

The Irish Hospice Foundation

Strategic Plan 2016-2019



**The Irish
Hospice
Foundation**

Striving for the best care
at end of life for all

Our Vision

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

Our Mission

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

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Introduction

The Irish Hospice Foundation (IHF) is a national charity, set up in 1986 to fund and develop hospice services. Since then we have expanded our scope to encompass the key issues affecting the end of life. Our programmes and services now seek to address the needs of people dying at home, in hospitals and in other care settings, and also the needs of those bereaved.

This strategic plan builds on the IHF's evolving agenda and maps out our direction until 2019.

What do we mean by care at end of life?

At The Irish Hospice Foundation we choose our words carefully. When we say “**care at the end of life**” or “**end-of-life care**” we refer to all aspects of care relating to dying, death and bereavement. In this context, “end of life” can be from the time of diagnosis, the months before death, the last hours of a person’s life, or the experience of loss and grief.

For the IHF, care at the end of life is holistic, and extends beyond the health services to areas such as justice, education, employment, social care and community-level activity. For example, teachers support children experiencing grief, employers struggle to provide the right support for bereaved workers, lawyers and legislators have introduced measures to underpin a person’s right to refuse certain treatment at end of life. Communities, if they are attuned to the realities of dying, death and bereavement, are well placed to compassionately support families and individuals with palliative care needs.

In the health services, the term “**palliative care**” is used to refer to the care given to a person who has a life-limiting illness. Palliative care is an approach that aims to improve the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and treatment of pain and other problems, physical, psychosocial and spiritual. This approach aims to achieve the best possible quality of life for people with serious illness and is acknowledged to be beneficial for anyone with a life-limiting illness, regardless of age or condition. It may be appropriate for a number of years, not just the weeks and days at the end of life. We would like to see this approach applied to all who are facing dying, death or bereavement.

Our thanks to the palliative care community, the public and stakeholders who shared their views and expertise in developing this strategy.

80

**people die every
day in Ireland**



Dying, Death and Bereavement in Ireland

Death, dying and bereavement are probably the most important issues that anyone has to face or deal with. End of life is an intensely meaningful time for those who are dying, their loved ones, and those who provide their care.

There is only one chance to get it right.

Getting end-of-life services right needs to have a higher place on the national agenda. Dying, death and bereavement affects us all at some time. Each year 29,000 people die in Ireland and, given that on average ten people are directly affected by each death, we estimate that up to 290,000 people are newly bereaved each year.

Palliative and end-of-life care services are inconsistent. Although equitable access to palliative care is a strategic concern for the Irish health service, national policies have been implemented unevenly and gaps remain: palliative care services are stretched; it is harder to access services with a diagnosis other than cancer; many health professionals have little training in palliative care. Best-quality palliative and end-of-life care should be available of people of all ages, with all diagnoses, in all parts of the country.

Over time, the public aspects of death and dying in Ireland, such as the wake at home, have become less common. Open conversation and community support have lost ground to the busyness of life and the expression of condolences via cards or even websites. However, concerns about how to adapt to the challenges serious illness presents: how to live with quality and dignity whilst enduring a terminal illness – how to face dying – how to navigate bereavement continue to be of huge significance for all who face them – which, effectively, means everybody.

The Irish Hospice Foundation wants to open up and respond to these vital concerns. Care at the end of life extends far beyond healthcare, the IHF wants to ensure that we all – health and other service providers, all levels of Government, state bodies, the general public, the not-for-profit sector and the business community - play our part in ensuring that the experience of dying, death and bereavement in Ireland is as gentle and supportive as possible.



57% of people say there is not enough discussion about death and dying in Ireland

(up from 51% in 2004)



Our Challenges

The Irish Hospice Foundation intends to play its part to address a number of issues and challenges:

- **End-of-life services** should occupy a higher place on the national agenda – everyone deserves a good death.
- **Palliative and end-of-life care services** are inconsistent – we want to change that
- **Public Conversation** on dying, death and bereavement– more talking means as a society we are better prepared for end of life.
- **Bereavement** is inadequately addressed in Ireland. Loss and bereavement underpins all end-of-life and palliative care, and affects us all.
- **Training** in end of life, bereavement and palliative care is not widespread. Staff in all care settings - hospitals, care homes, community settings and hospices - need support, training and development.
- More can be done to encourage people to **plan and think about end of life**. All people facing the end of life need to know that they matter and that their wishes for end-of-life care will be respected.



