

End of life care in practice; reflections from a residential care unit in Roscommon;

Submission to joint Committee on Health and Children on End of life Care in Residential Care

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13th November 2013

Introduction;

Working in a long stay residential care home in Roscommon for the past 10 years has given me a first-hand view of the context of older people living the remainder of their lives in care homes. During my time there I have witnessed many deaths, some happy and peaceful but others sad and troubled. Common to all of them, was the deep emotional and compassionate bond between the resident and care staff to facilitate the resident's journey to the next life.

There are three important components in the end of life care trajectory; the resident, the residents' family and the nurse. End of life care does not follow a predictable path, it is complex and can involve a great deal of uncertainty on the part of the resident and care giver. Nurses are frequently making decisions based on the resident's choices or understanding of choices.

Executive Summary

End of life care relies a lot on the quality of life the resident has experienced prior to admission and during the time he/she has spent in the care home. This is particularly dependent on the strength of the relationships forged with the care staff. Indeed many care staff develop a strong, and almost 'familial' bond with residents over many years and they too feel the sense of loss and grief following the death of a resident. Providing end of life care is an art which relies on the skills, sensitivity and moral values of care staff to provide care that is congruent with the resident's strongly held faith and culture.

Some of the challenges professional care staff find on a day-to-day basis are as follows;

Multi-disciplinary approach: Providing good end of life care requires a strong demand on nurse's time to provide optimal care to residents and their families. This involves liaising with members of the multi-disciplinary teams, (speech and language, dietetics, physiotherapy pastoral care and social care) and coordinating their input to support the diverse and complex care needs at end of life care. Recognising when to stop treatment, de-escalate treatment, manage pain, support informal care givers continues throughout the process amidst the backdrop of a busy care unit where other residents also in need of individualised care.

Continuity of care-A skilled team: There are often staff shortages and workload demands, which add to the pressures of the quality of life that residents enjoy in long stay care. Living well until death is an important factor in providing good end of life care. Providing residents with a purposeful life, engaging with their community and maintaining connectedness with staff and visitors optimises the

residents' senses regardless of their morbidities and illnesses. Maintaining continuity of skilled and educated staff who know the residents in their unique care needs is an essential component in facilitating good end of life care.

Writing and reporting care; There are many documentation files, which require that the nurse leave direct clinical care to write up lengthy case notes. This practice removes the nurse from the bedside which is at the point of care delivery. Nurses more frequently default to the clinical role, which places pressure on their time to 'catch up' on the documentation required to meet regulatory standards.

Conversations around the topic end of life care; Currently residents are being asked what are their wishes regarding their care at end of life, however well intentioned their carer is, often the resident does not have the language skills to articulate their wishes; end of life care is relatively new phrase, as too is palliative care and terminal care. Acknowledging the fact that many residents now in long stay care were born in the 1920/30's where this terminology is unfamiliar to them and possibly uncomfortable for them also. Many rely on the word of the nurse or the attending doctor to help them and guide them on this new way of caring. However, having the conversation is useful to facilitate quality at end of life care.

The environment can also play against the process of good end of life care. Often residents request to stay in a shared area accommodation, especially, if they have developed relationships with other residents. However, there are times when a resident or their families requests a single room accommodation. Maintaining dignity and privacy is further facilitated by ensuring there are adequate single room suites to support residents and their families.

Counselling and support for residents during their time in long stay care homes. It is important to support residents who have many unresolved issues, conflict situations with relatives and concerns over money or property. There is little support available in the form of social worker, therapist or counsellor, and frequently the nurse is the one to support the resident with their concerns. Much of bereavement care should be offered before the death of a resident, this will also help care staff who are providing care and will help to reduce stress and possible burnout among staff.

Fortunately, many of these constraints have been alleviated with our organisations' clear leadership and a strong management structure which supports good clinical practice and staff education. Good governance procedures, monitoring and supervision identifies any early signs of sub-optimal care and appropriate intervention alleviates unnecessary emotional distress.

Having had a recent thematic inspection on end of life care, has helped us increase our collective awareness on this topic and spurred us on to strive to deliver a comprehensive, skilful and well informed care to residents and their families. Maintaining an organisation's ethos of care where residents are respected and their opinions are cherished and valued. Having the Eden Alternative framework of care has facilitated a positive approach to care for residents, staff and visitors.

We are also very fortunate to have the support of our local community who maintain an ongoing connection with residents who provide social involvement in our care home. Local schools, third

level colleges, religious organisations, football clubs, business, and voluntary organisations have a strong level of involvement in our activities here; this is the lifeblood of the organisation, to provide the energy to sustain a life worth living and a positive lifestyle for all involved in our organisation.

Recommendations to be considered:

Policy makers and budget holders could continue to support ongoing education, replacement staff for nurses who have retired or who are on extended leave, re-design building and technology structures and increase the involvement from social care professionals to support residents' involvement with life in the care home and their relationships with communities outside the care home.

Education should be further developed to inform carers to be more familiar with the terminology and to become ethically aware of their own position regarding end of life care. Training should be offered to include aspects of religion, and rituals to follow the tradition of the individual regardless of their culture or ethnicity.

Structures such as the ward layout should include single rooms, lounge areas, gardens and outside enclosures, the use of technology to document, record and archive residents' care-plans would improve the workload of clinical staff to give them more time to spend at the bedside with residents and carers.

