

The Irish Hospice Foundation

1986 - 2006

The First 20 Years



THE IRISH
HOSPICE
FOUNDATION

1986-2006

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A large, stylized sunflower graphic in shades of green and teal, set against a light yellow background. The sunflower has a dark teal center and a ring of lighter teal petals. The stem and leaves are also in shades of green. The graphic is partially enclosed by a large, dark teal circular shape on the right side of the page.

our vision

That no one should have to face death or bereavement without appropriate care and support.

our mission

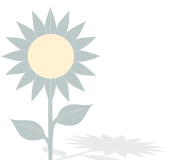
- To build support for the hospice philosophy;
- To improve the experience of end-of-life care for patients and their families;
- To support the development of a world-class hospice and palliative care service.

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Beginnings



FOUNDER DR MARY REDMOND

On May 6th 1985 Dr Mary Redmond, who had just begun her solicitor's practice in Dublin, wrote to Sister Francis Rose O'Flynn at Our Lady's Hospice in Harold's Cross with an offer of help.

Her father, Dr John Redmond, had died "in the expert and loving hands" of the sisters at the hospice the previous January, she told Sr Francis Rose.

Until her father's last illness, "we had never encountered the difficulties which were faced by families in such circumstances," she wrote. "We had no previous experience of the worry and anguish that can be felt when the task is to find a suitable place for a dearly loved one who is dying."

"The point of my letter is that I wish to do more than simply thank you and your sisters for all that they have done."

She understood that there was no formal committee or group looking after the raising of money for the hospice in Harold's Cross and "I believe I could be of most use in contributing my legal and administrative skills to fund raising of some sort."



Dr Mary Redmond with Our Lady's Hospice matron, Sr Francis Rose.

THE GENESIS

This letter could be said to mark the beginning

of the Irish Hospice Foundation (IHF). Since it was set up in 1986, the IHF has raised many millions of euro for hospice services in Ireland, and has supported the spreading of the hospice philosophy throughout the country.

THE HOSPICE PHILOSOPHY

At its core, the hospice philosophy, as explained in an early briefing document, is that the life of the person who is dying should be made "worth living to the end so that peaceful death becomes an achievement, not a defeat."

The IHF has put this philosophy into practice in three major ways: by financially supporting the development of hospice facilities, by spreading knowledge about hospice and palliative care and by engaging in education and training.

The early briefing document went on to say that "pain in terminal illness can and should be prevented: it is not necessary or acceptable that so many people should be allowed to suffer so much. This does not mean patients must be drugged into semi consciousness: with skilled medication their pain is removed but they remain mentally alert."

"Hospice care should be available to all who need it," the document added.

DAME CICELY SAUNDERS

As part of her preparation for what was to become the founding of the IHF, Dr Redmond visited the late Dame Cicely Saunders whose work in London is seen as the starting point of the modern concept of hospice and palliative care. That work is grounded in a holistic approach to human need and honours emotional, intellectual, spiritual and physical needs. This approach is reflected in the philosophy of the IHF and of the hospice movement generally in Ireland.

A week after she sent off her letter in 1985, Dr Redmond met Sr Francis Rose at Our Lady's Hospice. As it happened, the hospice was planning to build a Research and Education Centre. The cost would be about

Also in 1986

1. The UK and France announced plans to construct the Channel Tunnel.
2. The European Community adopted the European flag and the community of nations expanded with the entry of Spain and Portugal.
3. One of the reactors in the Chernobyl nuclear plant exploded in the Ukraine creating the world's worst nuclear disaster.
4. Phil Lynott, lead singer with Thin Lizzy, died at the age of 35.
5. Irish citizenship was conferred on the Speaker of the United States House of Representatives, Tip O'Neill.
6. Jack Charlton was appointed as Ireland's new soccer team manager.
7. Knock airport was officially opened.
8. A divorce referendum was defeated.
9. Some 30,000 Irish people emigrated during the year.
10. The national office of the Progressive Democrats was officially opened.

£2 million. The IHF committed and raised £1.6 million for the Research and Education Centre

Dr Mary Redmond suggested that a "Friends' movement" be set up and that, at the start, "our target should be a high one."

She began to gather together the group of people who would form the nucleus of the new organisation. She knew that an uncle of Dr (now Professor) Antoin Murphy of the Department of Economics at Trinity College Dublin, had died at the hospice at around the same time her father was there. She asked for his help with the new venture and he agreed.





Beginnings

Chartered Accountant Nicholas O’Conor was also an early member and put a great deal of work into the establishment of the IHF. This involved the drawing up of a constitution under which the IHF is governed by a Board of Directors. The Board is responsible, through the chief executive officer, for the day to day running of the work of the IHF and coordinates the activities of its sub-committees.

Two of these early sub-committees were the Research Committee and the Ethics Committee. The Research Committee assessed applications for financial assistance for research projects relevant to the aims of the IHF. All projects recommended by the Research Committee were vetted by the Ethics Committee.



Building the Research and Education Centre at Our Lady’s Hospice, Harold’s Cross in Dublin.

The first Board of Directors of the IHF was made up of Dr Redmond (chairperson), Sister Francis Rose O’Flynn, Sister Ignatius Phelan, Dr Antoin Murphy, Mr John Lynch, Mr Nicholas O’Conor and Ms Gerardine Montgomery.

THE LAUNCH

The IHF was formally launched on Monday, 21st April 1986. “All pain can be controlled by careful medical care. Our patients are told there will be no pain and this promise is always kept,” the press release announcing the launch

stated, quoting Dr John McCarthy, Director of Continuing Care at Our Lady’s Hospice.

It listed the three main objectives of the Hospice Foundation (‘Irish’ was added to the name at a later date) as:

- to facilitate the practice of hospice care in all aspects including home care;
- to promote awareness of hospice;
- to conduct research.

A word from the IHF Founder, Dr Mary Redmond



“I had no idea when I started the process of setting up the Irish Hospice Foundation that it was going to become so big and the work would be so challenging. But we were carried along on the crest of passion. I would like to acknowledge and thank everyone who shared that vision beginning in 1986.

The IHF has established itself as a strong player and is very, very necessary because of the leadership it has demonstrated and the support it has given to various voluntary groups, hospices and hospitals all over Ireland.

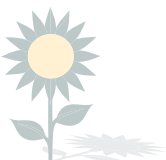
In less than a year after the IHF was set up, hospice movements at different stages of development were set up in Galway, Sligo, Cavan, Wexford, Waterford, Kilkenny, Donegal, West Wicklow and Kildare.

The IHF continues to have a really important role to play in nurturing and supporting the social movement that has emerged in support of hospice. Today, there are volunteers throughout the country who are harnessing the goodwill of their communities to support local services. The tremendous energy of hospice volunteers is something that will never be diminished.

The challenge ahead for the Foundation is to work with the hospice community and the State to advocate that hospice services are available to all who need it irrespective of where they live in the country their means or their diagnosis. Its challenge is also to ensure that volunteers will always be a cherished feature of hospice, partners in the provision of care.

This is a very ambitious objective but the IHF and its supporters have always thought big whether it was building a Research and Education Centre at Our Lady’s Hospice, Harold’s Cross or starting what has become St Francis Hospice for the northside of Dublin.

Behind all of these plans about bricks and mortar is our abiding mission to ensure that individuals and their families are able to face death with the appropriate care and support.”



Beginnings



TV EXPOSE

The launch coincided with a *Today Tonight* programme on RTÉ on the suffering which the scarcity of hospice and palliative care brought to people with terminal illnesses and on the plans of the new IHF. The response from the public was immediate and emotionally raw.

“After the programme we had a phone-in,” Dr Mary Redmond recalled later. “Telecom Éireann gave us free access to lines. The phones never stopped ringing. They were mostly painful calls from every part of Ireland.”

Story after story of relatives dying in pain came over the phone lines. “It was almost like a hidden grief in the country, that hadn’t been exposed,” she said.

Professor Antoin Murphy has never forgotten the telephone calls that came through on the night of the broadcast. “The stories coming through were absolutely harrowing,” he said. “It seemed there was a reluctance on the part of many medical practitioners to give opiates in the course of treatment. People were dying in the most acute pain.”



Sr. Ignatius of Our Lady’s Hospice in Harold’s Cross who served on the first Board of the IHF.

At the time of the launch there were three

hospices in Ireland (Dublin, Limerick and Cork) and a home care service had been launched by Our Lady’s Hospice the previous year

Following the success of the IHF fundraising drive, Our Lady’s Hospice opened its Research and Education Centre in 1987. This allowed for important advances in education in palliative care. A nurse tutor was appointed and courses commenced. Eventually a Higher Diploma in Palliative Nursing was developed by Our Lady’s and University College Dublin. There are now similar courses in University College Galway and Trinity College Dublin.

EARLY DAYS

In 1988 George Byrne joined the IHF as its Business Manager. Over the next 15 years, he travelled throughout the country on IHF business. He retired in 2003 and continues to work on a voluntary basis for the IHF. One of Dr Mary Redmond’s closest allies in the establishment of the IHF was Thérèse Brady who was the Director of the Master’s Programme in Clinical Psychology at University College Dublin when Dr Redmond asked her to help set up a bereavement support service.

She did so willingly and helped groups throughout the country to do the same. She trained those who provided the service and she started Heber, an alliance of bereavement counselling services. Thérèse was one of the founders of St Francis Hospice in Raheny and she joined both the St Francis board and the board of the IHF. She also initiated the IHF’s education and training work and its library.

In her tribute at Thérèse’s funeral Mass in 1999, Dr Redmond described her as “the jewel and not only the jewel but also the crown of the Irish Hospice Foundation.”

While the IHF began with certain specific objectives, mainly in relation to funding for Our Lady’s Hospice in Harold’s Cross, it soon took on a broader goal and set about raising money for a new hospice on Dublin’s northside. The result was that St Francis Hospice in Raheny launched a home care

service in 1989 and opened its doors as an inpatient unit in 1996.

CHANGING ROLE

This event marked a strategic shift for the Foundation. With the new hospice in place, “we looked at our own identity,” said Dr Redmond. “What were we going to be?”

The choice was to run a hospice or to take a broader strategic role. The decision was to turn the ownership of St Francis over to an independent board and to take a strategic role within the hospice movement. “We had more strategic work to do,” said Dr Redmond. “Hospice was at a stage where leadership was very necessary.”

That role manifested itself in the approach the IHF has taken since then: to identify areas of need and then offer strategic leadership and funding leading to the launch of independent services. In this way, the IHF has established itself as a pioneer.

But its greatest achievement, as Dr Redmond sees it, lay in stimulating the development of a “social movement”, a groundswell of energy which saw people in local communities creating hospice services for their relatives, neighbours and friends. “That groundswell is really what got the hospices going all over Ireland,” she believes.



