FIGHT FOR EQUALITY IN DEATH”

Bono

INTRODUCTION

We are all going to die. Most people – three out of four of us – want to die at home if we can. Only 5% of us would prefer to die in a hospital. At the end of their life people want to be surrounded by their loved ones, to be free from pain, to have privacy and dignity, to be in a calm and peaceful atmosphere, and to have professional medical support on standby for emergencies.[1]

TO DIE AT HOME. THAT'S WHAT WE WANT. UNFORTUNATELY, THE REALITY IN IRELAND IS THAT MOST OF US WILL DIE IN HOSPITAL. 43% OF ALL DEATHS OCCUR IN ACUTE HOSPITALS.

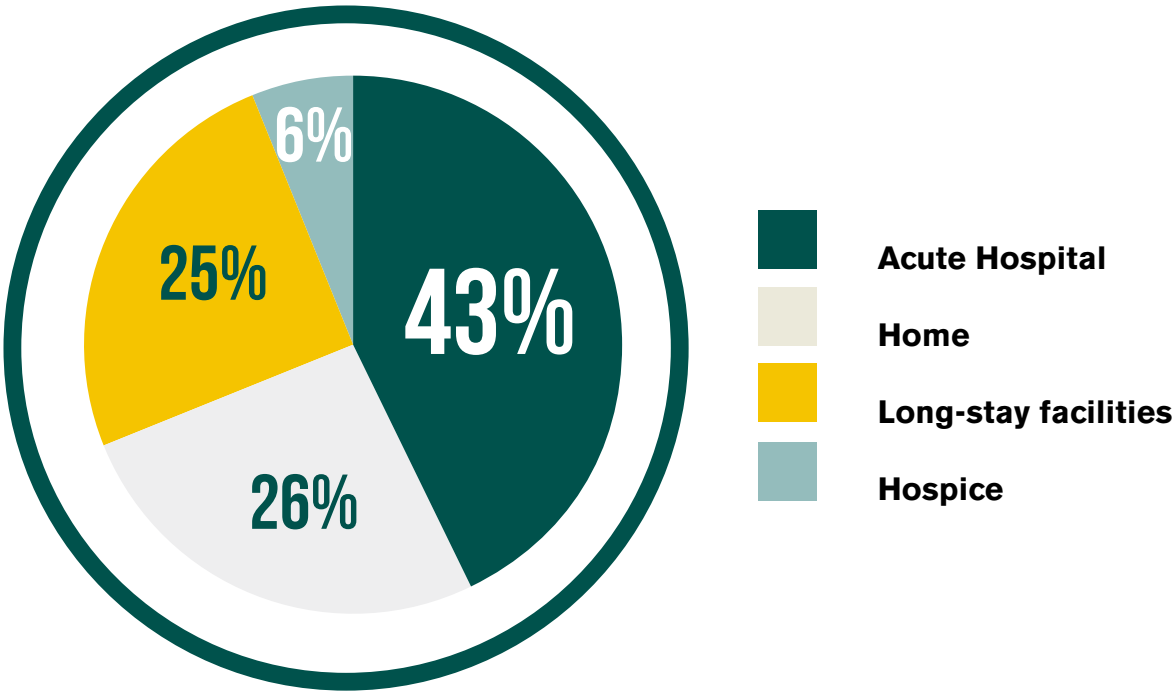


Figure 1: Place of death in Ireland[2]

Typically, patients dying in hospital today have been admitted through the emergency department, are in their late seventies, spend over three weeks in hospital and will die on a multi-bedded ward, most likely from a circulatory disease[3].

Hospitals are designed to treat people's illnesses, injuries and emergencies. They were not designed to support people at the most vulnerable time of their lives. But improving hospitals' way of caring for patients at end of life is not difficult. Together with the Health Service Executive (HSE), we in the Irish Hospice Foundation are changing the way it's done. Our joint Hospice Friendly Hospitals Programme puts hospice principles into hospital practice and ensures that end-of-life care is treated as a priority.

The initiative has been highly successful so far, with many examples of local excellence. **Now is the time to embed this Hospice Friendly Hospitals approach fully throughout the hospital group structure, so that it becomes the national standard.** This short proposal outlines how we think it can be done but first we'd like to give you an overview of death and dying in hospital and the Hospice Friendly Hospital Programme.

DEATH AND DYING IN HOSPITAL

Consider these facts

Some 43% of deaths occur in acute hospitals. That's about **12,500 people dying in hospitals each year**, or around 35 people a day. This number is likely to go up due to increased life expectancy and rising illness rates.

