Houses of the Oireachtas
Joint Committee on Health and Children

Report on End of Life and Palliative Care in Ireland

July 2014

Volume 1
Foreword by the Chairman of the Joint Committee on Health and Children, Jerry Buttimer TD.

Dying, death and bereavement are universal certainties.

On average 29,000 people die in Ireland each year. With up to 290,000 people newly bereaved. End of life issues will affect every member of the population without exception, encompassing both physical and mental health areas.

A significant amount of our health budget is expended caring for our citizens who are dying or facing death and bereavement. Some evidence suggests that this –largely unplanned – expenditure may be as high as €1.3 billion each year. It is appropriate, therefore, that we examine how we can best provide a quality service for people who are dying, and those who care for them, while making best use of our finite resources.

Given these facts, the Committee on Health and Children decided to turn its attention to how we currently care for our dying citizens and those who grieve for them. In October and November 2013 the Committee embarked on an unprecedented series of meetings to learn about the many issues related to dying, death and bereavement in Ireland to help us make recommendations to Government about how services should be planned for the future.

The six Committee sessions covered all of the major aspects of dying, death and bereavement:

- Why it is important to take account of end of life issues
- Specialist palliative care
- Death in community settings
- Children
- Diversity and bereavement and
- End of life care in hospitals

It was a great privilege to hear from the 32 people who came to address the Committee and the 46 organisations and individuals who sent in written submissions.

It was very enlightening to hear from practitioners - clinical and non-clinical, specialist and generalist, medical and legal, governmental and non-governmental, advocates, development organisations, researchers and academics – about their work with and for people and their families who are facing death and loss. We didn’t only get statistics but we heard about the
practicalities of care – often in challenging circumstances - and the philosophy, psychology, cultural and educational aspects of dying, death and bereavement.

The Committee heard that people die at all ages at all times and in all places. We learned that the majority of people would prefer to die at home, but currently most will die in acute hospitals. Some do die at home – with or without support, some die in long stay facilities and some die in hospice care.

Hospice care, with special palliative services, is associated in the public mind as the gold standard for those facing death and with life-limiting illness, supporting people to live as well as possible until death. Comprehensive national policy on specialist palliative care has been in place for a number of years. This vital service is part state funded but remains heavily reliant on donations and fundraising by a range of voluntary bodies. This is particularly true of children’s palliative care programmes. This dependence on variable state funding and public donation leaves services vulnerable and stifles much-needed capital and other development. The Committee has made a number of specific recommendations aimed at stabilising and developing these services and overcoming geographical and other inequities in line with national policy.

It was heartening to hear evidence of good practice and innovation in all care settings outside of hospice care, but encompassing its core values, aimed at supporting those facing death and the bereaved. The Committee makes a number of recommendations about practical issues to encourage further development in this area.

The majority of people in Ireland die in acute hospitals. The recent report by the Ombudsman (“A Good Death: A Reflection on Ombudsman Complaints about End of Life Care in Irish Hospitals”, June 2014) is a salutary and timely reminder to us how things can go wrong and the distress that can be caused to a dying patient and their loved ones. It underlines the importance of supporting all staff in acute hospitals to deliver the best end of life care possible, even in the most challenging and difficult circumstances.

It is clear that much of this practice is being developed in an uncoordinated way without an overall national framework of support and strategic planning. Therefore the Committee recommends the development of a National Strategy on Palliative Care, End of Life and Bereavement for the health sector. It would make sense to bring together all of these developments, and to augment and reinforce them. A strategic approach would – at the very least – ensure that we spend our €1.3 billion in a more planned and focussed way. Even more importantly it might ensure that we get that one chance for good end of life care right more and more often.

This Committee has a very specific role. We examine current and proposed health policy. We evaluate and assess the future planning of health services. We scrutinise any proposed changes to the way healthcare is delivered in this country. Our examination of the issues relating to dying, death and bereavement and our recommendations are strictly in line with that role. However, in this report we recognise that dying, death and bereavement cannot be neatly packaged and handed over to the palliative care services or the health service generally as their
exclusive remit and responsibility. As dying, death and bereavement affect us all without exception, so too are they the responsibility of us all, as individuals and as citizens.

We therefore recommend that any national strategy on palliative, end of life care and bereavement should form part of an overarching, interdepartmental end of life and bereavement framework encompassing wider societal, legal, financial, educational, administrative and cultural aspects. This could help us to weave all of these separate threads of good practice and support into the tapestry of our common humanity for the benefit of all.

I would like to thank all the members of the Joint Committee for their contributions and cooperation on this important body of work, and in particular, those of the opposition party spokespeople on Health. I would also like to thank the Clerk to the Committee, the staff of the Committee Secretariat and Library and Research for their assistance during the course of our hearings and in the production of this report.

Jerry Buttimer, T.D.,
Chairman,
Joint Committee on Health and Children.
July 2014.
### 31st Dáil

Members of Joint Committee on Health and Children

**DEPUTIES**

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CHAIRMAN (Fine Gael) |
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**Senators**

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These recommendations are based on the Committee’s analysis of secondary sources, stakeholders’ submissions and Committee hearings.

OVERALL CONCLUSIONS AND RECOMMENDATIONS

NATIONAL STRATEGY
1. The development of a National Strategy on Palliative Care, End of Life and Bereavement could be considered a priority for the development of this sector of health policy and extend to non-health areas of public policy.

Such a strategy could form the major part of an overarching, interdepartmental End of Life and Bereavement strategy informed by public consultation, encompassing the wider financial, legal, social, cultural educational and administrative issues relating to end of life.

HOSPITALS
2. The Department of Health could consider the possibility of legislatively underpinning the Quality Standards for End of Life Care as recommended by the NESC.

3. In the context of the new hospital groups, all hospitals should draw up strategies for dealing with palliative, end-of-life care and bereavement.
   - A designated person within each hospital should be given responsibility for implementation and compliance with these Standards
   - The provision of single occupancy rooms for patients who are dying should be considered a priority.

SPECIALIST PALLIATIVE CARE
4. There are many competing demands placed on our health budget and support could be expressed for the proposal that the specialist palliative care budget be ring fenced for a minimum of five years to prevent an undermining of the services currently available and to protect future investment in the sector.

5. The Government could make the opening of the hospice beds in St. Francis Hospice, Blanchardstown, Marymount Hospice, Cork and reopening the beds in Milford Care Centre, Limerick, a priority.

6. The Government could be asked to address the regional disparities which exist in the provision and funding of specialist palliative care services in Ireland, to ensure that the needs of all those who require specialist palliative care services are met - whether it be in the home, in the community or in a specialised hospice. In particular to progress development of capital projects related to the provision of specialist palliative care in-patient units in the Midlands, North East and South East.

7. The Department of Health should consider consulting with key stakeholders in
undertaking a needs analysis in respect of the current and future provision of specialist palliative care and end of life care in Ireland

8. The Department of Health in conjunction with key stakeholders should undertake a comprehensive cost benefit analysis in respect of the current and future provision of specialist palliative care in Ireland.

FUNERAL SERVICES INDUSTRY
9. Quality standards should be developed for the funeral services industry in Ireland and some oversight mechanism should be developed to support these standards and ensure they are met and exceeded.

ADVANCE CARE DIRECTIVES
10. Provisions governing the use of Advance Care Directives should be included in the Assisted Decision-Making (Capacity) Bill 2013 and such provision speedily commenced when enacted.

TRAINING AND DEVELOPMENT
11. Palliative, end of life and bereavement care should form part of the core undergraduate curriculum of all health care professionals.

12. A National Strategy on Palliative Care, End-of-Life and Bereavement should recognise the importance of mandatory training and development for all healthcare staff in all care settings.

INFORMATION SYSTEMS AND COORDINATION OF CARE
13. All healthcare providers should be encouraged to develop systems and practices which would ensure continuity of care for palliative and end of life patients across all care settings. Consideration must however be given to the law on data protection, and the right to privacy in the development of any such systems.

14. A move away from paper based information systems to electronic systems in all care settings should be facilitated and prioritised within the relevant business plans in line with the Government’s E-Health Strategy.

15. The proposal that palliative care and end of life patients be granted a ‘special patient status’ that prioritises their needs across all healthcare and community services should be considered.

MEDICAL CARDS
16. The automatic sanctioning of medical cards, without renewal, for those requiring end of life care should be considered.

17. Alternatively, a proposal extending the renewal period for discretionary medical cards for those requiring end of life care to 12 months could be considered.

18. Any renewal of a discretionary medical card for those nearing end of life could be considered on the basis of a covering letter from a patient’s G.P. or consultant rather than by reference to a means assessment.
BEREAVEMENT CARE

19. The development of a national framework to govern the provision of bereavement care/support services by private, statutory and voluntary agencies should be considered.

20. The Government should consider, on the basis of Committee hearings, to review its decision to abolish the bereavement grant.

ACCESS TO LONG STAY FACILITIES

21. Palliative care patients waiting to access beds under the Fair Deal Scheme could be prioritised with the aim of enabling them to access residential care in a timely manner and thereby facilitate their final medical care in a more appropriate setting.

22. In reviewing the current Fair Deal Scheme consideration could be given to extending the definition of Long Term Residential Care Services, and the range of services covered by the Scheme.

23. In reviewing the current Fair Deal Scheme an evidence-based cost of care model could be used in assessing the real cost of residential nursing home care in Ireland.

CHILDREN

Planning

24. Consideration could be given to the development of a national standardised data collection system/register which would allow for the efficient planning and development of palliative and end of life services for children in Ireland as per national policy.

25. Consideration could be given to making calculations in respect of the current and future palliative and end of care needs of children on the basis of the number of children living with life limiting illnesses rather than the number of children who die from such illnesses.

Training

26. All healthcare professionals working with children with life limiting illnesses should undergo specific training to enable them to better understand and cater for the unique needs of such children.

Medical Cards

27. Consideration should be given to the automatic sanction of medical cards for children who require palliative or end of life care; without their being subject to a renewal process.

28. Alternatively, any renewal could be on the basis of a covering letter from a child’s G.P. or consultant, rather than by a means assessment.

29. The Department of Health, in consultation with the Registrar of Births, Deaths and Marriages, and any other interested party, could consider an alternative procedure for the issuing of medical cards to infants who have not been issued with a Personal Public Service Number (PPS Number).
**Funding and staffing needs**

30. Consideration could be given to providing State funding to the LauraLynn Ireland’s Children’s Hospice

31. Consideration could be given to increasing State funding to the Jack & Jill Foundation to enable the expansion of its end of life care service to support children up to the age of 6

32. The Health Service Executive (HSE) could consider planning for the on-going and sustainable funding of the post of Consultant Paediatrician with a Special Interest in Paediatric Palliative Care after May 2016

33. The Health Service Executive could consider the appointment of a second Consultant Paediatrician with a Special Interest in Paediatric Palliative Care

34. The Health Service Executive could consider planning for the on-going and sustainable funding of the 8 Children’s Outreach Nurses posts, and consider the expansion of this service

35. The provision of respite for children with life-limiting conditions and their families should be progressed in line with the needs identified in the 2013 Needs Assessment

**REGULATORY CHANGE**

36. Provision should be made for the pronouncement of death by advanced paramedics and senior nurses.

37. Nurse prescribers in Private Nursing Homes should be allowed routine access to prescription pads.

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2. Executive Summary

The Joint Committee on Health and Children recently examined the issue of end-of-life and palliative care in Ireland in order to assess:

- the system of care currently in place for those who are dying, and
- how our health services are organised to deal with end-of-life and palliative care.