Place of death

Most people say they want to die at home (74%) but only 26% actually do so. We need to make it possible for more people to achieve this wish.

43% Acute Hospital

26% Home

25% Long-stay Facility

6% Hospice



Delivery of health services

Rising expectations and changing demand are putting pressure on the Irish healthcare system. The call for high-quality and effective care is challenging and the health service is continually evolving in its effort to meet demand. Performance quality varies considerably: often exemplary, but sometimes not.

As the population ages, the level of chronic disease, including dementia, is set to rise. Advances in medical knowledge and technology promise longer lives, improved health and functioning and the elimination of pain and suffering.

On the other hand, research on the quality of care reveals a system that frequently falls short in its ability to translate knowledge into practice. Continuing economic pressures and rising healthcare costs beleaguer health and social care services, both statutory and voluntary bodies. Healthcare workers are trying hard to do their jobs well in an increasingly difficult environment and changing culture.

Each of these challenges impacts on the experience of Irish people facing dying, death and bereavement. The Irish Hospice Foundation works alongside the health service to highlight and address gaps as they arise.

What We Do

The Irish Hospice Foundation funds, delivers (and enables the delivery of) a targeted range of work programmes and services, including:

Service innovation

- Nurses for Night Care:** We fund this free national service for people who are dying from illnesses other than cancer, enabling more people fulfill their wish to die at home. This service has grown considerably since it began in 2007, with 600 families expected to benefit in 2016.
- Hospice Home Care for Children:** In 2011, through seed funding and in partnership with the HSE, we pioneered Ireland's first-ever national paediatric palliative care service (including a medical consultant and a team of out outreach nurses). In 2015, this service supported approximately 240 families.
- Hospice Friendly Hospitals:** This ambitious programme aims to improve the end-of-life care in hospitals countrywide. We now work with 42 acute hospitals across Ireland.
- Primary care and care in people's homes:** We support initiatives in primary care, along with our partners in the Healthcare Service Executive (HSE) and Irish College of General Practitioners (ICGP), so that better end-of-life care can be delivered in the community, for everyone.
- Bereavement:** We host the Complicated Grief Programme, the Irish Childhood Bereavement Network and a bereavement support group development programme. We incorporate the most up to date evidence in delivering improved models of bereavement support. Bereaved.ie is a dedicated resource providing information and support for bereaved and those working with them.
- Palliative Care for All:** Since 2008 we have campaigned and supported initiatives to ensure that people with life limiting diseases such as heart failure, dementia, respiratory disease and advancing neurological disease receive a palliative approach to care and have full access to specialists palliative care services.
- Innovation and development:** We are committed to nurturing new areas of service. In 2013 we succeeded in attracting philanthropic funding for an ambitious national programme, Changing Minds, which promotes excellence in end-of-life care for people living with dementia in all care settings, particularly in residential.





Education, research & information

- **Education and training:** Education is central to achieving our vision that no-one should face death or bereavement without appropriate best-quality care and support. Every year about 3,000 people take part in our training programmes in bereavement, communications and end-of-life care.
- **Research:** Through the All Ireland Institute of Hospice and Palliative Care, and other means, we fund pioneering research on end-of-life and palliative care issues, with a growing focus on policy-oriented research.
- **Information and library service:** We provide information services to professionals, students and the public through our online resource collection and the Therese Brady Library, housed in our Nassau Street offices.

Support to the voluntary hospice movement

- We coordinate two national fundraising programmes for voluntary hospice groups across Ireland each year: Sunflower Days and Ireland's Biggest Coffee Morning. These events raise an estimated €2.5 million for hospice care all across Ireland annually.
- We champion and act as the national voice on the development of hospice services through our advocacy programme.

Advocacy and public engagement

- **Awareness-raising:** We strive to promote a better understanding of end-of-life care issues and to influence decision-makers to make services more widely available to all who need them.
- **Public engagement:** We provide a public information service, to actively engage the public on all matters relating to dying, death and bereavement. Creating a culture where end-of-life planning, bereavement care and awareness of dying, death and bereavement are seen as a normal and integral part of life planning and experience.
- **Think Ahead:** This programme promotes the concept of thinking, planning and talking about one's own death. The Think Ahead form facilitates putting your wishes on paper. Over 40,000 copies of the Think Ahead form have been distributed since 2012.
- **Forum on End of Life:** We support an active National Council of the Forum on End of Life and host public conferences on issues related to the end of life.