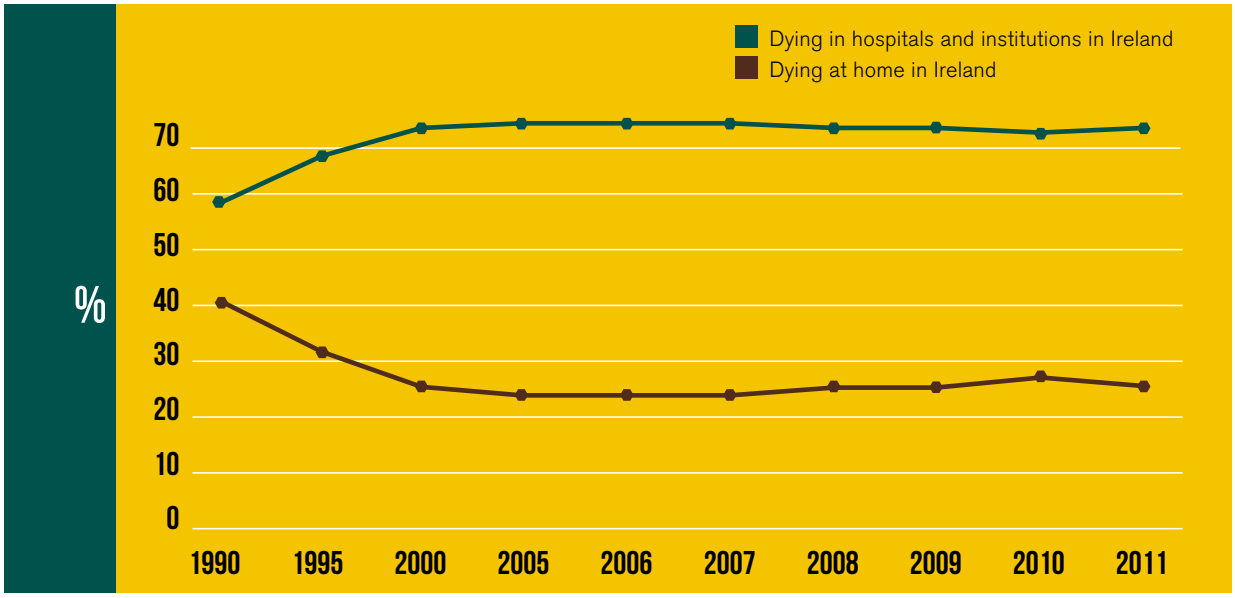


Figure 2: Place of Death in Ireland 1990 – 2011[3]

A staggering number of people in hospital today will be dead by this time next year. A recent Scottish study shows that up to **30% of inpatients in hospital today will be dead within a year**. In fact, nearly one 1 in 10 of all hospital patients will die during their admission.[4] A recent Irish study[5] found that 1 in 12 people with dementia admitted to hospital will die while they are there.

3 OUT OF EVERY 4 DEATHS WHICH HAPPEN IN HOSPITAL ARE EXPECTED.[3]

WE CAN PLAN BETTER FOR THESE.

- More people could die at home. The National Audit of End-of-Life Care in Hospital (2010) found that **20-25% of people** who die in hospital could have died at home with appropriate supports.[6] A study commissioned by the HSE found that 40% of patients being cared for in hospitals could be more appropriately cared for elsewhere.

- More than four out of every five people dying in hospital – 84% in all – are admitted through the emergency department.[3] Many of them have chronic conditions and are known to the hospital well before their last admission.

- Over 12% of deaths in hospital occur in the emergency department. Another 20% take place in Intensive Care Units.[3]

- In 2007, the Irish Hospice Foundation found that only a quarter of acute hospitals have a full specialist palliative care team.[7] These teams are critical in the care of people with life-limiting illnesses in acute settings. As well as providing high quality care, international research has shown that palliative care teams save money. An audit of current provision is sorely needed.

- **A RECENT US STUDY SHOWED THAT PALLIATIVE CARE CONSULTATIONS SAVED OVER $1.3M IN A 300-BEDDED HOSPITAL [8]**

- Only 15% of beds in acute hospitals are in single rooms[3], and many of these are kept for patients with healthcare acquired infections, while others are prioritised for private patients. The majority of hospital mortuaries require modernisation and refurbishment. Too often bad news is broken on corridors or in storage rooms due to the severe lack of appropriately designed family and meeting rooms.

- The quality of end-of-life care is not equitable. For example, patients who have advanced cancer are much more likely to have an acceptable death when compared to patients with advanced dementia or who are frail.[3]

- Only a little over half of patients are involved in discussions about end-of-life care with only 55% of patients involved, as against 96% of families.[3]

FINANCIAL COSTS

IN 2012 IRELAND'S BUDGET FOR SPECIALIST PALLIATIVE CARE WAS €78 MILLION. BUT INTERNATIONAL EVIDENCE SUGGESTS THAT IN REALITY 10-15% OF NATIONAL HEALTHCARE SPENDING GOES ON CARE AT THE END OF LIFE. IN IRELAND, THAT'S €1.3 BILLION.[9]

- International evidence shows that the majority of our healthcare money is spend during the last few months of our lives. See figure 3.
- The fact that 75% of deaths in hospital are expected suggests that resources could be targeted more effectively. Better approaches towards the management of patients nearing end of, life will have most impact on those who have long stays in hospital – in many cases their care may be more appropriately delivered in other settings – home or long stay facilities.

So how much is this extended care costing? Over half (52%) of patients who die in hospital die within 9 days of admission; we can assume these patients are closest to death and therefore very ill, and interventions to get them home to die or to other care settings would not deliver better quality care or lower hospital costs. However, for the remaining 48% of patients who die, their average length of stay is 37 days. With an estimated day rate of €300 for a ward bed day the estimated direct cost of care for patients who die in hospital with a length of stay greater than 9 days is €60 million per year. [i]

More strategic planning for those patients nearing end of life in hospitals aligned with greater investment in community services could significantly impact on appropriateness and quality of care and could significantly reduce for the health services, costly in-hospital deaths.

