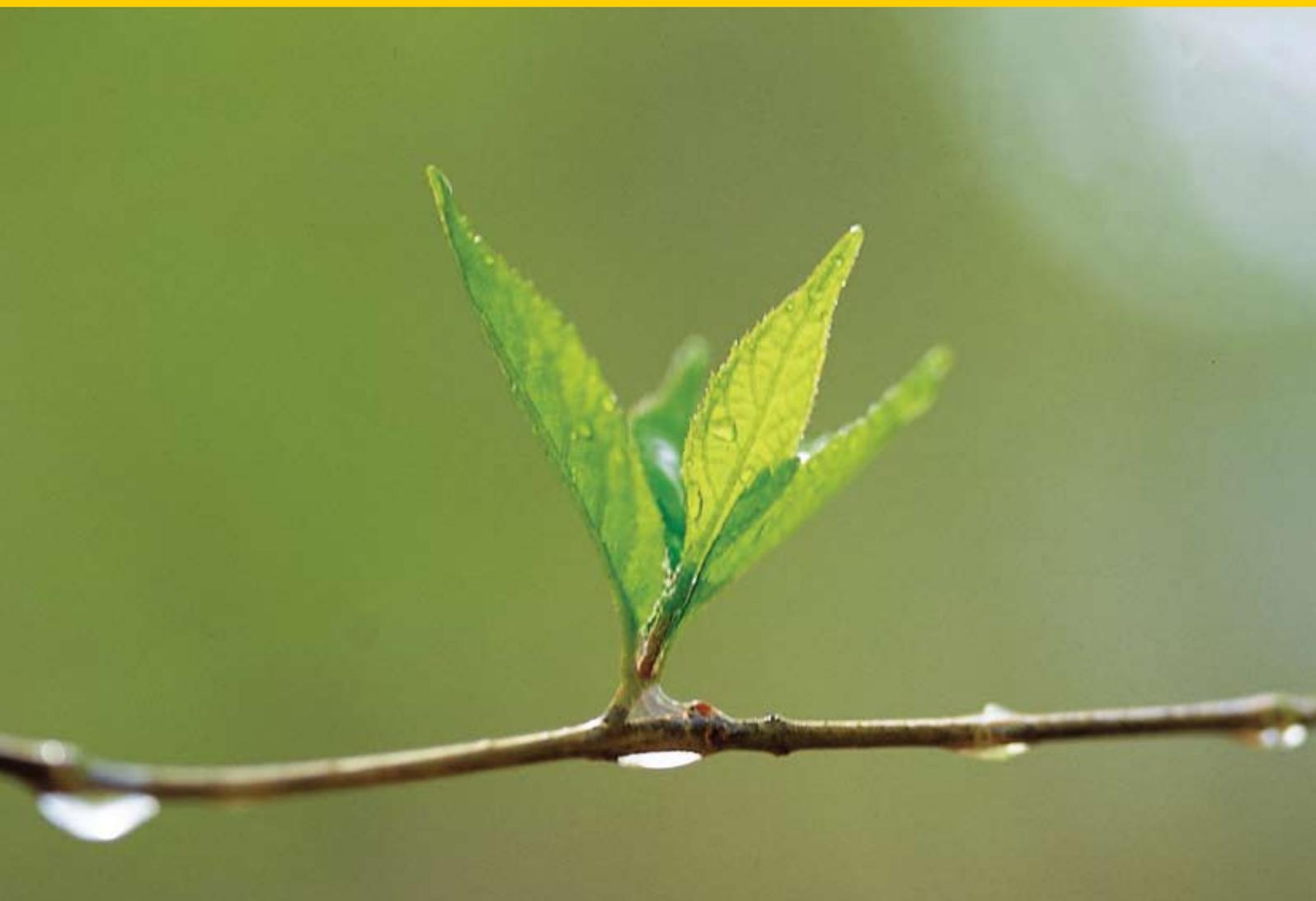




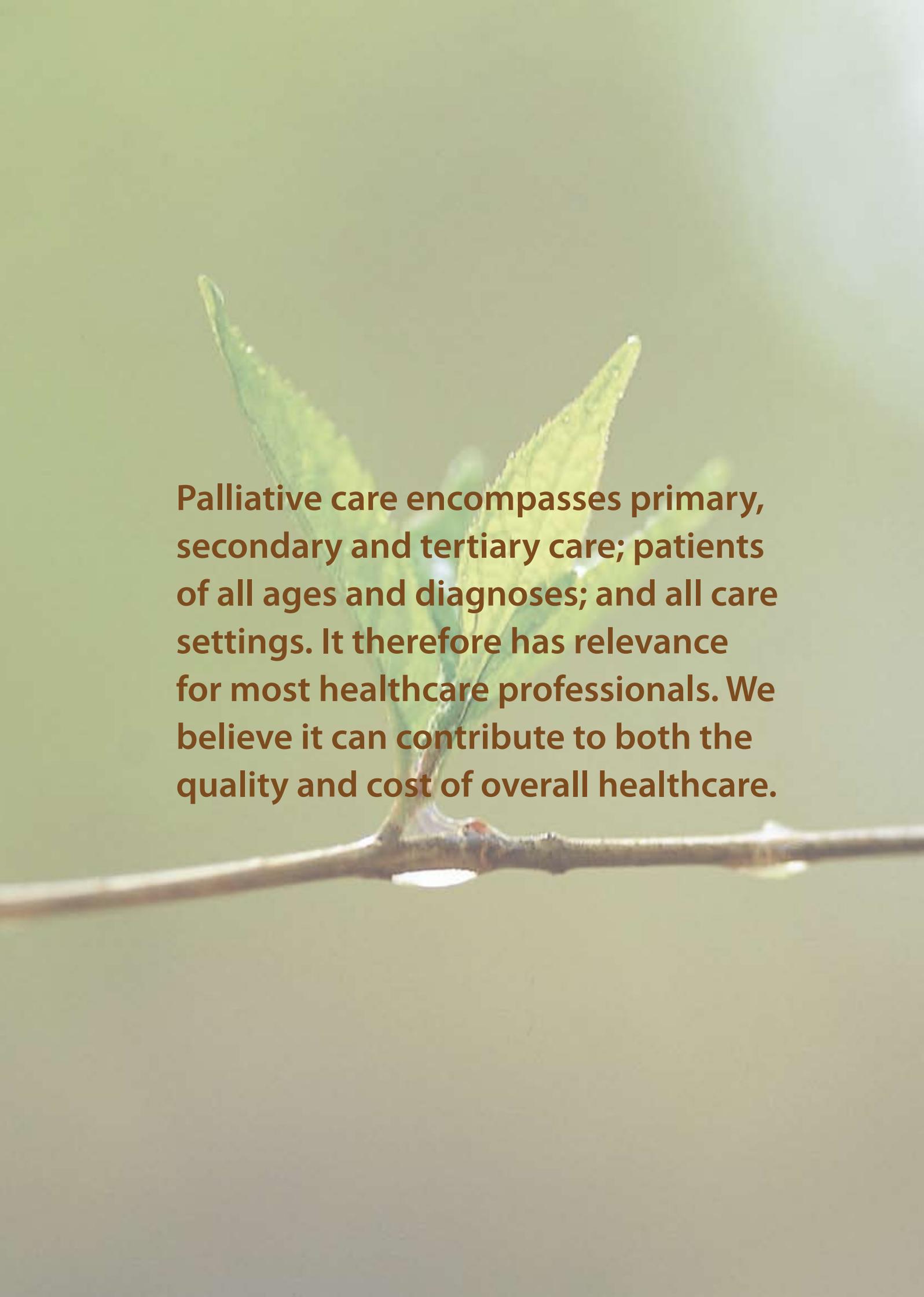
THE IRISH  
**HOSPICE**  
FOUNDATION

# The strategic importance of palliative care within the Irish health service

## Perspectives on future service delivery



IHF Perspectives Series: No. 1

A close-up photograph of a tree branch with several green leaves against a soft, out-of-focus background. The branch is horizontal and runs across the lower third of the frame. Several leaves are attached to the branch, with two prominent ones pointing upwards and outwards. The leaves are a vibrant green color with visible veins. The background is a light, hazy green, suggesting a natural outdoor setting. The overall mood is calm and natural.

**Palliative care encompasses primary, secondary and tertiary care; patients of all ages and diagnoses; and all care settings. It therefore has relevance for most healthcare professionals. We believe it can contribute to both the quality and cost of overall healthcare.**

# Summary

Palliative care encompasses primary, secondary and tertiary care; patients of all ages and diagnoses; and all care settings. It therefore has relevance for most healthcare professionals. We believe it can contribute to both the quality and cost of overall healthcare.

Any element of a national healthcare system that cares for a significant proportion of the population, expects client numbers to continue to grow, and commands a significant direct and indirect budget, must plan effectively for the future delivery of services. This is particularly the case with palliative care. The management of our approach to death, dying and bereavement within our health service matters – not only to patients but to the health system as a whole.

A truly strategic approach to the care of people facing the end of life makes political and economic sense for the government because:

- Death is a natural life experience which **affects a significant proportion of the population** – 27,000 people die in Ireland each year, and up to 270,000 are newly bereaved<sup>1</sup>.
- **Demand for palliative care is growing**, as more people are living longer with life-limiting conditions and will therefore have increasing palliative care needs.
- Anticipating and planning for people's palliative care needs will ensure that they have a **better quality of life**, and will increase the chance of each person dying in the care setting of their choice.