George Byrne who was one of the first staff to join the IHF



Fundraising

For the IHF to set out, as it did, to raise the bulk of the £2 million cost of an Education and Research Centre at Our Lady's Hospice, Harold's Cross, was daring, almost audacious, in the late 1980s.



Padraig O hUiginn, Dermot Desmond, John Magnier and J.P McManus - winners of the inaugural Hospice golf classic in 1988 at the Grange Golf Club.

The economy was in poor shape and money was scarce at the time. Yet not only did the IHF raise the promised funds for Our Lady's Hospice but within a couple of years it had embarked on a new venture which would require another massive fundraising exercise: the provision of a hospice in Raheny to serve Dublin's northside.

Much of the credit for the success of the earlier fundraising exercise is due to people such as Lawrence Crowley, who chaired the Finance Committee, Susan Magnier, Margaret Heffernan, Norma and Michael Smurfit and Oona Linehan.

"It wasn't all an easy ride," said George Byrne. "The end of the 1980s were not prosperous times."

"We were very lucky that Margaret Heffernan was drafted in," recalls Board member Professor Antoin Murphy. "She was a real hero in the early stages."

Though the committee members were well-known figures in Irish society and business,

raising the money was no simple matter.

But instead of losing heart, the fundraisers threw themselves into the work with an array of projects and events which enabled the IHF to meet the tough goals it had set itself. Without that work, the IHF would not exist today, nor would those services for which it has provided essential financial support.

Ireland's Biggest Coffee Morning was the brainchild of indefatigable Oona Linehan. Meanwhile, Abbey actor John Kavanagh has recorded the voice-over for the radio advertisement for *Sunflower Days* over many years.

EARLY PROJECTS

Among the special projects which helped raise money were the sale of a portfolio of prints by Louis Le Brocqy and prints of flowers by Patricia Jorgensen, the auctioning of an MG sports car and a print of the Phoenix Park racecourse by Peter Curling. A major fundraising drive was built around the Champion Stakes in the Phoenix Park.



An early fundraising venture - the sale of vintage MG cars

The bicycle on which Stephen Roche won the Tour de France in 1987 was auctioned by the IHF not once but several times as a number of the buyers re-donated it. Roche quipped

Marie Donnelly

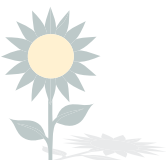


Marie Donnelly is one of Ireland's most innovative and successful fundraisers who has led ambitious fundraising projects for the IHF.

As Chairperson of the IHF, Marie Donnelly spearheaded a number of projects including *The Whoseday Book* which raised €2.5 million for the charity in Ireland. Within a few years, she had overseen *Art: pack* and *Peter & The Wolf* which once again harnessed the goodwill of the artistic community, caught the imagination of the public in Ireland and overseas and raised significant funds for hospice services at home and overseas.

later that the IHF made more money out of his victory than he did.

In what Dr Redmond described as a "magnificent" gesture in 1988, Dr Michael Smurfit pledged to donate the difference between what was raised by the IHF and the target it had set itself. That donation provided the initial capital for the planned St Francis Hospice in Raheny.



NATIONAL FUNDRAISING

A series of New Year's Eve dances in the Powerscourt Centre in Dublin proved successful. A host of other events including fashion shows, pub evenings, a wine auction and golf outings, kept the money flowing in during the early years.

Sunflower Days and *Ireland's Biggest Coffee Morning*, which were organised from the early 1990s, have grown to become among the best-known and well-supported national events which bring in substantial funding for local hospice services around the country every year.

These two events provide a good example of the synergy which exists between the IHF and the local hospice groups. The IHF sources materials such as sunflower pins (more than 345,000 of them!) and 25,000 packets of coffee (kindly donated by Bewleys over the past 13 years) for the local groups which organise the fundraising events in their own



The launch of the 2006 Sunflower Days

areas. The IHF organises publicity campaigns around the events. In the case of Hospice *Sunflower Days* the cost of advertising and publicity has been sponsored by Tayto since 2005.

The principle behind these national fundraising events is that "all money raised locally stays locally". That principle has enabled the IHF to be a valuable source of support to local groups. Meanwhile, a myriad of fundraising events, organised by local committees, take place throughout the country all year round to support home care and other services.

In addition to *Sunflower Days* and *Ireland's Biggest Coffee Morning* events, the IHF itself engages in a number of ongoing fundraising activities, among them mail-shots, the sale of sympathy cards and Christmas cards and sponsored participation in the Evening Herald Women's Mini Marathon and Dublin City Marathon.

SPECIAL PROJECTS

Every two to three years, the IHF also runs a special project to bring in a substantial amount of money. Indeed, these groundbreaking ventures have become a signature of the IHF.

The best known example is the Christmas bestseller *The Whoseday Book*, which was published as a millennium diary for the year 2000. It featured an introduction from Nobel Laureate Seamus Heaney and contributions from writers, philosophers, politicians and other prominent figures in Irish public life.

Based on an idea by journalist John Waters and developed by Marie Donnelly, *The Whoseday Book* brought in €2.5 million. The originals of the artwork which featured in the book were bought up by AIB and donated to the National Library of Ireland. It certainly caught the public imagination with people queuing for hours to get pages from the various contributions autographed during a public signing in the RDS.

Marie Donnelly's genius for fundraising on a large scale also resulted in *Art:pack* and *Peter*

Fundraising



John Waters



Celebrated columnist, author and playwright, John Waters, has been centrally involved in some of the IHF's most successful projects.

He conceived the idea for both the best-selling *Whoseday Book* and the non-denominational *Soláis* sympathy cards which are sold by the IHF.

Gavin Friday



Singer, composer and painter Gavin Friday has brought his artistic genius to the IHF's fundraising efforts.

Gavin collaborated with his musical partner Maurice Seezer to adapt *Peter & The Wolf* which he also performed. Gavin designed one of the jokers in *Art:pack* and later devised *Muc* to support the development of hospice care for sick children in Ireland.



Fundraising



Viewing the Peter & The Wolf exhibition.

& *The Wolf* projects.

The Art:pack was launched in 2001. This was a deck of 54 playing cards featuring original work from a number of artists including Robert Ballagh, Matthew Barney, Basil Blackshaw, Felim Egan, Guggi, Anne Madden, Patrick Scott and Sean Scully. Bono and Gavin Friday created the jokers in the pack. It was essentially an art gallery in the palm of your hand.

At a public signing in the Four Seasons Hotel, the queue of people extended to the car park for most of the day. The originals were donated by the artists and were auctioned in April 2002 by Christie's in the Royal Hibernian Academy in Dublin. For the first time for the IHF, the product was sold internationally via the internet. *Art:pack* brought in €550,000 for the IHF.

The year 2003 saw another unique venture. This time it was the first Irish adaptation of Sergei Prokofiev's *Peter & The Wolf*. The production was performed by Gavin Friday and the Friday Seezer Ensemble.

A box set was produced which contained an enhanced CD and book with illustrations by Bono with his daughters Jordan and Eve. This pack was the bestselling children's book for weeks and has been published in editions in several countries. The original artwork by

Bono, some featuring canvases as large as 20ft long, were brought on a three country tour. His works were put on display in the city hall in Dublin and Christie's in London, Los Angeles and New York before being auctioned in New York. Prokofiev's grandchildren attended the London launch. The entire venture raised €850,000 for the IHF.

ANNUAL EVENTS

Among the annual events one that is worthy of particular mention is the Howth Walk, organised every year since 1989 by lady golfers from clubs throughout Dublin. The sponsored walk to Howth Head is organised by an enthusiastic volunteer committee under Chairperson Joan Wylde and raises substantial funds for the Children's Oncology Nursing Liaison Service at Our Lady's Hospital for Sick Children in Dublin. Indeed, a total of €480,000 has been raised for services for children.

In 2003, the IHF was chosen by Royal & Sun Alliance Insurance as one of the selected

organisations to benefit from its *Give As You Earn* initiative. Other organisations whose employees have contributed through salary deductions include FÁS, Independent Newspapers, Irish Distillers, Irish Motor Distributors, the Communications Workers' Union and SAP Ireland.

In 2005, Hospice was chosen by Tesco as its *Charity of the Year*. An estimated 12,000 staff organised or took part in over 2,000 fundraising events which in turn were supported by Tesco customers. All money raised locally stayed locally. Some €1.5 million was raised for Hospice representing the largest sum ever raised under the company's *Charity of the Year* programme.



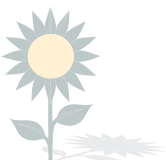
Muc in for Hospice was a fundraising initiative which involved young people raising funds for sick children.



Mark Cagney and Claire Byrne of TV3 announce that €1.5 million was donated by Tesco staff and customers for hospice care under *Charity of the Year* programme.

The Muc in for Hospice initiative was again the brainchild of Gavin Friday and artist Laurent Mellet. Travellers at Dublin airport would have been familiar with *Muc* as it was the 12-foot high, 8-foot wide flying pig which stood outside the terminal building for a number of years. It became the emblem of a fundraising venture aimed at supporting the development of Hospice care for sick children in Ireland.

Muc in for Hospice involved a series of events nationwide, targeting every sector of the community. Schools and children were particularly encouraged to participate and

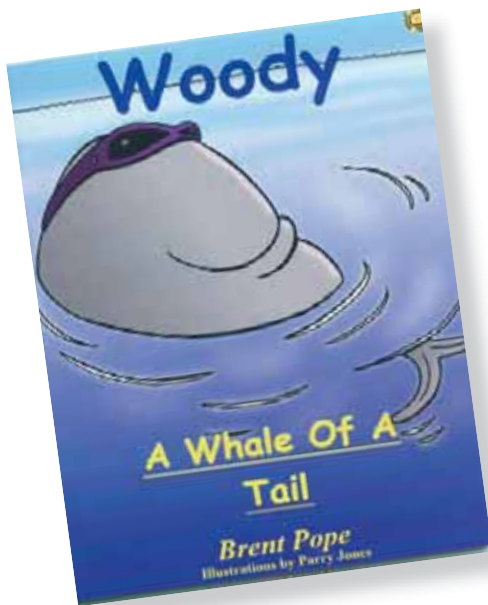


Fundraising



four primary schools won the prize. Secondary school students took part in a sponsored 'Mobile Phone Switch-off' as well as a 'No Homework Day'.

Children's hospice home care also benefited from the sale in 2004 of *Woody* - a children's book written by New Zealand-born rugby player, coach and TV commentator, Brent Pope, and colourfully illustrated by his artist friend, Parry Jones.