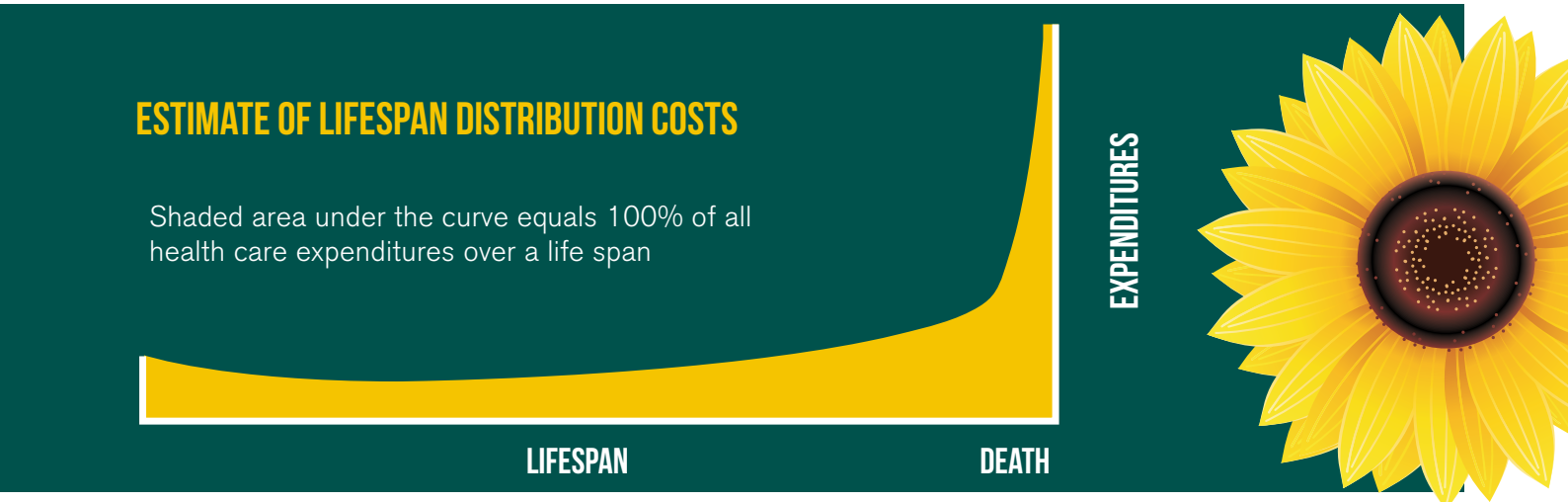


Figure 3. Pattern of US healthcare expenditures throughout a person's life.[10]

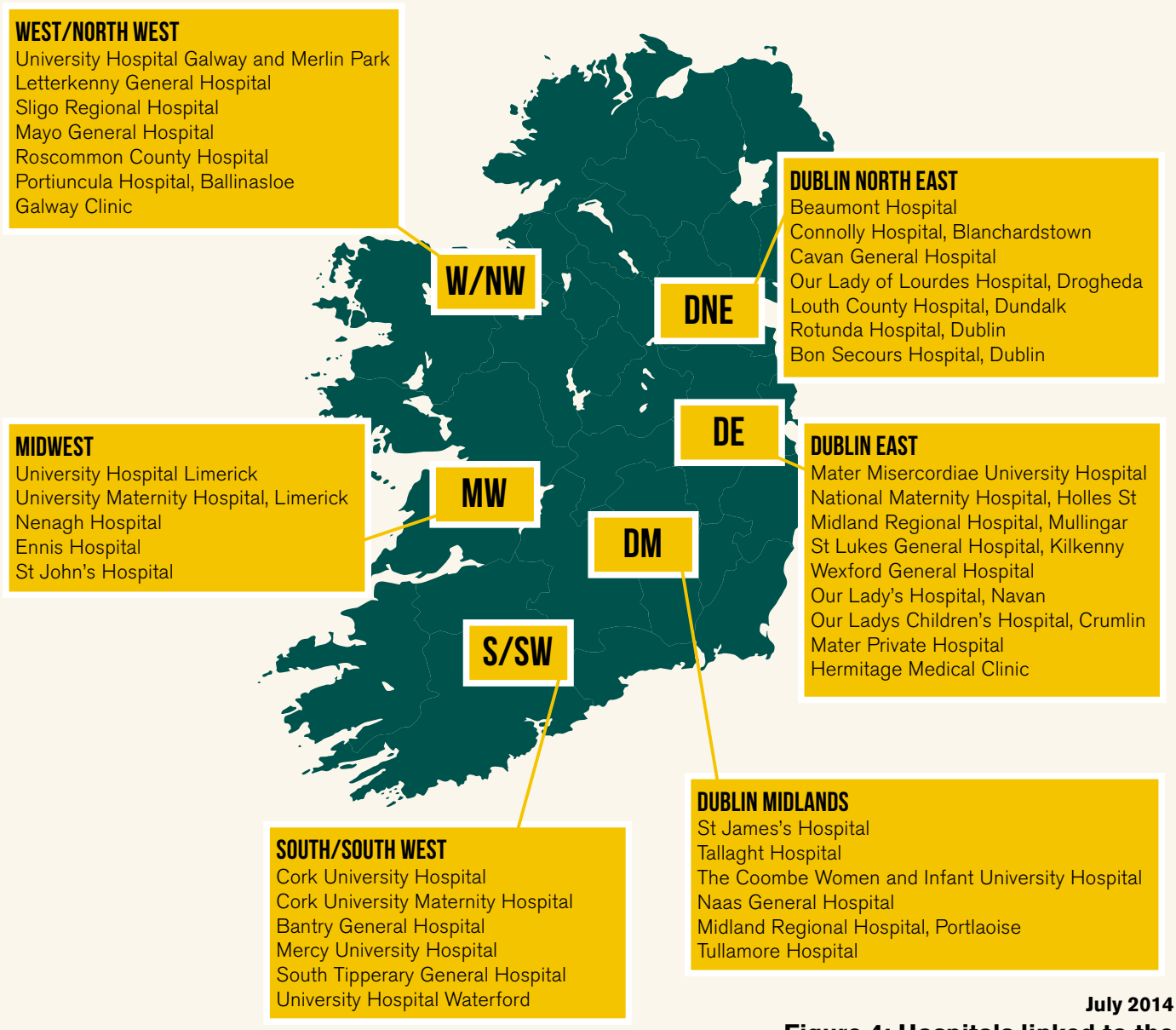
[i] Noting that €300 for a ward bed day is a conservative estimate. These costings have been calculated using data from HIPE and information available from HSE Corporate Services.