- While the state budget for specialist palliative care currently (2012) stands at €78 million, international evidence suggests that in reality **10%-15% of national healthcare spending goes on care at the end of life**<sup>2</sup>. In Ireland, this would be about €1.3 billion. With careful attention, better patient and service outcomes can be achieved for this expenditure.
- Anticipating and planning for the palliative care needs of the population will allow the government **to fulfil many of the welcome and ambitious commitments made in the Programme for Government**.
- Anticipating needs and planning for palliative care can assist in **preventing inappropriate emergency admissions** to expensive care settings such as acute hospitals, and can **facilitate discharge and the provision of care closer to home, in line with patient preferences**. A study commissioned by the Health Service Executive (HSE) found that 40% of patients being cared for in hospitals could be more appropriately cared for elsewhere<sup>3</sup>.
- **Public interest** in end-of-life issues is increasing and is likely to result in more public demand that everyone should be able to have a 'good death'.
- **A significant resource is available in the form of the voluntary sector**, which is currently pioneering important developments in the area of care at the end of life, and is committed to innovation.
- Specialist palliative care services play a critical role in the development and provision of care for people with life-limiting illnesses **in all care settings**, which makes it an **important component of the overall health service**.

The reform of the health service offers a strategic opportunity to ensure the best possible outcomes for people with palliative care needs. However, to achieve better care for these patients will require development at a number of levels, and any new directions or structures for palliative care will need to be underpinned by clear principles:

- **Strategic leadership** at the highest level of the health service – this will be essential to drive the development of comprehensive palliative care services as a core government commitment.
- The **integrated provision of palliative care** to all patients in every healthcare setting, including – where clinically feasible and in keeping with the patient's wishes – in the home.
- **To ensure the seamless delivery of services** across all of the HSE's proposed new Directorates, a **mechanism for coordinating responsibility for palliative care**.

This paper proposes action in five key areas, with recommendations for each area, as outlined below. More detail is provided within the paper.

