Strategic Plan

2012-2015
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*Key terms and phrases as we understand and use them in this document*
Human history is punctuated by moments when we ask ourselves, ‘how could we not have seen the importance of this?’ Whether it is an issue of a fundamental human right, for example the right not to be enslaved, or an issue of basic equality such as universal suffrage, it is often only in retrospect that we see clearly how wrong we have been in the past.

There is a dawning realisation in our culture that the way we treat death and dying is such an issue; that the societal practice of focusing all our skills and expertise on ‘cure’ fails to address the broad and complex landscape of end-of-life. The early hospice movement questioned this, and that movement’s success – the comfort that it brought to the dying and the bereaved – has led to a growing acknowledgment of the hospice ethos: that everyone has the right to die with dignity and comfort.

How could we not have seen this more clearly before? It is an important question, because it suggests that there are many other issues that are critical to the enjoyment of full human rights that we still don’t see. It is not so long ago, for example, that even hospice care focused almost exclusively on cancer. But, at least we do now see these issues. Efforts are being made to extend the benefits of hospice to all who need it. A rigorous exploration of end-of-life issues is now evident in government policy development, in the medical professions, in academia and in the voluntary sector. Right across our society, individual people are striving to ensure that the dying person is afforded a special dignity befitting this most extraordinary moment in life, and that death, for all the loss and grief that it entails, can become an experience that enriches rather than diminishes us.

It is nothing less than this full exploration of end-of-life that informs the modern hospice movement. This is why the vision of the Irish Hospice Foundation is that no one should face death or bereavement without the care and support they need, and why our mission is to achieve dignity, comfort and choice for everyone facing the end of life.

This document – our strategic plan for the next three years – is a distillation of many hours of consultation, analysis and research, designed to ensure that we are doing the very best we can for those we serve.

The dying person is at the centre of everything we do. We are just one part of a broad coalition of individuals and organisations seeking to bring about change. Our particular role is to provide an active, indeed proactive, forum in which knowledge, expertise and most importantly, our basic human desire to relieve suffering, find a strong and articulate voice.

We are mindful of the privilege of being a part of this endeavour.

Michael O’Reilly
Chairperson
It gives me great pleasure to present the Strategic Plan of the Irish Hospice Foundation, which sets out our direction for the next three years. In preparing this plan, we are conscious that, as a society, we are faced by numerous challenges concerning the care of those who are dying and those left bereaved. These include:

- the economic realities facing our country and our health care services
- the need for protracted end-of-life care as people live longer
- the current regional inequity in the provision of hospice in-patient services
- the changes under way in the health service and in how services will be delivered
- the ongoing need for bereavement care.

These challenges require a brave response, and we intend to make a significant contribution to highlighting core issues as well as developing effective responses to identified needs, in partnership with services.

I would like to thank the members of the palliative care community, the public and the other stakeholders who submitted their views on our organisation and our work as part of the development of this strategy. Your input has been invaluable. This is an ambitious plan and we look forward to working with others to ensure that, by pursuing our strategic objectives, we achieve as much dignity, comfort and choice as possible for all people facing the end of life and their families.

Finally I am privileged to be able to work with the dedicated and professional team of the staff and Board of the Irish Hospice Foundation, who have greatly contributed to the development of this strategy and will be instrumental in its implementation.

Sharon Foley
Chief Executive Officer
The Irish Hospice Foundation (IHF) is a national charity dedicated to all matters relating to dying, death and bereavement in Ireland. Our work centres on development, aimed at:

- improving access to hospice services
- ensuring the continuous development of high-quality care for people with life-limiting illness and their families, from initial diagnosis through to bereavement
- building support for the hospice philosophy in all care settings.

Established in 1986 in response to a need to develop and fund specific hospice services, the Irish Hospice Foundation has endeavoured from the start to be innovative and pioneering. We believe that good end-of-life care is embodied by the hospice approach, which prioritises dignity and respect, seeks to relieve pain and distress, and is mindful of the role played by the physical environment in providing for the needs of those facing the end of life. The hospice approach allows people to live life as fully as possible to the end.

Over time, the Foundation’s work has expanded to embrace the needs of people dying in hospitals, at home and in other institutions, as well as those who cannot easily access hospice care because of the nature of their illness. Where service gaps appear, we work to see them closed by engaging in a variety of initiatives and partnerships. In addition, we actively promote discussion of a broad range of issues related to dying, death, and bereavement in order to identify what matters most to Irish people at the end of life and how best to address their concerns.

Governed by a Board of Directors, the Irish Hospice Foundation is funded through its own fundraising and the generosity of supporters, and receives no core funding from the State.
Among our current programmes and areas of focus are:

**Advocacy/communications**
Raising awareness, lobbying, engaging with policy-makers, the media and the public

**Education/training/information**
With particular emphasis on bereavement, this includes direct education provision (in-house postgraduate courses; workshops; and outreach training), a specialist library, strategic initiatives with partner organisations, and grants

**‘Hospice Friendly Hospitals’ Programme**
Five-year national programme aimed at improving the culture of care relating to dying, death and bereavement in acute and community hospitals. This programme formally concludes in 2012; its work will be progressed and supported through the emerging Network of Hospice Friendly Hospitals.

**‘Palliative Care for All’ Programme**
Working to improve access to appropriate levels of hospice/palliative care for people with life-limiting illnesses other than cancer

**Paediatric palliative care**
Includes funding Ireland’s first children’s palliative care consultant, children’s outreach nurses and education initiatives

**Primary palliative care**
Exploring ways to support and develop end-of-life care in the community, as provided by GPs, community nurses, etc.