THE HOSPICE FRIENDLY HOSPITALS PROGRAMME

The Hospice Friendly Hospitals Programme has been creating positive change in the approach to dying, death and bereavement in Irish hospitals and residential care settings. It is an initiative of the Irish Hospice Foundation in partnership with the HSE and has been running since 2007. Since 2007 the Hospice Friendly Hospitals Programme funded up to 12.5 WTE End-of-Life Care Coordinators. Three of these posts were based in large teaching hospitals: the Mater, St. James's and Beaumont. The rest of the team worked across regions, supporting clusters of acute hospitals, while one team member supported community hospitals in the greater Dublin area. The coordinator posts in hospitals were funded for an average of two years and supported by the core Hospice Friendly Hospitals Team based in the Irish Hospice Foundation.

The Hospice Friendly Hospitals Programme covers attitudes, skills, systems, management, governance, the physical environment and ethical issues. It has won several prestigious awards and is described as "a sophisticated, multi-faceted advocacy programme". [11]

So far 40 adult, maternity and children's hospitals all over the country are involved in the programme. Some 200 residential care settings are also engaged.



July 2014

Figure 4: Hospitals linked to the Hospice Friendly Hospitals Programme

HFH KEY MILESTONES

2005-2006	2007	2007-2013	2009-2010	2013	2014	2014
Joint IHF & HSE pilot in Our Lady of Lourdes Hospital, Drogheda	HFH Programme launch	12.5 End-of-Life Care Development Coordinators recruited to support national roll out	Acute & Community Hospital Networks established	Maternity & Neonatal Network established	40 hospitals linked to the HFH programme	4 acute hospitals directly employ End-of-Life Care coordinators

WHAT HOSPICE FRIENDLY HOSPITALS HAVE ACHIEVED SO FAR...

The HSE can be proud of the many successes achieved to date through the Hospice Friendly Hospitals Programme and the Irish Hospice Foundation.

RAISING THE STANDARD OF END-OF-LIFE CARE IN HOSPITALS

Since 2010 some 35 hospitals have plans in place for implementing the Quality Standards for End-of-Life Care in Hospitals. These standards set out a shared vision for what hospitals should aim to provide for patients and their families at the end of life, and what patients and families should expect. They were developed through the Hospice Friendly Hospitals Programme with the support of HIQA and are also referenced in the HIQA National Standards for Safer Better Healthcare.

NATIONAL AUDIT OF END-OF-LIFE CARE IN HOSPITALS

The National Audit of End-of-Life Care in Hospitals, held in 2008-9, was the first ever such study conducted in the EU. Some 24 acute and 19 community hospitals participated. The audit collected data from families, nurses and doctors about the quality of care provided to 1,000 patients who died. The findings raised questions about how care is organised and delivered, and the audit report suggests ways for hospitals to improve care for patients and their families.

Conscious that an audit of this magnitude cannot be easily repeated, the Hospice Friendly Hospitals Programme is exploring other ways of continuing to audit end-of-life care in hospitals, include surveying bereaved relatives on the care their loved one received at end of life

END-OF-LIFE CARE COMMITTEES

Over the course of the Hospice Friendly Hospitals Programme some 34 hospitals have set up end-of-life care committees. These committees look at the whole range of end-of-life care issues and involve a mix of clinical, support and administrative managers and front-line staff.

HIQA

In 2013 the Hospice Friendly Hospitals Programme played an instrumental role in the development of guidance for residential care settings as part of the HIQA inspection process. HIQA inspectors also attended training developed through the Hospice Friendly Hospitals Programme to support them in inspecting people's overall quality of life at the end of life.

IMPROVING COMMUNICATION WITH PATIENTS AND FAMILIES AT THE END OF LIFE

To deal with low levels of satisfaction with communication and the lack of standardised training available, the Hospice Friendly Hospitals Programme developed a series of communication skills courses:

- "Final Journeys" for staff in acute hospitals
- "What Matters to Me" for staff working in residential care
- "Dealing with Bad News" for doctors and other healthcare professionals. This course is also now run through the RCPI.

In order to maximise the rollout of these very popular courses, over **150 facilitators were trained within existing HSE education structures**. To date, a massive **6,000 staff have participated**, many of whom attended in their own time.