The Woody book by Brent Pope

The book tells the story of Woody the Whale, who stays out in the sun too long and enlists the help of his friends, the children, to help him deal with his sunburn. The characters are loosely based on the Irish rugby team.

Funds raised by the IHF go to predominantly Irish services. However, the IHF has contributed to the work of The Chernobyl Children's Project as part of its commitment to a hospice service for children and it has contributed towards the cost of hospice care in South Africa and to the work of organisations such as Trócaire in recognition of the fact that

some of the funding raised, especially through projects such as *Art:pack* and *Peter & The Wolf*, came from abroad.



The four politicians who took part in the *Charity You're A Star* competition to raise funds for the IHF.



Colombian dancers celebrate the start of the 2006 nationwide *Ireland's Biggest Coffee Morning* event.



Leading golfer Christy O'Connor Jnr. presents awards to the winners of the inaugural *Nearest the Pin* competition to mark World Hospice and Palliative Care Day in 2005.



A youngster attends the *Art:pack* signing.



The Tánaiste and Taoiseach joined Marian Finucane for the 2004 *Ireland's Biggest Coffee Morning*.



Home Care

The concept of hospice as a bricks and mortar building in which people spend their final days has long been seen by the hospice movement itself as too limited.

The reality is that throughout a person's contact with a hospice service only a relatively small proportion of time might be spent in the hospice itself.



Hospice care is person-centred.

Almost everybody prefers to be at home during a serious illness and most people prefer to die at home. A national survey conducted by the IHF in November 2004 found that 67% of Irish people want to die at home and only 10% would wish to die in a hospital. Some 62% of respondents over 65 years would prefer to be cared for at home when they are dying.

The hospice movement, for two decades now, has placed home care at the heart of its service. This allows the dying person to live at home while the home care team provides whatever help is needed. The person only goes into a hospice for intervals for pain control or other treatment best given in that setting.

From the start, the Board of the IHF was anxious to see home care more widely available for both adults and children. The IHF made a point of encouraging local groups to establish home care teams in their own areas.

"When I was invited to different groups I used to say, 'You can do it'," Dr Redmond recalled.

"It's not impossible. It's people who stimulate the change. That was my message."

This encouragement was taken up by groups all over the country. Within a relatively short space of time every county had a home care team - a remarkable tribute to the commitment and energy of local communities. The Irish Cancer Society (ICS) was also crucial to this development for which it provided funds through its Daffodil Day collection.

The first initiative in home care was taken in 1985 by Our Lady's Hospice and the ICS when the Society funded the service launched by Sister Francis Rose O'Flynn and Sister Ignatius Phelan. Within a few years, Cork, Limerick and Carlow/Kilkenny also had home care services.

The IHF supported a fledgling home care team on the northside of Dublin in 1989, a precursor to what was to become St. Francis Hospice.

Nationally the IHF supported the development of home care services, especially in the late 1980s and early 1990s by supporting many local groups to raise money for their home care services. It also funded the first liaison nurse for Our Lady's Hospital for Sick Children, Crumlin.



The vast majority of people want to be cared for at home.

Dr Tony O'Brien



Dr Tony O'Brien is the Chairperson of the National Council for Specialist Palliative Care which was set up in November 2005 by the Minister for Health and Children.

The role of the National Council is to examine, monitor and make recommendations on the development and implementation of national policy on palliative care services for adults and children in Ireland. It meets three times a year and prepares an annual report for the Minister.

Dr O'Brien is the Medical Director of Marymount Hospice and Consultant Physician in Palliative Medicine at Cork University Hospital. He served as Chairperson of the National Advisory Committee on Palliative Care which prepared a report on the future development of palliative care services in Ireland. The recommendations of this report were formally adopted as government policy in October 2001.



Home Care



NATIONAL PICTURE ON HOMECARE

There is a significant body of work to be done to ensure equity of access to services throughout the country.

One of the most significant reports on hospice care in Ireland - the 2001 Report of the National Advisory Committee on Palliative Care (NACPC) - called for more investment in home care. The IHF was represented on the National Advisory Committee by its then CEO, Louise Richardson. This report provided a blueprint for the development of hospice services in Ireland and was adopted as Government policy.

An IHF report entitled *A Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland* was launched in March 2006 and measured progress in implementing the NACPC report since 2001.



John Healy of The Atlantic Philanthropies, the Minister for Health and Children Mary Harney and IHF Chief Executive Officer Eugene Murray at the launch of the Baseline Study.

It showed that significant progress has been made in almost all areas in the provision of specialist palliative care nurses in the community. By 2004, there were 22 home care teams nationwide, employing 150 specialist palliative care nurses. In 2004, care was provided to over 6,000 patients through more than 90,000 home visits.

However, there is still a dependence on voluntary contributions for one-third of

home care staff costs, in spite of government commitments to fully fund core staff. Some areas are 100% funded by the State while other parts of the country are 100% reliant on voluntary donations to keep this vital service going.

There is also wide variance in home care service delivery with only two of the 22 home care services being available for 24 hours over seven days - most services are operational for eight hours over five days.

The report also found that few home care teams were consultant-led and multi disciplinary and there was still a very low level of service delivery to non-cancer patients.

CHILDREN

A report entitled *"A Palliative Care Needs Assessment for Children"* - a collaborative project undertaken jointly between the Department of Health and Children and the IHF which was launched in September 2005 - found that home was the preferred location of care. However the services to support care at home were deemed inadequate by many families. A major source of stress for families was the difficulty encountered in accessing essential aids, appliances and equipment for their child.

It was recognised that parents caring at home needed substantial support from professional health and social care networks to help them provide home-based care.



Funds raised from national events such as *Sunflower Days* each year support hospice services including home care.

World Health Organisation's definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.



Inpatient Hospice Care

INPATIENT UNITS

When the IHF was formally launched in 1986, there were only three hospice services in the country. These were Marymount Hospice, part of St Patrick's Hospital in Cork; Our Lady's Hospice in Harold's Cross, Dublin and Milford Hospice in Limerick. The first two were established by the Irish Sisters of Charity and the Milford Hospice was set up by the Little Company of Mary.

St Francis Hospice in Raheny was an early and important project. It was made possible by a donation of land in Raheny by the Capuchin Fathers combined with the support of Bishop Dermot O'Mahony, the enthusiasm of the Daughters of Charity and a donation from the industrialist Michael Smurfit.

A telephone call from Dr Hugh Raftery, an anaesthetist at St Anne's cancer hospital in Dublin, had led to the vital link between the IHF and the Daughters of Charity. The Congregation, which ran St Anne's, foresaw that the hospital would eventually merge with the larger St Luke's and was anxious to become involved in hospice care.



Dr Mary Redmond and Aisling Kilroy of the IHF at the site of the new hospice.

Despite the generous donations of land, money and energy the St Francis project was a daring one for the late 1980s when the country was on its knees economically and there was no real expectation of the boom which was to come in the mid-1990s.



Norma Smurfit, Phil Purcell and Margaret Heffernan who were early fundraisers for the IHF.

ST FRANCIS HOSPICE

The new hospice service for the northside of Dublin began by providing support for a home care service which began its operation from a portacabin.

"It was in mid December 1988 that a portacabin weighing many tonnes was raised high in the sky above houses, trees and monastery and dropped gently in the yard next to the Capuchin friary," Dr Mary Redmond recalls of this event. The home care service was launched from this portacabin the following September.

The first board meeting of St Francis Hospice was held in January 1990 with the late Justice Mella Carroll in the chair.

The IHF raised £1.75 million for St Francis hospice and the community contributed more than £2 million. A total of £4 million was raised which allowed a new building and day care centre to be opened in 1995. On 1st February 1986, Minister for Health, Michael Noonan T.D., opened the 19-bed inpatient unit at St Francis Hospice.

HIV/AIDS

When the idea for a northside hospice was being discussed, the rising problem of HIV and

AIDS was very much in the public mind. There was considerable hysteria about AIDS patients, which meant many of those with AIDS died without the support of friends or neighbours.

The IHF responded to the special needs of AIDS patients. When St Francis Hospice was still at the planning stage, it was decided that it would help people with AIDS. The IHF also provided funding for four beds for AIDS patients in Our Lady's Hospice, Harold's Cross. A similar unit was funded in Portlaoise General Hospital which included the provision of training in HIV nursing. The IHF also contributed towards the cost of research into palliative care for HIV patients.

OTHER GENERAL DEVELOPMENTS

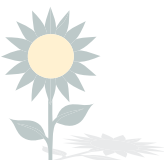
Today the general situation is radically different both in terms of inpatient hospice care and of palliative care given in the home. This development has been the result of the funding support given by the IHF and primarily from the energy and hard work from local communities.



The infamous portacabin being hoisted onto the land at Raheny. From this structure grew St Francis Hospice.

Since 1986, the landscape in terms of inpatient hospice care has advanced throughout the country.

In Connacht, Galway Hospice opened in 1997 as an inpatient unit though the Galway Hospice Foundation began by launching a home care service. The North West Hospice, which was



Inpatient Hospice Care



providing a home care service from 1989, opened an eight-bed unit on the site of Sligo General Hospital in 1998.

The Letterkenny Hospice opened in 2003 as a project of the Donegal Hospice and the North Western Health Board.

Our Lady's Hospice opened a palliative care unit in Blackrock, Co Dublin in 2004.

BASELINE STUDY

Despite these significant developments, the IHF report *A Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland* found that a major body of work needed to be done to redress the deficits in hospice care.

At December 2004 there were eight specialist palliative care inpatient units dispersed across the 10 former health board areas of Ireland. These units provided care for 1,499 patients during 2004. But to ensure that everyone can have access to the service when needed, there should be at least one inpatient unit in each former health board area.

In 2004, seven health board areas had inpatient units but the remaining three (the Midlands, the North-East and the South-East), covering 12 counties, had none.

Even those health board areas with existing inpatient units were experiencing hospice bed deficits. Ireland should have a national total of 390 hospice inpatient beds. In December 2004, there were 131 inpatient hospice beds, a deficit of 259.

Several counties in areas which have inpatient units in neighbouring counties have an identified need for satellite units.

REGIONAL DEVELOPMENT

The IHF is now piloting two posts of Regional Development Officer to work with local voluntary hospice groups and statutory bodies to help advance service development in areas where no hospice inpatient units exist.

IHF Ethics Committee (Members from 1986)

Rev. Dr P Bastable,
Mr. James Nugent
Sr. Francis Rose
Ms Ellen Rice
Miss Kathleen Maher
Dr Mary Redmond
Dr Teresa Iglesias
Prof. Enda McDonagh
Dr Vivian O'Gorman
Prof. Niall O'Higgins
Dr A Walsh
Dr Ivor Drury



The Taoiseach Bertie Ahern with Ms Mella Carroll - the former High Court judge and first Chairperson of the board of St Francis Hospice - who died in January 2006.