1. Based on Central Statistics Office figures, 2010

2. Murray, E., How advocates use health economic data and projections, Journal of Pain and Symptom Management, Vol. 38(1), July 2009

3. Prospectus Consulting, Acute Hospital Bed Use Review, Health Service Executive, 2007

\* The Irish Hospice Foundation's Forum on End of Life in Ireland enjoyed significant public engagement during its period of public consultation in 2009-2010

## THEMES

### Strategic and structural support

## SUMMARY OF KEY RECOMMENDATIONS

- The palliative care service strategy should be managed by a senior official of the Department of Health with responsibility for overseeing the entire palliative care budget.
- Strategic mechanisms should be developed to allow the HSE's Palliative Care Clinical Care Programme to work logically across the Department of Health and all of the HSE's new health Directorates.
- The government's 2001 palliative care policy should be updated to take account of more recent developments and research findings.
- An updated five-year development plan for palliative care services should be drawn up and implemented, with the aim of addressing inequities in services and facilities, and providing both specialist and generalist palliative care across all care settings and for all patient diagnoses.
- Clear mechanisms should be developed for the inclusion of the voluntary sector in the planning process, given that it leads and delivers most of the country's inpatient specialist palliative care services.
- The national strategy should address public education needs in order to promote a greater understanding of palliative care and more discussion of dying, death and bereavement in Irish society.

### Strengthened financial support

- To support high-quality patient-focused services, there should be a dedicated, trackable budget for palliative care under the annual health budget.
- The palliative care budget should be viewed in context. This is an evolving area which needs championing and protection – further cuts will have a direct impact on service delivery.
- Within each of the new HSE Directorates, an annual core budget should clearly establish the resources allocated to palliative care, and should allow for tracking and monitoring of expenditure.
- Palliative care should be included in the Universal Health Insurance (UHI) 'basket' of services.
- The Department of Health's commitment to introduce UHI and complete a prospective funding model for palliative care in 2013 should take account of these recommendations

### Planned service delivery

- Palliative care services should be managed as a single entity in order to avoid fragmentation.
- To facilitate the effective delivery of service plans for palliative care across all care settings so that there is equitable access to palliative care, a senior official, supported by a professional staff, should be assigned responsibility for the operational delivery of palliative care.
- Palliative care services should be available in the full range of care settings in which people die. While overall responsibility will be retained within the Social and Continuing Care Directorate, the remit should extend to palliative care services provided in other areas of the healthcare system, such as primary care. This will mirror structures at the level of government departments.

## THEMES

### Planned service delivery cont'd

## SUMMARY OF KEY RECOMMENDATIONS

- A mechanism should be identified to coordinate and direct all organisational and developmental responsibilities for palliative care across all Directorates. This should include regional service managers with responsibility for the development of palliative care.
- Existing levels of service should be maintained and sustained as a matter of utmost priority - any deterioration in the level of services available to patients who are dying would be unacceptable.
- Each hospital group should be required to develop a strategic plan for end-of-life care within each of its hospitals. The Hospice Friendly Hospitals Programme – an Irish Hospice Foundation (IHF) initiative – can assist in the development of these plans. The HSE's Palliative Care Clinical Care Programme will provide leadership as regards clinical care pathways.
- Systematic gathering and sharing of information on matters relating to end-of-life and palliative care is needed throughout the health service in order to support the development and adoption of minimum data sets for palliative care in all care settings. This will inform and strengthen service delivery.

### Building capacity through the HSE's Clinical Care Programmes

- Support is required for the HSE's Palliative Care Clinical Care programme to continue to develop service-wide policies and approaches.
- Interdisciplinary models of integrated care for palliative care patients should be developed by the Palliative Care Programme as a matter of urgency.
- A workstream under the direction of the Palliative Care Programme should be supported to develop a commissioning model for palliative care. Building on the work currently under way in Trinity College under Prof. Charles Normand, this should be capable of being implemented across all of the new HSE Directorates.
- All of the Clinical Care Programmes should be directed to include a workstream on palliative care. This will ensure that palliative care approaches are embedded in the care of all patients with life-limiting illnesses, whatever their diagnosis.
- Membership of the HSE's national Palliative Care Working Group should be extended to include the representation of those voluntary agencies which are contributing significantly to policy and service development.

### Support for staff development and training

- A system of education for health and social care professionals should be developed in partnership with training bodies and health service training structures, to promote competencies, link to practice development and incorporate continuing professional development.
- To supplement the education of individuals, training and staff development initiatives should be developed for teams, units and organisations. Voluntary agencies, such as the voluntary hospices and the Irish Hospice Foundation, can assist.
- Staff release for training must be preserved, as there is a need for a technically and socially competent workforce which can meet patient needs within a range of role remits and care settings.

# IHF Perspectives

## on future palliative care service delivery

### Introduction

The Irish Hospice Foundation (IHF) is the national charity dedicated to all matters relating to dying, death and bereavement in Ireland. 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, in all care settings.

It is our belief that the current re-organisation of the Irish health service provides a real opportunity to ensure better and more cost-effective care of the dying – potentially a powerful measure of success for the reforms proposed. We also believe that improving services and access to them for people with palliative care needs has important implications for the overall health service, especially in difficult economic times.

Some 27,000 people die in Ireland every year and about 270,000 people are newly bereaved<sup>4</sup>. Palliative care meets the needs of patients with life-limiting conditions, and specialist palliative care services cater for those with complex needs. Figures show that in 2010, 6,733 deaths in Ireland were supported by specialist palliative care<sup>5</sup>. This accounted for 25% of all deaths and 72% of all cancer deaths. A population that is both (a) increasing and (b) ageing means that the numbers requiring end-of-life and palliative care are set to rise in the coming years. People are also living longer with life-limiting conditions and with multiple morbidities. They will therefore have specific palliative care needs.

International evidence suggests that **while only a small proportion of our healthcare budget is explicitly allocated to specialist palliative care (approximately 0.5%), 10-15% may actually be spent on the care of people approaching the end of life<sup>6</sup>**. For example, one UK study found that **while people in their last year of life made up only 1% of the population, they accounted for 29% of hospital expenditure<sup>7</sup>**. An integrated approach to the planning and delivery of this care across all care settings is essential to ensuring the best possible outcome for those facing death and their families, as well as the most effective use of resources.