After attending a course, participants consistently report feeling more competent and confident in communicating with patients and families at the end of life.

Hospital managers have also been impressed with the impact of the programme.

"I NOW HAVE THE COURAGE TO TALK TO PATIENTS ABOUT THEIR END OF LIFE CONCERNS"

(STAFF NURSE)

"I HAVE NOTICED A REDUCTION IN COMPLAINTS SINCE FINAL JOURNEYS STARTED"

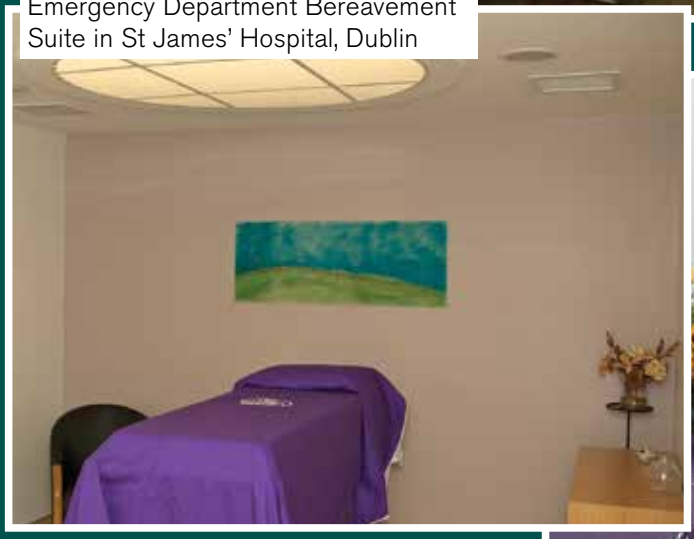
(HOSPITAL CEO)

THE DESIGN AND DIGNITY PROJECT: IMPROVING THE PHYSICAL ENVIRONMENT OF HOSPITALS ONE ROOM AT A TIME

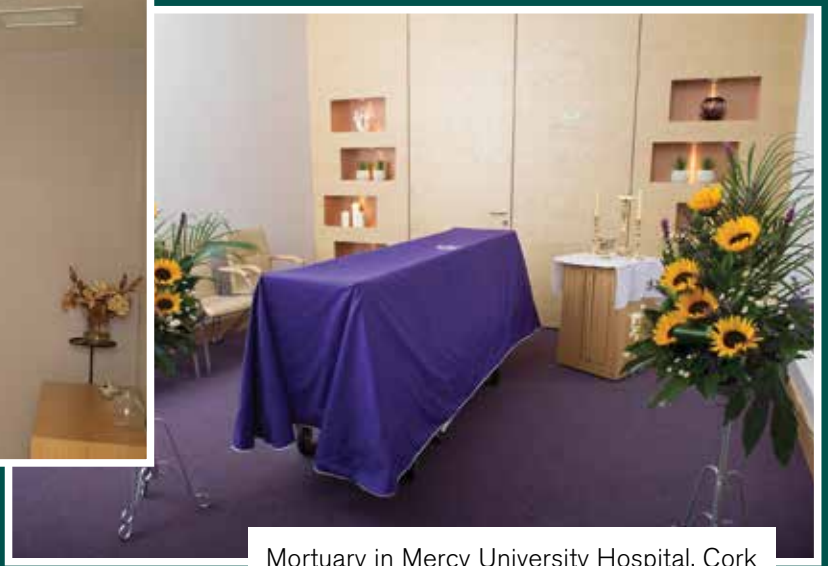
Together with HSE Estates, the Hospice Friendly Hospitals Programme is working to protect the dignity of patients and their families at end of life by improving the physical environment of hospitals. This truly practical initiative has so far funded 11 projects – family rooms, bereavement suites, mortuaries and more – by offering financial support and design expertise to the tune of €1.5 million. Submissions for the next round of funding are underway.

Furthermore, the Design & Dignity Guidelines for the Physical Environment of Hospitals Supporting End-of-Life Care developed through the Hospice Friendly Hospitals Programme have been adopted by the HSE for all new and refurbishment projects.

Family Room in Nenagh Hospital, Tipperary



Emergency Department Bereavement Suite in St James' Hospital, Dublin



Mortuary in Mercy University Hospital, Cork

END OF LIFE CARE RESOURCES

Hospitals throughout Ireland are now using high-quality resources to enhance end-of-life care. The Independent newspaper in the UK explains the difference these simple resources can make for patients and families at the end of life.

"My mother died in the busy stroke unit at an overstretched [Irish] hospital but nurses behaved in keeping with what is a profound, almost sacred moment for the family. They lit candles and placed a Celtic "triskele" (a pre-Christian symbol of life, death and rebirth) on the door of her room to alert other staff and patients. They covered her in an elegant purple drape and, when we eventually left, they hugged us, handing over a woven bag, her things neatly folded inside. When it seems unbearable that your mother has just died and the rest of the world is carrying on as normal, these gestures are comforting." [12]

These resources were also recognised by HIQA in their inspection reports as "a particularly sensitive way of reminding staff, in an otherwise busy and possibly noisy unit, that a resident was dying".[13]

The resources was commended by An Taoiseach Enda Kenny at an end-of-life care event in July 2014. The spiral was recognised as a signal "to staff and visitors alike that they are entering a sacred space" and "similarly the use of the specially designed family handover bag now has more formality…in keeping with the dignity of the person and the grief and loss of the family."

