OUR IMPACT 1986–2016 : Celebrating 30 years of what your charitable giving has achieved

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The Irish Hospice Foundation

1986 30 2016

Hello and welcome

We are delighted to invite you to celebrate with us as we mark 30 years of The Irish Hospice Foundation (IHF). You are reading our first ever Impact Report. It tells our story and charts our achievements over the past 30 years.

These achievements have been made alongside great strides in the expansion of hospice and palliative care services.

This report outlines the difference you, our funders and supporters, have made in supporting people at the end of life, and those facing bereavement. Your generous support has allowed us to work in partnership with services throughout Ireland to make a real impact on the experience of dying, death and bereavement.

On behalf of the Board, staff and the people we serve, we thank you sincerely for your help and support. You have made a tremendous difference to families throughout Ireland.

Jean McKiernan,
Chairperson

Sharon Foley,
CEO

The Merciful Hours

Because we have known Death come the hard way –
knock at the door in the dark of the night,
all of us breaking with the shock of day –

this precious time to sit with our living
while they enter their peace, is pure gift.
It falls like healing light on our waiting

for heaven, or nothing, or another lifetime,
be we lovers or father or mother
or child to each other. Our mortal dream

is to step out together the long road home,
hand fast in hand whatever the weather,
whatever the twists and turnings to come.

So: to the vigil bring candles, bring flowers,
heart's gratitude for the merciful hours.

Paula Meehan

Paula Meehan kindly gifted this poem
to the IHF to mark our 30th anniversary.

Contents

"We had no previous experience of the worry and the anguish felt when the task is to find a suitable place for a dearly loved one who is dying"

Dr Mary Redmond

IHF Founder Mary Redmond speaking at the 1st anniversary celebrations May 8th 1987

At the celebration of the Irish Hospice Foundation's 1st anniversary May 8th 1987 – (L–R) Laurence Crowley, Mary Redmond & Sr Ignatius Phelan

At the ground breaking ceremony for St Francis Hospice September 1989; Mary Redmond founder of IHF and Aisling Kilroy Development Executive

IHF in numbers

Our Social Impact: **2.1 million** people in Ireland benefit annually from the work of the IHF

€72m invested in care at end of life

50,000 Think Ahead forms in circulation

€35m raised for hospices nationwide through sunflower days & Ireland's biggest coffee morning

103 nursing homes participating in "a journey of change"

2,475 families cared for by **nurses for night care** service

7,200 nights of care

3,000 trained in bereavement & communication annually

48 hospitals involved in **hospice friendly hospitals** programme

Funded **85%** of start-up costs for National Children's Palliative Care programme including Ireland's first Paediatric Palliative Care Consultant and Children's Outreach Nurses.
400 families receive care each year.

24 Transformed family spaces through Design & Dignity hospital improvement and renovation projects

Our Vision

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

Our Mission

To strive for the best care at end of life, for all.

What we stand for

Our core belief is simple: everyone deserves a good death, and we have only one chance to get it right.

We believe that excellence in end-of-life care will ensure each person is:

- Respected for who they are
- At the centre of all decisions made about their care
- Confident about the quality of care provided to them
- Prepared for what lies ahead
- Given choice, where possible, on their preferred place of care
- Given supports needed for a good death
- Treated with dignity and comfort as death approaches
- Assured that their family and those important to them will be supported and cared for after their death

Where we have come from: about hospice care in Ireland

An inevitable part of life is that we all experience death, dying, bereavement and loss. This universal reality forms the underlying context for all of our work in the hospice movement.

References to hospices as special places for people who were incurably ill appear as early as the 11th century. Hospices run by religious orders flourished in the Middle Ages, but then disappeared. They were revived in France in the 17th century by the Daughters of Charity of Saint Vincent de Paul. The modern hospice movement started in the 19th century, with Ireland playing a significant role. The Religious Sisters of Charity opened Marymount Hospice Cork and Our Lady's Hospice in Harold's Cross in the 1970s, then took the concept to Australia and the UK.

"Whilst palliative care was born in England, it was conceived in Ireland."

Attributed to **Dr Jack McCarthy** *RIP, formerly of Our Lady's Hospice, Harold's Cross; sourced through personal communication with Dr. Tony O'Brien, Consultant Physician in Palliative Medicine, February 2016*

The numbers of available hospice beds was so tiny as to be almost insignificant in relation to need. But in the 1950s a nurse at St Joseph's in London, who also trained as a social worker and then later became a doctor, developed the foundational principles of modern hospice care. Dame Cicely Saunders, as she became, was the pioneer who established St Christopher's Hospice in London in 1967, created as a medical, teaching and research facility dedicated to the physical, emotional and spiritual care of dying people. She summarised her approach to hospice when she said:

May 8 1987

To dearest Mum,

This is the letter that started it all. Behind this letter is the true origin of the Foundation: the manifest love of Dad and you for each other and for us in the family.

All my love,

Mary

> *"You matter because you are you and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully but to live until you die."*
>
> **Dame Cicely Saunders**

Since that time hospice care, with its concentration on quality of life, excellent symptom control and care of both the dying person and those who matter to them, has become a global movement that has radically changed people's expectations for the end of life.

In 1986, seventy years after Ireland began its journey into independence, the Irish Hospice Foundation came into being. Founded by Dr Mary Redmond as a response to her struggle to find care for her father, over the past 30 years the concept of hospice has evolved from being about care provided in a place – "the hospice" – to being about attitudes and the type of care – physical, emotional and spiritual – delivered where it is needed.

Hospices today provide specialist palliative care and a range of services, including out-patient and day-care services that enhance the lives of those living with an advanced, life-limiting illness, their families and carers. Every county now has a specialist palliative care homecare team working to enable more people to stay and be cared for at home longer, and to die at home, in many cases. This success is testament to the dedication, vision and tremendous work of the hospice movement and the health services throughout Ireland. The Irish Hospice Foundation, through our prolonged advocacy work, has helped support the case for strong palliative and hospice care services across Ireland.

The IHF, along with specialist palliative care providers, continues to strive for comprehensive "hospice care" – dignity, peace and calm – which can be delivered in homes, hospitals, residential care settings, and wherever else it is needed.