Our Priorities

Taking into account our current work, our concerns about dying and death in Ireland, and the challenges in providing high-quality care at end of life, in 2016-2019. The following priority is:

- Bring the work we've done through pilot and demonstration projects into the mainstream delivery of health services so that everyone can receive excellent end-of-life and bereavement care.
- Continue to ensure bereavement, palliative and end-of-life care is available to all, across Ireland.
- Develop and maintain relationships, partnerships and alliances so that care at the end of life can be improved throughout Ireland.
- Ensure that our work is grounded in the needs of those who fund us - the public – and is informed by evidence and good practice.
- Communicate effectively about what we do and the value we add to care at the end of life
- Secure enough long-term sustainable funding to enable us to continue our work.



74%

of Irish people want to be cared for at home at end of life,

Our Strategy

Our beliefs and values

We believe:

- Everyone has the right to be cared for and die with dignity and respect in the care setting of their choice.
- Care at end of life is everyone's business. People die at home and in every kind of healthcare setting. Everyone deserves to have access to best-quality care at the end of life. There is only one chance to get end-of-life care right.
- People facing death and bereavement have the right to be listened to, and their wishes respected.
- As a party to the WHO's World Health Assembly Resolution (2014), Ireland's healthcare system has a responsibility to provide best-quality palliative care nationwide.
- Investment in the education and development of healthcare staff can transform the delivery and experience of end-of-life care.
- Support through bereavement nurtures healing.
- Public policy should comprehensively address issues arising at end-of-life.

We value:

- That our work is reflective of the needs of the public
- Achieving great results through teamwork and respectful relationships
- Positivity, creativity and innovation
- Working in partnership and collaboration
- Non-duplication - if others are doing great work, we do not replicate
- Efficiency and transparency





82%

**of people want to be
surrounded by loved
ones at end-of-life.**

Our Goals

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

- 1** Innovating excellence in palliative, end-of-life and bereavement care
- 2** Enhancing end-of-life care and bereavement through education and training
- 3** Driving debate and policy change on key issues related to dying, death and bereavement in Ireland.
- 4** Enhancing our credibility and sustainability

1

Innovating excellence in palliative, end-of-life and bereavement care

We believe that palliative, end-of-life and bereavement care must extend far beyond hospitals and hospices. A wide range of health and social care settings can provide the backdrop for meaningful services and conversations. The IHF is proud of its long tradition of identifying gaps in services and working with care providers to create innovative and cutting-edge solutions. We strive to be an agent of change, collaborating with partners to imagine and realise creative and effective ways to bring about positive change.

Our healthcare programmes – **Hospice Friendly Hospitals, Palliative Care for All, Primary Palliative Care Programme and Journey of Change** – are all run in collaboration with partners such as the HSE and the ICGP. We support primary health and social care professionals and NGOs to identify, assess and respond to the end-of-life and palliative care needs of people in acute care settings or living at home or in residential care and to the related issues which affect their carers.

A key focus of our work is to ensure that people with life-limiting conditions gain access to best-quality end-of-life and palliative care services. We also have a long tradition of innovation and development in bereavement care, taking a lead in devising and promoting evidence-based treatment models and implementation of national standards for bereavement care.

Through 2016-2019, these programmes will continue to add value and innovation to the healthcare section.

We will achieve this goal through:

- a Further embedding the Hospice Friendly Hospitals programme in acute hospitals through centralised support, guidance and resources, and promoting the Design and Dignity scheme;
- b Developing the Journey of Change programme as a model of support for fostering excellence in the delivery of end-of-life care for people living in residential care settings;
- c Formalise the Primary Palliative Care Programme as lead advocate for developments in this area;
- d Strengthening carer support initiatives;
- e Reviewing, and charting a new programme of work for, the Palliative Care for All programme;
- f Developing more sustainable sources of funding for the Nurses for Night Care programme;
- g Influencing the development and implementation of Care for Children;
- h Supporting the development of national standards and models for bereavement care.