For photographs and descriptions of the resources, see appendix 1.

WHAT SYSTEMS SUPPORT THESE ADVANCES IN END-OF-LIFE CARE IN HOSPITAL

OVERALL GOVERNANCE

Since 2007, the IHF, in association with the Atlantic Philanthropies, have invested €10 million in the Hospice Friendly Hospital programme, and in 2015 we will have 1.5 staff directly supporting work of this programme.

LOCAL HOSPITAL GOVERNANCE STRUCTURES

The majority of hospitals have put in place End-of-Life Care Committees chaired by a senior member of the management team. These Committees developed Quality Improvement Plans aimed at implementing the Quality Standards for End-of-Life Care. These positive steps are all part of the Memorandum of Understanding between the Irish Hospice Foundation and those hospitals which have signed up to the Hospice Friendly Hospitals Programme.

END-OF-LIFE CARE COORDINATORS

Until now, **hospitals' success in improving end-of-life care for patients and families is largely due to the work of dedicated coordinators**. Funded by Atlantic Philanthropies and others in 2007-2012, the Mater, Beaumont, St James's and Connolly hospitals in Dublin have since retained the role of dedicated coordinator to manage the Hospice Friendly Hospitals Programme locally. The University of Limerick (UL) Hospitals Group has a full-time coordinator working across the acute hospital and community hospital sectors in the Mid-West. Other hospitals, such as Drogheda and the Midlands Hospitals, have incorporated the End-of-Life Care Coordinator function into existing roles in their nursing departments. The South/South West Hospital Group and Tallaght Hospital are also in the process of establishing full-time coordinators.

THE HOSPICE FRIENDLY HOSPITALS ACUTE HOSPITAL NETWORK.

The national Hospice Friendly Hospitals Acute Hospital Network has been running since 2010. Composing of senior managers from hospitals linked to the Hospice Friendly Hospitals Programme, it also has representation from the HSE Acute Services Directorate and the HSE National Clinical Programme for Palliative Care. See figure 5.

This dynamic network facilitates a shared approach to improve end-of-life care in hospitals. It tackles practical issues such as releasing staff for training and prioritising transport for patients who want to die at home. It also deals with the practicalities of implementing important policies, such as the recently published DNAR policy and the Standards for Post-Mortem Examinations. In 2013 the Chair of the Network spoke at the Oireachtas' Health Committee's End-of-Life Care Hearings and proposed recommendations on how to improve end-of-life care in hospitals. These recommendations form a key part of Oireachtas' report published in July 2014.

MATERNITY AND NEONATAL HOSPICE FRIENDLY HOSPITALS NETWORK

The Maternity and Neonatal Hospice Friendly Hospitals Network was set up in 2013 and involves all 19 maternity units nationwide. Already this network is proving to be an important constituency in the consultation of bereavement guidelines which are being developed following the investigation into the death of Ms Savita Halappanavar. The Hospice Friendly Hospitals Quality Standards for Babies and Children at End of Life are also being used as a basis for the development of the National Bereavement Guideline for Maternity Services.

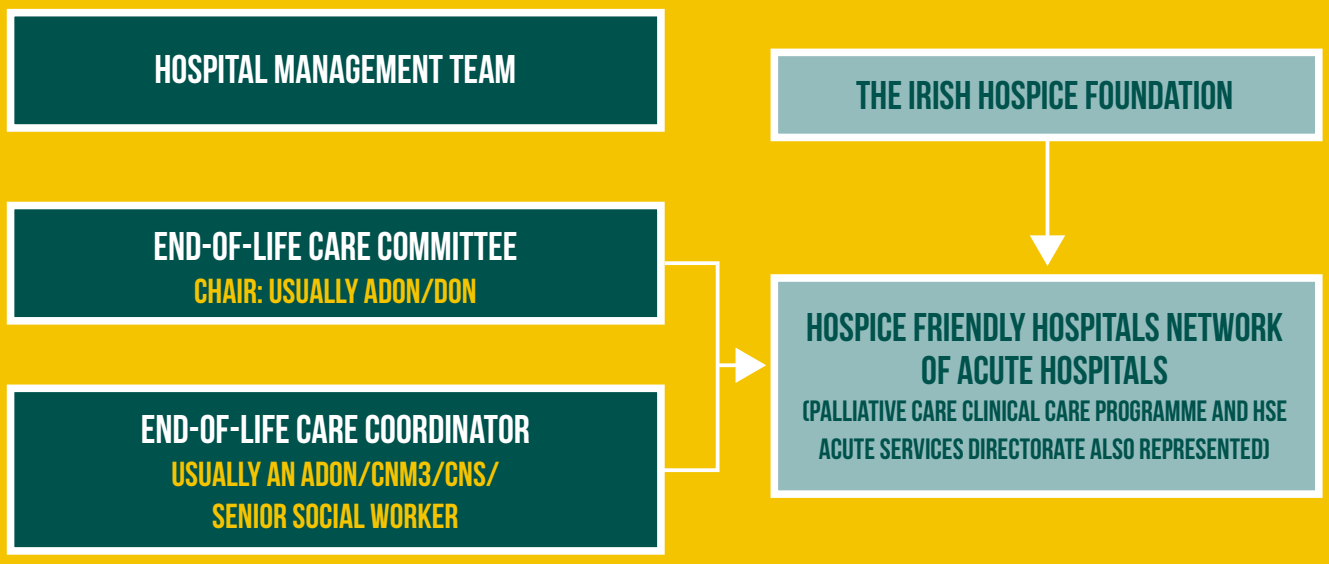


Figure 5: Hospice Friendly Hospitals Structures to support end-of-life care improvements in hospitals