Achieving excellence in care at the end of life is about supporting each person to live as well as possible up to the moment of their death. The palliative care principles of pain management and symptom control are now recognised as an integral part of the total care of people in their final illness. Excellent care at the end of life is person-centered, built around the needs of the individual, with the person always at the hub of every decision. It is a holistic approach to care that responds to the person's physical, social, spiritual and psychological needs.

The IHF will continue to strive for the right of every individual in Ireland to access that holistic care, and to die with dignity. Everyone wants a good death, and we aim to ensure that as many people as possible get the chance to achieve it through access to good palliative and end-of-life care.

With your help, and the help of our partners, we have made much progress; with your continued support, we can do much more.

What your support enabled us to achieve over 30 years

"The Irish Hospice Foundation can look back with great pride on its many achievements over the past 30 years in promoting and supporting the concept of ensuring access to palliative and end-of-life care for all. During this time it has played a huge advocacy role for patients, families and service providers alike, as well as financially supporting many pioneering initiatives, all of which combined have made a significant impact for the various stakeholders along the way.

I would like to offer both my congratulations and gratitude to The Irish Hospice Foundation for its contribution to date and I look forward to continuing to work together in the years ahead."

Pat Quinlan
CEO, Milford Care Centre

Campaign for quality care at the end of life

The challenge

In 1986 there was little understanding of the holistic approach to palliative care. The IHF, along with those who deliver palliative and end of-life-care, had to advocate tirelessly to make sure that people facing death and bereavement get the spiritual, physical, emotional and social care that they need at end of life.

We set out to **drive the debate on key issues related to dying, death and bereavement.**

How we did it

We advocated! Strongly, all the time, without giving up. We talked to everyone: the public, people approaching the end of life, opinion leaders, politicians, policy makers, the media, palliative care and other medical specialists and service providers. We put the need for quality care at the end of life on the national agenda. We continually demand equity of access to specialist palliative care, no matter what a person's diagnosis or age, no matter where they live. We show where parts of the country are lagging behind in the provision of palliative and end of life care. We have become a national resource for authoritative information on all aspects of the end of life.

Our impact

We continue to shape opinions and raise awareness.

"Both my parents died in the care of Our Lady's Hospice in Harold's Cross, my father after a short stay in 2005, my mother after almost a year in Our Lady's. I can therefore testify in a very personal way to the humane and dignified way in which my parents' final days were attended to by all the staff, from the ward assistants to the nurses and the doctors.

Death is not easy, neither for the dying nor for those who watch over them in those last days, but it is the recognition of the enormity of this life event that marks the spirt of the hospice movement and guides all of its actions. That spirit has now moved out of the hospice gates and its values are slowly taking root in hospital and nursing home settings. When this work is completed, the true legacy of the hospice movement will have been realised."

Emily O'Reilly
European Ombudsman

Support access to hospice and palliative care

The challenge

In 1986 there were few hospices and little community action to support them but a vibrant voluntary hospice movement was the beginning. The IHF helped stimulate the growth of 35 active vibrant groups in every corner of Ireland.

We set out to **support the voluntary hospice movement throughout the country.**

How we did it

Over 20 years ago we began to co-ordinate nationwide initiatives, such as Sunflower Days, now in its 26th year, and Ireland's Biggest Coffee Morning, now 25 years old. We established these for local groups to run and all funds raised locally stay locally. So far, we estimate that these two projects alone have raised more than €34m for hospice services throughout the country. We also connect with all hospice groups every year, and bring them together to discuss fundraising developments.

We have also invested directly in hospice services. We have contributed over €5m to in-patient hospice service and a further €800,000 for setting up of the All Ireland Institute of Hospice and Palliative Care.

Now there are over 2,000 hospice beds in Ireland: a testament to the great work of all in the hospice movement and the health services in Ireland. Every year 2,433 new patients stay in hospices, nearly 8,900 receive hospice care in the community, and nearly 950 attend specialist palliative daycare.

Our impact

We've supported the development and re-development of hospice and palliative care services in Ireland.

Transform children's palliative care

The challenge

There are 4,000 children living with a life-limiting condition in Ireland. 350 die each year.

We set out to **ensure children and their families get best-quality palliative care services. We also set out to ensure bereaved children and young people get the support they need.**

How we did it

We funded the first national study of the end-of-life care needs of children. That led to broad consensus on the need to further augment children's palliative care services and strong government policy on the issue. Then we contributed 85% of the start-up costs of a Children's Hospice Care for Children Programme, designed to augment existing services, including a team of nurses and a paediatric consultant specialising in children's palliative care. This service is now 100% state funded – a great achievement.

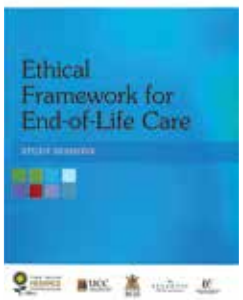
For 12 years we also funded a children's oncology liaison nurse in Our Lady's Children's Hospital Crumlin, and we continue to fund a specialist night nursing service which supports children to be cared for and die at home. We funded a national training programme for the nurses and professionals who work with children with palliative care needs. We support bereaved families through the Irish Childhood Bereavement Network, including a website and booklets.

Our impact

We have invested €4.5m into the further development of palliative care services for children since 2005.

"From the moment we met her, she was so helpful. She built me up and gave me the confidence to be able to care for my son when I felt ready to fold."

Darragh's Mum
Talking about the difference having a Children's Outreach Nurse



Raise standards and invest in expertise

The challenge

In 1986 it was clear that education and training would be essential for spreading the hospice approach throughout the health services.