**Development of bereavement support**
Working with service providers, statutory and voluntary, to raise awareness of bereavement issues and promote and develop bereavement support services

**Support for the voluntary hospice movement**
Development grants, coordination of national fundraisers for hospice care (Sunflower Days and Ireland’s Biggest Coffee Morning), advocacy support

**Carers**
Dedicated website, grants

**Forum on End of Life**
A unique engagement with all sectors of Irish society to consider and address the broadest possible range of issues relating to dying, death and bereavement

**Fundraising**
All of our work is underpinned by our fundraising programme, which includes targeted campaigns, events, special projects and partnerships with corporate supporters
Vision and Mission

Our vision is that no one should face death or bereavement without the care and support they need.

Our mission is to achieve dignity, comfort and choice for all people facing the end of life. We do this by addressing, with our partners and the public, critical matters relating to dying, death and bereavement in Ireland.

Values

- We believe in the hospice approach as the best way of upholding the right to a ‘good’ death
- We are respectful of all and committed to working in partnerships to meet established needs
- We are considered and informed in our approach
- We are innovative and pioneering in our quest for solutions to problems
- We are a progressive organisation, committed to internal learning and development
- We are transparent and accountable in our processes and programmes.

Strategic objectives

Strategic objective 1:
To advocate for quality services for care at end of life for all, including bereavement care

Strategic objective 2:
To continue, through partnership, to build capacity to meet the end-of-life and bereavement care needs of patients and their families in all care settings, irrespective of age or diagnosis.

Strategic objective 3:
To develop innovative responses to specific end-of-life care challenges in the areas of service equity, patient choice and the physical environment

Strategic objective 4:
To inform, educate and empower about key issues at end of life, including bereavement.

Strategic objective 5:
To further strengthen our independence and operational efficiency through our fundraising programme, underpinned by effective governance and internal development.
In mid-2011 – the year of our 25th anniversary – the Irish Hospice Foundation completed a review of its strategy which included internal and external consultation with a wide range of stakeholders. From this emerged a broad picture of the organisation’s strengths, core areas for development and challenges to be faced. This overview, and the ever-changing environment in which we work, have informed the development of the current strategy.

It emerged from the review that there is strong support for our work and that we are responding to many needs effectively. The IHF’s particular strengths are:

- our national remit and experience in advocacy, which means that we can champion change nationwide
- our organisational and financial independence, which allow us to be an outspoken and consistent voice for change
- our comprehensive vision, which ensures a focus on all people facing the end of life, whatever the nature of their illness or place of care
- our proven capacity for innovation, teamwork and creative thinking, which enable us to devise new approaches to service development
- our staff, who are highly respected and are perceived to demonstrate a strong team spirit.

The review also highlighted areas for development and the need to:

- ensure the overall sustainability and cohesion of the various strands of our work
- ensure that the outputs from our development programmes can become mainstreamed into public health and social services
- continue to collaborate and build strong relationships with our key strategic partners in order to achieve the best possible outcomes for those who are dying and those caring for them
- clarify our identity with the general public as regards our mission and role.

The task facing the Irish Hospice Foundation over the coming years will be to build on our strengths and work on the areas highlighted for development.
There are a number of key challenges facing us in achieving our vision:

**Gaps in the availability of hospice services**

Policy documents produced by the Department of Health and the Health Service Executive have clearly identified what is required to provide good, equitable palliative care services in Ireland. However, significant gaps remain. In particular, there are still geographical regions without an inpatient hospice to serve as the hub around which comprehensive community services can develop. Furthermore, because hospice services have evolved mainly around the needs of people dying of cancer, they are not yet routinely available to those dying with other illnesses. While 25% of deaths in 2010 were cancer-related, diseases of the circulatory system accounted for over one-third of all deaths. This challenges the healthcare system to respond to the needs of all people with a life-limiting illness, whatever its nature.

**Limited choice of care settings for the dying**

There has been an overwhelming shift over the last century towards dying in institutional care. In 2004, 67% of 'well' Irish people who were surveyed indicated that their wish would be to be cared for and if possible to die at home. The reality, however, is that most people die in healthcare settings, with only 25% dying at home. Even allowing for the fact that some people may change their mind as death approaches or their care needs become more complex, this strongly suggests that the wishes of many are not being fulfilled. Today, almost half of all deaths occur in busy hospitals, and while our Hospice Friendly Hospitals Programme is working for change, hospitals are often poorly equipped to provide the care culture and environment that are conducive to a 'good' death. There is a challenge to provide people with greater choice as regards where they are cared for and where they ultimately die, and in particular, to facilitate their wish – where it exists and is feasible – to remain at home.

**Death, dying and bereavement are sensitive subjects**

The hospice philosophy is a positive one, which emphasises quality of life and looks to relieve suffering, whether physical, emotional, psychosocial or spiritual. For many people, however, death and dying are difficult subjects, raising questions they may be reluctant to think or talk about, even though these are fundamentally important to everyone. The hospice movement has worked hard to convey the life-enhancing aspects of hospice and the benefits of referral to palliative care early in the course of illness, but fears often persist, sometimes to a point where such care is refused. There is a challenge to educate and inform the public, and to encourage more open dialogue about all issues relating to dying, death and bereavement.