WHAT HAVE WE LEARNED

As part of work to evaluate the Hospice Friendly Hospitals Programme, the Irish Hospice Foundation began a review of the programme's activity. The history, outputs and outcomes of the Hospice Friendly Hospitals Programme from 2007-2013 are examined in the two studies commissioned by the Irish Hospice Foundation. The Hospice Friendly Hospitals Programme in Ireland: A Narrative History, Clark & Graham (2014) and The Hospice Friendly Hospitals Programme: Overview 2007 – 2013, Walsh, K. (2014). [11] [14]

The Hospice Friendly Hospitals Programme generated a range of learning, both strategic and operational, across a number of areas. Most notably, the programme has helped to ensure that end-of-life care is seen as a concern of all hospital staff through the establishment of governance structure to oversee the implementation of end-of-life care quality improvement plans.

Following the publication of these recent studies the Irish Hospice Foundation is working to grow the number of peer reviewed, evidence based publications which illustrate the value of the Hospice Friendly Hospitals Programme and its activities. Work is also underway to promote the programme internationally.

Both studies helpfully point to ways the Hospice Friendly Hospitals Programme can nurture and sustain what has been achieved to date at the level of individual hospitals while also continuing to work at a national level to sustain the engagement of the HSE. The studies have highlighted that continued support from corporate HSE is required to help ensure the long term sustainability of the programme.

NEXT STEPS

The Hospice Friendly Hospitals Programme has shown that a good death in hospital is possible. Here are our proposals for how the HSE can strive towards excellence in end-of-life care in all hospitals.

1. ASSURE ACCESS TO SPECIALIST PALLIATIVE CARE FOR ALL PATIENTS WHO NEED IT
2. IDENTIFY AN END-OF-LIFE CARE CHAMPION IN THE HSE ACUTE SERVICES DIRECTORATE
3. EMBED THE HOSPICE FRIENDLY HOSPITALS APPROACH WITHIN THE NEW HOSPITAL GROUPS
4 APPOINT DEDICATED END-OF-LIFE CARE COORDINATORS
5. SUPPORT THE HOSPICE FRIENDLY HOSPITALS HOSPITAL NETWORKS
6. IMPLEMENT THE RAPID DISCHARGE POLICY TO ENABLE MORE PEOPLE TO BE CARED FOR AND DIE AT HOME

PROPOSALS

1. ASSURE ACCESS TO SPECIALIST PALLIATIVE CARE FOR ALL PATIENTS WHO NEED IT

Government policy published in 2001 says that "that all acute general hospitals with over 150 beds should have a full, consultant-led specialist palliative care team".[14] Meanwhile, IHF figures from 2005 (the latest figures) show that only a quarter of hospitals have a full team.[7] Specialist palliative care teams are vital in promoting a better quality of life for patients with life-limiting illnesses and, when properly resourced, can also reduce costs for the hospital. A repeat national audit of staff provision is sorely needed.

2. IDENTIFY AN END-OF-LIFE CARE CHAMPION IN THE HSE ACUTE SERVICES DIRECTORATE

Sustainability has been a challenge from the start of the Hospice Friendly Hospitals Programme. So far, HSE involvement has depended on the interest and commitment of passionate individuals at both corporate and hospital level. Hospital managers and staff closely engaged in the work of Hospice Friendly Hospitals are almost entirely positive and appreciative. But it leaves the work of the Hospice Friendly Hospitals Programme vulnerable when people change role, whether that's senior HSE managers at corporate level, champions within hospitals or members of hospital End-of-Life Care Committees. The mainstreaming of Hospice Friendly Hospitals principles and the implementation of end-of-life care quality improvement plans will skate along the surface if the commitment of the HSE, at directorate level, is not secured.

A second phase of this commitment is to develop a joint annual action plan with the IHF for national initiatives.