This paper was prepared against a backdrop of austerity and cuts in health spending, including in the palliative care budget. The government continues to pursue the reform and restructuring of the health service, as articulated in the document, *Future Health*, released in late 2012<sup>8</sup>. The aim is to develop a single-tier service, with access based on need rather than on income, to be achieved via Universal Health Insurance. The roll-out of the reform requires significant investment in primary care, the creation of not-for-profit hospital trusts and a 'money follows the patient' model of funding.

The development of specialist and generalist palliative care services is already supporting the delivery of some of the healthcare commitments made in the Programme for Government. The continued development of these services – particularly if managed strategically and with a clear overview – could contribute significantly to the achievement of the aspirations of reform.

While mindful of our current economic difficulties, this paper focuses on the opportunities now presenting. It suggests that there are five key areas that need to be addressed if we are to achieve quality and equity in care at the end of life for everyone who needs it:

- **Strategic and structural support**
- **Strengthened financial support**
- **Planned service delivery**

4. Based on Central Statistics Office figures, 2010

5. HSE Minimum Data Set for Specialist Palliative Care, 2010

6. Murray, E., How advocates use health economic data and projections, *Journal of Pain and Symptom Management*, Vol. 38(1), July 2009

7. Seshamani, M. and Gray, A.M., Time to death and health expenditure: an improved model for the impact of demographic change on health care costs. *Age and Ageing*, Vol. 33(6), pp. 556-561, 2004

8. Department of Health, *Future Health – A Strategic Framework for Reform of the Health Service, 2012-2015*, November 2012

- **Building capacity through the HSE's Clinical Care Programmes**
- **Support for staff development and training**

The overall aim, of course, is to ensure that the needs of patients facing the end of life and their families are recognised, planned for and properly addressed by our health service. Put simply, that every person who is dying is assured of comfort and dignity, and that their bereaved loved ones are supported in their loss.

This paper is aimed at key decision makers within the health service and the palliative care community. Its purpose is to:

- stimulate debate about the opportunities currently presenting for the development of palliative care services, with a view to ensuring improved service effectiveness and better patient outcomes
- influence service developments by including some practical recommendations on the structural positioning and management of palliative care services within the overall health service.
- present some challenges that will need to be addressed.

We welcome comments.

## Policy context

Many countries have recognised that increasing longevity and ageing populations mean that demand for end-of-life care is likely to rise sharply in the years ahead<sup>9</sup>. Countries with end-of-life care strategies already in place include the UK, Australia and New Zealand.

Within Ireland, the development of palliative care services has been determined over the past decade by three key government policies, as set out in the following documents:

1. *Report of the National Advisory Committee on Palliative Care (2001)*
2. *Palliative Care Services – Five Year/Medium Term Development Framework (2009)*
3. *Palliative Care for Children with Life-Limiting Conditions – A National Policy (2010)*.

These policies represent important commitments to the development of equitable patient-centred palliative care services in this state. To date, however, they remain at best only partially implemented, with no progress at all under some headings.

## Current palliative care service delivery

Palliative care is a distinct care approach which helps people with life-limiting conditions to live life as well as possible for as long as possible. Specialist palliative care services are concerned solely with the delivery of palliative care. Generalist palliative care is often provided within other areas of healthcare, such as primary care.

The range of specialist palliative care services in Ireland is broadly described as encompassing:

- Inpatient units (hospices)
- Community-based services (home care)

9. The Quality of Death: Ranking End of Life Care Across the World: A report from the Economist Intelligence Unit commissioned by the Lien Foundation, 2010

- Day care services
- Specialist palliative care services in acute general hospitals
- Indirect services (role in education, advocacy, etc.)
- Service linkages with other healthcare providers

The HSE's minimum data set showed that in 2010, nearly 4,000 patients were treated in specialist inpatient units or hospices<sup>10</sup>. The voluntary hospices play a unique role in the delivery of palliative care in Ireland, providing a majority of the specialist inpatient services. In 2010, the 'Voluntary Hospices Group', comprising Galway Hospice, Marymount University Hospice, Milford Care Centre, North West Hospice, Our Lady's Hospice & Care Services (including Blackrock Hospice) and St Francis Hospice (Raheny and Blanchardstown) estimated that they had provided 141 of 149 inpatient beds<sup>11</sup>. In addition to providing a model for the delivery of palliative care, the voluntary hospices also add significant financial resources to the state budget for palliative care, achieved through their own fundraising efforts.

The specialist palliative care sector can build on its existing strengths, including its capacity to:

- reduce inappropriate emergency admissions to hospitals
- provide high-quality care to those with complex conditions and support about one quarter of all Irish deaths
- share expertise with generalists working in the community
- work cooperatively with disease-specific specialists in hospitals in order to reach more patients with illnesses other than cancer.

It also offers:

- strong roots in the voluntary sector, which is willing to contribute both financially and in terms of experience to service planning and delivery
- well-developed services in some regions that are piloting innovative programmes and are willing to assist and share their experience with services based in less developed regions.

It is clear that any health service reform programme must preserve and protect current levels of service delivery.

## Impact of the current organisation and resourcing of services

Gaps in policy implementation, uneven service development and the under-resourcing of palliative care in Ireland is having significant consequences for patients and their families, as well as for other areas of the health service and for healthcare expenditure.

### Impact on patients and families

Many international studies have reported that palliative care services deliver better patient outcomes by improving quality of life. Palliative care provides more effective symptom control, enhances patient and carer satisfaction and can even have a positive impact on length of life. Good palliative care services also enable people who are dying to spend more time in their own home, and, when the time comes, to die at home if at all possible.