Our targets for 2019:

- The need for palliative and end-of-life care and bereavement support is recognised by clinicians, health service management and care staff as a core aspect of care for all people with life-limiting diseases, regardless of diagnosis and place of care.
- Individual hospitals and Hospital Groups include palliative, end-of-life and bereavement care in their service plans, informed by the Hospice Friendly Hospitals programme.
- Excellence in end-of-life care is embedded into the culture and practice of residential care settings.
- Statutory and voluntary agencies providing health and social care are using high quality tools including IHF-developed tools and resources in community settings to deliver best-quality services to people at the end of life, and their carers.
- The Care for Children programme is strengthened and is part of mainstream national healthcare delivery.
- The cost of the night nursing care is shared with health providers.
- A clear nationally-endorsed framework for bereavement care is agreed and appropriate evidence-based services and supports are resourced.
- Delivery of a strong suite of activities in primary palliative care

2

Enhancing end-of-life care and bereavement through education and training

Dying, death and bereavement are everybody's business. We believe that education and training can transform attitudes to death. Our programmes aim to foster the skills, attitudes and competencies that care staff and others need in order to support people as they experience terminal illness, death and bereavement, ensuring that their needs are met and their wishes honoured.

In 2016-2019 we will enhance our formal education programme, run in partnership with Royal College of Surgeons in Ireland (RCSI), to deliver a quality-assured programme to meet needs. Working in partnership with the HSE and other employers we aim to train volunteers, staff and others from a range of settings and communities. Our work will be based on credible research, and engagement with our partners.

We will achieve this goal through:

- a Grounding our education and training on public and professional need, and on best available evidence;
- b Providing relevant, quality-assured education programmes to meet identified needs;
- c Providing a flexible and innovative programme of training and development which enhances communication, compassion and competence in end-of-life and bereavement care;

- d Building the capacity of healthcare staff through facilitator training and our education grant programme;
- e Influence the development of palliative, end of life and bereavement care training and education through collaboration with others.

Our targets for 2019:

- Participants in our courses have more confidence and competence when communicating about, and responding to, end-of-life and bereavement care needs.
- Our range of high quality education approaches, comply with the HSE's Palliative Care Competence Framework, are accredited and have a hugely positive effect on the care received by people facing death, loss and bereavement.
- Flexible and innovative training is available in a wide range of locations and formats.
- Our training and education programmes respond to emerging needs concerning dying, death and bereavement.



3

Driving debate and policy change on key issues related to dying, death and bereavement in Ireland

The vision of Cecily Saunders, the founder of modern palliative care services, continues to inspire the Irish Hospice Foundation. She wrote,

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

Because everyone in Ireland matters right to the end of their life, we seek to create a coherent demand for better end-of-life, bereavement and palliative care services. Our policies and stance are informed by the conscientious use of research, as well as by building trust and meaningful connections with care providers public policy makers and the general public and listening carefully to them.

Because dying, death and bereavement are affected by, and impact on all areas of life, we aim to foster a more compassionate society. Through advocacy and public engagement, and our work with the National Council of the Forum on End of Life, we campaign for the right of people at the end of life to be heard, including through the provision of advance care directives.

In 2016-2019 we will use effective public, political, civic and NGO engagement to drive debate on dying, death and bereavement in Ireland. We will base our engagement on a bedrock of trust and the enhancement of honest relationships with all interested parties. In particular, we will strive to deepen the involvement of the general public in our work. A strong communications programme will lead this work.

We will achieve this goal through:

- a Effective engagement with the public on dying, death and bereavement;
- b A strong external communications programme;
- c Effective political and NGO advocacy;
- d Effective consultation and relationship-building with all, prioritising the voluntary hospice movement and the palliative, end-of-life and bereavement care sectors;
- e Using evidence, rigorous research, needs assessment and reliable information sources to ground and inform our communications.

Our targets for 2019:

- From communities to decision-makers, people in Ireland find it easier to discuss and respond to death, dying and bereavement.
- People in Ireland have a clearer understanding of what is best-quality care at end of life.
- Policy-makers respect the IHF as a strong, credible and confident agent for change.
- Our stance is visible in public policy related to dying, death and bereavement.
- Our relationships with the voluntary hospice movement and the palliative, end-of-life and bereavement care sectors, including NGOs, are strengthened.
- We effectively communicate our messages for change to the public and our stakeholders through an comprehensive external communications programme.