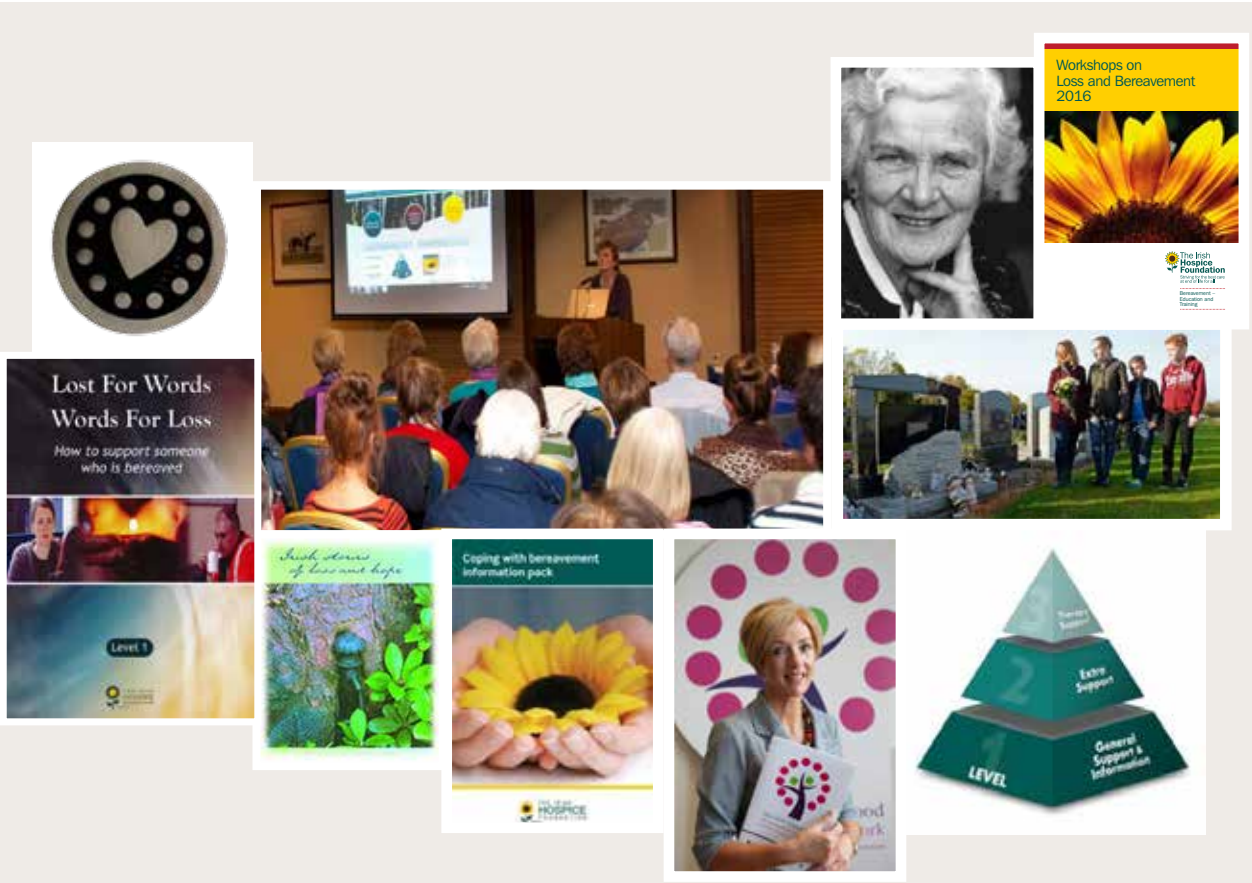
We set out **to support staff and volunteers who work with people facing death and bereavement through education programmes.**

How we did it

We developed a wide range of programmes which we deliver in nursing homes, hospitals and workplaces, as well as in our own offices, and eLearning courses that people can follow from any setting including home, complementing training available in other health care settings. HSE staff are among those who facilitate our hospital-based training courses. Together with the Royal College of Surgeons in Ireland we convene two postgraduate programmes. Up to 3,000 people participate in our programmes each year. Every year our €50,000 grant scheme supports professionals to undertake study in palliative care and bereavement. We work with other concerned organisations to make sure that education on these topics stay on the national agenda.

Our impact

Our programmes are accredited, we have linked them to the HSE Palliative Care Competence Framework, and our graduates have gone on to shape important national bereavement and palliative care policies and standards.



Pioneer development in bereavement care

The challenge

In 1986, bereavement care, a core component of palliative and hospice care was very undeveloped. Thérèse Brady, Director of Clinical Pyschology at UCD, and a board member of the IHF was looking for ways to expand support for bereaved people in Ireland.

We set out **to make sure that bereaved people get the information, support and help that they need, when they need it.**

How we did it

Starting in 1986, we set up a volunteer bereavement support service in first one, and later a second hospice. We gave grants to help other services get off the ground. We devised systems of support based on three levels of bereavement care: for communities, for people going through the process of bereavement and for those who need therapeutic help as a result of bereavement.

Our bereavement group programme helps hospices and community groups to run group-based bereavement programmes. In 2003 we set up our Bereavement and Education Resource Centre with its specialist library, website, leaflets, information events and other resources. We set up a national "Grief at Work" programme and, in consultation with IBEC, ICTU and others, developed bereavement policies for workplaces.

Our "Complicated Grief Programme" trains health and psychology professionals throughout Ireland to support those who need it. We founded the Irish Childhood Bereavement Network, now co-funded by TUSLA and the IHF (see page 11).

We worked closely with the HSE on national bereavement standards for maternity hospitals. We also work with the National Office for Suicide Prevention and have developed strong international links ensuring an evidence base to our work.

Our impact

Information and support on bereavement care is available nationwide for those who need it, when they need it, at the level they need it.

HospiceFriendly HOSPITALS
Putting Hospice Principles into Hospital Practice

DESIGN & DIGNITY

Develop ground-breaking work to bring hospice care into hospitals

The challenge

The majority of people want to die at home, but 43% of deaths, amounting to around 12,500 a year, occur in acute hospitals. Hospitals are traditionally designed to treat illness, injuries and emergencies, not to support people at the most vulnerable time of their lives.

We aim to **support hospitals throughout Ireland to deliver best care at end of life for everyone facing death or bereavement.**

How we did it

Between 1995 and 1999 we funded specialist palliative care nurses and social workers in two major Dublin hospitals to 'kickstart' palliative care in these settings. Today in 2016 all acute hospitals in Ireland have palliative care teams. Together with the HSE, and with funding support from Atlantic Philanthropies, in 2007 we set up the Hospice Friendly Hospitals programme, one of the first of its kind in the world. It puts hospice principles into hospitals, and works to ensure that end-of-life, palliative and bereavement care are central to hospitals' everyday activity. To date, 48 hospitals throughout Ireland are involved. Now nearly 20 hospitals have access to end-of-life care coordinators, implementing the national standards for end-of-life care that we developed with the HSE in 2010. Over 24 family spaces in hospitals have been transformed through the Design & Dignity hospital improvement renovation projects. So far, we have invested €11.5m in the Hospice Friendly Hospitals programme.