During October and November 2013 the Joint Committee met with a number of key stakeholders and experts, including those involved in delivering end of life and palliative care in hospices, hospitals, nursing homes and in the community. A public consultation process was also run which resulted in a large number of submissions being received.

The Joint Committee wishes to recognise the significant work which has been done, particularly, by the voluntary sector, in developing and improving palliative and end of life care in Ireland. According to a 2010 Report\(^2\) from the Economist Intelligence Unit, which investigated the care services in 40 countries, Ireland rates very favourably, taking fourth position in overall ranking and fifth for quality of death. Ireland was also noted as one of the nations with the highest levels of public debate about end of life care.\(^3\) However, evidence presented to the Joint Committee at its hearings on this issue suggests that significant deficiencies exist in the provision of end of life and palliative care in Ireland, in particular, inequalities based solely on geographic location.

This report it focuses on the most significant issues identified throughout the course of the Joint Committee’s deliberations. The report sets out the key facts and figures presented by stakeholders, and identifies a number of key issues upon which its bases its conclusions.


3. Background

Key Facts and Figures on dying and death in Ireland

The following key facts and figures emerged following the Joint Committee’s meetings with Stakeholders, the public consultation process, and independent research on the topic:

Number, causes and place of deaths (2012)

- Almost 29,000 people died in Ireland in 2012. Approximately 80% of these deaths were of people aged 65 years and over;
- Causes of death in that year include diseases of the circulatory system (32%), cancer (29.6%), and diseases of the respiratory system (12%). There were 9,267 deaths due to diseases of the circulatory system, 8,544 due to cancer and 3,473 due to diseases of the respiratory system. There were 507 deaths by suicide and 956 due to accidents.
- While the majority of people express a preference to die at home, only 26% of Irish people actually achieve that preference. This figure rises to 40% of all patients who are cared for by hospice home care teams.
- An audit conducted in 2008/2009 found that 43% of Irish people die in busy acute hospitals. Of these deaths, 12% take place in an emergency room, and only 40% in a single room. The audit also found that one in four of these deaths could have taken place in the community if the necessary supports were in place. Only 4% of deaths occur in hospices but 40% of people who die at home are supported by specialist palliative care home care teams.
- 22% of deaths take place in nursing homes or other long-stay facilities.

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Population trends

- The number of people aged 65 years and over increased by 14.4% between Census 2006 and 2011. Indications suggest that by 2046, the population of those aged over 65 will account for approximately 21% of the Irish population, and approximately 7% will be aged 80 years or older.

- Almost 42,000 people in Ireland live with dementia. Projections indicate that by 2041 this will have risen to 147,015. While the majority of people with dementia live at home, an estimated 14,266 (i.e. 63% of all long stay residents) live in various public and private long-stay facilities across the country, and almost 20% of acute medical beds are occupied by people with persistent cognitive impairment. The overall cost of dementia care in Ireland is over €1.69 billion per annum;

Specialist palliative care

- The specialist palliative care services budget for 2013 was €72m, a reduction of 1.6% on 2012. According to international research however, it is estimated that €1.3b is spent annually on end-of-life care;

- The estimated cost of a hospital stay per night is €900, compared to €480 for 24 hour specialist palliative home care, representing a potential saving of over €400 per person per night;

- There are currently 156 specialist palliative care beds in Ireland - 139 of these are provided by the Voluntary Hospice Group. A further 46 hospice beds are waiting to be opened;

- A 2013 report estimated that 2,500 patients each year are denied access to the hospice inpatient care they need because of shortfalls in the provision of hospice services countrywide;

- In 2012, the Voluntary Hospice Group cared for 2,449 in-patients, 5,076 patients in the community, and 871 patients in day care. It is estimated that by 2016, more than 12,500 patients will require access to specialist palliative care;

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13 Alzheimer Society of Ireland, Submission to the Joint Committee on Health and Children, November 2013.
14 Irish Hospice Foundation, Submission to the Joint Committee on Health and Children, 24 October 2013.
15 Home and Community Care Ireland, Submission to the Joint Committee on Health and Children, November 2013.
16 The Voluntary Hospices Group (VHG) is a membership group, representative of the major voluntary specialist palliative care service providers in Ireland (i.e. Galway Hospice, Marymount University Hospice, Cork, Milford Care Centre, Limerick, North West Hospice, Sligo, Our Lady’s Hospice & Care Services (including Blackrock Hospice) and St. Francis Hospice (Raheny & Blanchardstown).
17 Irish Hospice Foundation 11 December 2013.
In 2001 the Report of the National Advisory Committee on Palliative Care made a number of recommendations in relation to specialist palliative care teams, and the appropriate staffing and bed number ratios to ensure that palliative care services could be available in all care settings, including that:

- there should be at least 8 – 10 specialist palliative care beds per 100,000 population to meet the increasing need for specialist palliative care services in Ireland (Ireland currently has a ratio of one bed to 130,000 people\(^{20}\));
- there should be a minimum of 1 Whole Time Equivalent (WTE) specialist palliative care nurse per 25,000 population; not less than one WTE specialist palliative care nurse to each hospice bed, and a minimum of 1 WTE specialist palliative care nurse per 150 beds in each acute general hospital.

Cancer patients are currently the biggest group of specialist palliative care users in Ireland. In 2010 there were 33,741 cancer cases in Ireland. It is anticipated that this number will rise to 42,000pa by 2020\(^{21}\).

Of all deaths that occur in hospital, the percentage due to cancer is generally lower in regions where spending on specialist palliative care is in line with national policy\(^{22}\).

Only 7% of home care patients in the better-resourced hospice services of the Mid-West die in acute hospitals, in contrast with 32% in the North East\(^{23}\).

The 2010 National Cancer Register shows that just 21% of all cancer deaths in the Mid-West occurred in an acute hospital, compared to 52% in the North East, 41% in the South East and 37% in the Midlands\(^{24}\).

The 2010 Hospital Inpatient Enquiry data shows that cancer accounts for just 16% of all deaths in hospitals in the Mid-West compared to 29% in similar hospitals in the South East and North East where there are no specialist palliative care inpatient units\(^{25}\).

In 2012, the Irish Cancer Society provided 7,600 nights of care to 2,161 cancer patients. The average cost per night of care is €350. The demand for this service increases annually at a rate of approximately 7%. It cost €2.6 million to deliver the service in 2012\(^{26}\).

The Irish Hospice Foundation provided 950 nights of care to 317 adult and child patients with non-malignant disease receiving specialist palliative care in 2013, at a cost of €385,574. Demand for this service has increased each year since 2007 and is expected to increase by 20% in 2014\(^{27}\).

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\(^{21}\) Ibid

\(^{22}\) Ibid

\(^{23}\) Ibid

\(^{24}\) Ibid

\(^{25}\) Ibid


\(^{27}\) Irish Hospice Foundation statistics 2013.
Children

- According to 2005 statistics an estimated 1,400 children in Ireland live with a life limiting condition and almost 350 children die from such conditions every year. Only 11% of these children die at home;29
- The average annual cost of Jack & Jill homecare provision is €16,422, nine times less than the annual cost falling on the State to deliver acute hospital care at €147,365;30

Nursing homes

- There are 447 private and voluntary nursing homes in Ireland, providing care to more than 75% of the country’s long-term care residents (i.e. almost 22,000 people);31

Carers

- There are approximately 274,000 family carers in Ireland;32

Health Sector Staffing

- At the end of December 2012, the health sector employed 101,506 whole-time equivalent (WTE) staff. This was a reduction of 2,886 WTEs (-2.8%) compared to the end of 2011. Since September 2007, the health sector has reduced its numbers by 10% (11,265 WTEs);33

International comparisons

- In 2010, The Economist Intelligence Unit ranked Ireland fourth out of 40 countries overall in its quality of death index34.

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28 Lauralynn Ireland’s Children’s Hospice suggests that these figures are likely to be severely underestimated and could be closer to 4,000.
30 Nursing Homes Ireland, Submission to the Joint Committee on Health and Children, 5 November 2013.
31 Care Alliance Ireland Submission to the Joint Committee on Health and Children, November 2013.
4. Specialist Palliative Care

End-of-life care may encompass, but is not confined to, palliative care.

**World Health Organisation definition of palliative care**

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

*The Report of the National Advisory Committee on Palliative Care (2001)*[^35] defines three levels of palliative care premised on the expertise of the health professionals delivering the palliative care services:

- **Level 1 (Generic Palliative Care)** is ‘a core skill that every healthcare professional working in hospital or community care settings should possess’. Such core skills include the ability to communicate openly and sensitively; place highest premium on the patient’s quality of life including the best possible symptom control; adopt a whole person approach which takes into consideration an individual’s circumstances, spirituality and sexuality; care for all concerned (family and those important to the patient) and respect for patient autonomy and choice.

- **Level 2 (General Palliative Care)** is at ‘a more specialised level and is undertaken by health professionals who, although they do not work full time in palliative care, have had some additional training and experience in palliative care settings e.g. pain management’.

- **Level 3 (Specialist Palliative Care)** is the highest level of palliative care undertaken by specialists in palliative medicine ‘for patients whose needs are so complex that they require the care of a multidisciplinary specialist palliative care team’.[^36]

Palliative care aims to provide the best quality of life possible for a person living with a life threatening/limiting illness.

Traditionally, when most people think about specialist palliative care, they think about hospice care, often limited to cancer patients. However, this is no longer the case. As many stakeholders have pointed out palliative and end-of-life care is not confined to any one care setting: people die in acute hospitals (about 43% of the 29,000 people who die each year), people die in long-stay residential care settings (about 25%), in primary care settings (about 26% of people will die at home) and in hospices (about 6%).


[^36]: Prof. Cillian Twomey, retired Geriatrician, HSE South, Submission to the Joint Committee on Health and Children, 14 Nov 2013
Specialist palliative care is increasingly provided to patients with a range of other illnesses, such as motor neurone disease, end-stage cardiac failure, COPD (chronic obstructive pulmonary disease), and MS (multiple sclerosis).

End-of-life care is an important part of specialist palliative care and involves but is not confined to the provision of appropriate medical, social, spiritual and legal care to persons in order to ensure that they may die well and with dignity.