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3. Health Service Executive, 2009, *Palliative Care Services – Five-Year/Medium-Term Development Framework*
**Need for care to be both of a high quality and cost-effective**

The current economic crisis is putting severe pressure on public health and social care services and on voluntary bodies. International research suggests that most of a person’s healthcare costs occur in the last year of life. A Dutch study found that the cost of caring for people in their last year represented 10% of the country’s total health budget. There is, therefore, an increasing challenge to ensure that this care is cost effective – while also retaining the high quality exemplified by the hospice approach. With comprehensive specialist palliative care and primary care services in place, more end-of-life care could be provided at home, delivered by GPs and home care teams with the back-up of the specialist services. This could provide a very cost-effective model of care – although a sound evidence base is needed to underpin the economic arguments in an Irish context, particularly in light of our evolving healthcare structures.

**Increasing population with chronic life-limiting diseases**

At present, about 28,000 people die in Ireland every year. However, projections indicate that the population aged over 65 will double over the next 30 years. While many people will maintain good health into old age, this is likely to give rise to a significant increase in the number of people with chronic life-limiting diseases, requiring care over longer periods. It will be a challenge to ensure that high-quality end-of-life care is available to people with all life-limiting illnesses, in all care settings. Of particular concern is the projected increase in dementia.

**Changing structures and agencies**

End-of-life care in Ireland is provided through both statutory and voluntary agencies. The health service is currently undergoing major transformation, which, underpinned by the Health Service Executive’s new clinical care programmes, will result in changes in the way services are delivered. Future development will also be influenced and supported by the work of such organisations as the Irish Association for Palliative Care (IAPC), the Irish Cancer Society (ICS) and other voluntary and professional bodies. The All-Ireland Institute of Hospice and Palliative Care (AIIHPC) – to which the IHF has committed €1m over the next five years – will be an important resource for all, helping to build knowledge, promote learning, influence policy and shape practice. Establishing and maintaining strong relationships through cooperation and collaboration will be essential in order to avoid duplication and deliver the best outcomes for patients and families.

**Strengthening/supporting the voice of the public & the voluntary hospice movement**

Our focus is to speak out for those who are dying and those left bereaved. At times this means that we are working very closely with the statutory services to deliver innovative responses to identified needs. At other times we are challenging these same services. We also seek to empower the public to plan and discuss their wishes for their care at the end of life and their death, which may in itself create pressure for service providers. These are inevitable tensions which need to be managed and resolved.

The origins and much of the development of hospice services in Ireland can be traced to the voluntary hospice movement. Even today, many voluntary hospice fundraising groups are essential to service delivery. As with the voluntary hospice groups, the IHF itself is continually challenged to raise the funds that underpin our services. Fundraising tensions need to be understood and managed. Some of the smaller groups around the country have expressed a need for support so that they can adapt to emerging challenges.

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Towards meeting the challenges

Over the coming three years, the Irish Hospice Foundation will:

- continue to work for the development of specialist palliative care services, focusing in particular on those regions where services are falling behind national policy
- continue to support the extension of palliative care to patients with life-limiting illnesses other than cancer
- continue to work with our service partners and the Network of Hospice Friendly Hospitals to improve the culture of care surrounding dying, death and bereavement in general hospitals
- continue to pursue an evidence-based approach to the development of hospice and bereavement care across all of Ireland
- explore ways to enable more people to have a ‘voice’ and greater choice as to where they will be cared for as they face the end of life and where they will ultimately die
- work to strengthen the capacity of primary care and community services to provide high-quality end-of-life care to patients and their families in the home
- work to build strong partnerships with all other stakeholders working in the area, both to inform our own development and for the benefit of the sector as a whole.

Implementation of our strategy

In the pages that follow our Strategic Plan 2012-2015 is described in detail. The planning process, however, is only the start of the work that will be needed to help us achieve our vision. As the first step in the implementation of our strategy, we will identify immediate, medium-term and longer-term timeframes for each strategic objective and action, according to their priority. These will be developed further in our annual business plans. For all activities, project plans will continue to be developed and used as a basis for organisational discussion and agreement.
Our strategic foundations

Vision and mission

Our vision is that no one should face death or bereavement without the care and support they need.

Our mission is to achieve dignity, comfort and choice for all people facing the end of life. We do this by addressing, with our partners and the public, critical matters relating to dying, death and bereavement in Ireland.

Our core belief is that everyone has a right to die with dignity and respect, and to have access to high-quality services in the care setting of their choice.

By promoting the principles of the hospice approach in all care settings, we can try to ensure that people have a ‘good’ death and can live life fully to the end. There may be many opportunities to have a positive impact on a person’s final journey, but there is only one chance to get it right.

We serve those facing the end of life and those who are important to them. We exist to empower and speak out for the dying person, whom we place at the centre of our focus at all times. For this reason, we work with staff and services delivering end-of-life care. We advocate in particular for those who have least choice and least access to high-quality care at the end of life. At a very broad level, we serve Irish society by raising awareness of dying, death and bereavement.

Values

The values set out below shape our thinking and inform our approach to achieving our vision. All these values are of equal importance and each of them influences how we do what we do. Their consistent application means we can work effectively, robustly and with integrity.

• We believe in the hospice approach as the best way of upholding the right to a ‘good’ death
• We are respectful of all and committed to working in partnerships to meet established needs
• We are considered and informed in our approach
• We are innovative and pioneering in our quest for solutions to problems
• We are a progressive organisation, committed to internal learning and development
• We are transparent and accountable in our processes and programmes.