Our impact

The Hospice Friendly Hospitals programme is transforming culture and practice concerning end of life in hospitals.

> *"... the Hospice Friendly Hospitals programme which has brought dying, death and bereavement from the margins of planning and delivery in acute hospital care to the mainstream."*

Diarmuid Ó Coimín
End of Life Care Coordinator,
Mater Misericordiae University Hospital

IHF HEALTHCARE PROGRAMMES

nurses for night care

43% die in Hospitals

25% die in residential care

70% die with diseases other than cancer

25% die at home

Extend access to palliative care to people irrespective of illness or location

The challenge

Some 30% of deaths in Ireland are due to cancer, however, more people die from heart or lung disease (42%) and 14% of the population die from dementia. Yet, palliative care services are still aimed primarily at people who have a cancer diagnosis.

We aim to **ensure that all people with life-limiting diseases gain access to best-quality end-of-life and palliative care services.**

How we did it

We have invested nearly €3m since 2006 in our Nursing for Night Care programme for people with life-limiting conditions such as heart failure, advancing neurological disease, advancing respiratory disease and dementia. Through this scheme more people are able to die at home – 2,400 to date. We have invested nearly €3m in research and development grants, and €1m in educational grants so that palliative care is available for people with all life-limiting diseases. We have contributed €2.4m to build staff capacity so that health services can try new approaches. We've worked with a wide range of medical specialities and patient groups to raise awareness of care at end of life and to improve understanding and access to palliative care, and we advocate tirelessly for everyone's right to quality end of life care.

Our impact

Today there is a much clearer understanding of the importance of best-quality palliative care for people with all kinds of life-limiting conditions.

" the simple and transformational changes taking place in Irish hospitals make death more bearable for those at end of life and for family and friends left behind "

Gabriel Byrne
IHF Patron talking about Design & Dignity project

Improve end-of-life care for people with dementia

The challenge

Dementia is now recognised as a progressive life limiting condition and over 4,000 people die with dementia in Ireland each year. People with dementia should have opportunities to make informed decisions about their future care at an early stage in the disease, particularly as their ability to communicate their needs changes as their disease progresses. Healthcare staff have told us they need support to deliver good end-of-life care for people with dementia.

We aim to **make sure that more people with dementia live and die with dignity, whether done at home or in residential care or hospital.**

How we did it

With funding support from Atlantic Philanthropies, we set up Changing Minds, a 3-year programme aiming to bring about excellence on end-of-life care for people with dementia. We ran workshops and education programmes to help healthcare staff to develop skills in palliative and end-of-life care specifically for people with dementia. Our Journey of Change programme built on these by working with residential care centres. We gave grants to support healthcare professionals to implement innovations in this field. We engaged with people with dementia, their families and carers, and enabled their voices to be heard and their leadership acknowledged. With the Alzheimer Society we developed information about planning for the future with dementia.

Our impact

Healthcare staff, families and people with dementia themselves are more able to discuss end-of-life issues, and plan for a good death.

Publish impactful research to provide evidence for change

The challenge

We have always known the need to support our arguments with solid evidence. In 1986 this area was so under-researched, little was understood about how to meet the needs of those facing death or bereavement.

How we did it

Over the years we have researched and evaluated our programmes by examining best evidence and listening to the views of patients, carers and professions. We have a core information and library service at IHF – the Thérèse Brady Library. This service also provides current information and updates to those working in palliative care and bereavement.

In 2009-10 we ran the Forum on the End of Life which saw over 167 written submissions from individuals and organisations, 23 workshops and public meetings in nine locations countrywide. This led to the publication of a ground breaking report on perspectives on end of life and the establishment of the Council of the Forum on end of Life, chaired by Justice Catherine McGuinness who worked on many of the issues identified through the consultation. We are currently engaged in a national HaveYourSay campaign to seek the views of the public on dying, death and bereavement.

Our impact

We have commissioned ground breaking research including;

- The first Irish nationwide survey of public attitudes on death and dying and explorations of public perceptions of end-of-life care and bereavement
- Baseline and feasibility studies for the expansion of palliative care for non-cancer conditions and in primary care settings
- Children's palliative care and respite needs assessments
- The first nationwide audit of end-of-life care of its kind in Europe
- The first nationwide review of public experiences of death and dying
- Perspective papers on Advance Care Planning, the economics of palliative care and place of death[1]

1 See more at http://hospicefoundation.ie/publications/reports/

Change how people plan for end of life

The challenge

Lack of awareness and confidence among the public about their rights concerning end-of-life preferences means that many do not put arrangements in place.

We aim to encourage people to consider the end of life, and express their preferences.

How we did it

The flagship project of the Council of the Forum on End of Life was the development of Think Ahead, which provides a guide to help people to discuss and record their preferences in the event of an emergency, serious illness or death. We have disseminated 50,000 Think Ahead forms so far, enabling people to record their wishes about care in the event of serious illness or death. A recent study with the Civil Service recommends that Think Ahead should be included in staff supports. We have published research on advance planning.

Our advocacy on the issue informed the introduction of the Assisted Decision-Making (Capacity) Act 2015.

Our impact

The Think Ahead programme is widely accepted and government and Irish society are more aware of the need to plan for, and to provide, better care at end of life — including supporting people facing dying, death and bereavement. In 2016, the Programme for Government included a commitment to work with NGOs to improve information and awareness of end-of-life services.

We can't take all the credit but we are proud to have played our part.

"Dying and death is everyone business - wider than the realms of health services alone. The Irish Hospice Foundation's initiative to support a Forum on End of life allowed a national conversationon all aspects of dying death and bereavement to begin. As chairperson on the Council of the Forum on End of Life, I, along with my fellow Forum members, have been delighted to support the IHF in addressing many different aspects of dying and death and in particular the work needed to progress advanced health care directives."

Justice Catherine McGuinness

Maintain independence and good governance

The challenge

There is increasing focus on the charitable sector, and the public are demanding ever higher standards.