In a survey in 2004, 67% of 'well' Irish people indicated that their wish, if they were dying, would be to be cared for and to die at home<sup>12</sup>– but only 25% of people actually achieve this. Over 70% of Irish people die in care institutions of one kind or another, and 43% of deaths occur in acute hospitals.

10. HSE Minimum Data Set for Specialist Palliative Care, 2010

11. Voluntary Hospices Group, Service Provision for Specialist Palliative Care in Ireland: A Briefing Paper, 2010

12. Weafer & Associates, A Nationwide Survey of Public Attitudes and Experiences regarding Death & Dying, commissioned by the Irish Hospice Foundation, 2004



Of particular concern is that access to specialist palliative care is very uneven across Ireland, with huge gaps in local service development. A significant number of the priorities outlined in the HSE's 2009 Development Framework remain unfulfilled. Almost half of all counties lack hospice inpatient beds – notably in the North-East, South-East and Midlands but also including Mayo, Wicklow and Kerry; while new inpatient beds in facilities in Cork and North Dublin lie unused because of a lack of resources. This has serious consequences for people with life-limiting conditions and their families, and impacts significantly on where people die.

In 2009, for example, 65% of people who died from cancer in the area of the former Mid-Western Health Board did so either at home or in a hospice, compared to 38% in the North-East, 35% in the South-East and 40% in the Midlands<sup>13</sup>. The Mid-West has a modern hospice inpatient unit and is considered well-resourced as regards palliative care.

Acute hospital services are not geared towards dying. In the absence of specialist hospice beds, however, patients whose symptoms cannot be managed at home have little choice but to be admitted – and often to die – in busy acute hospitals, many of which lack the physical environment, culture of care and staff training conducive to helping people experience a 'good death'.

It should also be noted that even where inpatient hospice/specialist palliative care services *are* provided, having traditionally evolved largely around the needs of people with cancer, they are not yet routinely available to those with other life-limiting conditions, whose palliative care needs often go unrecognised. Yet in 2010, 33% of deaths in Ireland were due to diseases of the circulatory system, compared with 29% due to cancer.

Whatever the nature of their diagnosis, wherever in the country they may happen to live, people facing the end of life deserve better access to services and greater choice as regards where they are cared for and where they ultimately die. This includes children with life-limiting conditions, 350 of whom die in Ireland every year. Most of these children's families also want to care for their child at home. The Children's Hospice Home Care Programme, a joint statutory/voluntary initiative agreed in 2010 between the (then) Department of Health & Children and the Irish Hospice Foundation, is working to improve supports for families.

## **Impact on the health service**

As already noted, over 70% of Irish people die in hospitals or nursing homes. Some 43% die in acute hospitals. This has huge implications for the health service, particularly for the acute hospital sector. A national audit of hospital deaths conducted by the IHF's Hospice Friendly Hospitals Programme found that up to 25% of patients could have died at home if community resources were in place, but without hospice beds or hospice-at-home support, families are often left with little choice, as the patient's condition deteriorates, but to look for admission to acute hospitals or residential care<sup>14</sup>. This ultimately impacts significantly on emergency departments, trolley waits, bed utilisation and discharge rates.

In the Mid-West region, Milford Care Centre's hospice-at-home programme was able to reduce the rate of hospital deaths among its clients to just 6%<sup>15</sup>. Nationally, palliative home care services increase the proportion of deaths at home from 26% to 42%, and reduce the proportion of deaths in hospital from 43% to 21%<sup>16</sup>.

Studies undertaken in the US, Spain and Canada illustrate the positive impact of the development of regional palliative care programmes on the cost of acute care. In the Barcelona region the use of hospital resources by patients with incurable life-limiting illness fell by 61% following the implementation of a palliative care programme. Deaths in the home increased from 31% to 42%. Length of hospital stays were reduced by 25% and use of emergency hospital rooms was reduced by 42%<sup>17</sup>.

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13. National Cancer Registry, 2009

14. Hospice Friendly Hospitals Programme, National Audit of End-of-Life Care in Hospitals in Ireland 2008/9, 2010

15. Murray, E. *Forthcoming*, 2013

16. *Ibid.*

17. Gomez-Batiste, X., et al, Resource consumption and costs of palliative care in Spain: A multicentre prospective study, *Journal of Pain & Symptom Management*, Vol. 31(6), June 2006, pp. 522-32

## Potential for better outcomes

The hospice/palliative care approach empowers patients in so far as possible to play a more active role in the management of their own care, and supports families in caring for their loved one at home. With active planning and anticipation of needs, this can help reduce reliance on professionals. In addition, specialist palliative care services can provide expert advice and support to medical and nursing colleagues in general practice and other disciplines, further reducing the need to resort to acute services.

In short, a more vigorous, coherent and equitable approach to the development of palliative care services could provide:

### Better patient outcomes

- More people spending their last days at home and dying there, in comfort and dignity, surrounded by family and friends
- More equitable access to hospice inpatient beds for all patients with complex care needs that cannot be managed at home, regardless of the nature of their illness
- Fewer admissions and deaths in acute hospitals, in accordance with patient preferences
- A better quality of life for patient and family.

### Better outcomes for the health service

- The freeing up of resources in acute hospitals
- More care delivered in the community in cooperation with patients and families
- The harnessing of the resources of the voluntary sector to deliver better care.

## Cost of palliative and end-of-life care

The current budget for specialist palliative care in Ireland is €78 million, representing 0.6% of a total health budget in excess of €13 billion. During the past two years, the specialist palliative care budget has been reduced in line with other cuts in health spending.

International evidence would indicate that between 10-15% of a country's healthcare budget is actually invested in end-of-life care<sup>18</sup>. This suggests that at least €1.3 billion of the Irish healthcare budget is spent on the care of patients in the last year of life. This expenditure needs to be recognised and planned for appropriately.