To help achieve our vision and mission, the Irish Hospice Foundation has identified five strategic objectives arising from our core areas of activity which will define the focus of our work over the next three years. These are described in the following pages.
Strategic objective 1 - Influencing and challenging

To advocate for quality services for care at end of life for all, including bereavement care

Through our research and experience, we have endeavoured to become an informed and trustworthy voice on end-of-life care and bereavement education and support. We work to continually develop our knowledge and awareness. As a national advocacy and development body, we are committed to engaging with service providers to understand and support their needs. We challenge and work with policy makers and legislators to bring about change. Where we can, we join forces with others to strengthen our voice and our advocacy impact. Ultimately, we seek to empower Irish society to debate and respond to the needs of those who are dying or bereaved.

Despite considerable national investment, there has been an unacceptably uneven development of specialist palliative care services across Ireland. We advocate for a life-cycle approach to policy development, so that people’s end-of-life needs are given the same attention as other needs at other life stages. We work to ensure that official national strategy (as laid out in the 2001 Report of the National Advisory Committee on Palliative Care) is reflected in specific policy decisions and action. Although now somewhat dated, the 2001 report and the HSE’s subsequent implementation framework still represent important commitments. Over the coming three years, we will place a particular focus on the development of specialist hospice inpatient units in areas which lack them, as well as seeking improvements in all areas where the full range of services has not been developed.

Achieving objective 1 – strategic actions over three years

1.1 We will unify our approach to advocacy across the whole organisation, clarify our advocacy messages and ensure that we influence through a range of channels. We will develop an engagement and communications strategy to maximise awareness of our agenda among politicians, policy makers and senior health service management.

1.2 We will strengthen the evidence to support the adoption of the hospice approach as policy in all end-of-life care settings, and will use the available evidence to focus on areas of least investment in hospice care to date. Much of this work will be furthered by working with our partners to examine the evidence base supporting current development, and through a planned programme of discussion on key issues.

1.3 We will continue to engage with the media on all aspects of our work. By maintaining a high media profile, we will ensure that end-of-life issues are kept in the public mind, thus encouraging debate. This will also enable us to play a strategic role in influencing the policy agenda, as well as helping to attract public and commercial funding for our work.

7. Health Service Executive, 2009, Palliative Care Services – Five-Year/Medium-Term Development Framework
1.4 We will further develop our support for the advocacy and communications work of local hospice fundraising groups by:

- continuing to coordinate Sunflower Days and Ireland’s Biggest Coffee Morning in partnership with them
- continuing to build relationships with them, particularly in areas where the implementation of national policy has been slowest, so as to gain a better understanding of local needs and issues and how best we might assist in responding
- offering advice in relation to advocacy and communications where requested, and encouraging local groups in the same region to work together.

1.5 We will ensure that our knowledge of the issues relating to end-of-life, palliative and bereavement care remains robust by establishing an advisory function for the Foundation which will draw, in a structured manner, on national and international expertise to inform our work. We will also meet with key service agents, including specialist and generalist palliative care providers, to identify how we can best support their work.

1.6 We will explore the interest in and potential for developing a national end-of-life and bereavement strategy for Ireland. We will do this through consultation, research in other jurisdictions and building on previous public engagement, in particular the work of the Forum on End of Life.

**Expected outcomes:**

- Clear and consistent messages on our core positions and on all relevant issues
- A solid and evolving evidence base to support our advocacy and communications agenda
- Closer partnerships with the political and policy-making systems and with statutory, voluntary and professional bodies
- Increased public awareness of end-of-life issues and more public debate on dying, death and bereavement
- Clearer understanding between the IHF and critical stakeholders on key issues
- Enhanced advocacy/communications support for local voluntary hospice groups
- Structured access for the IHF to expert advice on a range of issues of relevance to our work
- Greater understanding of the resources required to deliver an end-of-life strategy.
Strategic objective 2 - Achieving change through capacity building and partnership

To continue, through partnership, to build capacity to meet the end-of-life and bereavement care needs of patients and their families in all care settings, irrespective of age or diagnosis

The Irish Hospice Foundation has developed a number of programmes that are having a positive impact on end-of-life and bereavement care. We will continue to oversee and support the integration of these programmes as appropriate. We seek to empower both the health service and the Irish public to debate and explore how patients can access a full range of quality services to meet their end-of-life care needs and preferences.

To date, we have succeeded in influencing the care of people at the end of life by initiating collaborative programmes that support staff and services alike. Several such programmes are nearing the end of an initial phase and we are now looking to embed them into mainstream services. Sustainability will require meaningful and consistent engagement from all involved, and we will continue to work with health care staff and with the health service itself to maximise the long-term impact of these programmes and to develop robust monitoring and review arrangements.

As outlined on page 5, key programmes include the following:

The Hospice Friendly Hospitals (HFH) Programme was launched in 2007 and now has over 60 hospitals (acute and community) linked to its work. End-of-life care is firmly on these hospitals’ agendas, thanks to the establishment of hospital standing committees, staff development programmes, the Design & Dignity grants scheme, the roll-out of a range of practical resources, the National Audit of End-of-Life Care in Hospitals and the development of both Quality Standards and an Ethical Framework for end-of-life care.

The Palliative Care for All Programme supports the development of palliative care for people with advancing life-limiting diseases other than cancer, and includes action research projects currently under way in relation to advanced respiratory disease, heart failure and dementia. It also provides funding for a night-nursing service for patients dying at home with illnesses other than cancer.

The Primary Palliative Care Programme was started in 2010 and has begun to explore how support for those facing the end of life in primary care settings can be strengthened. A report8 on its initial phase, developed between the Irish Hospice Foundation, the Irish College of General Practitioners and the HSE, has identified some practical initiatives that will support primary care teams in identifying, anticipating and responding to the palliative care needs of their patients.