We aim to **be fully transparent, especially about how our donors' money is spent and to comply with all laws and appropriate standards, so as to remain independent to advocate and work on behalf of those who need it most.**

How we did it

We strive for excellence in governance standards. We advocated for the setting up of the Charities Regulatory Authority, and were among the first to adopt the Code of Practice for Good Governance of Community, Voluntary and Charitable Organisations in Ireland. We comply with all financial best practice in our sector. We continue to be funded through the generosity of our supporters as traditionally we have not sought significant State funding. This allows us to retain our strong independent voice.

Our impact

We have grown over 30 years from being a small volunteer-led charity to being a large, independent organisation with influence and impact, while also striving for excellence in governance, transparency and openness.

Our heartfelt thanks

to all our donors, philanthropic benefactors, sponsors, corporates, event participants and committee members for their amazing support over the last 30 years. Your generosity of spirit has helped us achieve meaningful impacts across many sectors.

How did we achieve this?

We have brought about meaningful change because of people like you. Your financial support is our driver of change and backbone of the IHF. We couldn't deliver all the programmes we have described without you. We would not be independent, viable and impactful without you.

"It's 100 years and no time at all in the history of a country since 1916. It is said that we live not just our own life but also the life of our times and I know that with The Irish Hospice Foundation's campaign more of us will live and die with the kind of care, the quality of experience befitting our dignity, our humanity and our intrinsic value on this earth.

I commend The Irish Hospice Foundation for taking up this challenge – one which promises to engage the public on a topic common to us all – the challenges of living with, after and through dying, death and bereavement."

An Taoiseach, Enda Kenny

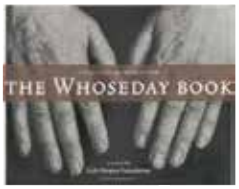
Throughout our 30 years, you've made it happen by supporting us in so many ways

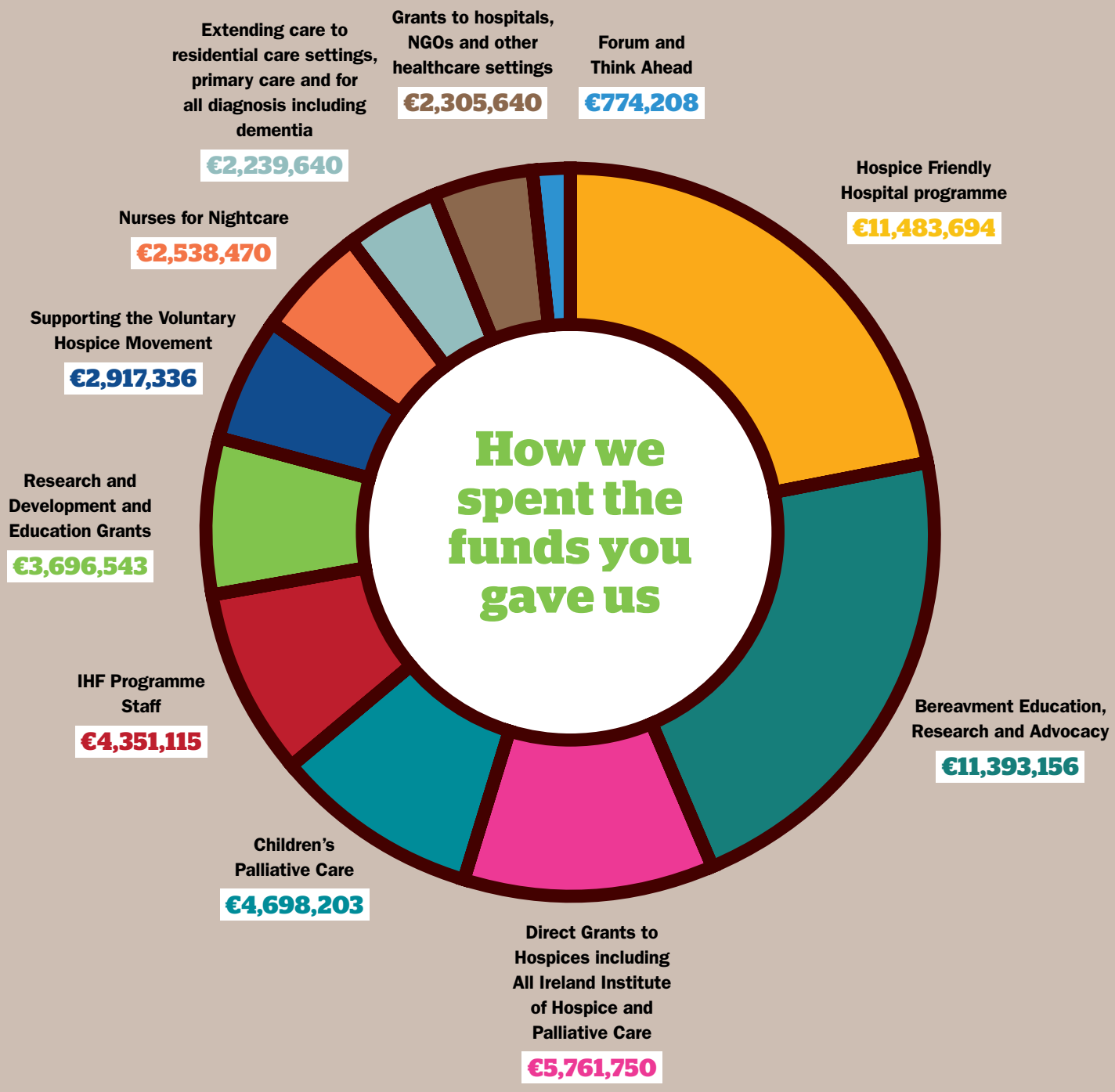
- Throughout our 30 years, fantastic people have supported our work by volunteering their time and expertise to our Board and many committees, our extensive fundraising projects and by encouraging friends and families to support our work – this success of the IHF has been a team effort and we are grateful to all who have helped us.
- You supported the great fundraising events we run, such as our Annual Cycle, Godbox Tour, Riverdance DanceAthon, the Howth Walk, Race Day, IHF Camino, National Pyjama Day (through Early Childhood Ireland) and many more.
- Throughout the country thousands of people support us financially each month through planned giving – they are our backbone and the driving force behind our mission.
- You supported us by buying our well-known fundraising books, such as sons+fathers, The Whoseday Book, Artpack, Life Story, The Gathering – Reflections on Ireland, Peter and the Wolf, Zest! Cookbook, Stories of Loss and Hope, and our Thank You book. Each year many thousands of supporters do their bit by participating in our national raffle, buying our books and attending our events.
- Companies play a big role in our family of supporters, by donating financially or through their staff members raising funds by running activities and events.
- Each year a large number of people respond to Never Forgotten Appeal, our annual Christmas appeal that raises funds for the Nurses for Night Care programme.
- The support of grant-making trusts and foundations has enabled us to fund a number of major programmes over the years. In particular we acknowledge the support of Atlantic Philanthropies and Community Foundation of Ireland,
- Some of our supporters choose to make a final gift to us through their will. This type of support enables the work we do, and these legacies have a significant impact.