Compelling international evidence shows that investment in comprehensive specialist palliative services across all care settings (the home, inpatient hospice, daycare and acute hospital) yields significant savings, by reducing the length and frequency of hospital admissions and expensive medical interventions<sup>19</sup>. Inpatient hospice care can stabilise life-limiting conditions, enabling people to return home to be with their families. An appraisal of the cost effectiveness of alternative models for delivering palliative care in Ireland is currently being undertaken at Trinity College Dublin, but as an example, in 2010, of the 133 day-care patients seen at St. Francis Hospice in Raheny, 52% had no hospital admission in the last six months of life<sup>20</sup>.

There is emerging evidence to suggest that the cost of the delivery of palliative care in Ireland is on a par with care provided in acute settings. The Voluntary Hospices Group, in a paper developed in 2010 noted that while the average yearly bed cost for 2010 was calculated at €262,000 or €718 per day for specialist inpatient units, data from the HSE Performance Monitoring Office had indicated that the average cost of an acute hospital bed in 2010 was €909 per day<sup>21</sup>.

18. Murray, E., How advocates use health economic data and projections, *Journal of Pain and Symptom Management*, Vol. 38(1), July 2009

19. *Ibid.*

20. St. Francis Hospice's Annual Report, 2010

21. Voluntary Hospices Group, *Service Provision for Specialist Palliative Care in Ireland: A Briefing Paper*, 2010

The low level of statutory funding means that, as in many other countries, palliative care services in Ireland are heavily reliant on the voluntary sector. The delivery of night nursing care in the home requires a significant contribution by both the Irish Cancer Society (ICS), which provides this service free of charge to cancer patients, and the Irish Hospice Foundation, which funds the same service for people with other conditions. The direct cost of running the ICS's night nursing service in 2007 was €1.7m., while the IHF has had to raise around €250,000 in 2012 to fund its service. Night nursing enables more people to fulfil their wish to die at home with dignity.

Voluntary sector funding complements and adds value to statutory funding, representing a tremendous resource for the State. There is huge potential to develop new and innovative funding models for palliative care services.

## The health service reform agenda

Announced in late 2012, the Department of Health's strategic framework for the reform of the health service is welcome in that it provides for a universal healthcare system which will give people equal access, based on need rather than on ability to pay, to integrated, multidisciplinary care by GPs, nurses, physiotherapists, occupational therapists and others, working in collaboration<sup>22</sup>. Particularly welcome is the commitment to complete a prospective funding model for palliative care.

However, the framework indicates that while primary and hospital care will be funded mainly via the Universal Health Insurance (UHI) system, specialised and social care services, including palliative and long-term care, will be funded by general taxation.

While we understand that this is an evolving field, we believe that palliative care should be covered by UHI, as it is in other European countries. The exclusion of palliative care from the UHI 'basket' of services may discriminate against those with complex chronic and other conditions, who require fully integrated care in all circumstances and settings. The final funding model adopted for palliative care should not place a disproportionate burden on older people with chronic life-limiting illness or those at end of life.

### Current opportunities

The health service reform process is having, and will have, a significant impact on local services for people with life-limiting conditions. It offers real opportunities to deliver better patient and health service outcomes:

- **Integrated healthcare:** Current government health policy aspires towards integrated service provision across all healthcare settings. A robust palliative care framework can deliver the right care in the right place for people of all ages, with all life-limiting conditions, all over Ireland.
- **Embedding best practice:** Through the HSE's Palliative Care Clinical Care Programme, palliative care can be embedded in other programmes which interact with patients approaching the end of life.
- **Strengthened strategic and operational management,** through structures to improve palliative care planning and delivery at all levels.
- As palliative care will be situated within Social & Continuing Care, **strengthened palliative care delivery across services within this Directorate.**

22. Department of Health, Future Health – A Strategic Framework for Reform of the Health Service, 2012-2015

## Current risks

If changes are introduced too hastily, however, problems could arise. At a time of rapid organisational change, specialist palliative care needs to be protected as an integral and strategic part of the health service. The following concerns exist:

- **Fragmentation of services could lead to specialist palliative care being seen as an add-on** or optional extra, or even as a non-essential service. Palliative care is a discrete and specialist service component and must be protected under the health service reform.
- Further disproportionate **budget cuts would undermine the progress made in specialist palliative care** in recent years, and could preclude the integration of end-of-life care. Reform must not be allowed to reduce current service levels.
- To be effective, the delivery of care needs to be seamless and integrated – from the hospital setting to care in the community. Without advance consideration of this issue, **the development of the new HSE Directorates could actually impede the ability of palliative care services to work effectively across all**, thus limiting their ability to provide better patient outcomes. For example, without the central driving force of key programmes such as the HSE's 2009 Development Framework for Palliative Care, strategic plans could lose momentum and see their impact reduced.
- At present it can be difficult to see how palliative care is prioritised, managed and directed at all levels within the health service. **Care needs to be taken to improve the national management of palliative care** and avoid further damage to the sector.
- There is a risk that **the reform programme could result in further delays** in the implementation of the government's 2001 policy and the HSE's 2009 Development Framework, which is currently behind schedule.
- **The positioning of palliative care within Social & Continuing Care could prove to be a challenge** to the equitable delivery of this care across acute hospital and primary care settings.

## THE WAY FORWARD

### How to deliver better service and patient outcomes through better palliative care

The reform of the health service offers a strategic opportunity to ensure the best possible outcomes for people with palliative care needs. To achieve better care will require development at a number of levels, and any new directions or structures for palliative care will need to be underpinned by clear principles:

- **Strategic leadership** at the highest level of the health service – this will be essential to drive the development of comprehensive palliative care services as a core government commitment.
- The **integrated provision of palliative care** to all patients in every healthcare setting, including – where feasible and in keeping with the patient’s wishes – in the home.
- To ensure the seamless delivery of services, **the development of a mechanism for coordinating responsibility for palliative care** across all of the HSE’s Directorates, with clear strategic and operational responsibilities and accountability.