Paediatric Palliative Care. The publication by the (then) Department of Health and Children of a policy on children’s palliative care in 20109 provided the context for the further development of children’s palliative care services. Arising from this, the IHF is currently funding Ireland’s first children’s palliative care consultant, and will also fund five out of a team of eight outreach nurses caring for children with life-limiting illness in the home.

8. Health Services Executive, Irish College of General Practitioners, and Irish Hospice Foundation, 2011, Primary Palliative Care in Ireland
Our strategic objectives

Development of bereavement support
Our Education and Bereavement Resource Centre was established in 2003. In addition to its education and training functions, it includes public and professional information services focusing on loss and bereavement. We aim to promote best practice in bereavement care and integration across the voluntary, health and education sectors. We do this by working in partnership with the HSE on bereavement care projects. We have also been working to promote national networks and links for bereavement care providers. At the Irish Hospice Foundation, we consider bereavement care at three levels:

- Level 1 is about making the most of natural support networks and providing information in people’s local communities.
- Level 2 comprises access to volunteer support, befriending, and informed professionals
- Level 3 aims to provide access to specialist mental health professionals for the small number of people with more complex or prolonged grief.

Development grants
Our development grants programme supports local innovation associated with specialist palliative care.

Partnership is a core value for the Foundation – we seek to add value to the work of others, and equally, are dependent on relationships with key partners. It is only by working together with others that we can build capacity to support end-of-life care needs. In particular, the contribution of the voluntary hospice movement to the development of services has been tremendous, and we seek to support that work, in line with national policy direction.

We work with the Department of Health, the HSE, the All-Ireland Institute of Hospice and Palliative Care (AIHPC), the Irish Association for Palliative Care (IAPC), the Irish Palliative Medicine Consultants Association (IPMCA), the Voluntary Hospices Group, Directors of Nursing in Specialist Palliative Care, the Network of Hospital Friendly Hospitals, educational institutions, bereavement support groups and local hospice fundraising groups. We will also work with NGOs in the ageing sector, such as Older and Bolder, and with disease-specific support organisations.

Strategic partners

Department of Health & other Government Departments
Voluntary hospice movement & service providers
Professional bodies* & educational institutions
Health Service Executive
All Ireland Institute of Hospice and Palliative Care
Political establishment

The Irish Hospice Foundation

*Includes the IAPC, Directors of Nursing in Specialist Palliative Care and Irish Palliative Medicine Consultants Association
Achieving objective 2 – strategic actions over three years

2.1 We will sustain the work of the Hospice Friendly Hospitals Programme (2007-2012) by supporting its National Steering Committee and the growing Network of Hospice Friendly Hospitals in implementing development plans based on the National Audit\textsuperscript{10} and Quality Standards for End-of-Life Care in Hospitals\textsuperscript{11}.

Development plans include: education, skills and practice development; audit and review of deaths; ethical awareness; improvement of the physical environment; and planning and co-ordination with primary and secondary services. We will develop a three-year plan to support the Network, taking into account what we have learnt from the programme and the need for effective partnering with the HSE, voluntary hospitals and the Department of Health in order to ensure sustainability.

2.2 We will work with our partners to disseminate the outcomes of the ‘Palliative Care for All’ action research projects in relation to heart failure, advanced respiratory disease and dementia, which are due for completion in 2012. We will use these findings to influence policy within the Department of Health and HSE-led clinical care programmes. This will support the integration of palliative care in the management of other chronic life-limiting diseases, including progressive neurological diseases and advanced kidney disease.

2.3 We will develop resources to equip and support primary health care professionals to respond to the palliative care needs of patients in the community. This work will be undertaken in partnership with the Department of Health, the HSE, the Irish College of General Practitioners and community-based health care professionals.

2.4 We will pursue the full implementation of Government policy on children’s palliative care. We will continue to fund the children’s palliative care consultant and part-fund a team of outreach nurses. We will support national development with an emphasis on the provision of a strategic direction and support for a governance and evaluation framework to assist in the overall sustainability of this programme.

2.5 We will develop a network for children’s bereavement services, in partnership with the Family Support Agency, to offer a collective focus for all agencies providing bereavement care to children. In an initial phase this will involve completing a study to assess the scope of such a network or umbrella organisation. We will continue to work with adult bereavement groups and to develop collective training resources.

2.6 We will review and strengthen the focus and administration of our grants programme to ensure that it continues to target strategic priorities and deliver sustainable outcomes for end-of-life care.

2.7 We will consider the end-of-life needs of such vulnerable groups as the homeless, people with intellectual disability and the frail elderly, and explore ways in which the hospice approach might be incorporated in their care. We will do this in partnership with key agencies, including the Department of Health, the HSE, other service providers and the AIHPC. We will use this work to make recommendations for further research and future service development.