Our heartfelt thanks to all our donors, sponsors, philanthropic benefactors, corporates, event participants, committee members for their amazing support over the last 30 years. Your generosity of spirit has helped us achieve meaningful impacts across many sectors.









We raised over €72 million during the past 30 years. Over €52 million was spent directly on service improvements across Ireland, in all settings, to make a meaningful impact for the Irish population. In line with good governance, over the 30 years, €3m was spent on administration and governance and €17m was invested in generating funds.

What we want to achieve from now on

The Irish Hospice Foundation strives to play its part in addressing vital issues. Our future work will deal with aspects of end of life in Ireland which remain unresolved

- **End-of-life services should be higher on the national agenda** – because **everyone deserves a good death.**
- **Palliative and end-of-life care services are not consistent throughout the country** – we want to ensure that everyone has access to best-quality services, no matter where they live and no matter what life-limiting condition they have.
- **More public conversation is needed on dying, death and bereavement**– more talking means that as a society we will be better prepared for the end of life.
- **Bereavement is still inadequately addressed in Ireland** - loss and bereavement underpins all end-of-life and palliative care, and affects us all.
- **Training in end of life, bereavement and palliative care is not widespread.** Staff in all care settings – hospitals, residential care, community settings and hospices - need support, training and development.
- **Encourage people to think ahead and plan for the end of life.** We all need support at the end of life and need to know that our wishes for end-of-life care will be respected.
- **As a party to the WHO's World Health Assembly Resolution (2014)**, Ireland's healthcare system has a responsibility to provide best-quality palliative care nationwide.

Into the future

Over the past 30 years the landscape of end-of-life and palliative care in Ireland has been transformed. Without your help none of it would have happened. Your support every step of the way ensures we remain focused, independent, clear, innovative and creative voice. Because you are behind us, we can be effective and make a difference. Your contribution has worked wonders, and we are very, very grateful.

Our core belief is simple: everyone deserves a good death, and we have only one chance to get it right. Our core aim is to make sure everyone gets that chance – through collaboration with our partners, support to the hospice movement, training and education, advocacy, innovation and continued development. With your continued support, it won't take another 30 years until we achieve that. We look forward to working with you to make it a reality.

The IHF works in partnership with so many committed organisations and individuals without whom none of this would be possible. We wish to thank you all wholeheartedly. Apologies it is not possible to acknowledge every contribution in this report. We have been so lucky to benefit from all of our collaborations.

Thank you!

Our Goals for 2016-2019

During 2016-2019 we will achieve the best care at end of life for all by concentrating on four goals:

1 **Service Improvement:** Innovating excellence in palliative, end-of-life and bereavement care.

2 **Education and Training:** Enhancing end of life and bereavement care.

3 **Advocacy and Public Engagement:** Driving debate, awareness and change on issues related to dying, death and bereavement in Ireland.

4 **Good Governance and Sustainability:** Maintain our credibility, independence and long-term sustainability through good governance, financial independence and accountability, effective communications and a cohesive fundraising programme.

"The Think Ahead initiative helps prevent shock, helps avoid confusion... by encouraging us to think, talk and tell... It takes the attention, the intention and desire of the way we live and applies them equally and exquisitely to our death and dying, so we have some control, choice, peace, dignity at the end"

An Taoiseach, Enda Kenny
Launch of Think Ahead at Forum 2011

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Thank you.

"As anyone with a dream will tell you, not only does it never go away, you see it, you can touch it & you talk about it at every opportunity"