It will be important to ensure that existing progressive development programmes in adult and paediatric palliative care (often involving state/voluntary sector partnerships) are maintained and further developed. A number of good end-of-life care initiatives currently in place with the active engagement of the HSE are having a positive impact at the bedside, and provide a model for what could be mainstreamed and rolled out nationally.

It will also be important to challenge the prevailing healthcare culture, which focuses predominantly on cure and traditionally regards death as a failure. In this regard, the proposed ‘Health and Wellbeing’ pillar of the Department of Health’s reform programme is welcome, and should facilitate recognition of the benefits of the palliative care approach and encourage its introduction at an earlier stage in the course of illness.

### Our vision for the future

There are five key elements to our vision for the future

1. Strategic and structural support
2. Strengthened financial support
3. Planned service delivery
4. Building capacity through the HSE’s Clinical Care Programmes
5. Support for staff development and training

### Strategic and structural support

The delivery of palliative care needs to be endorsed at the highest level of government, and structures put in place for the strategic and operational delivery of robust services. At government policy level:

- The **palliative care strategy should be managed by a senior official of the Department of Health**. This person should have overall responsibility for developing the palliative care budget and determining its effective use prior to commissioning being introduced.
- **Strategic mechanisms, including a common framework of policies and guidelines** regarding palliative care, should be developed to allow the HSE’s Palliative Care Clinical Care Programme to work logically across the Department of Health and the new health Directorates. The Clinical Care Programme should be facilitated to take a lead in this regard.

- The **government's 2001 palliative care policy should be updated** to take account of more recent developments and international approaches to care at the end of life across health services and the wider society, with an intention to develop a longer-term national end-of-life strategy
- **An updated five-year plan for palliative care services should be drawn up and implemented**, with the aim of addressing existing inequities in the provision of specialist and generalist palliative care. It should clearly articulate priorities across all care settings in which people die – acute hospitals, community hospitals, the home, long-stay facilities and specialist hospice inpatient units – and should be informed by identified patient need as opposed to diagnosis. Short- and medium-term strategies should be actively monitored.
- **Clear mechanisms should be developed to involve the voluntary sector** in the planning process, given that it leads and delivers most of the country's inpatient specialist palliative care services. The IHF is also willing to support the development of national strategies.
- Alongside service development, **national strategy should address public education needs** to ensure a greater understanding of palliative care and more support for discussion of dying, death and bereavement in Irish society.

### Strengthened financial support

- To support high-quality patient-focused services, there should be **a dedicated, trackable budget for palliative care** under the annual health budget.
- **The palliative care budget should be viewed in context.** This is an evolving service which needs championing and protection – further cuts will have a direct impact on service delivery.
- **There should be an annual core budget for palliative care within each of the new HSE Directorates**, which should clearly establish the resources to be allocated to palliative care and should allow for the tracking and monitoring of spending.
- Palliative care should be included in the Universal Health Insurance (UHI) 'basket' of services.
- The Department of Health's commitment to introduce UHI and complete **a prospective funding model** for palliative care in 2013 should take account of these recommendations.

### Planned service delivery

We are acutely aware of the comprehensive change programme planned to enhance service delivery. Through the evolving operational arm of the health services, the following should be put in place:

- **Palliative care services should be managed as a single entity** in order to avoid fragmentation, which will damage the sector and its capacity to deliver optimum outcomes.
- **Palliative care services should be available in the full range of care settings in which people die.** While overall responsibility will be retained within the Social and Continuing Care Directorate, the remit should extend to palliative care provided through other areas of the healthcare system, such as primary care. This will mirror structures in place at the level of government departments.
- **A mechanism should be identified to coordinate and direct all organisational and developmental responsibilities concerning end-of-life and palliative care in all Directorates.** This should include regional service managers with responsibility for the development of palliative care.
- **Existing levels of service should be maintained and sustained as a matter of utmost priority** – any deterioration in the level of services available to patients who are dying would be unacceptable.
- To facilitate the effective delivery of service plans for palliative care across all care settings so that there is equitable access to palliative care, **a senior official, supported by professional staff, should be assigned responsibility for the operational delivery of palliative care.** Located at senior level within one Directorate, but with a remit to work across the whole system, the primary focus of this official's work should be the strategic development of both generalist and specialist services, providing patient-centred care

in the palliative phase and at the end of life. This official's main priorities should be:

- To provide leadership
- To support excellence and innovation
- To build capacity in palliative care in order to enhance patient care, quality of dying and service delivery.

Most importantly, s/he should support the full delivery of initiatives planned under the Palliative Care Clinical Care Programme and the HSE's 2009 Development Framework

Other initiatives, too, will need to be supported and developed, ideally through this official. For example, the statutory sector, the voluntary sector, academic institutions and professional organisations such as the Irish Association for Palliative Care, have worked in partnerships over the years to enhance the delivery of care at the end of life through a variety of approaches, including:

- The work of the voluntary hospices to progress the development of palliative care nationally, including initiatives to facilitate more patients to be cared for at home. Many such initiatives could be mainstreamed into national practice.
- The implementation of end-of-life care development plans in hospitals, based on quality standards, through the IHF's Hospice Friendly Hospitals (HFH) Programme.
- The development and implementation of a national system for audit and review of deaths in all care settings.
- Initiatives aimed at reducing the number of people with palliative care needs being inappropriately admitted and/or dying in acute hospitals (e.g. Special Delivery Unit work; rapid discharge pathways; the IHF's Primary Palliative Care Programme).
- Initiatives which enable more people to die in or closer to their homes (Milford Care Centre's 'Hospice at Home' project; the IHF's Pathfinder Project in Cork).
- Staff training and development initiatives (competency framework; education programmes run by the hospices; the HFH Programme's Final Journeys).
- Service projects initiated through the work of the All-Ireland Institute of Hospice and Palliative Care.\*

The Irish Hospice Foundation would be willing to provide resources to support this official. Over time, the role might evolve into a dedicated office similar to the National Renal Office or Office for Nursing and Midwifery Development.