While a comprehensive national policy on specialist palliative care has been in place in Ireland for many years (see Box 2 below), evidence suggests that regional disparities in the provision and funding of specialist palliative care services continue to exist, as do disease-specific and age-related inequalities.

### Relevant Reports, Policy documents and Strategies

Current national policy on palliative care is based on the principles and recommendations of a number of Reports, policy documents and strategies including:

#### REPORTS

- The Baseline Study on the Provision of Hospice / Specialist Palliative Care Services in Ireland (Irish Hospice Foundation (IHF) 2006);
- The Palliative Care Needs Assessment for Children (DOH and IHF 2005);
- Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks (IHF and HSE 2008);
- Access to Specialist Palliative Care Services and Place of Death in Ireland – what the Data Tells Us (IHF 2013).
- Respite Services for Children with Life-Limiting Conditions and their Families: A National Needs Assessment (LauraLynn Children’s Hospice and IHF 2013)

#### STRATEGIES

- The National Cancer Strategy (DOH 1996);
- The Primary Care Strategy (DOH 2001);
- The Cancer Control Strategy (DOH 2006);
- The Transformation Programme (HSE 2007);
- National Positive Ageing Strategy (Department of Health 2013)

#### POLICY

- The Report of the National Advisory Committee on Palliative Care (Department of Health (DOH) 2001)
- Palliative Care For Children With Life-Limiting Conditions In Ireland - A National Policy (DOH 2010)
- Palliative Care Services - Five Year/Medium Term Development Framework (HSE 2009 – 2013);
In 2001 the Report of the National Advisory Committee on Palliative Care\textsuperscript{37} made a number of recommendations in relation to specialist palliative care teams, and the appropriate staffing and bed number ratios to ensure that palliative care services could be available in all care settings, including that:

- there should be at least 8 – 10 specialist palliative care beds per 100,000 population to meet the increasing need for specialist palliative care services in Ireland (Ireland currently has a ratio of one bed to 130,000 people\textsuperscript{38});

- there should be a minimum of 1 Whole Time Equivalent (WTE) specialist palliative care nurse per 25,000 population; not less than one WTE specialist palliative care nurse to each hospice bed, and a minimum of 1 WTE specialist palliative care nurse per 150 beds in each acute general hospital.

Despite these recommendations and recent commitments in the 2013 Health Service Executive National Service Plan\textsuperscript{39} there remains a heavy dependency on the voluntary sector in the provision of specialist palliative and end of life care in Ireland. However, in order to provide modern, quality and responsive palliative and end of care services we need, as Dr. Karen Ryan said, to ensure 'that palliative care is commissioned and delivered as an integrated service (from referral to death) regardless of setting (acute, primary, community) and funding mechanism applied.'\textsuperscript{40}

While comprehensive specialist palliative care services are vital, as highlighted in many submissions, good end of life care is everyone’s business and there is only one chance to get it right. Dr. Paul Gregan gave evidence that:

‘Dying is something that each one of us will do in our turn. Only one in ten of us will die suddenly. Therefore, we are in a position to adequately plan the individual care of nine out of every ten people, but we are also able to plan adequate care at population health level for those living months before dying and those imminently dying. We need to plan the care of these people. It is relatively inexpensive and it is entirely predictable. We need to do the simple things and the important things well\textsuperscript{41}.’

\textsuperscript{37} http://www.dohc.ie/publications/pdf/nacpc.pdf?direct=1
\textsuperscript{38} Professor Dominic Ó Brannagáin, Consultant Physician in Palliative Medicine, Submission to the Joint Committee on Health and Children, October 2013.
\textsuperscript{39} http://www.hse.ie/eng/services/Publications/corporate/NSP2013.pdf
\textsuperscript{40} Karen Ryan, Consultant in Palliative Medicine, St Francis Hospice and the Mater Hospital; Clinical Lead, Palliative Care Programme, HSE, Submission to the Joint Committee on Health and Children.
\textsuperscript{41} Dr.Paul Gregan, Address to the Joint Committee on Health and Children, October 2013
5. Key issues

The Joint Committee received in excess of 50 submissions in relation to end of life care. The following key issues were identified by the Joint Committee following discussions with stakeholders, and a public consultation process:

5.1 A National Strategy

Many stakeholders, including the Irish Hospice Foundation, highlighted the need for a National Strategy on Palliative Care, End of Life and Bereavement.

Sharon Foley, CEO of the Irish Hospice Foundation stated:

‘A national strategy is needed to help us to plan, develop and co-ordinate end-of-life care in hospices, hospitals, homes and communities, as well as addressing the wider economic, legal and administrative issues. This must be a strategy for the entire population, from those who need GP support up to all those who need specialist palliative care to manage their pain and other complex symptoms. This strategy needs to be relevant and supportive of all health care and social care staff who are required to deliver health and social care. The strategy must be relevant to all patients, young and old, to patients all over Ireland and to patients with all conditions, including dementia.’

The need for such a strategy to acknowledge the diverse needs of the population was mentioned by a number of stakeholders including Dr. Paul D’Alton and Dr. Regina McQuillan and was described by Odhrán Allen of GLEN.

‘An end-of-life policy should be based on principles such as equality, diversity and respect for individual autonomy, and LGBT people should be named as a population group with specific needs; and end-of-life services should be based on a model of inclusive practice that recognises and responds to the needs of different groups’

This Strategy would cover all aspects of dying, death, and bereavement in Ireland, and apply to all patients with a life-limiting illness regardless of age, condition, sexual orientation or religion. It would enable better planning, development, and co-ordination of end-of-life care in hospices, hospitals, homes and communities, as well as addressing wider economic, legal, and administrative issues.

Patricia Rickard-Clarke highlighted the fact that end of life issues are not solely the remit of the health services:

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42 Sharon Foley, CEO, Irish Hospice Foundation. Oral Statement to the Committee, 24th October 2013
43 Odhrán Allen, GLEN, Oral Statement to the Committee
‘Issues arising at end of life are wider than simply health care. Any of us who has had a loved one die knows only too well that there is a myriad of financial, legal, social, cultural and administrative issues related to a person’s wishes other than those related directly to health care. For this reason, we need a comprehensive interdepartmental strategy which can address all areas of end of life and ensure the issue is effectively addressed by Government policy.

‘Death remains the biggest threat as well as the greatest challenge to humanity. It is the single universal event that affects all of us in more ways than we care to know. There is a growing amount of literature that points to the fact that death is not a discrete event; rather, we die as we live. In this way dying well does not simply involve the last days or weeks of life; rather, it is the product of attitudes and values that we hold as citizens and governors of the State. These attitudes and values underpin how we prioritise and organise our services, how we interact on a personal level, and fundamentally how our society responds to the issue of death and dying.

Conclusions

The development of a National Strategy on Palliative Care, End of Life and Bereavement could be considered a priority for the development of this sector of health policy and extend to non-health areas of public policy.

Such a strategy could form the major part of an overarching, interdepartmental End of Life and Bereavement strategy informed by public consultation, encompassing the wider financial, legal, social, cultural educational and administrative issues relating to end of life.

5.2 Legislative change to underpin Quality Standards for End of Life Care in hospitals.

Kate Bree, Assistant Director of Nursing at Sligo Regional Hospital gave evidence to the Committee of current programmes to improve end-of-life care in acute hospitals.

‘A good death in hospital is possible. Our challenge is to make it happen.’

The Quality Standards for End of Life Care, developed as part of the Irish Hospice Foundation’s Hospice Friendly Hospitals Programme, are currently being implemented by hospitals on a purely voluntary basis. It would be desirable to see these Standards implemented by all Irish hospitals. In order to ensure compliance and participation these

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44 Patricia Rickard-Clarke, Forum on End of Life in Ireland, Oral Statement to the Committee, 24th October 2013
45 Dr. Paul D’Alton, Address to the Joint Committee on Health and Children, November 2013
46 Kate Bree, Chairperson, Hospice Friendly Hospitals Programme, Oral Statement to the Committee
Standards should be made mandatory by way of legislation as recommended by the National Economic and Social Council (NESC)\textsuperscript{48}. A senior manager within each hospital should be designated as the person responsible for implementation.

The challenge of preserving the dignity and privacy of patients dying in public wards was presented by Margaret Naughton of the National Association of Healthcare Chaplains.

‘To die in a public ward is not conducive to dying with dignity\textsuperscript{49}.’

### Conclusions

The Department of Health could consider the possibility of legislatively underpinning the *Quality Standards for End of Life Care* as recommended by the NESC.

In the context of the new hospital groups, all hospitals should draw up strategies for dealing with palliative and end-of-life care and bereavement.
- A designated person within each hospital should be given responsibility for implementation and compliance with these Standards
- The provision of single occupancy rooms for patients who are dying should be considered a priority

### 5.3 A dedicated budget for Specialist Palliative Care

Stakeholders, including the Voluntary Hospice Group, have expressed concern that any further cuts to the specialist palliative care budget could seriously undermine the provision of palliative and end of life care in Ireland. The specialist palliative care services budget for 2013 was €72m, a reduction of 1.6% on 2012. Stakeholders called for this budget to be ring-fenced in line with the recommendations of the 2001 Report of the National Advisory Committee for Palliative Care\textsuperscript{50} that the State should fund all core specialist palliative-care services and that this funding should be protected.

### Conclusion

There are many competing demands placed on our health budget and support could be expressed for the proposal that the specialist palliative care budget be ring fenced for a minimum of five years to prevent an undermining of the

\textsuperscript{48} NESC Council Reports 130: Quality and Standards in Human Services in Ireland: Home Care for Older People, and Quality and Standards in Human Services in Ireland: End-of-Life Care in Hospitals

\textsuperscript{49} Ms. Margaret Naughton, National Association of Healthcare Chaplains, Address to the Joint Committee on Health and Children, November 2013

\textsuperscript{50} http://www.dohc.ie/publications/pdf/nacpc.pdf?direct=1
services currently available and to protect future investment in the sector.

5.4 Consistent and coherent provision of specialist palliative care.

In 2006, the Baseline Study on the Provisions of Hospice/Specialist Palliative Care Services in Ireland\(^51\) highlighted the inconsistencies and inequalities in accessing specialist palliative care services throughout the country. The Study found that there was still a wide divergence in the range of services and care options available in different parts of the country, and that access to comprehensive services largely depended on the region of the country in which the patient resided. These findings have been confirmed by stakeholders’ submissions, and the evidence presented to the Joint Committee during its hearings.