from **Mary Redmond's** speech at inaugural Mary Redmond day lecture Feb 13 2004

30 years of milestones

1985	Mary Redmonds letter to Sister Francis Rose O'Flynn to help Our Lady's Hospice
1986	Mary Redmond meets with Dame Cicely Saunders to discuss hospice development in Ireland
	Founding of Irish Hospice Foundation
	Today Tonight programme highlighting lack of palliative and hospice care is broadcast
	Thérèse Brady sets up volunteer bereavement service in Our Lady's Hospice
	Frist Volunteer Bereavement Training Course is run
	IHF Research Committee is established - First Research Committee chair Nicholas O Connor
1987	Beginning of IHF bereavement service
	Launch of IHF fundraising activities
	Opening of the education centre at Our Lady's Hospice - Funding from IHF
1988	Business Manager George Byrne is recruited by IHF
1989	Homecare services for northside of Dublin offered by St Francis Hospice
1990	First Board meeting of St Francis Hospice takes place
	IHF supports the Association of Hospice and Allied Bereavement Groups in Ireland (HEBER)
	Began co-ordinating nationwide initiatives Sunflower Days and Ireland's Biggest Coffee Morning for Hospice. These projects have raised €34m plus for local hospice services
1991	IHF organises a series of workshops on loss and bereavement.
1993	First Ireland's Biggest Coffee Morning takes place.
	1st HEBER Conference in association with IHF Speaker Dr. Colin Murray Parkes
1994	HEBER in association with IHF introduces a course to train people to work with bereaved children and adolescents
	2nd HEBER Conference in association with IHF
1995	IHF supports a palliative care service in acute hospital setting in St James's Hospital.
	3rd HEBER Conference in association with IHF - guest speaker Dr. Michael Kearney
	IHF moves from Waterloo Road to F'tizwilliam Place. Medical Council recognised Palliative Medicine as a speciality.
1996	St Francis Hospice in Raheny opens on February 1st.
	Report entitled "*A position paper on the development of hospice and specialist palliative care serviced in Ireland*" produced by IHF and Irish Association for Palliative Care.
	Antoin Murphy becomes chairperson of the IHF.
	4th HEBER Conference in association with IHF guest speaker Julie Stokes
1997	Galway Hospice opens as an inpatient unit.
	Marie Donnelly becomes chairperson of the IHF.
	5th HEBER Conference in assoication with IHF - guest speaker Barbara Monroe
	Beaumont palliative care team established in 1996 with support from IHF
1998	The North West Hospice opens an eight-bed unit on the site of Sligo General Hospital.
	Report entitled *'A study of partnership between the voluntary and statutory sectors in palliative care in Ireland"* is published.
	6th HEBER Conference in association with IHF guest speaker Maurice Ward
	IHF appoints Assistant Director of Bereavement Service (Howard Kunin)
1999	Thérèse Brady dies. Therese bequeathed her house and all her journals and books to IHF
	Research on relatives' experience of the quality of care during the last year of life at St James's Hospital entitled Care for the dying: experiences and challenges published.
	7th HEBER Conference in assoication with IHF renamed Therese Brady Memorial Lecture - guest speaker Christy Kenneally
	Bereavement Steering Committee established ' to advise on planning Centre for Bereavemetn Education, Training & Research'
	IHF took owership of HEBER's Working with Bereaved Children and Adolescents Training Course
	The Whoseday Book is published for the millennium and raises €2.5 million for the IHF.
2000	Bill Shipsey becomes chairperson of the IHF
	Royal & Sun Alliance signs up to the IHF's Give as You Earn fundraising scheme.
	A new IHF Research Committee is formed
	A review of bereavement support, training and research needs is published.
	Children and Loss course developed into a workshop series and renamed Loss and Bereavement for Children and Adolescents
	8th HEBER Conference in association with IHF Thérèse Brady Memorial Lecture - guest speaker Dr. Tony Bates
2001	Report of the National Advisory Committee on Palliative Care is published and adopted as government policy.
	A postgraduate scholarship in bereavement research, the Thérèse Brady Scholarship established by the IHF
	Art:Pack launched raising €550,000 nationally and internationally.
	9th HEBER Conference in association with IHF Therese Brady Memorial Lecture - guest speaker Dr. Phyllis Rolfe Silverman
2002	End-of-Life Care in General Hospitals - RCSI planning document for IHF published.
	Co-founded by the IHF and the Department of Health and Children, a research team based at University College Dublin begins a national needs assessment on palliative care for children.
	10th HEBER Conference in association with IHF Thérèse Brady Memorial Lecture - guest speaker Patrick Shannon
2003	Peter & The Wolf is launched raising €850,000 for the IHF.
	Muc in for Hospice launched for children's hospice care.
	Letterkenny hospice opens as a project of the Donegal Hospice and the North Western Health Board.
	Bereavement support service at Our Lady's Hospice is transferred from IHF to Our Lady's Social Work Department.
	OLH takes ownership of HEBER Conference from IHF
	IHF launches its Education and Bereavement Resource Centre.
	IHF moved from Fitzwilliam Place to Morrison Chambers, Nassau Street with our own training rooms on site
	Opening of the Thérèse Brady Library - the first specialist bereavement information service in Ireland
	First ever Irish Research Fellowship in Palliative Care, sponsored by the IHF and the Health Research Board awarded to Philip Larkin.
2004	A two year Care for People Dying in Hospitals pilot project is launched at Our Lady of Lourdes Hospital in Drogheda.
	St Brigid's Hospice opens at Drogheda Memorial Hospital in Kildare.
	Palliative Care Unit in Blackrock opened by Our Lady's Hospice.
	IHF enters a partnership with the Royal College of Surgeons in Ireland enabling the IHF to offer a Higher Diploma and a Certificate course accredited by the RCSI.
	First students graduated in the Certificate in Children and Loss course accredited by the RCSI.
	Michael O'Reilly becomes chairperson of the IHF.
	Bereavement Care lisiason officer three year pilot project launched with South East Health Board
	A nationwide survey of public attitudes and experiences regarding death and dying published. An IHF initiative supported by the Health Services National Partnership Forum
	"Woody" by Brent Pope is published.
2005	National conference on care for people dying in hospital held in May.
	Children's Needs Assessment report launched in September by An Tanaiste and Minister for Health and Children, Mary Harney, T.D.
	Professor David Clark is appointed visiting professor of Hospice Studies.
	Hospice services are chosen as the Tesco Ireland Charity of the Year - €1.5 million is raised.
	Denis Doherty appointed chairperson of the IHF
	First ever World Hospice and Palliative Care Day takes place on October 8th.
	First students with Higher Diploma in Bereavement Studies graduate.
	Atlantic Philanthropy fund towards Care for the People Dying in Hospitals Project and Review of Palliative Care Services