Iris Murray, the longest serving member of staff of the IHF.

St Francis Hospice in North-West Dublin



The site of the proposed hospice in Blanchardstown.

Some 10 years after opening the 19-bed inpatient unit in Raheny, St Francis Hospice has launched an ambitious project to open a new hospice on a three-acre site within the Abbotstown Estate at Dublin 15 to meet the needs of the people of North-West Dublin.

The project will initially involve the development of a base for its Home Care Team which is currently operating in the area and the building of a Hospice Day Care Centre, so that patients will not have to travel as far as Raheny. This major development will be complete with the provision of a 24-bed inpatient unit.

A design team has been appointed by the Board of Directors of the Hospice and it is hoped that building works will commence in early Summer of 2007.

A project to pilot Minimum Data Sets (MDS) for palliative care is now in place. This project is based on the MDS research report prepared by Dr Catherine Sweeney of St Patrick's Hospital/ Marymount Hospice in Cork. This project, where information is collected in a systematic way, is being piloted with six hospices and hospital-based palliative care services.



Hospice Friendly Hospitals

Most of us want to die at home but we will die in hospital unless trends change significantly. In fact, almost two thirds or 66% of deaths in this country occur in a hospital or other institution.

Dr Michael Kearney



Dr Michael Kearney was the first Consultant in Palliative Medicine appointed in Ireland. He was Medical Director of Our Lady's Hospice in Harold's Cross from 1989 and held a joint position with Our Lady's and St Vincent's Hospital in Dublin from 1991.

He trained at St. Christopher's Hospice, London and St. Thomas' Hospital, London, and has worked as a specialist in palliative medicine for over twenty years.

He is currently based in Santa Barbara, California, where he works as visiting professor at the Santa Barbara Graduate Institute and at Santa Barbara Cottage Hospital, where he is helping to establish a hospital-based palliative care service.

According to a 2004 survey, the three most important things for Irish people when they are dying are:

1. To be surrounded by people they love;
2. To be free from pain;
3. To be conscious and able to communicate.

Therefore, spreading the hospice philosophy and practices into the general hospital setting is a service of immense value to dying people and their families.

Such experiences as being handed a loved one's clothes in a plastic bag within an hour of the death can bring back distressing memories for years into the future.

Strangely, the person who is dying, and his or her family, can be "out of place" in an acute hospital, which is geared entirely to treatment and cure.

PALLIATIVE CARE TEAMS IN HOSPITALS

The establishment of hospital-based palliative care teams is fundamental to addressing this situation. These teams act as a source of advice, support and information for those doctors, nurses and paramedics who are involved in the care of the dying patient. They do not take over the direct care of the patient but help those who are already providing that care.

There are now 28 such teams and the IHF has been involved in funding a number of them. This funding is generally in the form of start-up financing to pay for the salaries of palliative care nurses.

ST. JAMES'S INITIATIVE

The IHF's first substantial involvement with general hospitals came in 1995 when it approached St James's Hospital in Dublin with a proposal to launch a palliative care service within its acute hospital setting. The IHF funded the salaries of two palliative care nurses until State funding was provided some years later. Funding for a palliative care consultant was provided by the Department of Health and Dr Liam Ó Sioráin was appointed to this post.

The IHF also funded palliative care nurses at St Vincent's University Hospital, Beaumont Hospital and St Lukes Hospital in Dublin and Cork University Hospital. Funding for palliative care nurses in these hospitals was later

Findings of Survey

The first-ever national survey on death and dying was released in November 2004. The survey was conducted by Weafer and Associates Research, with TNSmrb. It was commissioned by the IHF and supported by the Health Services National Partnership Forum. It found:

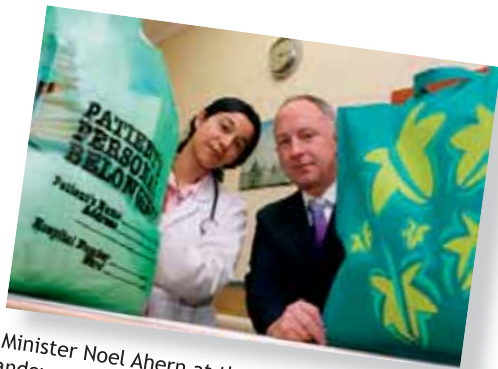
- Over 80% believe hospital care for people who are dying or terminally ill needs improvement.
- Nearly 40% believe it needs urgent or considerable improvement.
- 67% want to be cared for at home if they are dying.
- Only 10% would wish to die in a hospital.
- 86% of Irish people have not told anyone where they would like to be treated, if dying.
- 40% of people felt they would be "completely or very comfortable" discussing death and dying.
- 51% of people felt there is not enough discussion of death.



The IHF's Care for People Dying in Hospitals pilot project has won two awards. The IHF's Mervyn Taylor (far left back row) and Dr Doimínic O'Brannagáin of Our Lady of Lourdes Hospital in Drogheda (far right back row) attend the 2006 public sector awards ceremony.



Hospice Friendly Hospitals



Minister Noel Ahern at the launch of the Family Handover Bag which allows the sensitive hand-over of a person's belongings to their loved ones.

taken over by the Department of Health and Children.

The IHF has also funded a Clinical Nurse Specialist in Palliative Care for Our Lady's Hospital for Sick Children, Crumlin. This nurse works closely with the consultant in Palliative Medicine and has under her care children who have been diagnosed with various life-threatening illnesses including cancer.

RESEARCH IN 1999

In 1999, a key piece of research on relatives' experience of the quality of care during the last year of life at St James's Hospital was published. The project had been proposed by Thérèse Brady, director of the IHF's bereavement services.

The study was conducted by the Health Services Research Centre at the Royal College of Surgeons in Ireland on behalf of the IHF and with the full participation of the Palliative Care Service at St James's. It was entitled: *Care for the dying - experiences and challenges: A study of quality of health service care during the last year of life of patients at Saint James's Hospital, Dublin, from their relatives' perspective.*

The main findings of the 1999 study in St James's hospital included:

- Relatives felt that their loved one had a 'good death' and had been prepared for death.
- Most relatives were satisfied with the location of death but almost half believed their loved one would have preferred to die at home.
- Many relatives were unhappy at the way their loved ones had been told they had a terminal illness. Problems arising included telling people when they were alone, being too direct, removing hope or appearing insensitive.
- Having a private room at the time of death was considered important by relatives.
- Most patients who had palliative care were seen as having a choice regarding treatments while only a minority of those who did not have palliative care were seen as having a choice.
- Hospital doctors were rated as the most informative of all the people relatives spoke to about the illness. Nevertheless, most relatives would like to have been given more information sooner.
- One third of relatives felt they were not kept in touch with by hospital staff and 36% rated communication as fair or poor.
- Reducing family distress and controlling symptoms were the areas where relatives felt the palliative care service made a big difference.
- The palliative care service was rated as excellent by 75% of those who identified the palliative care input and as good by 23%.
- Long delays at A&E departments were especially criticised as making the hospital experience worse during the last year of life.

CARE FOR PEOPLE DYING IN HOSPITALS

Building on this work, the IHF launched its

Innovations

A number of innovative measures were introduced by the project in Drogheda:

- The process of invoicing bereaved relatives was delayed to allow for staff sympathy cards to be sent to families.
- A Family Handover Bag was designed to replace the practice of returning a deceased person's belongings in a plastic bag and is now in use in a range of hospitals in Ireland and has generated interest in the UK and Australia.
- The experiences in developing the process of change in Drogheda inspired the first national conference in care for people dying in hospitals in May 2005.

Care for People Dying in Hospitals pilot project in 2004. It aimed to determine how the principles of best practice in hospice care might be extended to the general hospital setting.

The project was located for two years at Our Lady of Lourdes Hospital, Drogheda, Co Louth, and represented an important development of the IHF's earlier work with acute hospitals. It indicated that a national programme was needed and much was learned.

In May 2005, the IHF held a national conference on conditions for people dying in hospital. The conference heard that, in Irish hospitals, there was often no private space for patients and families on public wards. There was often no dedicated room for dying patients which can cause distress to the dying person, their family and other patients and there are few facilities for families to talk in private.

As CEO of the IHF, Eugene Murray, told the conference: "Our own public opinion surveys



Hospice Friendly Hospitals

show that over 80% of Irish people do not want to die in hospital, and we need to ask why.” “Every hospital needs to give priority to the needs of the dying and their families, as well as those of staff and health managers. This must be done urgently.”

The *Care for People Dying in Hospitals* Project won the Best Hospital Project at The Irish Healthcare Pharmaceutical Awards 2005. Most significantly, it was also chosen as one of three projects to represent Ireland at the 4th Quality Conference for Public Administrations in the EU (2006). The conference showcases the best examples of excellence and innovation across the European public sector.



The Ombudsman Emily O'Reilly attended one of the strategic workshops organised as part of the planning process for the Hospice Friendly Hospitals programme.

HOSPICE FRIENDLY HOSPITALS PROGRAMME

During 2006, The Atlantic Philanthropies supported the IHF in using the learning from the pilot project to inform the planning and development of a national programme. The IHF has now launched a national *Hospice Friendly Hospital* programme to mainstream hospice principles in hospital practice. It will focus on four key themes generated from the project: integrated care, communications, dignity and design and patient autonomy.

A series of strategy workshops and consultations were organised to consider issues

relating to each of these themes and a public call for “Expressions of Interest” in taking part in the programme resulted in submissions covering half of the country’s acute hospitals with emergency facilities. Interest has also been expressed by significant groupings of community hospitals and facilities for older people.

Development co-ordinators are to be employed to develop the capacity of the hospitals to improve services and standards. Training in communications skills will be organised.

Information, awareness and education strategies are also to be developed around patient autonomy and end-of-life issues. Finally, specialist advice and capital grants will be provided to improve facilities and enhance dignity.

A new training DVD entitled ‘Breaking Bad News - Communicating in Difficult Circumstances’, was launched in September 2006 in a bid to improve the skills of healthcare personnel in communicating bad news to patients.

The DVD was developed with significant support from the Health Services National Partnership Forum (HSNPF) which contributed to the cost of producing the film. The film is dedicated to the memory of Sarah Davis and the Sarah Davis Memorial Trust provided support for the distribution of the film as its last act of funding before the Trust was wound up.

The DVD will be used from early 2007 as part of the compulsory training process which is organised by the Northern Ireland Medical and Dental Authority for doctors in the first two years after their graduation.

The Hospice Friendly Hospitals programme will be undertaken in two phases over a five year period in a creative partnership with the HSE and a range of public service and academic organisations.