<table>
<thead>
<tr>
<th>Hospice</th>
<th>Beds</th>
<th>Unopened</th>
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<tbody>
<tr>
<td>Marymount University Hospice (Cork)</td>
<td>24</td>
<td>20</td>
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<tr>
<td>Our Lady’s Hospice (Dublin)</td>
<td>36</td>
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<td>Blackrock Hospice (Dublin)</td>
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<td>St Francis Hospice (Dublin)</td>
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<td>24</td>
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<td>Galway Hospice (Galway)</td>
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<td>North West Hospice (Sligo)</td>
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<td>St Brigid’s Hospice (Kildare)</td>
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<tr>
<td>Milford Care Centre (Limerick)</td>
<td>28</td>
<td>2 (to re-open)</td>
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<tr>
<td>Donegal hospice (Donegal)</td>
<td>8</td>
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<tr>
<td>Waterford Regional Hospital</td>
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</tbody>
</table>

(Admission rights to these beds are only by Consultants in Palliative Medicine)

156 46

Source: Irish Hospice Foundation 11/12/13

Despite recommendations that there should be at least 8 to 10 specialist palliative care beds per 100,000 population\(^52\), there are only 156 hospice beds available in Ireland. There is no specialist palliative care inpatient unit (hospice) in the Midlands or the Northeast and only two specialist palliative care beds in the Waterford Regional Hospital in the South East. A further 46 beds remain unopened in St. Francis Hospice, Blanchardstown, and Marymount University Hospice, Cork. Two beds are currently closed in Milford Care Centre, Limerick.


\(^{52}\) According to Mr. Kevin O’Dwyer, The Voluntary Hospices Group, based on the 2011 Census this would equate to between 367 and 458 beds.
Equality of access to hospice care has been consistent Government policy over many years but is as yet unrealised.

In 2007 the then Government committed to remove the regional disparities in the provision and funding of palliative care services in Ireland, and to ensure that the needs of all those who require palliative care services were met, whether this is in the home, in the community or in a specialised hospice within a five year period. The provision of care in a setting close to the patient’s home is also a key priority of a number of programmes and policies including the Health Service Executive Transformation Programme (2007 – 2010), the 2011 Programme for Government and the Department of Health policy “Future Health” (2012).

Conclusions

The Government could make the opening of the hospice beds in St. Francis Hospice, Blanchardstown, Marymount University Hospice, Cork and reopening the beds in Milford Care Centre, Limerick, a priority.

The Government could be asked to address the regional disparities which exist in the provision and funding of palliative care services in Ireland in the context of the new hospital groups, so as to ensure that the needs of all those who require palliative care services are met, whether it be in the home, in the community or in a specialised hospice. In particular to progress development of capital projects related to the provision of specialist palliative care in-patient units in the Midlands, Northeast and South East.

5.5 Future proofing our palliative care services

Ireland’s population is ageing. In 2011, there were over half a million people aged over 65 years. Living longer, often with chronic illnesses such as cancer, dementia and obstructive pulmonary disease means additional demands are, and will be, placed on our health-care system in years to come. It is estimated that in 2016 up to 13,000 patients will require access to hospice and specialist palliative care. According to the Irish Hospice Foundation:

‘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 and end-of-life care.

Programme for Government 2007

Irish Hospice Foundation, Submission to the Joint Committee on Health and Children, October 2013
The management of our approach to dying, death and bereavement within our health service matters – not only to patients and the health system, but to the whole of society.\textsuperscript{55}

It would seem advisable to future-proof our health care services, in particular our palliative and end-of-life care services, in order to meet increasing demands. Anticipating, and planning for the future palliative care needs of all patients will help ensure that we all have a better quality of life until death.

**Conclusion**

The Department of Health should consider consulting with key stakeholders in undertaking a needs analysis in respect of the current and future provision of palliative and end-of-life care in Ireland.

5.6 The need to incorporate palliative care into the mainstream care of patients of all ages – Integrated care planning

Dr. Margaret Clifford, representing the Irish Association for Palliative Care, explained the role of specialist palliative care healthcare professionals in providing both direct care and in supporting their colleagues in other disciplines.

‘Not every patient who gets palliative care needs the direct care of a specialist palliative care team, but they need the specialist palliative care service to be sufficiently resourced to care directly for those who have more complex needs and also to provide that education we called “shared learning”. It is a two-way process when we talk about educating our colleagues in other specialties.’\textsuperscript{56}

Evidence suggests that clear benefits exist for patients, their families and the healthcare system when palliative care is introduced at an earlier stage in the standard care approach to a number of life-threatening illnesses (these include an improvement in symptoms, quality of life, and patient satisfaction, with reduced caregiver burden).

The Joint Committee supports the proposal that integrating palliative care in the treatment of patients with advanced life limiting illnesses needs to be established as practice to enable care planning and especially end-of-life care plans.

As Professor Declan Walsh stated:

\textsuperscript{55} The strategic importance of palliative care within the Irish health service: Perspectives on future service delivery; Irish Hospice Foundation. 2012, \url{http://hospicefoundation.ie/wp-content/uploads/2013/01/The-strategic-importance-of-palliative-care-within-the-Irish-health-service-Perspectives-on-future-service-delivery.pdf}

\textsuperscript{56} Dr. Margaret Clifford, Submission to the Joint Committee on Health and Children, October 2013
‘The current evidence from the United States suggests earlier involvement of palliative care services reduces the average length of hospital stay and the likelihood of readmission to hospital. It is at the interface with community nursing homes that we can make sure the patient stays where he or she is best cared for. If he or she really needs to be in hospital, well and good. It is important that he or she should not have to go there because of some unanticipated crisis.’\textsuperscript{57}

Dr. Regina McQuillan also drew attention to the fact that specialist palliative care services – particularly those in the community - have a unique role in caring for people from ethnic and other minorities.

‘Specialist palliative care, which emphasizes individual care and attention to detail, is in an ideal situation to address palliative care needs of ethnic minorities. This requires that specialist palliative care recognise the individuality of people, the role of the family and the ethical implications and difficulties of dealing with different viewpoints. Cultural awareness training is important and a balance between education about cultures and avoiding stereotyping is important.’\textsuperscript{58}

5.7 Improved support for acute hospitals in the delivery of better end-of-life care

As things currently stand approximately 43% of Irish people die in an acute hospital. Only 44% die in a single room. More than 80% of people who died in Irish hospitals were admitted through busy emergency departments\textsuperscript{59}. Had the appropriate community supports been in place however up to one quarter of these patients could have died at home.

Anticipating and planning for palliative and end of life care could prevent inappropriate admissions to acute hospitals.

For the most part the role of our hospitals is to cure, and in many ways death can be viewed as a failure. The reality is however, that people die every day in hospital:

‘This is not a failure. This is life.’\textsuperscript{60}

Because over 40% of deaths take place in hospitals, hospitals need to put in place strategies for dealing with end of life care. The National audit of end-of-life care in hospitals in Ireland, 2008/9 identified 18 ways in which hospital care at end of life could be improved.\textsuperscript{61} These

\textsuperscript{57} Professor Declan Walsh, Address to the Joint Committee on Health and Children November 2013
\textsuperscript{58} Dr. Regina McQuillan, Consultant in Palliative Medicine and Medical Director, St. Frances Hospice, Raheny and Blanchardstown.
\textsuperscript{60} Opening Remarks, Ms. Sharon Foley, CEO, Irish Hospice Foundation, 24 October 2013.
include training in end of life care for all staff (see 5.10 below), and improving the physical spaces available in hospitals (e.g. the provision of single rooms for those who are dying, better mortuaries, family rooms, and viewing areas).

Professor Patrick Plunkett told the Committee about the particular challenges faced by healthcare professionals caring for dying patients in the emergency department setting.

‘The barriers to a high quality death in the emergency department include the physical setting, often overcrowded, noisy, and with high intensity lighting 24 hours a day. It is psychologically extremely difficult to be plucked from one’s bed at home, gasping for breath, and be brought by ambulance, careening through the streets with sirens blaring, to a noisy environment, where the bustle of life-saving measures applied to one person may interfere with the peace and quiet required by a dying woman contemplating her last few hours or minutes on this earth………What can be done to optimise end-of-life care in emergency departments? The first thing is to believe it can be improved, to examine each element carefully and to deal with every deficiency in a constructive fashion.’

Dr. Geoff King, Director of the Pre Hospital Emergency Council referenced the fact that senior paramedics are not able to pronounce death of patients on site without a doctor present. This means that ambulance staff can be delayed waiting at the scene of an accident or medical event, or that patients may have to be brought to the Accident an Emergency Department for a pronouncement of death.

‘It should be signed off that a paramedic can pronounce death. It is safe. It is crazy that we have to wait for a doctor, who has other work to do, to do it. That is where we need help.’

The Joint Committee wishes to take cognisance of the steps already taken in providing an improved culture for end of life care in hospitals. In particular, the launch of the Irish Hospice Foundation’s Hospice Friendly Hospitals Programme in 2007, which provides education and training in end of life care, and which has resulted in the development of a number of key resources used by hospitals in end of life care including the end of life symbol (used during or following the death of a patient, and to make resources relating to the end of life instantly identifiable), and the family handover bag (used for returning the deceased patient’s personal belongings to their family). The Hospice Friendly Hospitals Programme is being run in partnership with the HSE.

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62 Professor Patrick Plunkett, Address to the Joint Committee on Health and Children, November 2013
63 Dr. Geoff King, Director, Pre-Hospital Emergency Care Council
Professor Cillian Twomey highlighted the need for a coordinated approach to end of life care throughout the country and the importance of local leadership and support.

‘I support the notion of strategy. It has to be part of every service plan that there is an end-of-life, bereavement, death package. We need local leaders. Of the Hospice Friendly Hospitals programme, which involved 40 hospitals, there are only four coordinators of end-of-life care paid on an ongoing basis.’  

Further, the Design and Dignity projects undertaken in St. James Hospital, the Mater Misericordiae Hospital, Dublin, and the Mercy University Hospital, Cork have received extremely positive feedback from patients, families and staff. These are some of the eleven hospital projects around the country being co-funded by the HSE and the IHF.

According to Ms. Bree:

‘Similar projects in the UK have shown a greater sense of well-being amongst patients, families and staff. They have also resulted in a decrease in sick leave and waiting lists for staff seeking to work in the refurbished areas.’

**Conclusions**

In the context of the new hospital groups, all hospitals should draw up strategies for dealing with end of life care and bereavement.

The provision of single occupancy rooms for patients who are dying should be a priority.

Provision should be made for the pronouncement of death by advanced paramedics and senior nurses.

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64 Professor Cillian Twomey, Address to the Joint Committee on Health and Children, November 2013

65 Ms Kate Bree, Assistant Director of Nursing, Sligo General Hospital and Chair of the Hospice Friendly Hospitals Network.
5.8 Regulation of the funeral services industry/cremation service

During the course of its hearings on end of life care concern was raised about the lack of regulation and/or licensing of the funeral industry in Ireland. In 2011, a Private Members Bill the Burial and Cremation Regulation Bill 2011\(^{66}\) was introduced in the Dáil. This Bill, which sought to establish a Burial and Cremation Regulatory Authority, did not pass Second Stage. In light of the concerns raised the Joint Committee believes that this is an area to which the Government might turn its attention.