\textsuperscript{10} Hospice Friendly Hospitals Programme, 2010, National Audit of End-of-Life Care in Hospitals in Ireland, 2008/9
\textsuperscript{11} Hospice Friendly Hospitals Programme, 2009, Quality Standards for End-of-Life Care in Hospitals
Expected outcomes:

- Development plans in place to assist acute hospitals in implementing the Quality Standards for End-of-Life Care, with a designated member of the senior management team responsible for related support structures and processes
- Increased capacity for the integration of a palliative care approach in the management of non-cancer life-limiting conditions
- Development of resources for community-based health care professionals to support the delivery of primary palliative care
- Full implementation of the children’s palliative care programme
- Viable networks of children’s bereavement services
- Refined targeting of our grants programme to support our strategic objectives
- A deeper understanding of the end-of-life care needs of vulnerable groups

Strategic objective 3 - Innovating and pioneering

To develop innovative responses to specific end-of-life care challenges in the areas of service equity, patient choice and the physical environment

One of the particular strengths of the Irish Hospice Foundation is our capacity to pioneer new developments. We have steadfastly advocated for equitable and quality developments across all care settings. Given the economic climate and medium-term forecast, we are challenged now more than ever to think creatively about how best to meet the needs of people and their families who are facing the end of life. Specific challenges which we have chosen to focus on at this time include equity of services, choice of care location and the physical and psychological environment.

Many of the priorities laid down in the HSE’s Five-Year Development Framework are increasingly unlikely to be addressed within the term of this strategy. So, while continuing to advocate for its full implementation, we will also be promoting the pursuit of innovative solutions to meet needs. Of particular concern are the areas of Ireland which have not developed the full range of palliative care services in line with national policy. We have termed these ‘blackspot’ areas; they include the North East, Midlands and South East. Hospice developments in these areas can only be undertaken by service providers, local hospice groups and concerned individuals working together, but we can stimulate and support this collaboration and help with the development of regional business plans. In so doing, we will be supporting concerted local efforts to achieve change.

Over the past few years, the Foundation has begun to consider all the care settings in which people die - making inroads to improve end-of-life care in places such as general hospitals and in primary care. In our next stage of development, we would like to work in partnership with community residential facilities to explore their needs in this regard.

12. Health Service Executive, 2009, Palliative Care Services – Five-Year/Medium-Term Development Framework
As stated earlier, there is a challenge to provide people with greater choice as regards their location of care, and particularly to facilitate the wish to die at home. Our emphasis is primarily on choice – and we recognise that patients’ wishes may change over time. Even so, we believe that services can adapt to facilitate greater choice, although achieving change will require considerable reflection and partnership between care providers. Our ‘Pathfinder Project’ recently established in Cork is beginning to look at this area, and we will build on this work.

The Irish Hospice Foundation has, through our Hospice Friendly Hospitals (HfH) Programme, played a leading role in highlighting the importance of high-quality physical environments both in the recovery of ill patients and in the care of people at the end of their lives. One of the key themes of the programme has been ‘The Physical Environment’. There is a growing body of evidence linking the physical environment to staff effectiveness in delivering care and to patient outcomes. This has recently been recognised by Government, which stated that:

_The driving force for capital investment in health and personal social care is to support the provision of the best possible service to patients. Suitable and appropriate facilities are required to provide safe and cost-effective care. In addition, a well designed and well maintained health estate impacts positively on patient recovery rates, and can lead to reduced pain in patients, decreased infection rates and greater patient satisfaction._

In 2007, a review of the physical environment of 20 hospitals was undertaken for the HfH Programme. This was used to inform the development of the Design & Dignity Guidelines in 2008. In 2010, the HfH Programme secured government support for a Design & Dignity grants scheme to assist projects aiming to improve aspects of the physical environment affecting the dignity of people dying in institutions such as hospitals. Over €1.5 million will be committed to this over the coming years, through the State, philanthropic support and other fundraising. We plan to build a deeper appreciation of the potential and importance of design where facilities are being upgraded or developed.

**Achieving objective 3 - strategic actions over three years**

3.1 We will strive to support the development of new hospice and palliative care services and facilities in the ‘blackspot’ areas of the country where to date development has been weakest. This will be a key focus of our advocacy programme but we will also support, in partnership with service providers and the voluntary hospice movement, the development of integrated regional approaches to the provision of end-of-life care and hospice services. Where agreement on the shape of future services can be developed, we will further support the realisation of these plans.

3.2 We will devise, in partnership with key stakeholders, a programme for supporting quality of life at the end of life in residential care settings. This will combine the learning emerging from the HfH Programme (Community Hospitals Network), the Primary Palliative Care Programme, the dementia projects under way as part of our Palliative Care for All Programme, the nursing homes education programme, the link nurse initiative funded by the Irish Hospice Foundation and the work of the HSE regarding the development of models of care for older people.

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3.3 We will consider how patients and families can be supported in having more choice regarding where they receive end-of-life care and where they die. We will place particular focus on how to facilitate the wish to die at home. This will involve working with a range of service providers (including primary care services), developing supports for carers and exploring the use of new technologies. From our work to date – in particular the Primary Palliative Care Programme – we know that many more people want to be cared for and to die at home.

We will develop projects and feasibility studies which will explore how choice can be facilitated, and how the numbers of people dying inappropriately in acute hospitals can be reduced. One such study will address the need for emergency support to carers in the home and how the Foundation might ensure related services are developed.

3.4 We will further recognise and support family carers as they respond to the needs of dying relatives by informing and directing them to practical supports already available. We will also continue to develop supports for those caring for people facing the end of life.

3.5 We will build on work completed to date by our HfH Programme, by hospice service providers and by international experts in healthcare design. We will develop further the Design & Dignity grants scheme, so as to provide a comprehensive range of exemplar design projects addressing all areas of hospital environments which have an impact on end-of-life care. We will also seek further guidance and advice to support evidence-based design and how the healthcare system can be supported to achieve excellence.

3.6 We will explore how technology might contribute to increased choice for patients regarding place of care, by enhancing communications and support mechanisms between care staff involved in the delivery of end-of-life care. We will do this through our existing projects in primary care and in partnership with a range of service providers from health, information technology and research backgrounds.