- **Each hospital group should be required to develop a strategic plan for end-of-life care within each of its hospitals.** The Hospice Friendly Hospitals Programme can assist in the development of these plans. Equally, the Palliative Care Clinical Care Programme will provide leadership as regards clinical care pathways.
- **Systematic gathering and sharing of information on end-of-life and palliative care issues is needed** throughout the health service in order to support the further development and adoption of minimum data sets for palliative care across all care settings. This will inform and strengthen service delivery.

### **Building capacity through the HSE's Clinical Care Programmes**

The Palliative Care Clinical Care Programme is critical to embedding real changes in service delivery. A palliative care approach also needs to be embedded within other care programmes, such as acute medicine, primary care and chronic disease management.

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\*We recognise that many of the listed initiatives are IHF-based. There are many other examples of voluntary and charity-led practice.

The following needs to be put in place:

- Support for the Palliative Care Clinical Care Programme to **continue to develop service-wide policies and approaches.**
- **Interdisciplinary models of integrated care for palliative care patients should be developed by the Palliative Care Programme as a matter of urgency.** Increased collaboration between specialist palliative care and other services will facilitate the delivery of more appropriate, targeted services for patients in all healthcare settings, so that their palliative care needs are anticipated and their access to services that enhance quality of life is improved. As is planned, these models of integrated care ought to recognise the role of both specialist and generalist palliative care (GP and primary care teams, community home carers, acute hospitals, etc). Such models should be developed nationally and agreed locally. Detailing local care pathways, roles, responsibilities and funding arrangements, the new models must be clearly defined and understood by all. They then can become part of the commissioning model for palliative care.
- The commitment given in the Department of Health's reform framework to complete a prospective funding model for palliative care should be supported through **the continuation of the workstream under the Palliative Care Clinical Care Programme charged with developing a clear funding/commissioning model.** It could be a hybrid model that allows for funding under the social care model and as part of UHI. This will build on the work currently under way in Trinity College under Prof. Charles Normand, and should be capable of being implemented through all the Directorates. It will streamline:
  - the commissioning and support of specialist palliative care services as part of local models of integrated care, under the Social and Continuing Care Directorate
  - the financial management of palliative care services, including ensuring that funds are used where planned
  - the development of indicators for quality palliative care services (in conjunction with the Palliative Care Clinical Care Programme, clinical leads and other critical stakeholders)
  - the commissioning and support of generalist palliative care services as part of local models of integrated care in non-specialist settings, such as acute hospitals and long-stay facilities.
- **Each of the Clinical Care Programmes should be directed to include a work-stream on palliative care.** This will ensure the embedding of palliative care approaches in all end-of-life care – for all patients and all diagnoses.
- **Membership of the HSE's National Palliative Care Working Group should be extended** to include the representation of those voluntary agencies that are contributing significantly to policy and service development.

### Support for staff development and training

In these difficult financial times, education can represent excellent value for money and can contribute to embedding palliative care in the general system and facilitating good patient outcomes. For system change, we need to see:

- **A system of education for health and social care professionals** to be developed in partnership with training bodies and health service training structures, to promote competencies, link to practice development and incorporate continuing professional development.
- **On-going training and staff development initiatives for teams, units and organisations,** so as to supplement the education of individuals. Voluntary agencies, such as the voluntary hospices and the IHF, can assist with this.
- **Staff release for training** to be preserved, as there is a need for a technically and socially competent workforce which can meet patient needs within a range of role remits and care settings.

# Challenges for the future

A number of challenges could hamper the efficient use of resources and contribute to poor patient outcomes. These include:

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

There has been an overwhelming shift over the last century towards dying in institutional care. A majority of Irish people now die in healthcare settings, with only 25% dying at home. Almost half of all deaths occur in busy hospitals. 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.

## **How to retain a focus on dying, death and bereavement across all Directorates**

In the face of tremendous service change, the organisational focus within the health service will naturally be on establishing the new Directorates. Palliative care is not solely concerned with the dying phase; it is often relevant throughout the course of long-term illness, and it covers all care settings. It remains a challenge to facilitate seamless transitions between care settings at the different stages of the disease trajectory, and to find the right mechanisms for this to happen.

## **Fulfilling national policy and addressing enduring service inequity**

Policy documents produced in the past by the Department of Health and the HSE have clearly identified what is required to provide good, equitable palliative care services in Ireland. However, significant gaps remain. Of particular concern are those areas of Ireland which have still not developed the full range of specialist palliative care services in line with national policy. While some capital investment would be required, the voluntary sector has funded significant capital development in the past and is potentially a willing funding partner.

Also, because palliative care services have evolved mainly around the needs of cancer patients, they are not yet routinely available to people with other life-limiting conditions. While 29% 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 all patients with life-limiting conditions, whatever their diagnosis, particularly in areas of least service provision.

## **Efficiently harnessing the resources of the voluntary sector to achieve common goals**

The IHF recognises the scale of the task required to build strategic capacity to improve patient outcomes at the end of life. The voluntary sector is willing to play its part not only in service provision, but also in offering assistance in determining strategic priorities. In reality, palliative care in Ireland is provided through both statutory and voluntary agencies. The health service reform programme 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 IHF, 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 (AIHPC) – to which the IHF has committed €1m over 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.

The resources and expertise of the voluntary sector should be harnessed in a structured and transparent manner. At present this is happening in an ad hoc and inefficient manner. For voluntary agencies, there is deep frustration in having funds and other resources available to support the delivery of palliative care priorities, while being unable to influence change or engage with the operational structures. Interaction with voluntary agencies should be enhanced through the creation of appropriate mechanisms – even if it is a challenge to identify the right model. New models, perhaps building on public/private partnerships developed in the past, should be explored with the voluntary sector.







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