‘In respect of the regulation of the funeral industry, there is no bar to entry and no licence provision at the moment. There is no qualification for the embalming of bodies or opening of a crematorium. We need regulation.’\(^{67}\)

**Conclusion**

Quality standards should be developed for the funeral services industry in Ireland and some oversight mechanism should be developed to support these standards and ensure they are met and exceeded.

5.9 Advance care planning/directives

Dr. Deirdre Madden highlighted the importance of patient autonomy about their end-of-life care issues.

‘It is important to acknowledge that although those providing health care can usually claim greater expertise in decisions regarding the means to achieve the end of better health, such as what medication to use, we must bear in mind that the patient is the expert in deciding what ends matter to him or her, how they want to live their lives, what risks they are prepared to take and so on’\(^{68}\).

Advance Care Directives give people the opportunity to contemplate and make decisions in respect of their future healthcare. They ensure that people, even at end of life, retain a level of autonomy and control in relation to healthcare decisions which affect them.

Professor Patrick Plunkett pointed out the importance of end-of-life care plans being drawn up and notified to family and healthcare professionals.

‘It behoves us all to consider how and where we would wish to die and to plan for “a good death” on a personal basis. Once such a plan is devised, it should be shared with others,’


\(^{67}\) Ms. Patricia Rickard-Clarke, National Council of the Forum on End of Life in Ireland, Address to the Joint Committee on Health and Children, October 2013

\(^{68}\) Dr. Deirdre Madden, Address to the Joint Committee on Health and Children, November 2013
such as the next-of-kin and the family doctor, with clarity achieved on the wishes of the person involved.\(^{69}\)

Advance Care Directives are recognised in Irish law provided certain conditions are fulfilled (e.g. that the author was competent), but there is currently no legislative framework governing their use. The Minister for Justice and Equality, Deputy Alan Shatter has however indicated that provision will be made for such directives in the \textit{Assisted Decision-Making (Capacity) Bill 2013}\(^{70}\) when it reaches Committee Stage. According to the National Council of the Forum on End of Life in Ireland:

\begin{quote}
'The enactment of this legislation and its inclusion of provision for advance care directives would go toward fulfilling Ireland’s obligations under the 2006 UN Convention on the Rights of Persons with Disabilities.'\(^{71}\)
\end{quote}

\textbf{Conclusion}

Provisions governing the use of Advance Care Directives should be included in the \textit{Assisted Decision-Making (Capacity) Bill 2013} and swiftly implemented.

\textbf{5.10 Education and training}

‘I have met fully qualified staff nurses who have never even seen a person die or never even seen a dead person, so we cannot assume the people looking after the dying person know what is appropriate and what happens next. We would say that everybody needs some education. There are some who need more and then a small group of people probably need everything.’\(^{72}\)

At the end of December 2012, the health sector employed 101,506 whole-time equivalent (WTE) staff.

The 2008 Joint report of the National Council on Ageing and Older People (NCAOP) and the Irish Hospice Foundation: “End-of-Life Care for Older People in Acute and Long-Stay Settings in Ireland” found serious deficits in training in end-of-life and/or palliative care for nursing, medical and allied healthcare professionals, care and support staff in long stay and acute units; and only 43% of acute hospitals reported that their doctors/consultants had specialised training in end-of-life care.

\begin{flushright}
\textit{69} Professor Patrick Plunkett
\textit{70} Library and Research Service Bills Digest: \textit{Assisted Decision Making (Capacity) Bill 2013} \url{http://eolas.library.oireachtas.local/mental-capacity-bill/}
\textit{71} Patricia Rickard-Clarke, National Council of the Forum of End of Life in Ireland, address to the Joint Committee
\textit{72} Bryan Nolan, Communications and Development Coordinator (Final Journeys) IHF, address to the Joint Committee.
\end{flushright}
Professor Doiminic Ó Brannagáin pointed out that:

‘Palliative care is part of the undergraduate curriculum in many of our medical schools, but not all of them. A module on palliative care is offered in many of our nursing schools, but not all of them. Such a module is not provided, in the main, when occupational therapists and physiotherapists, etc., are being trained. My view is that it should be a mandatory part of the basic formation of all health care professionals that they should have core competencies in palliative care. The postgraduate training of doctors and nurses in the medical, surgical and paediatric areas should enable them to maintain their skill sets and thereby ensure they are able to provide palliative care for patients in whatever context they are being cared for.’

Concerns were raised by stakeholders that a lack of appropriate education and training in palliative, end-of-life, and bereavement care among staff in all care settings hinders the provision of good quality care. The National audit of end-of-life care in hospitals in Ireland, 2008/9 suggested that:

‘...basic training on end-of-life issues should be provided for all professional, support and administrative staff who come into contact with patients and relatives, with more intense training for clinical staff in areas such as breaking bad news, end-of-life discussions, diagnosing dying, managing symptoms, understanding bereavement and loss, and dealing with death at a personal level. In addition, end-of-life care is rarely mentioned in staff induction, unlike the practice in Northern Ireland where it is an integral element of induction, and this is something that needs to be addressed.’

The Joint Committee wishes to note that it is important for all care staff, not just palliative care staff, to understand end-of-life care and bereavement issues. In order to achieve this all care staff should undergo training in order to ensure a basic knowledge of these issues so that they are confident to provide such care to patients regardless of where they work within the health service (e.g. hospital porter, public health nurse or G.P.)

Ms Anne Tan of the Institute of Community Health Nursing commented:

‘Opportunities for education and training in palliative care are urgently provided for all levels of staff (including, disease-specific specialties and primary care staff) that interface with people with both cancer and life-limiting, non-malignant disease in the community.’

She also highlighted the need for practical supports for healthcare professionals caring for patients approaching end of life in the community recommending that:

73 Professor Doiminic Ó Brannagáin, address to Joint Committee on Health & Children, October 2013
74 http://epubs.rcsi.ie/mwg-internal/de5fs23hu73ds/progress?id=OUnzf9/D62&dl
75 McKeown, K., Haase, T., Pratschke, J., Twomey, S., Donovan, H., and Engling, F., 2010. Dying inHospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life, Report 5,
76 Anne Tan, Institute of Community Health Nurses
‘Increased access to home support including access to 24/7 nursing care and specialist palliative care on call support in the community and access to aids & appliances should be immediately available for ‘End of Life ‘care in the community.’

Ms. Paddie Blaney of the All Ireland Institute for Hospice and Palliative Care commented:

‘Regulatory bodies should seek to ensure that palliative care principles underpin all undergraduate and post graduate education programmes. Palliative care education providers should be supported to contribute to other areas of health and social care education to ensure contemporary palliative care education is available and accessible.’

It was also suggested by Dr. Joan McCarthy that the establishment of an end-of-life health care ethics observatory would improve the training and continuous professional development of clinicians and health care staff involved in caring for dying patients, as well as providing educational support to the general public.

‘Care of the dying is a complex art that demands a range of many skills, including ethical skills and competencies so that sight is not lost of the fundamental bond between professional and patient. Where ethics support is part of a standard practice of health care organisations, the international evidence indicates that health care staff are more ethically literate leading to improved patient and family outcomes and less moral stress, desensitisation and burnout for health professionals who are struggling at the coalface due to current budgetary constraints.’

Conclusions

A National Strategy on End of Life Care and Bereavement should recognise the importance of mandatory training and development for all healthcare staff in all care settings.

Palliative, end of life and bereavement care should form part of the core undergraduate curriculum of all health care professionals.

5.11 Continuity of care

Improving continuity of care across various care settings (e.g. home to hospital to hospice) was raised by a number of stakeholders during the course of the Joint Committee’s

77 Ibid
78 Ms. Paddy Blaney, CEO, All Ireland Institute for Hospice and Palliative Care
79 Dr. Joan McCarthy, BA, MA, PhD, Coordinator MSc End-of-Life Healthcare Ethics, Lecturer Healthcare Ethics, School of Nursing and Midwifery, University College Cork.
80 Dr. Joan McCarthy, BA, MA, PhD, Coordinator MSc End-of-Life Healthcare Ethics, Lecturer Healthcare Ethics, School of Nursing and Midwifery, University College Cork.
meetings. However, in order to achieve a seamless journey a number of issues would need to be addressed.

Firstly, there needs to be better communication between the various service providers in respect of a patient receiving palliative care (e.g. between a patient’s own G.P. and the out of hours G.P., and between specialist palliative care services and G.P.s). According to the 2011 Report *Primary Palliative Care in Ireland: Identifying improvements in primary care to support the care of those in their last year of life* more than one in three family doctors never informed their out-of-hours service about patients in their care who were receiving/required palliative care. While some out of hours services operate a notification system whereby a G.P. can inform the out of hours team of any potential problems which may arise in respect of the patient the development of a national electronic notification system would greatly enhance communication between service providers and ultimately the care received by the patient.

Professor Declan Walsh commented that:

> "The explosion in modern information technology will allow us to look after people in a much more comprehensive and efficient manner in the community and we will be able to do things in the community that one could only do in the hospital until recently. This has significant implications for training, manpower in the context of the provision of specialists and generalists in the area and for returning to some old fashioned values in medicine such as the ability of GPs or specialists to visit patients in the home and so on. There are important services that need to be delivered on a 24-7 basis. There needs to be specialist back up for the community services throughout the country."

Stakeholders also suggested the appointment of a dedicated G.P. liaison person within specialist palliative care services to allow quick access for G.P.s to advice and direct access to services. According to the 2011 Report, 72% of respondents wanted access to a Specialist Palliative Care 24 hour helpline.

Secondly, there needs to be a move away from paper based information systems. Stakeholders suggested the development of an electronic clinical information system. This would ensure the easy transfer of patient information across various care settings, which would be of huge benefit to patients and healthcare staff.

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81 Primary Palliative Care in Ireland, Identifying improvements in primary care to support the care of those in the last year of life, Irish Hospice Foundation, HSE and Irish College of General Practitioners [http://www.lenus.ie/hse/bitstream/10147/299044/1/PrimaryPalliativeCareinIreland.pdf](http://www.lenus.ie/hse/bitstream/10147/299044/1/PrimaryPalliativeCareinIreland.pdf)

82 Professor Declan Walsh, Professor of Palliative Medicine: Faculty of Health Sciences Trinity College Dublin; University College Dublin; Consultant Physician in Palliative Medicine: Our Lady’s Hospice & Care Services
Dr. Karen Ryan highlighted the benefits of such a systems transfer of information:

“It would be of huge benefit if we had the ability to facilitate the electronic transfer of information across systems. The out-of-hours issue is also of relevance to clinical information systems. If general practitioners or primary care teams that are looking after patients had a facility that enabled them to communicate effectively with out-of-hours services, including ambulance, emergency department and specialist palliative care services, and if patients were able to register their preferences regarding the place where they receive care or the type of care they might receive in the event of an unanticipated out-of-hours situation, it would be of huge benefit in improving the quality of care provided to patients.”