Expected outcomes

- Regional plans in place for areas where the development of the full range of palliative care services has been weakest (beginning with one area)
- Deeper understanding of the needs of residential care settings regarding end-of-life care
- Increased understanding of the core enablers and barriers to patients being cared for in the home setting
- A range of IHF supports for carers in place and a strong relationship with agencies supporting carers
- Recommendations for emergency support to carers in the home setting
- A wide range of exemplar projects developed through the Design & Dignity grants scheme
- Improved understanding of evidence-based design with clear recommendations for further development
- Increased understanding of the role of new technologies in aspects of end-of-life care in primary, community and home care settings
Strategic objective 4 - Communicating, educating, empowering

To inform, educate and empower about key issues at end of life, including bereavement

We cannot achieve our vision without considering education, both in the formal sense of that word and in the broad sense of informing and raising awareness.

By providing training and education to staff and carers, we seek to empower them to initiate and broker conversations about death and dying with patients and families, and to understand their own roles and their personal impact. By developing our own staff, we help them to uphold the hospice approach in their work.

We are involved in education through funding and support (for example, children’s palliative care education, and core and individual grants); direct education provision (our bereavement education programmes, and our Final Journeys awareness-raising and communications training); and through capacity development initiatives connected to our projects (for example, developing facilitators).

Originating from work completed by the Irish Hospice Foundation over the last decade, the recently formed All-Ireland Institute of Hospice and Palliative Care (AIHPC) will be a key driver of development in palliative care education and research. We will work with the Institute on strategic approaches to education and training in end-of-life and bereavement care. We look forward to supporting and becoming involved in its work.

We also engage with the public on matters concerning death and bereavement, to ensure that the patient’s voice is reflected in all developments. By raising people’s awareness and expectations, we empower them to seek better end-of-life care.

The Forum on End of Life in Ireland is an IHF project which was initiated to find out what people in Ireland believe about dying, death and bereavement and to promote a national conversation on these matters. The National Council of the Forum is now looking to realise the recommendations and vision arising from the initial consultation exercise. Think Ahead, a system to guide people in recording and registering their preferences in the event of emergency, serious illness or death, was recently launched by the Forum and will be developed further over the coming years. We intend to continue to consult with the public in meaningful ways so that we can best understand their needs.

Service development can only happen where there are strong leaders who can advocate and influence to best effect. We hold a particular interest in fostering greater leadership within services – particularly in those regions where the development of hospice services has not kept pace with national policy. We would look to work with the statutory services as well as the AIHPC and the Irish Association for Palliative Care in order to arrive at leadership solutions.
Achieving objective 4 - Strategic actions over three years

4.1 We will develop an integrated strategy within the Irish Hospice Foundation for education and training in end-of-life and bereavement care, which will encompass education, awareness and development initiatives from all our programmes, and effective linkages with relevant developments in the statutory, voluntary and private health sectors; professional and representative bodies for healthcare providers; education and training organisations and the AIIHPC. It will also include our internal capacity-building function on end-of-life issues.

4.2 We will develop an inclusive and coherent three-year plan for our Education & Bereavement Resource Centre. This will include the delivery of courses on bereavement at ascending levels of complexity, to address the needs of the public, volunteers, support workers and clinicians. We will prioritise activities that promote integration across the three levels of bereavement care (see diagram, left, and page 16). The aim will be that bereaved individuals and families, and the professionals and volunteers who work with them, can access what they need, when they need it. We will also extend our bereavement resource function and develop a bereavement website.

4.3 We will develop our capacity to provide information to the public through our published materials, stands at conferences and events, our website, our media work, and through fundraising events such as Sunflower Days and Ireland’s Biggest Coffee Morning. We will also work to deepen understanding of the public’s needs concerning dying, death and bereavement, and to promote public education and information through advocacy and engagement.

4.4 We will develop a strategy for the IHF’s information function and library which will preserve, promote and facilitate access to the Foundation’s knowledge base and literature (in print and electronically) and which will serve the information needs of staff in the organisation.

4.5 We will support the National Council of the Forum on End of Life in addressing the issues raised in the Forum’s 2009 report\(^\text{15}\) and organised through its 10 ‘key action areas’. In particular, we will support the ongoing development of the Think Ahead project to guide people in discussing and recording their preferences in case of emergency, serious illness or death.

4.6 We will, by working with partner organisations, explore how leadership within palliative care can be developed with particular focus on regions of least investment. This will tie in with leadership developments already under way within the HSE, the public service and the HfH Programme.

Expected outcomes

- Development of an integrated Irish Hospice Foundation education strategy which will see the Foundation recognised as a key provider of quality education and training in end-of-life and bereavement care
- Increased availability and prominence of end-of-life and bereavement education and training across services
- Responsive library service
- Defined effective public education role as part of our communications function
- Measurable progress across all 10 key action areas identified by the National Council of the Forum on End of Life, including implementation of the Think Ahead project

Strategic objective 5 - Maintaining independence, organisational health and sustainability

To further strengthen our independence and operational efficiency through our fundraising programme, underpinned by effective governance and internal development.

Our independent voice enables the Foundation to be a strong and forceful advocate for the dying and bereaved. While we seek to work in partnership with both statutory and voluntary services, we also need to maintain our independence in order to be able to continuously strive for service development and improvement. Financial independence is central to this.