Crucial to its success will be the development within the first three years of a comprehensive

framework of standards regarding dying, death and bereavement for all hospitals.

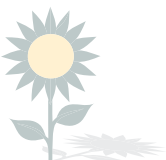
A new website has been developed at www.hospicefriendlyhospitals.net with information on the programme.

The IHF has also supported other projects concerned with hospital care at the end of life including a project based in St Vincent’s Hospital in Dublin which is seeking to establish a consistent standard of care for dying patients, based on a “care pathways” system developed in Liverpool.

Developments in Drogheda

Other outcomes of the project in Drogheda include:

- A permanent Standing Committee on Dying, Death & Bereavement being set up in the North Eastern Area Hospitals Network.
- A pioneering set of publications devised which other hospitals can adapt.
- An Advisory Committee on clinical care for people dying in hospitals being established to standardise practices and care levels across the hospital focusing on physical, social, psychological dimensions of care.
- An Educational Awareness Programme which was delivered to front-line staff within the hospital resulted in 96% of participants stating their practice in caring for patients who are dying would change as a result.
- A detailed plan to develop a series of multi-functional rooms throughout the hospital to create greater privacy for the patient/family meeting with medical staff and rest breaks for overnight carers.



Bereavement Services



GRIEVING

From its earliest days, the IHF was concerned about the plight of the bereaved. All too often, bereaved people suffer social isolation as they are avoided by people who do not know what to say or are fearful of saying the wrong thing.

As a result, the bereaved person may have less contact with acquaintances, relatives and friends following the death of a loved one than he or she had before. The emotional distress of this can add to their pain.



Joe Duffy and Patrick Riordan highlight the series of leaflets on bereavement which have been supported by BUPA Ireland and Johnson and Johnson.

Indeed, studies have shown that those who experience a lack of support following a bereavement are at an increased risk of developing both physical and psychological problems.

In 1985, Dr Mary Redmond approached Thérèse Brady, Director of the Master's Programme in Clinical Psychology at University College Dublin, to see what could be done about this.

VOLUNTEER SUPPORT SERVICES

Ms Brady reacted with the energetic generosity which was typical of her and undertook to set up a volunteer bereavement service. It was to be based at Our Lady's Hospice, Harold's Cross and the idea had the support of the Sisters there.

She visited St Joseph's Hospice in London to study the volunteer counselling service provided there in preparation for the establishment of the Irish service.

The first committee set up to organise the service was chaired by Thérèse Brady herself. The other members were Sister Teresa Avila, Sister Laboure, Dr Veronie Hanly (all of Our Lady's Hospice) and Rev Myles O'Reilly SJ, Tabor House.

In 1986, nine people undertook a 10-week training course and the service began the following year.

When St Francis Hospice was set up in Raheny, bereavement support was one of the first services established there. Before long, the training programme was expanded to one year and since that time many thousands of people have been helped by the bereavement service. People who did the training course also set up bereavement services in other parts of the country.

THÉRÈSE BRADY INFLUENCE

Thérèse Brady helped with this work too, travelling all over Ireland to address local groups as well as running the bereavement service for the IHF and doing her job in UCD.



Dr Jerusha Hull McCormack whose book on bereavement *Grieving: a Beginner's Guide* was launched in the IHF's offices in 2006.

Joint IHF/ICI College Bursaries



St Francis Hospice bereavement support volunteers Mary Byrne of Clontarf (right) and Bernadette Farrington of Raheny were presented with joint bursaries by the IHF and PCI College in May 2006.

The two students were nominated through a selection process and passed the PCI College application requirements and interview process.

Together, the bursaries are worth almost €25,000. Each bursary covers tuition fees for all four years of the BSc in Counselling and Psychotherapy degree programme with PCI College as well as the registration fee with Middlesex University who validate the programme.

Ms Brady put psychology at the service of those in need. Psychology, to her, was no abstract academic exercise but a means of helping people. As fellow-psychologist Tony Bates wrote in an appreciation in *The Irish Times* following her death in 1999, "She made space for the humanity in others to grow, even when it became obscured by their severe mental suffering."

The importance of this service can be appreciated when one considers the extent of the loss suffered by the bereaved. Where a person has died from a life-limiting illness,



Bereavement Services

carers will have devoted anything from weeks to years to caring for that person. Even when a person is in a hospice or hospital, it is not unusual for the carer to visit every day, in some cases spending several hours there on each visit.

When the loved one dies, the carer loses the person around whom he or she has organised time, a routine, energy and even a career. The visits to a hospice, hospital or nursing home have become part of that person's life. The carer will have made friends with other people there and with the staff. All this is lost when the loved one dies.

This explains the importance of the

bereavement service. *"I have seen a number of bereaved people at our service who might well have ended up attending a psychiatric service in the absence of the support given by the Hospice Foundation Volunteer Service,"* Ms. Brady wrote in 1990. (Report to the Board, December 1990).

The mainstay of the service was the monthly meeting for bereaved people. People chose from three such meetings each month.

"It is the only time I can talk for myself without feeling guilty," said one young widow of these meetings. *"I know that when I go there I can be exactly as I feel. If I still want to talk about Michael's death, no one will*

get bored and tell me I should be over it by now. If I want to laugh, I know that no one will consider this strange and wonder whether I have forgotten Michael or didn't really care for him after all. I return home with a sense of relief, secure in the knowledge that I am normal." (Report on the Volunteer Bereavement Counselling Service, Our Lady's Hospice, Harold's Cross, for 1993).

Volunteer bereavement services are now organised independently at Our Lady's Hospice and St Francis Hospice in Dublin.

WORKSHOPS ON LOSS

Quite apart from the training course for

Thérèse Brady



Before she turned her attention towards setting up a bereavement service for hospice, Thérèse Brady was already an established and powerful resource to psychology - she was a founding member of the Psychological Society of Ireland and the Director of Postgraduate Training in Clinical Psychology at UCD. Thérèse's initial involvement with the IHF was based in her early conversations with Dr Mary

Redmond, in their shared understanding of the hospice movement and in Thérèse's large capacity for care.

As Honorary Director of Bereavement Services at the IHF, during 1986 Thérèse set about filling her 'spare time' - convening a Bereavement Support Service Committee at Our Lady's Hospice, Harold's Cross, to oversee the development of the country's first 'Bereavement Support Service'.

The service was explicitly aimed at providing support rather than professional counselling and comprised a thorough and rigorous procedure for the recruitment, training and supervision of bereavement support volunteers who offered their services through three sessions in each month.

The current shape and direction of the Education and Bereavement Resource Centre at the IHF is strongly rooted in Thérèse's vision - which included service, education and research. Thérèse held an immense respect for education and developed training programmes for professionals on all aspects of loss and bereavement. She eventually took up

the role of Chair of the IHF Research Committee and actively encouraged her own students to engage in research into bereavement. Underlying her actions was a conviction in the strength of the human spirit and optimism in the face of adversity. In her own words:

"Joy and suffering are two sides of the same coin. A pursuit of psychological well-being which rejects the legitimacy of distress and suffering fails to take account of the vital role which both play in stimulating growth and maturity and underestimates the resilience of human beings".

Dr Mary Redmond, in her tribute to Thérèse Brady, who died on January 29th 1999, gives an idea of the scale of gratitude extended.

"Thérèse.....you were and are and for me always will be the jewel and not only the jewel but also the crown of the Irish Hospice Foundation.....the tall tapers of your memory will glow always forever, gently and silently as you would wish. We will never forget you".



Bereavement Services



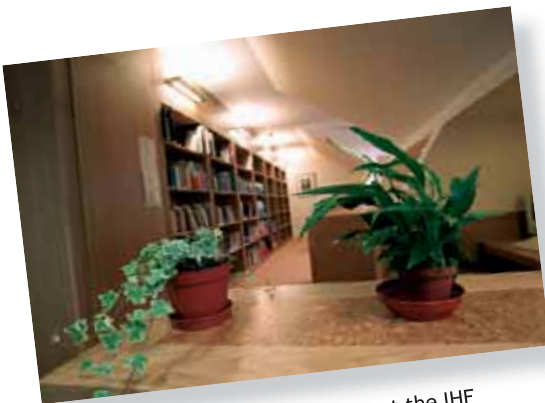
volunteers, the IHF also initiated workshops on loss and bereavement issues. These began in 1990 with six two-day workshops. Participants came from all parts of the country and included nurses, psychologists, social workers, hospital chaplains and pastoral care workers as well as non-professionals with a special interest in bereavement work.

In 1994, the IHF introduced a course to train people to work with bereaved children and adolescents.

The IHF's training courses are traditionally over-subscribed - an indication of the hunger there is for the information and skills which they provide.

Through this growth period Dr Howard Kunin was appointed Assistant Director of the bereavement service. He oversaw the integration of the bereavement support volunteers into the St Francis social work service and worked on developing plans for the IHF education and bereavement service.

The IHF continued to organise the bereavement support service at Our Lady's Hospice until 2003 when this function was transferred to Our Lady's social work department. "This separation is inevitably tinged with sadness, given our long and close relationship with the volunteers involved in the service," the annual report for 2002 notes.



The Thérèse Brady Library at the IHF



Dr Susan Delaney, the IHF's Bereavement Services Manager.

However, the move was in line with the IHF's policy of assisting others to develop services which eventually become independent.

EDUCATION & BEREAVEMENT RESOURCE CENTRE

The bereavement activities of the IHF are focused on supporting those who work with grieving people, ensuring the best services and information are available and promoting high quality education and research.

In 2003, the IHF launched its Education & Bereavement Resource Centre - the first dedicated information and training focal-point for bereavement in Ireland.

As the then CEO, Ms Jean Manahan, said at the launch: "...the new Centre will allow the Foundation to further develop its information, education and training services in the area of bereavement. A key focus will be the provision of training for those whose work brings them into contact with the bereaved: social workers, nurses, teachers, HR managers and hospice volunteers for example."

Bereavement Services Manager Dr Susan Delaney continues to train volunteers for St. Francis Hospice and some community groups. The IHF has published a series of leaflets aimed primarily at people who have been bereaved, along with additional

information material intended to be of use to bereavement support services in a start-up situation.

BEREAVEMENT CARE LIAISON OFFICER

A partnership project with the HSE South-Eastern Area got under way in January 2005 with the appointment of Brid Carroll as Bereavement Care Liaison Officer. This post is based in Waterford.

The project set out to investigate the availability of bereavement information, support and professional care in the area and to identify any training or other needs. By the end of the year, a comprehensive picture of bereavement care had been identified and initiatives developed to respond to these needs.



Denis Doherty, current Chairman of the IHF.