## Conclusions

All healthcare providers should be encouraged to develop systems and practices which would ensure continuity of care for palliative and end of life patients across all care settings. Consideration must however be given to the law on data protection, and the right to privacy in the development of any such systems.

A move away from paper based information systems to electronic systems in all care settings should be facilitated and prioritised within the relevant business plans in line with the Government’s E-Health Strategy.

## 5.12 Cost analysis

Evidence has been presented to the Joint Committee which suggests ‘...that where people die has an impact on how they die, and that those who die at home and in the place they prefer have a better ‘quality of dying’ than those who do not, and this positively impacts on the bereavement and loss experience of their families.’

Evidence presented to the Joint Committee suggests that specialist palliative care services are cost effective. According to Home and Community Care Ireland, the estimated cost of a hospital stay per night is €900, compared to €480 for 24 hour specialist palliative home care, representing a potential saving of over €400 per person per night, and ‘the average annual cost of Jack & Jill homecare provision is €16,422, nine times less than the annual cost falling on the State to deliver acute hospital care at €147,365.’

Evidence provided by some health-care systems internationally was used to demonstrate that palliative-care services can reduce the overall cost of care, while at the same time

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83 Dr. Karen Ryan, Clinical Lead, HSE Palliative Care Programme, October 2013
84 Dr. Paul Gregan, Submission to the Joint Committee on Health and Children, November 2013
85 Home and Community Care Ireland, Submission to the Joint Committee on Health and Children, November 2013.
improving the quality of life for patients and often by avoiding inappropriate – and costly - hospital admissions. This was highlighted by Dr. Brian Creedon:

‘Health-care systems in Canada and Catalonia have demonstrated that palliative-care services are cost effective - even reducing overall cost of care - yet greatly enhance the quality of life for patients. This is largely achieved by avoiding inappropriate hospital admissions which are often traumatic for the patient and family, and costly for the health service as a whole. At the same time, early evidence in lung cancer patients is showing that patients receiving palliative care are living longer, despite - and perhaps because of - receiving less aggressive active treatments near the end of life.87

Conclusion

The Department of Health in conjunction with key stakeholders should undertake a comprehensive cost benefit analysis in respect of the current and future provision of specialist palliative care in Ireland.

5.13 Statutory entitlement to a medical card for people who are living with advanced incurable illnesses; 88

The Joint Committee heard evidence in relation to the provision of medical cards to those confirmed to have less than 6 months to live:

‘This one intervention has had an extremely positive effect on the experience of those coming to the end of their lives. It has given them access to free G.P. care, medications that were required to optimise their comfort, equipment to make care at home possible and access to the services of members of the wider primary care team such as the public health nurse, occupational therapist, home help and others. It is an essential support in practical and financial terms.89

While the provision of such a card is welcome a number of stakeholders, including Dr. Paul Gregan, raised concerns about the 6 month eligibility period:

‘If we feel a person will die within six months then he or she will qualify for the service. However, we are not going to get it right every time. Based on unpublished research we believe that approximately 20% of the time the six month period will be over-run. We are currently running over by one or two months. To ask a person within a month or two of dying to reapply for a medical card on a means test rather than discretionary basis is inhuman. This has to

88 For more information on medical card eligibility please see the Library & Research Service Note: Medical Card Eligibility in Ireland: Origins, Coverage and Costs, 31 October 2013, http://vlms-a01/AWData/Library2/Medical_Card_Eligibility_in_Ireland_Origins_Coverage_and_Costs_160116.pdf
89 Hospice and Palliative Care Social Workers’ Group, Submission to the Joint Committee on Health and Children
change….not being able to access sufficient carer support when a person is
deteriorating or dying, or the unavailability of equipment in the community for this
priority grouping, arguably represents a fundamental breakdown in care
provision.  

The Hospice and Palliative Care Social Workers’ Group stated that:

‘…for the small number of patients who live longer than 6 months, the process of
renewing this card is much less responsive of, and less sensitive to their needs.
They are often renewing the medical card at a time when they are much less
well. In order to extend their card, and retain the basic and necessary services
needed for them to die at home, a full means test must now take place, which
requires an extraordinary level of detail and paperwork, at a time when a patient
may be in their final days or weeks of life.’

Stakeholders suggested that renewal could be made on the basis of a covering letter from a
patient’s G.P. or consultant thereby eliminating the need for onerous paperwork. Another
alternative is to provide the discretionary card for a 12 month period, something which the
Joint Committee has previously raised with Mr. Tony O’Brien, Director General of the Health
Service Executive.

The Irish Cancer Society recommends that patients in the advanced stage of illness be
granted a special or priority status which would alleviate them from being financially
assessed at a time of significant distress.

Conclusions

The proposal that palliative care and end of life patients be granted a ‘special
patient status’ that prioritises their needs across all healthcare and community
services should be considered.

The automatic sanctioning of medical cards, without renewal, for those requiring
end of life care should be considered.

Alternatively, a proposal extending the renewal period for discretionary medical
cards for those requiring end of life care to 12 months could be considered.

Any renewal of a discretionary medical card for those nearing end of life could
be considered on the basis of a covering letter from a patient’s G.P. or
consultant rather than by reference to a means assessment.

90 Dr. Paul Gregan, Parliamentary Debates, 5 November 2013 available at
http://oireachtasdebates.oireachtas.ie/Debates%20Authoring/WebAttachments.nsf/($vLookupByCon
structedKey)/committees~20131105~HEJ/$File/Daily%20Book%20Unrevised.pdf?openelement
91 Hospice and Palliative Care Social Workers’ Group, Submission to the Joint Committee on Health
and Children
5.14 Bereavement Support

‘We need to build communities of care. Bereavement is not an illness, but it does have health consequences for people. It is psychologically painful and there are economic implications for them. Given it is not an illness, we need to promote a natural community response. Bereavement care should be embedded into the fabric of society.’

The Joint Committee heard evidence of the variation in the specialist and therapeutic bereavement supports in Ireland. Approaches are inconsistent, ranging from comprehensive (e.g. Beaumont Hospital, Dublin) to sparse, due to lack of resource, staffing and training.

While many voluntary and state-supported organisations provide bereavement support in a voluntary capacity in Ireland, there are no national guidelines or standards governing bereavement services. According to Orla Keegan:

‘A common purpose and vision, shared language, agreed practices and training approaches would be a welcome addition to the landscape of bereavement care.’

Evidence of the special needs of bereaved children was heard in which it was asserted that bereavement in childhood is a whole life experience. Brid Carroll pointed out that:

‘A child who is bereaved in childhood is bereaved for life. Every milestone of his or her life, including the transitions of First Holy Community, Confirmation, changing school, going to college, getting a job, getting married and having children, will have the shadow of the loss of childhood hanging over it.’

A 2010 study showed childhood bereavement services in Ireland to be fragmented and without recognised standards. A network of support for people working with bereaved children was recommended.

‘Therefore, we recommend the establishment of an agreed network for community, public, volunteer and professional education with respect to childhood bereavement…... The Government, the Department of Health, the Department of Finance and the Department of Social Protection can work with us to realise our vision.’

Stakeholders, including the Irish Hospice Foundation, believe that the decision to abolish the bereavement grant should be reversed:

‘Bereavement support begins with practical help and sound information in the aftermath of a death and at the time of the funeral. Any systematic societal approach to bereavement care must begin with such support, including financial

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92 Orla Keegan, Head of Education, Research and Bereavement Services, Irish Hospice Foundation, address to the Joint Committee on Health and Children
93 Orla Keegan, Bereavement Education & Resource Centre, Irish Hospice Foundation
November 7th 2013
94 Brid Carroll, Chairperson, Irish Childhood Bereavement Network
95 Ibid
Conclusions

The development of a national framework to govern the provision of bereavement care/support services by private, statutory and voluntary agencies should be considered.

The Government could be asked, on the basis of Committee hearings, to review its decision to abolish the bereavement grant.

5.15 Long-Stay Facilities

Professor Eamon O’Shea highlighted the particular challenges arising in end-of-life care for older people in acute and long-stay settings, particularly in relation to integrated care.

‘End-of-life care is broader in scope than palliative care and allows a longer lead time to death. It takes into account the potential uncertainty surrounding dying and death, including the possibility that some people follow complex and non-linear pathways to death. End-of-life care is intimately bound-up with quality of life issues for older people living in acute and long-stay care settings. Loss and decline are common and recurring features of life in long-stay care settings, from admission, through on-going care, to death. The challenge for the future will be to find an equilibrium between the care of the living and the dying in acute and long-stay care settings. What is needed is an integrated care structure for end-of-life care that embraces living and dying as part of the normal care structures and processes in all care settings.’

Nursing Homes Ireland and other stakeholders acknowledged the need for ongoing training and support for nursing home and long-stay facility staff caring for patients at end of life and highlighted a number of practical difficulties they face. One issue pertains to the fact that Nurse Prescribers working in private nursing homes are not routinely given access to prescription pads which could be used to prescribe symptom relief medication for people approaching end of life. Mary Burke of Nursing Homes Ireland said:

‘……The latter is of particular concern to palliative and end of life residents who may require prescribing for symptom relief. IHF et al. (2011) highlighted the potential of Nurse Prescribing “to enhance the access to medications for people with advancing progressive illness in the community”. It is disheartening therefore that it is current policy not to issue a prescription pad to Registered Nurse Prescribers who work in private healthcare facilities including nursing homes (HSE, 2011). In our view this discriminates against nurses working

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97 Professor Eamonn O’Shea
The Nursing Homes Support Scheme was introduced in 2009 to provide financial support for those assessed as needing long-term nursing home care. Concerns were expressed by Nursing Homes Ireland (NHI) about the narrow definition of Long Term Residential Care Services under the Nursing Home Support Scheme, and the range of services covered by the Scheme:

‘NHI, in tandem with many other stakeholders, is extremely concerned at the narrow definition of Long Term Residential Care Services under the Nursing Home Support Scheme (Fair Deal). Ombudsman Emily O’Reilly highlighted this anomaly on a number of occasions and in reports. “Another issue of concern is that in practice the range of services covered by the NHSS is quite narrow and excludes many elements which, on the face of it, are services which one would expect to be included as part of long-term nursing home care,” she stated in her report Who Cares – An Investigation into the Right to Nursing Home Care (November 2010).

This includes for example access to allied health services (where there is no access to HSE services); aids and appliances; and items not covered under the Primary Care Reimbursement Service... The HSE in 2012 published a policy which set out the specialised (non-standard) aids and appliances that would be provided to residents of designated centres for older people. This policy excludes many items which may be required for symptom control and comfort at end of life such as oxygen (including tubing and masks); nebulisers; Syringe drivers (and giving sets) and dressings, to name a few.