A history of creative fundraising initiatives has enabled us to foster many new developments in end-of-life care over the past 25 years – in specialist palliative care, in general hospitals, in children’s palliative care, in bereavement education and in primary care. We will continue to fundraise nationally to secure the resources necessary to enable us to achieve our strategic objectives.

We are fully committed to implementing the guide to best practice for charities known as the Statement of Guiding Principles for Fundraising, which promotes transparency, honesty and accountability. We will continue to contribute to the development and implementation of best practice in fundraising and governance across the charity sector. We are committed to ensuring that we are cost efficient and provide value in respect of the funds we raise so that we offer a model of good practice.

We are also committed to ensuring that our governance structures are effective and functioning. In adhering to high standards, we commit to regularly reviewing our internal governance processes.

Internally, the IHF has developed as a flexible and pioneering organisation. Its staff are experienced and driven by a passionate belief in access to high-quality care at the end of life as a human right. As the organisation evolves, we want to continue to develop our staff and support a learning environment relevant to people’s roles.
Our strategic objectives

Achieving objective 5 – strategic actions over three years

5.1 We will continue to develop and implement an annual fundraising programme to generate sufficient income to meet our needs, as set out in our yearly business plans. This will incorporate a range of fundraising activities, including, but not restricted to, direct mail, door-to-door campaigns, events, corporate fundraising and legacy promotion. All our fundraising activities are informed by the Statement of Guiding Principles for Fundraising and will be compliant with anticipated legislation arising from the Charities Act, 2009.

5.2 We will strengthen our fundraising support for local voluntary hospice groups. This will include the ongoing national coordination of Sunflower Days and Ireland’s Biggest Coffee Morning, as well as support for the development of the emerging ‘Support Your Local Hospice’ brand. Where requested, we will also make ourselves available as a source of advice and information on issues relating to fundraising, communications and governance.

5.3 We will develop further a robust governance and resources framework to facilitate the efficient and effective operation of the Irish Hospice Foundation and the achievement of its strategic objectives, building on ongoing reviews of its internal governance processes.

5.4 We will strengthen organisational structures and practices to encourage staff development, enhance internal communications and learning, and maximise efficiency and cost effectiveness.

Expected outcomes

- Successful fundraising programme
- Greater partnership with the voluntary hospice movement and strengthened development of Sunflower Days and Ireland’s Biggest Coffee Morning, as part of the ‘Support Your Local Hospice’ brand.
- Effective governance within the IHF
- Progressive organisational culture which encourages staff development and internal teamwork.
Glossary and References
Glossary

It is acknowledged that there is lack of agreement around the terms and definitions used today to describe illness from which people are unlikely to recover, the type of care these people may receive, and the final phases of life. For the purpose of this document, the following are key terms and phrases as we understand and use them.

**Life-limiting illness or condition**
A condition or illness from which there is no reasonable hope of cure, from which a person is expected to die.

**The hospice philosophy/hospice approach**
The hospice philosophy (or approach) takes as its starting point that death is a natural part of life; that dying is a part of our life experience. It aims to make sure that:
- people are treated with dignity and respect
- people are treated as individuals
- the physical, emotional, social and spiritual well-being of the patient are given equal emphasis
- family members and those important to the patient are included in the care approach.

**Hospice and hospice care**
The word ‘hospice’ refers to a whole philosophy or approach to the care of people with life-limiting illness, as well as to a building or care institution where hospice professionals and volunteers provide holistic care to such people and their families. Hospice care aims to improve the lives of people whose illness is no longer curable, helping them to live as fully as possible to the end of life, however long that may be. It is also concerned with providing support to families, and extends its reach into bereavement care. Hospice care can be provided in a hospice, at home, in a hospital or in a nursing home.

**Palliative care**
Palliative care is another term for the type of care provided by hospices, and also in other places, such as hospitals and care homes. According to the World Health Organisation, palliative care focuses on quality of life and attention to symptoms, which may be related to physical, psychosocial and spiritual needs. It is the term often used by those working in healthcare and medical settings, and most hospitals today will have palliative care consultants and other specialist palliative care staff.

In this document, we use both terms – hospice care and palliative care. As ‘hospice’ is part of our name, ‘hospice care’ is the term with which we most readily identify, but we do also use ‘palliative care’, as the term widely used by the public health service.

**Specialist palliative care/specialist palliative care service**
This is the care provided by a service which has palliative care as its core speciality. In principle, it involves a multidisciplinary team under the direction of a Consultant Physician in Palliative Medicine.

**Generalist palliative care**
This is care provided by a service which has another medical speciality at its core but includes the practice of palliative care principles, with a focus on quality of life.
Specialist palliative care unit or ‘inpatient unit’
These terms refer to residential or day care facilities staffed by palliative care professionals, and are sometimes used instead of ‘hospice’.

Care at end of life/end-of-life care
We use these terms in the Irish Hospice Foundation to refer to all aspects of care relating to dying, death and bereavement which a person receives towards the end of life. In this context, ‘end of life’ can be from the time of diagnosis, the months before death or even the last hours of a person’s life – it is a continuum, rather than a point in time.

Care at end of life includes care for:
- people living with advanced life-limiting conditions (for whom death within a period of 1-2 years is likely)
- people in the terminal phase of illness
- parents and families where there has been a death in the womb or in infancy
- the bodily remains of the deceased person
- those affected by sudden death
- families and friends of the person nearing the end of life, and also the staff who care for them
- the bereaved

Bereavement care
This term refers to the support, information and services available to bereaved people through their families and friends, communities, education systems and health care providers, regardless of the circumstances of their loss (see page 16 for details)

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