Education & Research

Education and research are cornerstones of the IHF. Influencing the wider education system is hugely important if the hospice philosophy and best practice are to be embedded in our health services.

The IHF has recognised this from the start: raising money for an Education and Research Centre at Our Lady's Hospice, Dublin was its earliest project.

Palliative medicine was recognised as a speciality in Ireland by the Medical Council in 1995. However, at the time of writing there is no academic department of palliative medicine in the medical schools.

THE THÉRÈSE BRADY LIBRARY

The education aspect of the IHF's work has blossomed in recent years and an education-friendly environment has been created at its offices in Nassau Street in Dublin. There, the education work benefits from the presence of the Thérèse Brady Library, which houses a comprehensive, well-maintained and growing body of work on loss and bereavement.

The library provides an information service for hospice and community-based professionals and volunteers and gathers together information for the general public. The collection is one of the primary sources of information in Ireland on all aspects of bereavement.



Celebrating the graduation of the Higher Diploma students in 2005.

Professor David Clark



In October 2005, it was announced that the internationally respected Professor David Clark from Lancaster University had been appointed as Visiting Professor of Hospice Studies in Ireland.

The Faculty of Health Sciences at Trinity College Dublin and the School of Medicine and Health Sciences at University College Dublin are co-hosting the visiting Professor and the IHF will fund the position until 2008.

Professor Clark is Professor of Medical Sociology and Director of the International Observatory on End of Life Care at Lancaster University. He has worked as a researcher and teacher in palliative care for 16 years.

A Professor since 1993, he has held Chairs in three universities. He established the International Observatory on End of Life Care when he moved to Lancaster University in 2003.

The Observatory, which is a part of the Institute of Health Research, aims to provide evidence and ideas to support improvements in end of life care around the world.

An elected member of the European Academy of Sciences and Arts, Professor Clark is also a Trustee of the UK charity Help the Hospices and a member of the board of the European Association of Palliative Care.

A public loan service has been developed by the Library to allow individuals as well as medical, nursing and therapeutic professionals to learn more about coping with death and bereavement.

That the library is named after the late Thérèse Brady is especially appropriate. She helped design the IHF's early education and training courses and was the instigator of the bereavement counselling service.

Thérèse Brady herself was insistent on the importance of research for the IHF and for the hospice movement generally.

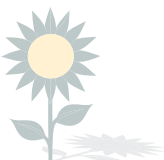
GRANTS FOR RESEARCH

Accordingly, grants to fund or part-fund

projects relevant to hospice work have always been a feature of the IHF's work, initially through a Research Committee and Ethics Committee.

In 2000, a new IHF Research Committee was formed, including palliative care consultants, psychologists, nursing and public health representatives. The committee awards grants to professionals working in hospice, palliative care and bereavement. The IHF's aim in establishing the committee was to create a research culture and to support research that would have real benefits for patients and their families.

IHF-funded research which falls under this heading includes studies into the effectiveness of morphine in pain control; a quality of life



Education & Research



expectation model for the terminally ill; the effect of bereavement on the family and the use of counselling as a means of coping. A new post-graduate scholarship in bereavement research, the Thérèse Brady Scholarship was established by the Board in 2001. The IHF's Thérèse Brady scholar, Amanda Roberts, is based at St Francis Hospice in Raheny and is researching hospice bereavement services.

FELLOWSHIP



The IHF's Education, Research and Development Manager Orla Keegan with Philip Larkin who was awarded the first ever Research Fellowship in Palliative Care.

An important advance in the IHF's research programme came in 2003 with the award of the first ever Irish Research Fellowship in Palliative Care, sponsored by the IHF in partnership with the Health Research Board.

Following an open competition and expert review process, the three-year fellowship was awarded to Philip Larkin, Palliative Care Nurse-Coordinator with the Western Health Board and previously of the Education Department at Our Lady's Hospice, Harold's Cross. Philip's research focuses on patients' experiences of the transition to palliative care services, not only in Ireland but across Europe.

This is just one of a number of valuable

partnerships into which the IHF has entered to further hospice-related research. Other programmes which have benefited from IHF and Health Research Board funds include investigations into how to provide palliative care for people with dementia; what factors influence where people die and how the travelling community perceives and accesses palliative care.

The IHF also supports research training by means of grant-aid for further education - for example, Master's programmes involving research dissertations. Dissertations sponsored in this way are housed and can be consulted in the Thérèse Brady Library. Examples of titles are:

- *Ethical decision-making in end-of-life care - an exploration of nurses' experiences* (Anna-Marie Lynch)
- *Palliative care - the meaning for public health nurses and general practitioners in the community* (Valerie McGinley)
- *Evaluation of a cognitive behavioural group intervention for the treatment of complicated grief* (Angela Pugh)

In hospice, palliative care and bereavement it is important that some evidence underlies policy decisions about how services are provided to people and communities. The IHF



Amanda Roberts is the Thérèse Brady scholar who is researching hospice bereavement services.

Facts at a glance

- The IHF runs two third-level programmes in association with the Royal College of Surgeons in Ireland, a Master's Degree/Graduate Diploma in Bereavement Studies and a Certificate in Children and Loss.
- It is preparing a Framework for Postgraduate Education in Palliative Care.
- The IHF runs an Education and Bereavement Resource Centre.
- The IHF invests €100,000 in research each year.
- In collaboration with the Health Research Board, the IHF has initiated a research fellowship in palliative care.
- Since 2004, it has co-funded three major palliative care studies through the Health Research Board's research partnership scheme.
- The current Thérèse Brady scholarship focuses on research in hospice bereavement services.
- An annual programme of seeding grants is awarded for pilot or small-scale research studies and research training.

has worked with the Department of Health and Children on the Children's Palliative Care Needs Assessment published in 2005. This research document is being used by the HSE to plan new nursing education and support services for children with serious life-limiting illness and complex needs.

In 2006 the IHF began another joint research study, this time focusing on older people and organised jointly with the National Council for Ageing and Older People. The research looks



Education & Research



The IHF's Training Officer, Breffni McGuinness.

at quality of care for older people dying in hospitals, nursing and residential home. It will have significant implications for our Hospice Friendly Hospitals programme and for national policy on services for older people.

TRAINING

The IHF runs a programme of workshops each year on aspects of loss and bereavement. The workshops began in 1991 and provide a forum for different professionals to share their experiences. Over the years the topics have expanded to include loss and the family, loss and bereavement for people with intellectual disability, and life after suicide. From January to July, there are one and two day workshops available in the training room of the IHF.

The IHF is a national organisation and in 2003 we appointed an outreach training officer, Mr Breffni McGuinness who can provide bereavement training in any part of Ireland. Breffni works with different voluntary and commercial groups. One of his newly developed programmes is training on 'Grief at Work'.

EDUCATION AND UNIVERSITY PROGRAMMES

The year 2004 saw a major step forward in the IHF's efforts to spread the hospice ideal through education. This came in the form of a partnership with the Royal College of Surgeons in Ireland (RCSI), working closely with Professor Ciaran O'Boyle of the Department of Psychology and Mr. Fintan Foy, Associate Director of Academic Affairs. This partnership enabled the IHF to offer a Postgraduate Higher Diploma in Bereavement Studies, the first of its kind not only in Ireland, but indeed internationally. It is accredited by the National University of Ireland.

There are six models to the course for the *Higher Diploma in Bereavement Studies*. These are: theories and models; perspectives (e.g. gender, age, disability); bereavement counselling skills; self care for carers; research and systems of bereavement support. Students come from different backgrounds (nursing, social work, teaching, voluntary organisations) and from different parts of the country.

In 2006 plans to progress this programme to an MSc were successful and the first MSc cohort will graduate in 2008.

The IHF's workshop series on children and adolescents' experience of loss and bereavement, co-ordinated and developed by Dr Susan Delaney, is accredited by the RCSI as a Certificate in Children and Loss. The first group of certification students graduated in 2004.

In the meantime, an Education Needs Assessment is currently under way and involves an evaluation of the current and planned future provision of education services for palliative care.



Journalist Kitty Holland at the announcement of the Mary Holland Commemorative Lecture.

IHF Research Committee (Members from 1986)

External Assessor: Prof Sam Ahmedzia,
Sheffield

- Dr Veronie Hanley
- Mr. Nick O'Connor
- Miss Thérèse Brady
- Prof. Ciaran O'Boyle
- Dr Michael Kearney
- Dr Liam O'Sioráin
- Dr Tony O'Brien
- Dr Barbara Dooley
- Ms. Agnes Higgins
- Prof. G Bury
- Ms. Helen Kelleher
- Dr Michael Moriarty
- Mrs. A Farmar
- Dr J Fleetwood
- Ms. E Rice
- Prof. J Feely
- Prof. McCormick
- Ms. M McDonnell
- Mr. Matt Russell
- Dr J McCarthy
- Dr Sinead Donnelly
- Dr Emer Feely
- Dr Colin Bradley
- Prof. David Clark
- Ms. Orla Keegan



The Future



In its first two decades, the IHF has encountered far more challenges than its founders could have forecast back in 1986. Yet the IHF is still at the beginning of its journey.

DEFICITS

There are still major deficits in core hospice services in some regions. Inpatient units, multi disciplinary home care and hospital teams still need to be provided in many areas of the country.

Many people still die without the benefit of palliative care either at home or in a hospice. This happens to some because they live in an area in which hospice provision is poor. Others suffer from an illness other than cancer and it remains the case that hospice care is mostly - though no longer exclusively - provided to people with cancer.

The Mary Holland Commemorative Lecture, held for the first time in 2005, was initiated by the IHF in honour of a great journalist and champion of the voiceless who died of scleroderma and without the benefit of hospice care. The lecture, delivered by former President of Ireland and United Nations Human Rights Commissioner Mary Robinson, raised awareness of the failure of our care systems to meet the needs of people dying from illnesses which are less widespread and less well understood than cancer.

The IHF is now funding night nursing services for patients with a non-cancer diagnosis.

Even if the need for hospice services did not increase beyond its present level, the IHF would have an enormous amount of work on its hands in helping to bring about, along with other organisations, the correction of those deficits that exist.

The number of people over the age of 65 is expected to more than double in the 35-year period ending in 2031. Therefore the demand for end-of-life care is increasing. There is also a need for the hospice philosophy of total care to be adopted for people who are dying in

hospitals, nursing homes or their own home.

A major report entitled *Home, hospice or hospital? A study of Irish Travellers' use of palliative care services* has called for innovative and culturally sensitive ways to be explored of meeting the needs of Travellers who are not accessing hospice services.