In addition many items previously accessible under the Primary Care Reimbursement Service are now currently unavailable providing further hardship to residents and families at the end of life. For example, a resident with a fungating tumour requiring specialised dressings at least daily could be required to pay upwards of €20-30 per day for the dressings alone. Whilst the HSE policy purports to supply specialised/ non GMS dressings, in reality getting access to these dressings is proving extremely difficult.’

Nursing Homes Ireland believes that the current review presents an opportunity to introduce an evidence-based cost of care model that acknowledges the true cost of residential nursing home care.

**Conclusions**

Palliative care patients waiting to access beds under the Fair Deal Scheme could be prioritised with the aim of enabling them to access residential care in a timely manner and thereby facilitate their final medical care in a more appropriate setting.

In reviewing the current Fair Deal Scheme consideration could be given to

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Mary Burke, Nursing Homes Ireland
extending the definition of Long Term Residential Care Services, and the range of services covered by the Scheme.

In reviewing the current Fair Deal Scheme an evidence-based cost of care model could be used in assessing the real cost of residential nursing home care in Ireland.

Nurse prescribers in Private Nursing Homes should be allowed routine access to prescription pads.
6. Key issues - Children

“We have done much and a lot has been achieved but there is much left to do. If we focus on the Department of Health policy and stick to the guidelines and recommendations in it, we will improve the position for all our young patients and families”.

While many of the key issues highlighted above are also relevant in the context of children requiring palliative or end of life care, it may be appropriate to recognise the differences in the needs of children living with life limiting illnesses:

“Children’s palliative care differs significantly from adult palliative care...Children continue to develop physically, emotionally and cognitively throughout their illness thus their care needs and palliative care needs change over time.”

Given the nature of their illnesses, children with life limiting illnesses may frequently be close to death, and may consequently spend up to 5 times longer under the care of a palliative care team than adults.

World Health Organisation Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care… the principles apply to other paediatric chronic disorders (WHO: 1998a):

- Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child’s physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children’s homes.

The term life limiting illness ‘refers to any illness for which there is no reasonable hope of cure and where the child is unlikely to survive beyond early adulthood. Many of these conditions cause a progressive deterioration leaving the child increasingly dependent on

99 Dr. Maeve O’Reilly, Consultant in Palliative Medicine, St Luke’s Hospital and Our Lady’s Children’s Hospital Crumlin on behalf of Specialist Children’s Palliative Care
their family or carers. Such illnesses have been categorised into four categories…ranging across a broad spectrum from children where imminent death is likely e.g. failed cancer treatment or major organ failure, to children with non-progressive brain injury who are increasingly susceptible to medical complications which will shorten their life but whose death is unpredictable, e.g. severe cerebral palsy.\(^{101}\)

6.1 Lack of data on children with life limiting illnesses

Every year almost 350 children die as a result of a life limiting illness. However, determining the number of children living with a life limiting illness in Ireland continues to prove difficult. Stakeholders have expressed concern that this lack of data is causing major problems in the planning and development of palliative and end of life services for children in Ireland. As pointed out in the 2005 Report *A Palliative Care Needs Assessment for Children*:

‘Comprehensive data on children with life-limiting conditions…are necessary in order to form the basis for service planning at local and national level. Accurate data collection is essential in order to provide key information on the number, location, diagnostic category and age range of children with life-limiting conditions at any given time.’\(^{102}\)

The 2005 Study estimated that there were approximately 1,400 children living with a life-limiting condition in Ireland.\(^{103}\) However, these figures should be treated with caution as they are based on a number of assumptions.\(^{104}\) It has been suggested, following recent research in the United Kingdom, that these figures are ‘are likely to be severely underestimated with true figures likely to be at least three times higher…resulting in a revised estimate of approximately 4,000 children living in Ireland with a life-limiting condition.’\(^{105}\)

Stakeholders have stressed the importance of planning for services based on the number of children living with a life limiting illness rather on the number of children who die from such illnesses:

\(^{101}\) Dr Maeve O’Reilly, Consultant in Palliative Medicine, St Luke’s Hospital and Our Lady’s Children’s Hospital Crumlin on behalf of Specialist Children’s Palliative Care available at [http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Maeve-OReilly-Submission.pdf](http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Maeve-OReilly-Submission.pdf)


\(^{104}\) Including, that prevalence rates in Ireland are similar to those in the UK, and that prevalence rates across the Health Service Executive areas are similar.

‘Life limiting illnesses are more prevalent than previously believed and these numbers, rather than numbers of deaths in childhood, should be used in planning services. Collection of more accurate figures is an important step in planning services and a good system of data collection needs to be developed.’

Conclusions

Consideration could be given to the development of a national standardised data collection system/register which could allow for the efficient planning and development of palliative and end of life services for children in Ireland.

Consideration could be given to making calculations in respect of the current and future palliative and end of care needs of children on the basis of the number of children living with life limiting illnesses rather than the number of children who die from such illnesses.

6.2 Child specific education and training

Children’s palliative care is a small but highly specialised area of healthcare. Evidence was presented to the Joint Committee that a major challenge in the provision of children’s palliative and end of life care in Ireland is the lack of suitably trained and qualified staff.

Life limiting illnesses in children can be quite complex, which may present difficulties for healthcare professionals whose expertise is for the most part confined to the care of adults:

‘Many life-limiting illnesses are so complex that a child can cross the boundary between episodes of critical illness and back to the management of chronic illness many times before death occurs.’

In addition, the fact that the number of children dying as a result of a life limiting illness is quite small, may mean that many healthcare professionals have little or no previous experience in the management of children’s palliative or end of life care.

106 Dr Maeve O’Reilly, Consultant in Palliative Medicine, St Luke’s Hospital and Our Lady’s Children’s Hospital Crumlin on behalf of Specialist Children’s Palliative Care available at http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Maeve-OReilly-Submission.pdf


Conclusion

All healthcare professionals working with children with life limiting illnesses should undergo specific training to enable them to better understand and cater for the unique needs of such children.

6.3 Medical cards

Many stakeholders highlighted the financial hardship associated with living with a life limiting illness. The provision of a medical card in such cases could alleviate much of the financial strain place on families coping with the inevitable loss of a child. The Joint Committee heard evidence that the current situation governing discretionary medical cards is causing ‘huge difficulty and trauma for families’. Stakeholders asked for more clarity around the long-term Illness card (for example in relation to the eligibility criteria, and what’s covered.)

The Joint Committee also heard evidence regarding the issuing of medical cards for infants who have not yet been issued a PPS number. According to Ms Sinéad Moran:

'We have serious issues with medical cards, especially for children, specifically for end-of-life care going home. If the parents of a child with Edwards’ syndrome wish to take the child home, they must go and register the child’s birth in the registration office, one parent if they are married and both if they are not married, to access a PPS number before the child receives a medical card to access whatever medication the child needs at home. That must change specifically for those children because sometimes they are only around for 24 to 36 hours and to ask the parent to leave that child and go and do that is unheard of and unfair.'

Conclusions

Consideration should be given to the automatic sanction of medical cards for children who require palliative or end of life care; without their being subject to a renewal process.

Alternatively, any renewal should be on the basis of a covering letter from a child’s G.P. or consultant, rather than by a means assessment.

The Department of Health, in consultation with the Registrar of Births, Deaths and Marriages, and any other interested party, could consider an alternative procedure for the issuing of medical cards to infants who have not been issued with a Personal Public Service Number (PPS Number).

109 Jack and Jill Foundation, Opening Statement.
110 Sinead Moran, Senior Liaison Nurse, Jack and Jill Children’s Foundation
6.4 State funding

The course of a life limiting illness in children is often unpredictable. Some require palliative care for a few days or months while others require palliative care over several years. One of the key findings of the study *A Palliative Care Needs Assessment for Children* was that most families of seriously ill children want them to be cared for and to die at home in familiar surroundings. However, in some cases home care is not an option for parents. In these circumstances hospice care should be available. The Joint Committee wishes to take this opportunity to acknowledge and commend the work carried out by organisations such as LauraLynn Ireland’s Children’s Hospice, the Jack and Jill Foundation and the Irish Hospice Foundation in relation to children living with life limiting illnesses.

LauraLynn House is Ireland’s only purpose built hospice for children. Opened in September 2011 it is an eight-bed unit providing respite, transitional, crisis and end of life care to children with life-limiting illnesses:

‘In the two years since opening…[it has] provided care to 198 children and their families.’\(^{111}\)

In addition, LauraLynn hopes to pilot a hospice-at-home service in 2014 which will reach out into the community and complement the work of the Jack & Jill Children’s Foundation and the HSE services that exist.\(^{112}\) LauraLynn Ireland’s Children’s Hospice is a voluntary organisation which receives no state funding:

‘Unlike adult voluntary hospices who receive 69% of their revenue funding and 19% of their capital funding from the state, 100% funding for Lauralynn Children’s Hospice has been achieved through fundraising activities including the capital costs of €5.5 million and annual revenue costs of €2.4 million.’\(^{113}\)

The Jack & Jill Children’s Foundation has been running for 16 years providing end-of-life care for children up to 4 years of age in their home. Since 1997 the Jack & Jill Foundation has supported nearly 1,700 children and their families, raising €47 million through


fundraising, while receiving €4.5 million from the HSE. Sixty per cent of Jack & Jill children died at home versus the national average of 11%. The Foundation employs 11 paediatric liaison nurses directly, who help co-ordinate up to 1,000 nurses who provide hands on care in every community in Ireland. According to the Foundation:

‘We require €2.7 million on an annual basis to do what we do and receive only 18% of this from the HSE, raising the rest ourselves.’

The Irish Hospice Foundation is supporting the implementation of Government policy through its investment in a number of key posts, education and research. As part of its Hospice Home Care for Children programme, it funds five of the eight children’s outreach nurses and the Children’s Palliative Care consultant. It supported healthcare professionals (such as public health nurses) caring for children with life limiting illness through an education programme developed in conjunction with Our Lady’s Hospital for Sick Children, Dublin. The Irish Hospice Foundation has committee €2.7 million to these initiatives over five years.

In 2011, Dr. Mary Devins was appointed Ireland’s first Consultant Paediatrician with a Special Interest in Paediatric Palliative Care, in line with one of the key recommendations of the Policy Document Palliative care for children with life limiting conditions in Ireland - A National Policy. This post is being fully funded by the Irish Hospice Foundation until May 2016. Stakeholders have called on the Health Service Executive to secure funding not only for this post but also for the creation of a second post:

‘There needs to be further expansion of consultant posts specialising in children’s palliative medicine. It is now known that for every 10,000 children attending hospital, 40 have LLI’s, challenging the myth that these conditions are rare. It is now recommended that given the evidence of much higher prevalence rates of LLI’s the number of Children’s Palliative Care consultants should be in proportion with the number of adult Palliative Care consultants i.e. about 1:4…There is an immediate need for a second post to support the consultant based in OLCHC. Such a post could also be based in Dublin to support the other children’s hospitals and with links to local maternity services. Ultimately these would merge as one team at the new Children’s Hospital.’