2006	National Council for Specialist Palliative Care is formed with IHF representation.
	Launch in March of the report; *"A baseline study on the provision of hospice/specialist palliative care servicesin Ireland"* by An Tanaiste and Minister for Health and Children, Mary Harney TD.
	Care for People Dying in Hospitals project wins a number of awards
	Hospice Friendly Hospitals national programme launched.
	Second IHF/Health Research Board research fellowship is offered.
	Dana represents the IHF in RTE's Celebrity Jigs and Reels.
	Politicians sing for the IHF in Celebrity You're a Star.
	Palliative care included in the new National Social Agreement entitled Towards 2016, ten-year framework social partnership agreement 2006-2015.
	The second annual World Hospice and Palliative Care Day takes place on October 7th with the theme Access to Care for All
	Publication of *"Exploring palliative care education in Ireland"*: A resource and discussion document
	"The Irish Hospice Foundation; 1986-2006 The First 20 years", published.
	IHF Night Nursing service started for all conditions other than cancer
	Atlantic Philanthropy fund Public Information & Education Campaign and grant for Hospice Friendly Hospitals Project
2007	Publication of *"Lifestory"*
	Publication of *"Irish stories of Loss and Hope"*. Stories of bereavement
	"The future of palliative care education in Ireland; a discussion paper", published.
	Atlantic Philanthropy fund Business Plan for an All-Island Institute of Hospice and Palliative Care
	Higher Diploma becomes MSc in Bereavement Studies with RCSI
	Published *'Grief at Work - Developing a Bereavement Policy'*
2008	National audit of end of life care in Irish hospitals conducted - it included 999 patient cases
	"Design & Dignity Guidelines for physical environments of hospitals supporting end-of-life care" published.
	Second Bereavement Care Liason Officer pilot established in the Midlands Health Board area
	Publication of End-of-Life Care for Older People in Acute and Long Stay Care Settings in Ireland
	"Palliative care for all; Integrating palliative care into disease management frameworks," published
	The Baxter International Foundation grant towards Nurses for Night Care service
2009	Launch of the *"Bereavement Pin"* by Pat Kenny. Developed by Dr Susan Delaney and designed by Alan Ardiff the pin is a symbol that a person is grieving
	The launch of the Forum on End-of-Life in Ireland and forum public consultations on end-of-life issues takes place
	Zest! 62 recipes from leading Irish restaurants is published
	The first IHF annual cycle challenge (Sponsored by Kingspan) takes cyclists from Dublin to Paris
	Publication of 'A qualitative study of public perceptions of end of life issues' by John Weafer
	Atlantic Philanthropy fund Audit of End of Life Care – Hospice Friendly Hospitals Programme
2010	Publication of *"Perspectives on End-of-Life; Report of the Forum 2009"* findings from the 2009 Forum investigations
	Publication of 'Dying in hospital in Ireland; an assessment of the quality of care in the last week of life' Report on the Hospice Friendly Hospitals audit of end-of-life care in Ireland
	Quality Standards for End of Life Care in Hospitals - Report formally launched in Clontarf Castle by Minister for Health Mary Harney following the HFH audit of end-of-life care in Ireland
	In October the Hospice Friendly Hospitals programme wins Irish Healthcare Awards – for excellence in healthcare management
	Publication of the 'Thank You Book' A graditude journal. Edited by Roisin Ingle and featuring quotes by a range of celebrities on what they are thankful for
	First national 'Thank You Day' encouraging people to practice gratitude. A Series of Thank You cards featuring quotes by celebrities launched to coincide woth the day
	Release of 'Lost for Words' bereavement training DVD
	"National Audit of End-of-Life care in Hospitals in Ireland 2008/2009" published.
	The All Ireland Institute for Hospice & Palliatice Care (AIIHPC) launched
	20th Anniversary of Sunflower Days fundraising campaign for local hospice groups
	JP McManus Charitable Foundation for Children's Hospice Project
	The All Ireland Institute for Hospice & Palliatice Care (AIIHPC) launched
2011	*"Ethical Framework for End-of-Life Care"* – collaboration between UCC, RCSI and IHF published
	Children and Loss course developed into Professional Certificate in Children and Loss (Level 9)
	ThinkAhead – a citizen led information and planning tool was developed by Forum on End of Life
	Sharon Foley becomes, CEO
	'What Matters to Me' Training starts for residential care staff
	The appointment of Ireland's first Consultant Paediatrician with a Special Interest in Paediatric Palliative Care, a network of Children's Outreach Nurses (8 initially) was established. Five of these posts were seed funded, for three years, by the IHF.
2012	Launch of the Irish Childhood Bereavement Network (ICBN) to support and develop services for bereaved children
	Publication of *"Irish Hospice Foundation Strategic Plan 2012-2015"*
	"The strategic importance of palliative care within the Irish health service. Perspectives on future service delivery" is published. (Perspective Series 1)
	1st Public Information Evening on Bereavement is held - guest speakers Tony Bates and Tom Inglis
2013	*"Access to specialist palliative care services and place of death in Ireland"*, published (Perspective Series 2)
	"National Practice Development Programme; End-of-Life-Care in acute hospitals in Ireland" published
	Oireachtas Joint Committee on Health and Children, public hearings on end-of-life care in Ireland chaired by Jerry Buttimer TD October 24th and 14th November
	"Respite Services for Children with Life-Limiting Conditions and their Families in Ireland; a national needs assessment", published March 4th
	Publication of *"The Gathering – Reflections on Ireland"*
	2nd Public Information Evening on Bereavement is held – guest speakers John Lonergan and Mary O'Rourke
	Journey of Change programme commenced for residential nursing homes
	Jean McKiernan appointed Chairperson of the IHF
	Atlantic Philanthropy Grant for Dementia Palliative Care project
2014	*"Irish Attitudes to Death, Dying and Bereavement, 2004-2014,"* report published
	3rd Public Information Evening on Bereavement is held - guest speaker Michael Harding
	Irish Childhood Bereavemet Network National Conference sees the launch of Bereavement Care Pyramid
	"Enabling More People to Die at Home: Making the case for quality indicators as drivers for change on place of care and place of death in Ireland". Published. (Perspective series 3)
	Grief at Work programme commenced for staff working in end-of-life care
2015	Hearing the Voice of Bereaved Relatives published.
	Publication of 'sons+fathers' book
	4th Public Information Evening on Bereavement *"Living with Loss"* is held - guest speaker Jane McKenna
	The Baxter International Foundation grant towards Nurses for Night Care service
	The Assisted Decision Making (Capacity) Act was signed into law by President Michael D Higgins on December 30th 2015. This ground-breaking legislation underpins and supports people's rights to make end of life decisions for themselves.
	An Taoiseach asks the IHF to support Senator Marie Louise O'Donnell work on end of life services across all Government departments. *Finite Lives* Part 1 was published in December 2015
2016	*"The Irish Hospice Foundation Strategic Plan 2016-2019"* published
	30th Anniversary of The Irish Hospice Foundation
	"Supporting people with dementia to die at home", report published.
	2nd International Children's Palliative Care conference take places in Farmleigh
	National Bereavement Forum held for bereavement services across Ireland
	First Hospice friendly Hospital conference takes places in Limerick
	"A Perspective on Advance Planning for End of Life" published. (Perspective series 4)
	5th Public Information Evening on Bereavement is held – guest speaker John McAreavey
	An Pobal & The Department of Housing, Planning, Community & Local Government Funding
	The Dr Mary Redmond Gala Dinner – InterContinental Dublin
	Digital Archive of 30 Years of The Irish Hospice Foundation
	ICBN Conference launch national standards for bereaved children during Bereaved Children's Week
	National "Have Your Say" survey on what is important to people at end of life with 2,500 responses

The Irish Hospice Foundation
Striving for the best care at end of life for all

"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

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You can browse the images, documents and videos that tell the story of our 30 year history at — **archives.hospicefoundation.ie**

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