Co-funded by the Health Research Board and the IHF, the report found that palliative care must be aware of and sensitive to cultural differences and palliative care professionals must ask if the services they provide are inclusive of all ethnic groups. This approach is essential as Ireland becomes a more ethnically diverse community

IHF PRIORITIES

The IHF will therefore intensify its advocacy efforts to improve access to hospice care services and to help bring about continuous

improvements in the quality of care. Its major priorities will be the provision of hospice services (inpatient, day care and home care) on a consistent basis in every region, more support for bereaved people, more hospice care for children in their homes and the adoption of the hospice approach by hospitals and nursing homes.

Education and training will become increasingly important as the State increases its funding of services which are currently funded, or part-funded, by the voluntary hospice movement.

STATE INVESTMENT

Much hospice development in the past was the result of the work of religious orders and the voluntary sector. The future development of hospice services, however, requires a major contribution from the State.

2001 Report of the National Advisory Committee on Palliative Care.

The 2001 report made a number of recommendations including:

- There should be a specialist inpatient unit in every health board region, which would act as the hub of the service.
- There should be between 8-10 inpatient hospice beds per 100,000 of population and at least one specialist palliative care home care nurse per 25,000 of population.
- Palliative care should be available in all care settings.
- Services should allow patients to move from one care setting to another.
- The concept of palliative care should be promoted in the wider community.
- Research should be undertaken on a national level to examine the needs of non-cancer patients.
- The medical and nursing care of children should be the responsibility of paediatric-trained medical and nursing staff.
- All palliative care patients should have adequate access to respite care in a setting of their choice.
- An adequate level of public funding should be provided for the provision of services.
- All day to day expenditure should be met by the health boards' specialist palliative care budget.
- There should be a separate protected budget for specialist palliative care services at the health board level.



The Future

This has been recognised by the State through the establishment of the National Council for Specialist Palliative Care and in other ways. The IHF is represented on the Council, which can do much to ensure that the new health management structures are responsive to regional needs for hospice services. The establishment of the National Council was an outcome of the 2001 NACPC report. The IHF is anxious to see that blueprint implemented.

In looking at the future of the IHF, it is important to look at the context in which it works. Hospice care is provided largely by non-statutory bodies. Their services may be specific and non-clinical, arranging transport for local hospice services for instance. Alternatively their services may include the provision of home care and inpatient care on a relatively large scale.

Within this setting, the IHF raises funds for hospice services provided by other bodies. It provides education for a wide range of professionals on issues relevant to hospice care. It seeks to further the provision of such education by others e.g. third level institutions. It seeks to influence policy on behalf of service providers and on behalf of those who need hospice services.

It aims to encourage a healthy relationship between the statutory and non-statutory sectors - getting this relationship right is vital



The launch of Muc which raised funds for children's palliative care. The clown comes from Fossetts Circus which has supported the IHF's work with children for a number of years.

for the future of hospice care in Ireland. This will be a key area for future work by the IHF in the interests of the voluntary hospice movement.

FUNDING

More funding is being invested in palliative care by the State. Some €13 million was allocated to palliative care in the 2006 Budget with an additional €150 million allocated to care of the elderly, which will also benefit some people with life-limiting illnesses.

Following the launch of a major report on children's palliative care needs in 2005, statutory funding was provided for community-based Children's Outreach Nurses which will be matched by voluntary funding and introduced on a phased basis over three years.

Significant state investment is also expected following the provision in the new Social Partnership agreement to prioritise hospice care over the next three years by "further developing palliative care throughout Ireland,

Positive Development since publication of the NACPC report (2001)

- Regional Consultative Committees formed in most of the formal health board areas.
- Regional Needs Assessments carried out which will lay the foundations for future development plans.
- More Consultants in Specialist Palliative Medicine appointed.
- More teams and resources attached to these appointments.
- Extension in the provision of home care services.
- Training scheme set up for Specialist Registrars.
- National Council for Specialist Palliative Care established.

Deficits

The report entitled *A Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland* highlighted continued inconsistency in the provision of hospice care.

The key deficits in December 2004 included:

- Three former health board areas - representing 12 counties - with no inpatient unit.
- National deficit of 259 palliative care beds.
- National deficit of 744 palliative care staff.
- Wide disparity in the current spend per capita between regions.
- State funding for core services varying from 100% to 0%.
- Only two of the 22 home care teams available on a 24 hour basis.
- Some 11 of the country's 38 acute general hospitals with over 150 beds with no palliative care teams.
- Non cancer patients do not have the same access to services as those with advanced cancer.



The Future



with particular reference to the Baseline Study on the provision of Hospice/Specialist Palliative Care Services.”

It is important in the future, as it has been in the past, that the hospice and palliative care community speak with one voice. For this reason, the IHF will continue to work closely with representatives of the voluntary hospice movement.

It is likely that the IHF's international links will grow in the future. These links began to be cultivated in recent years. The international sales of *Art:pack* and the raising of money internationally from the *Peter & The Wolf* project led the Board to decide in 2003 that the IHF should begin to support hospice projects in developing countries, for example in areas where AIDS is causing enormous suffering. This will be done through the intermediary of established Irish and international agencies.

CHILDREN'S NEEDS

For many years, the IHF has been concerned that hospice services for children are underdeveloped. The IHF's work with Our Lady's Hospital for Sick Children, Crumlin has helped to address this but Much more is

needed.

An estimated 1,369 Irish children live with life-limiting illnesses. An average of between 536 and 592 children die each year before their 18th birthday. Children die from a range of conditions such as cancer, cerebral palsy, cystic fibrosis and liver failure. Despite this, none of our paediatricians, at the time of writing, has a speciality in palliative medicine.

To address deficits in this whole area, a national children's palliative care needs assessment undertaken in partnership between the IHF and the Department of Health and Children was published in September 2005. The needs assessment aimed to identify the number of children in Ireland living with and dying from life limiting conditions and to identify their needs.

This needs assessment concluded that the preferred place of care and ultimately of death for children with life limiting conditions is home and therefore the development of palliative care services in the community specifically for children was seen as a priority.

DEVELOPING PAEDIATRIC PALLIATIVE CARE

An inequality was identified in the provision of paediatric palliative care services. Services currently provided are limited, and there is a

need for more paediatric trained staff (e.g. nurses, physiotherapists) to provide care at home.

Following the publication of the report, a Paediatric Palliative Care Steering Group was set up to direct the future of children's palliative care services based on the findings of the needs assessment.

It has been agreed that the most effective intervention in support of families and children with life-threatening illness would be to establish a team of initially eight regionally based Children's Outreach Nurses. These outreach nurses would have a specific remit to care for children with palliative care needs. It has been agreed to recruit eight outreach nurses in the first instance.

It is recognised that in the medium term there will be a need to recruit a Specialist Paediatric Palliative Care Consultant to provide clinical leadership. A register or database of children with chronic life limiting illnesses is essential for the formulation of service plans on a national and local level. A hospice for children is also being developed and the IHF has played a facilitative role in the joint venture between the Children's Sunshine Homes and the Laura Lynn Foundation. The IHF plans to fund a paediatric palliative care nurse in this facility

Challenges Worldwide

- There are 8,000 hospice and palliative care services in 110 countries.
- There are six million cancer deaths each year worldwide.
- Over 10 million new cases of cancer are recorded each year.
- The number of new cancer cases is expected to rise to 15 million by 2020.
- More than one million people worldwide die each week.
- It is reckoned that 100 million people worldwide could benefit from basic hospice or palliative care - 33 million people dying and 66 million family members and loved ones.
- Sub-Saharan Africa has twice as many deaths per 1,000 head of population each year as North America but only 1.5% of global palliative care resources compared to 55% in North America.
- In 2005 some 2.5 million people in Africa died from AIDS without access to hospice or palliative care services - half a million of them children.
- In Uganda, it costs the same amount to provide a cancer patient with enough morphine to keep them pain-free for two weeks as it does to buy them a loaf of bread.
- In India less than 1% of the population has access to any kind of hospice and palliative care services.



The Future

for an initial period after it opens.

Overall, the IHF looks to a future of continuing engagement with the hospice movement and with all relevant services both voluntary and statutory in the interest of those who are at the heart of its work: people who are dying and their families.

Perhaps the last word should go to the founder, Dr Mary Redmond. How was it possible to contemplate the creation of such a Foundation with targets which, financially, were dauntingly high, at a time when the economy was in poor shape?

“If we hadn’t been guided by a one hundred and twenty per cent passion we couldn’t have done it. One was completely guided by an absolute certainty it was going to happen. I don’t know where it came from. It doesn’t often happen in life but when it does it’s wonderful.”

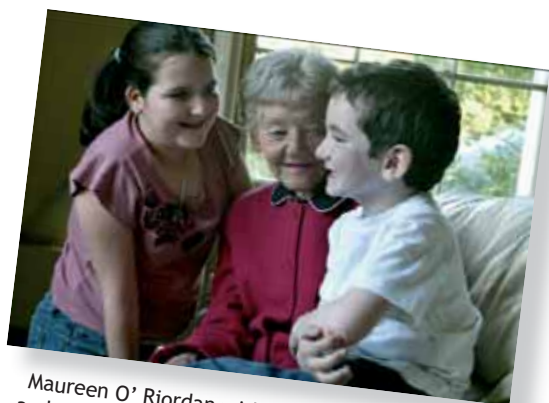


Professor Antoin Murphy who is the longest serving member of the Board of the IHF

Action for the Future

Some €70 million is currently invested annually in palliative care. The IHF is looking for a five-year strategy to be adopted where the recommendations of the NACPC report will be fully implemented. This will involve a commitment of an extra €15 million per year for the next five years.

To ensure that a quality end-of-life service is accessible in all care settings, a capital investment of €46 million is also required each year for the next five years. This €46 million will also include investment in care of the dying in acute and community hospitals- 66% of all deaths occur in acute hospitals or other institutions.



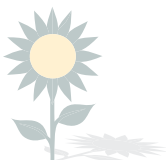
Maureen O' Riordan with her grandchildren Catie and Patrick Riordan. Hospice care meets the needs of the family.



The Children's Hospice Ball to raise funds for the Laura Lynn Foundation. From left to right, Brendan McKenna, Jane McKenna, Derek Davis, Avril Burgess and Eugene Murray.

Planned Developments

- Plans to relocate Marymount Hospice to a greenfield site at Waterfall Road and to build a 44-bed hospice.
- St Francis hospice in Raheny is building a 24-bed hospice facility at Abbotstown Estate in Dublin 15 to meet the needs of the people of North-West Dublin.
- Three hospice units are to be set up in Waterford, Tullamore and Drogheda.
- Additional beds will be provided in inpatient units in Galway and Blackrock.
- Satellite inpatient units will be provided in Kerry, Blanchardstown, Cavan, Wicklow, Mayo and Kildare.
- Day care and home care services will be improved.
- Improvements in facilities at community hospitals.