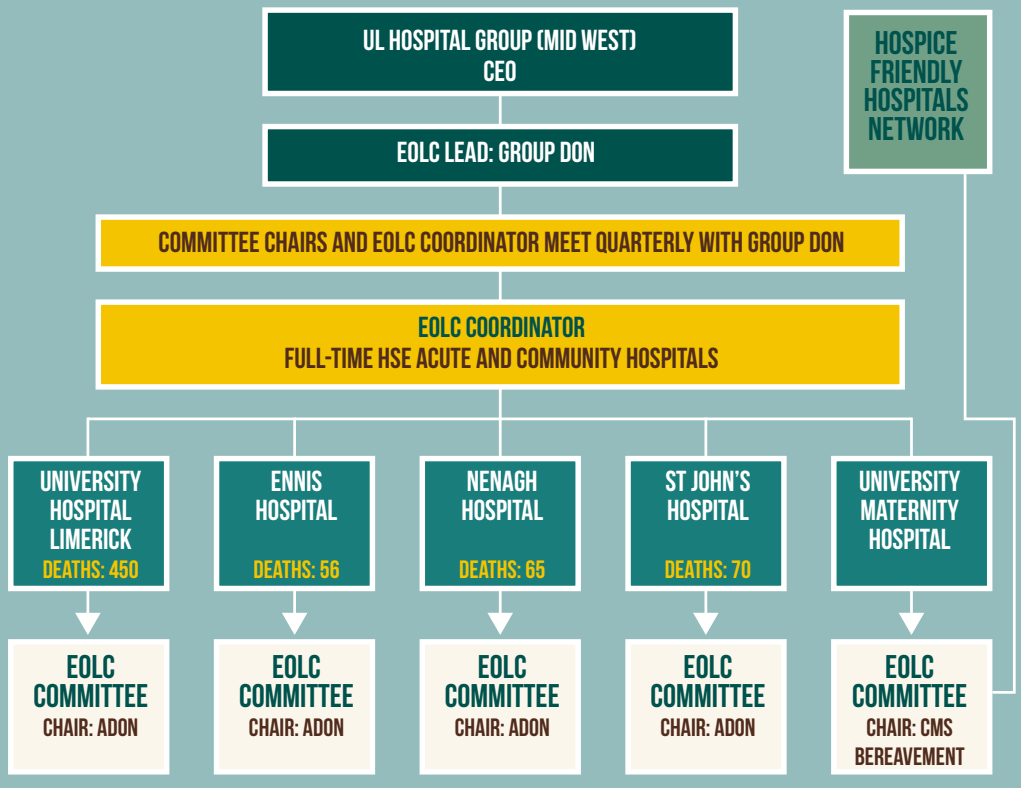


Figure 6: Hospice Friendly Hospitals governance model for the UL Hospitals Group

3. EMBED THE HOSPICE FRIENDLY HOSPITALS APPROACH WITHIN THE NEW HOSPITAL GROUPS

The first step is to assign a Lead for the End-of-Life Care Quality Improvement Plan in each Hospital Group. This proposal is also a key recommendation in Oireachtas' report on End-of-Life Care and Palliative Care in Ireland, published in July 2014. It is already happening in the UL Hospitals Group under the leadership of the CEO. Here the Group Director of Nursing has been assigned as the Lead for the End-of-Life Care Quality Improvement Plan throughout the Mid-West Region, delivering updates to the Executive Board and meeting with the Chairs of the End-of-Life Care Committees every quarter. This approach should be tailored to suit local circumstances and rolled out in all hospital groups. See figure 6.

The second step is to ensure that each hospital group has Quality Improvement Plans for Palliative and End of life Care. In the lead up to the establishment of the hospital groups – each hospital should be asked to prepare Quality Improvement Plans for the national office.

4. APPOINT DEDICATED END-OF-LIFE CARE COORDINATORS

Improving end-of-life care requires a whole-systems approach both within hospitals and throughout primary care. As with any culture change initiative a dedicated coordinator is vital within each hospital. While some Dublin hospitals and the UL Hospitals Group have all appointed End-of-Life Care Coordinators, others are still relying on enthusiastic staff to carry out this work on their own time. All Model 4 hospitals need full-time coordinators and Model 2 and 3 hospitals should assign part-time coordinators with protected time.

5. SUPPORT THE HOSPICE FRIENDLY HOSPITAL NETWORKS

These networks engage a diverse range of senior staff in a process of culture change. With the expressed backing of the HSE Acute Services Directorate, these networks could be linked more fully into the end-of-life care system.

6. IMPLEMENT THE RAPID DISCHARGE POLICY TO ENABLE MORE PEOPLE TO BE CARED FOR AND DIE AT HOME

Death in hospital is inevitable. However, the number of people dying in hospital can be reduced. The Rapid Discharge Policy developed by the HSE National Clinical Programme for Palliative Care is a positive step towards this goal, but hospitals need to be encouraged to implement this policy so that more people can be cared for and die at home. The HSE National Clinical Programme for Palliative Care requires ongoing support to realise its strategic initiatives and service developments.

The IHF will be publishing a new paper looking at the need to monitor place of death. The HSE should consider this and other options to support people to be cared for and die in their place of choice.

The proposals outlined in this document represent simple and practical ways to ensure better end-of-life care for patients in every hospital in the country.

The Irish Hospice Foundation is fully committed to continuing and supporting the drive for improvements in hospitals, but without ownership at HSE corporate level the impact will be severely compromised. However, with the right mechanisms in place in the HSE Acute Services Directorate, Hospice Friendly Hospitals can go from being examples of local excellence to become the national standard, and people who die in Irish hospitals will be able to die well. The challenge for the HSE is to make it happen.

APPENDIX 1

End of Life Care Resources

Hospitals throughout Ireland are now using high-quality resources to enhance end-of-life care.

END OF LIFE SYMBOL

This spiral is displayed on wards and units when a person is very close to death or has died. It is a symbol to all staff and other patients and families that an intensely personal and profound event is happening .

WARD ALTAR

This multi-denominational wooden locker can placed at the patient's bed-side. It contains articles to support spiritual and cultural care before and after a person's death.

BED/TROLLEY DRAPE

This is a special drape to be placed over the body of the deceased person to promote a dignified ceremony as the deceased patient is transferred from the ward to the mortuary.

FAMILY HANDOVER BAG

A dignified way of returning a deceased person's belongings to the family.

SYMPATHY CARD

The Quality Standards for End-of-Life Care in Hospitals recommend sending a sympathy card or letter of condolence within two weeks of the patient's death and before the hospital bill. Ideally, this is sent from a staff member who cared for the patient or their family.

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