4 OUT OF **10**

Irish people say there is room for improvement in end-of-life care

4

Enhancing our credibility and sustainability

The IHF's credibility depends on public trust. It is essential, therefore, that we conduct our business in a totally transparent way.

IHF accounts are audited externally and published annually. As part of our robust financial control framework we have adopted the Statements of Recommended Practice (SORP) of the Charity Commissioners for England and Wales. We are governed by a voluntary Board of Directors with a range of skills and competencies (including financial expertise). We are fully compliant with the Governance Code for Community and Voluntary Organisations in Ireland and have signed up to the Irish Charities Tax Research Statement of Guiding Principles for Fundraising.



We value our staff, they are central to the delivery of our goals and a positive culture supports high performance. Through continuous investment in staff development, open communication and trust we believe we can respond to emerging needs and retain our spirit of social entrepreneurship.

As we receive no core funding from the State, we maintain our independence. Our fundraising strategy allows us to generate sustainable sources of income clearly tied to the work we do to support care at the end-of-life throughout Ireland. This is enhanced by contributions from trusts and philanthropic organisations.

In 2016-2019 we will support the delivery of our strategy through effective internal and external communication and effective organisational development.

We will achieve this goal through:

- a Continuing to hone our policy of maximum transparency in our business conduct. We will publish our accounts and will comply fully with any directives issued by the Charities Regulatory Authority or any new applicable legislation. We will also continue to respond transparently to any public media queries we receive on our funding;
- b Strengthening and maintaining robust financial systems, and enhancing our strong internal and external audit procedures with ongoing monitoring and management of risk;
- c Implementing a system of robust governance to strengthen internal structures and processes and to ensure that the IHF is an efficient and cost-effective organisation;
- d Strengthening our internal team by encouraging staff development and enhancing internal communications;
- e Growing and developing our fundraising programme to generate sufficient income to meet the goals of this strategy.

Our targets for 2019:

- The IHF is fully compliant with any directives issued by the Charities Regulatory Authority or any new applicable legislation.
- Through effective governance, the IHF is recognised as an efficient and high-performing organisation.
- We have a positive internal culture supported by good communication, teamwork and staff development.
- Our internal communication and management systems are strong and robust.
- We remain financially independent through the application of a high-quality and efficient fundraising programme which meets our financial needs.

Implementing Our Strategy

This strategy is the result of in-depth consultation, analysis and discussion with our staff team, our board and our external partners and stakeholders. This is our roadmap to guide us over the coming three years. However, the strategic planning process is only the start of the work needed to achieve our vision, mission and goals.

Our next steps will be to identify immediate, medium-term and longer-term actions and timeframes for each of the four goals and their objectives. We will move from planning to reality through our annual business planning process. As always we rely entirely on public generosity for all our funding.

We will review the strategy from regularly to ensure that it remains relevant and fit for purpose. Therefore, the strategy may change according to circumstances.

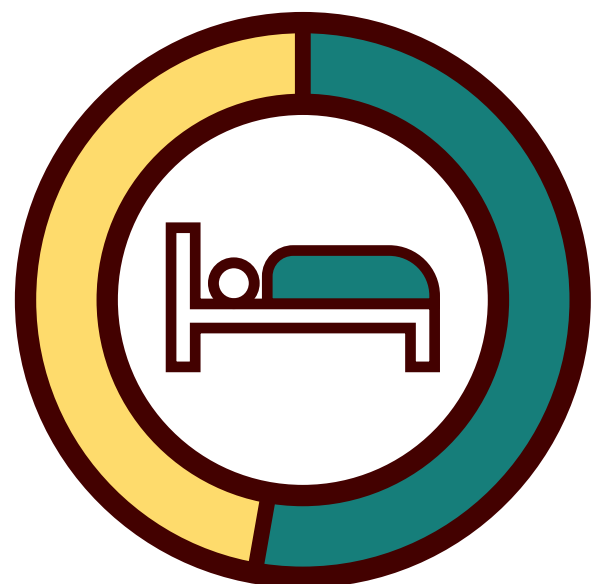
To ensure effective implementation, we will strengthen our organisational structures and practices, continue with team development and optimise the deployment of our resources.

Above all the person facing dying, death and bereavement will be at the centre of everything we do.

53%

fear their desired place of care will not be available to them when they need it.

(up from 45% in 2004)







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