CEOs, Directors & Chairpersons



CEOs, 1986-2006

1. Anna Farmar
2. Ellen Rice
3. Vincent Kenny
4. John Wilson
5. Claire Goddard
6. Louise Richardson
7. Jean Manahan
8. Eugene Murray



Eugene Murray, Chief Executive Officer of the IHF.

Directors 1986-2006

Maryrose Barrington
 Trevor Bowen
 Thérèse Brady
 P.J. Brigdale
 Brendan Butler
 Cynthia Clampett
 Tim Collins
 Hugh Cooney
 Lawrence Crowley
 Marie Donnelly
 Margaret Doyle
 Denis Doherty
 Frank Dunlop
 Marian Finucane
 Anna Farmar
 Muiris FitzGerald
 Bernadette Gallagher
 Tom Healy
 Miriam Hughes
 Sr Ignatius Phelan
 Gary Jermyn
 Oona Linehan
 John Lynch
 Brian McDonnell
 Gerardine Montgomery
 Antoin Murphy
 Donal Nevin
 Nicholas O'Conor
 Kevin O'Dwyer
 Ruairi O'Floinn
 Michael O'Reilly
 Eileen Pearson
 Robert Power
 Pat Quinlan
 Lochlann Quinn
 Dr Mary Redmond (Founder)
 Sr Francis Rose O'Flynn
 Matty Ryan
 Bill Shipsey
 Don Thornhill

Chairpersons 1986-2006

1985 - end 1996
 Dr Mary Redmond

1996 - 1997
 Prof. Antoin Murphy

1997 - mid 2000
 Marie Donnelly

Mid 2000 - end 2003
 Bill Shipsey

2004
 Michael O'Reilly

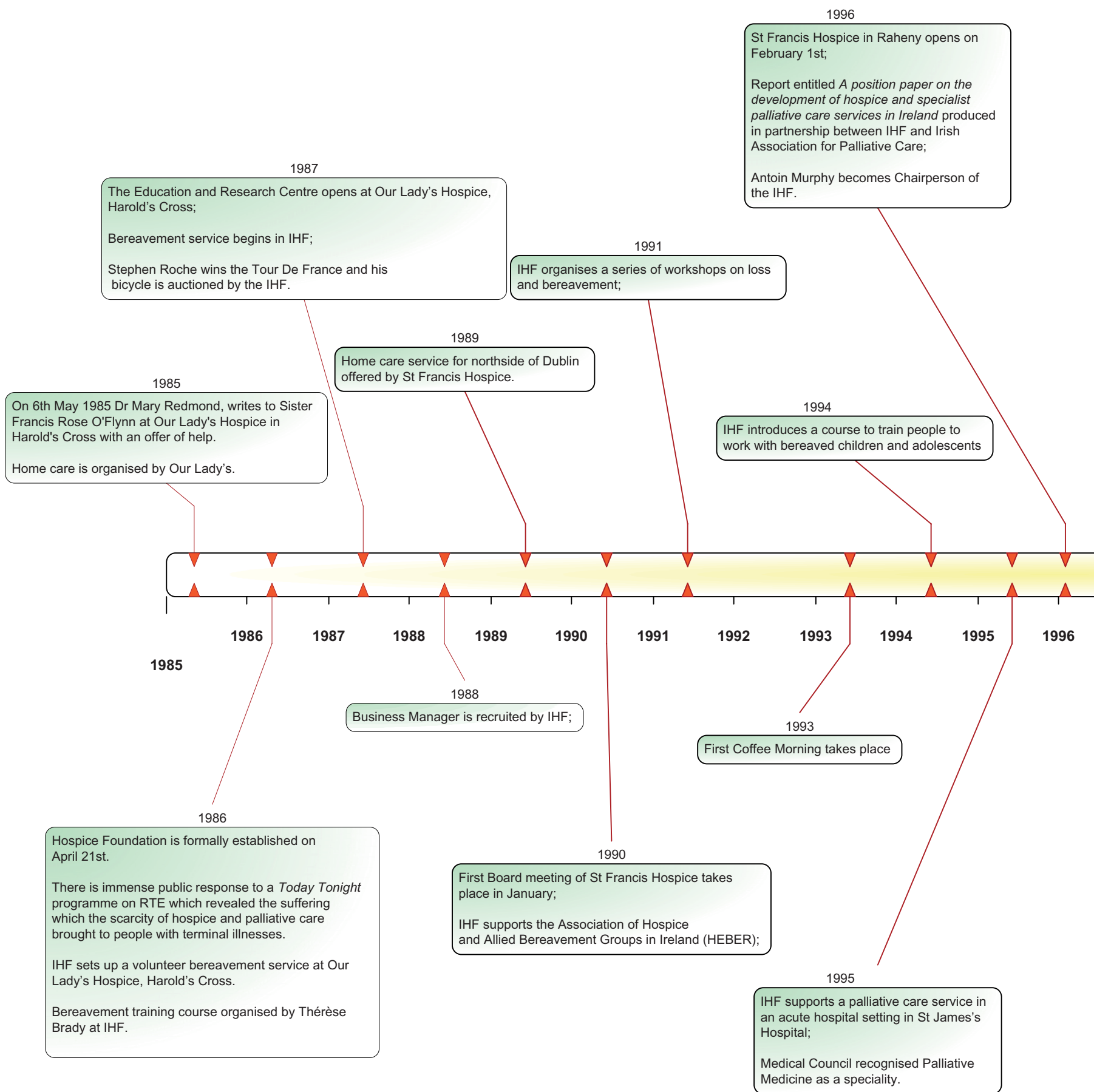
2005 - Present
 Denis Doherty

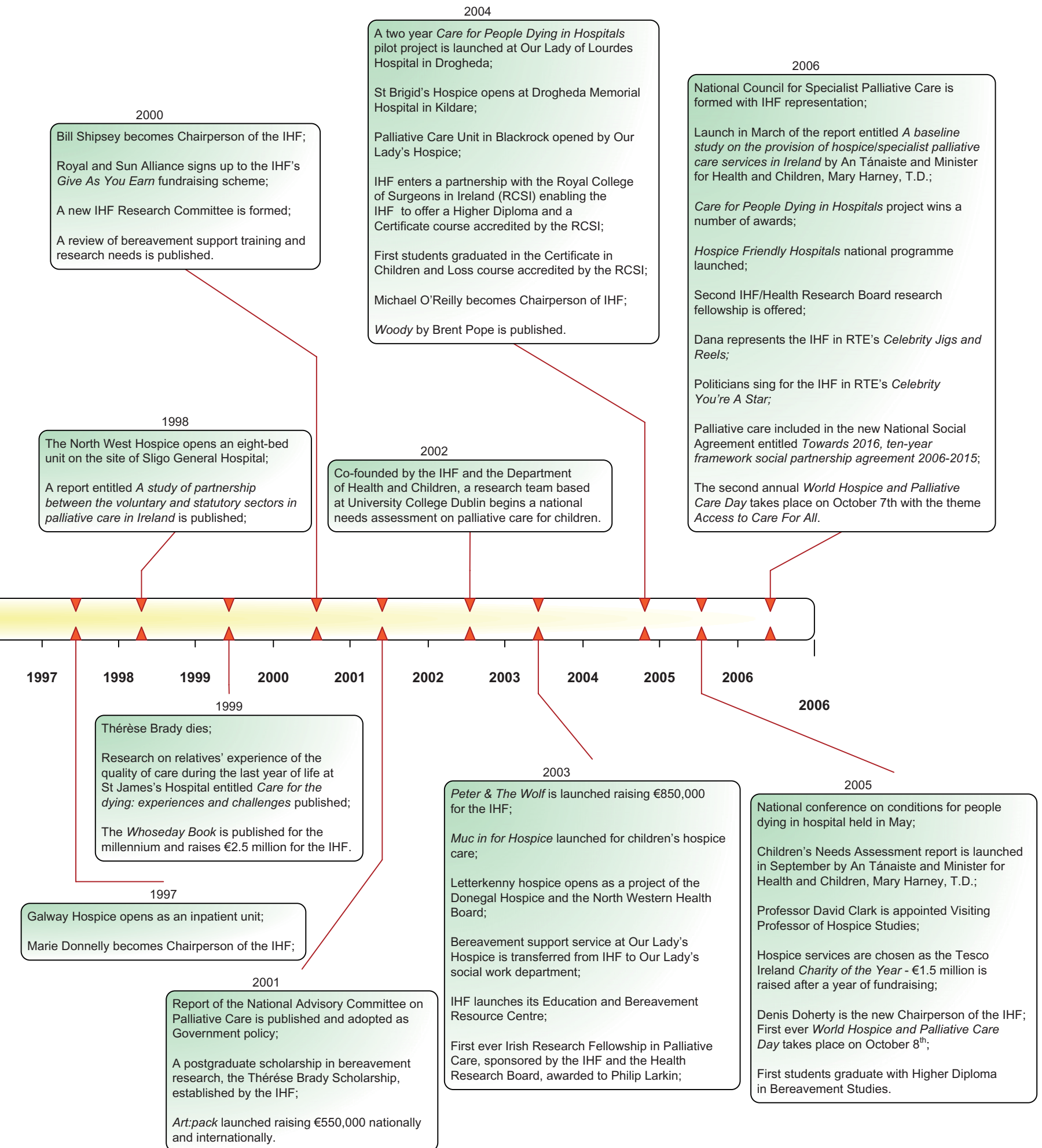


Anna Farmar served as CEO and a Director of the IHF in the 1980s.



Timeline





Photography

John Waters, p 11: Frank Miller, The Irish Times.
Politicians, p 13: Ciaran O'Brien.
Golfers, p 13: Noel Gavin/Allpix.
Youngster at *Art:pack* signing, p 13: Hazel McManus.
Hands and nurse with lady, p 14: Derek Speirs;
Dr O'Brien, p 14: Marymount Hospice.
Taoiseach and Judge Carroll, p17: the Gazette Group Newspaper.
Iris Murray, p 17: Mac Innes Photography.
Hospice site, p 17: Burke-Kennedy Doyle Architects.
Award ceremony, p 18: Maxwell Photography.
Library, p 23: Mac Innes Photography.
Dr Delaney, p 23; Mac Innes Photography.
Orla Keegan and Philip Larkin, p 25: Patrick Bolger.
Family, page p 30: Derek Speirs.

Most of the photographs were taken by Fennells photography.

While every effort was made to ascertain the source of the photographs used in this publication, it was not always possible to identify the photographer.

THE IRISH
HOSPICE
FOUNDATION

1986-2006



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