The 2010 Policy Document also recommended the appointment of a national network of Clinical Nurse Specialists – Children’s Outreach Nurses to provide advice and

115 Dr Maeve O’Reilly, Consultant in Palliative Medicine, St Luke’s Hospital and Our Lady’s Children’s Hospital Crumlin on behalf of Specialist Children’s Palliative Care available at http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Maeve-OReilly-Submission.pdf
support to parents and other professionals involved in the care of very sick children at home. Eight of these posts have since been created; five posts are currently being fully funded by the Irish Hospice Foundation, the remaining three by the HSE.

Stakeholders have stressed that Health Service Executive funding for these posts needs to be secured.\textsuperscript{116} The Irish Hospice \textit{Foundation} recommended that:

\begin{quote}
‘That the HSE plans for and provides the funding for the 8 outreach nurses, including the 5 nurses currently funded by the IHF, and immediately begin planning for the expansion of this service to allow for coordinated care for children with life-limiting illness throughout the country.’\textsuperscript{117}
\end{quote}

\begin{center}
\textbf{Conclusions}
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Consideration could be given to providing state funding to the LauraLynn Ireland’s Children’s Hospice.

Consideration could be given to increasing State funding to the Jack & Jill Foundation to enable the expansion of its end of life care service to support children up to the age of 6, as recommended in the Report \textit{There’s No Place Like Home}\textsuperscript{118}.

The Health Service Executive (HSE) could consider planning for the on-going and sustainable funding of the post of Consultant Paediatrician with a Special Interest in Paediatric Palliative Care post May 2016;

The Health Service Executive could consider the appointment of a second Consultant Paediatrician with a Special Interest in Paediatric Palliative Care;

The Health Service Executive could consider planning for the on-going and sustainable funding of the 8 Children’s Outreach Nurses posts, and consider the expansion of this service.

The provision of respite for children with life-limiting conditions and their families should be progressed in line with the needs identified in the 2013 Needs Assessment\textsuperscript{119}.

\textsuperscript{116} Dr Maeve O’Reilly, Consultant in Palliative Medicine, St Luke’s Hospital and Our Lady’s Children’s Hospital Crumlin on behalf of Specialist Children’s Palliative Care available at http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Maeve-OReilly-Submission.pdf


\textsuperscript{118} Respite Services for Children with Life-Limiting Conditions and their Families in Ireland – A National Needs Assessment. Irish Hospice Foundation and LauraLynn Children’s Hospice. 2013
SECTION 2: ORAL PRESENTATIONS

Sharon Foley, The Irish Hospice Foundation.
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Sharon-Foley,-Opening-Statement.docx

Patricia Rickard-Clarke, National Council on the Forum of End of Life in Ireland
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Patricia-Rickard-Clarke,-Opening-Statement,-National-Council-of-the-FELI..docx

Professor Eamon O' Shea, NUI Galway
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Eamon-OShea-Opening-Statement.docx

Dr. Joan McCarthy, School of Nursing and Midwifery, UCC.

Kevin O’ Dwyer, Voluntary Hospices Group

Dr. Brian Creedon, Irish Palliative Medicine Consultant Association
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Brian-Creedon,-Opening-Statement.docx

Dr. Margaret Clifford, Irish Association for Palliative Care
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Margaret-Clifford,-IAPC-Opening-Statement.pdf

Dr. Karen Ryan

Paddie Blaney, All Ireland Institute of Hospice and Palliative Care
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Paddie-Blaney,-AllHPC,-Opening-Statement.pdf

Professor Dominic Ó Brannagáin

Dr. Paul Gregan, Primary Palliative Care Initiative
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Paul-Gregan,-opening-Statement.docx

Mary Burke, Nursing Homes Ireland
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Mary-Burke,-Nursing-Homes-Ireland-Opening-Statement.pdf

Anne Tan, Member of Institute of Community Health Nursing
Gerry Martin, Alzheimer Society of Ireland

Professor Declan Walsh, Trinity College Dublin and University College Dublin
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Prof-D-Walsh-TCD--Opening-statement.docx

Dr. Maeve O’ Reilly, St. Luke’s Hospital and Our Lady’s Children Hospital Crumlin

Julie Ling, Lauralynn Children’s Hospice

Sinead Moran and Caroline Thomas, Jack and Jill Children’s Foundation

Brid Carroll, Irish Childhood Bereavement Network

Odhrán Allen, GLEN

Dr. Regina McQuillan, St. Francis Hospice

Dr. Paul D’Alton, UCD

Orla Keegan, Irish Hospice Foundation

Kate Bree, Hospice Friendly Hospitals Programme
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Kate-Bree,-Hospice-Friendly-Hospice-Programme,-Opening-Statement.pdf

Professor Patrick Plunkett, Irish Association for Emergency Medicine
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Professor-Patrick-Plunkett,-Emergency-Medicine-TCD-and-St-James,-Opening-Statement.doc
Dr. Geoff King, Pre-Hospital Emergency Care Council; HSE National Transport Medicine Programme

Margaret Naughton, National Association of Healthcare Chaplains
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Margaret-Naughton,-National-Association-of-Healthcare-Chaplains,-opening-statement.docx

Dr. Deirdre Madden, UCC
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Dr.-Deirdre-Madden,-UCC,-Opening-Statement.docx

Bryan Nolan, Irish Hospice Foundation

Professor Cillian Twomey, Consultant Geriatrician
http://www.oireachtas.ie/parliament/media/committees/healthandchildren/Professor-Cillian-Twomey,-consultant-geriatrician,-Opening-Statement.docx

Joan Kelly, Irish Cancer Society
SECTION 3: TRANSCRIPTS OF MEETINGS

Thursday, 24 October 2013


Tuesday, 5 November 2013


Thursday, 7 November 2013


Thursday, 14 November 2013

SECTION 4: TERMS OF REFERENCE

a. Functions of the Committee – derived from Standing Orders [DSO 82A; SSO 70A]

(1) The Select Committee shall consider and report to the Dáil on—
(a) such aspects of the expenditure, administration and policy of the relevant Government Department or Departments and associated public bodies as the Committee may select, and
(b) European Union matters within the remit of the relevant Department or Departments.

(2) The Select Committee may be joined with a Select Committee appointed by Seanad Éireann to form a Joint Committee for the purposes of the functions set out below, other than at paragraph (3), and to report thereon to both Houses of the Oireachtas.

(3) Without prejudice to the generality of paragraph (1), the Select Committee shall consider, in respect of the relevant Department or Departments, such—
(a) Bills,
(b) proposals contained in any motion, including any motion within the meaning of Standing Order 164,
(c) Estimates for Public Services, and
(d) other matters
as shall be referred to the Select Committee by the Dáil, and
(e) Annual Output Statements, and
(f) such Value for Money and Policy Reviews as the Select Committee may select.

(4) The Joint Committee may consider the following matters in respect of the relevant Department or Departments and associated public bodies, and report thereon to both Houses of the Oireachtas:
(a) matters of policy for which the Minister is officially responsible,
(b) public affairs administered by the Department,
(c) policy issues arising from Value for Money and Policy Reviews conducted or commissioned by the Department,
(d) Government policy in respect of bodies under the aegis of the Department,
(e) policy issues concerning bodies which are partly or wholly funded by the State or which are established or appointed by a member of the Government or the Oireachtas,
(f) the general scheme or draft heads of any Bill published by the Minister,
(g) statutory instruments, including those laid or laid in draft before either House or both Houses and those made under the European Communities Acts 1972 to 2009,
strategy statements laid before either or both Houses of the Oireachtas pursuant to the Public Service Management Act 1997,

annual reports or annual reports and accounts, required by law, and laid before either or both Houses of the Oireachtas, of the Department or bodies referred to in paragraph (4)(d) and (e) and the overall operational results, statements of strategy and corporate plans of such bodies, and

such other matters as may be referred to it by the Dáil and/or Seanad from time to time.

Without prejudice to the generality of paragraph (1), the Joint Committee shall consider, in respect of the relevant Department or Departments—

(a) EU draft legislative acts standing referred to the Select Committee under Standing Order 105, including the compliance of such acts with the principle of subsidiarity,

(b) other proposals for EU legislation and related policy issues, including programmes and guidelines prepared by the European Commission as a basis of possible legislative action,

(c) non-legislative documents published by any EU institution in relation to EU policy matters, and

(d) matters listed for consideration on the agenda for meetings of the relevant EU Council of Ministers and the outcome of such meetings.

A sub-Committee stands established in respect of each Department within the remit of the Select Committee to consider the matters outlined in paragraph (3), and the following arrangements apply to such sub-Committees:

(a) the matters outlined in paragraph (3) which require referral to the Select Committee by the Dáil may be referred directly to such sub-Committees, and

(b) each such sub-Committee has the powers defined in Standing Order 83(1) and (2) and may report directly to the Dáil, including by way of Message under Standing Order 87.

The Chairman of the Joint Committee, who shall be a member of Dáil Éireann, shall also be the Chairman of the Select Committee and of any sub-Committee or Committees standing established in respect of the Select Committee.

The following may attend meetings of the Select or Joint Committee, for the purposes of the functions set out in paragraph (5) and may take part in proceedings without having a right to vote or to move motions and amendments:

(a) Members of the European Parliament elected from constituencies in Ireland, including Northern Ireland,

(b) Members of the Irish delegation to the Parliamentary Assembly of the Council of Europe, and

(c) at the invitation of the Committee, other Members of the European Parliament.
b. Scope and Context of Activities of Committees (as derived from Standing Orders [DSO 82; SSO 70]

(1) The Joint Committee may only consider such matters, engage in such activities, exercise such powers and discharge such functions as are specifically authorised under its orders of reference and under Standing Orders.

(2) Such matters, activities, powers and functions shall be relevant to, and shall arise only in the context of, the preparation of a report to the Dáil and/or Seanad.

(3) It shall be an instruction to all Select Committees to which Bills are referred that they shall ensure that not more than two Select Committees shall meet to consider a Bill on any given day, unless the Dáil, after due notice given by the Chairman of the Select Committee, waives this instruction on motion made by the Taoiseach pursuant to Dáil Standing Order 26. The Chairmen of Select Committees shall have responsibility for compliance with this instruction.

(4) The Joint Committee shall not consider any matter which is being considered, or of which notice has been given of a proposal to consider, by the Committee of Public Accounts pursuant to Dáil Standing Order 163 and/or the Comptroller and Auditor General (Amendment) Act 1993.

(5) The Joint Committee shall refrain from inquiring into in public session or publishing confidential information regarding any matter if so requested, for stated reasons given in writing, by—

(a) a member of the Government or a Minister of State, or

(b) the principal office-holder of a body under the aegis of a Department or which is partly or wholly funded by the State or established or appointed by a member of the Government or by the Oireachtas:

Provided that the Chairman may appeal any such request made to the Ceann Comhairle / Cathaoirleach whose decision shall be final.