Involvement from social care personnel in the form of counsellors, social worker or older people, activity therapists, horticulturist, who would engage with residential care units and involve them in interests that are unique for residents reflect the lives residents have lived prior to admission to long stay care would be a positively regarded by residents and staff.



**Simon Communities in Ireland
Submission to Joint Committee on Health and Children
on End of Life Care in Ireland –
November 2013**

Introduction

There is a very clear link between homelessness and health. A study, by the Simon Communities of Ireland in 2011, amongst people using Simon services indicated that 65% of people were experiencing at least one diagnosed physical health condition, 47% were experiencing at least one diagnosed mental health condition, and 46% of people were experiencing a combination of one or more diagnosed physical and mental health condition. In addition, 50% of people reported alcohol use and 31% reported drug use. The average age of respondents of this study was 43 years.

There is currently no definitive information on the average life expectancy of a person who is homeless in an Irish context. However, a study currently being finalised by the Simon Communities of Ireland, looking at the needs of older people who are homeless as they age and are faced with the issues of serious ill health and dying, has found that people who are homeless in Ireland have a higher risk of illness and have earlier mortality rates than the general population¹. International studies have shown that definitions of age status for people who are homeless/ have experience of homelessness vary from study to study, given that individuals who have experience of homelessness over a sustained period/s have generally been found to have a lower life expectancy than the general population. The interim findings of a recent University of Sheffield study² investigating homeless mortality in England found the average age of death of a man who is homeless is 47 years old. It is even lower for women at just 43³, which was the average age of respondents from our homelessness and health study.

¹ O'Connell, James J. (2005) *Premature Mortality in Homeless Populations: A Review of the Literature*. National Health Care for the Homeless Council, Inc., Nashville:

² Crisis (2011) *Homelessness: A silent killer: A research briefing on mortality amongst homeless people*

³ Research has also found that people who have serious mental illness like schizophrenia or bipolar disorder can have a life expectancy 10 to 15 years lower than the UK average according to research undertaken by the Biomedical Research Centre for Mental health at Maudsley Hospital in London in 2011 (Chang et al.)

Summary

End of life care is a vital service to many individuals who have advanced life limiting conditions. For people who are homeless, engagement with end of life care services is more difficult than for people in the general population, if, indeed, it takes place at all. There are many reasons for this, some which include the following:

- **Lower life expectancy:** Life expectancy for people who are homeless is a lot lower than for the general population. A study in the UK reported average age of death for people who are homeless is 47 for male and 43 for a female. The health needs of a person who is homeless in their 40's or 50's can be very similar to the health needs of a person in their 70's or 80's from the general population. As this is not considered old in the general sense, they may feel it is not applicable to them.
- **Lack of access:** There is also a lack of awareness among people who are homeless about end of life care and hospice services. Lack of a medical card and the cost of access to a GP or through Accident and Emergency means that people who are homeless tend not engage with the health services. This in turn means that they are not accessing information about end of life care and hospice services.
- **Lack of options:** People who are homeless may only be engaging in health services at crisis levels. In most cases, they are then discharged back to the hostel, even though they may be in need of additional care. They are not given the option of palliative care beds or if required end of life care. This may be because they present at a younger age with health problems similar to those of older people in the general population.
- **Human Resources:** Isolation and the sensitivity of the subject does not allow for people who are homeless to have the opportunity to discuss their death and dying. This can be due to staff in support services not having the time to sit and have a conversation with people or staff are not comfortable talking about death and dying.

Opportunities

There are opportunities to extend end of life care to people who are homeless. Whether this is through hospice services, acute hospital beds or within homeless services, it is an area that must be given attention. Awareness of End of Life Care for people who are homeless needs to be addressed at Government level and indeed among staff within homeless services. More information on end of life care needs to be available to people who are homeless and more choice needs to be given to people regarding their end of life care.

End of Life Care

As outlined above, the life expectancy rate for people who are homeless is lower than that of the general population. A person who is homeless aged 40 or more may have the same health needs or indeed the same end of life care needs as a person aged 80 or more.

There are no specific health services targeting older people who are homeless. There is little, if any, information available on the experiences and attitudes of older people who are homeless towards dying and death, in an Irish context. Neither is there any information available on the mortality rates and causes among people who are homeless, making it difficult to quantify and qualify both the extent of the problem and the nature of the issues involved.

Dealing with Death and Dying

How people working in the homeless sector deal with death and dying is an area that needs attention. The research undertaken for the Simon Communities found that the interviewees commended the staff and volunteers, who were identified as an important source of information and support, in terms of helping and supporting individuals to manage their health and access the health system, when required. However, interviewees noted that there was little time to chat and that the volunteers, who tended to be young, were not very comfortable if and when the interviewee brought up the conversation of mortality and thoughts of their death.

Most of the interviewees in the study had poor health, similar to those of older people in general. Because of this, they thought about their death quite a lot. Most either did not want to die or were afraid of dying. A small number said they were happy to die and, were the opportunity to present itself, they would consider suicide.

One of the things the vast majority of interviewees were concerned about was where they might die. Most expressed a very strong desire to die where they were living, or, failing that, in hospital. Some interviewees had hoped, when they were younger, that their siblings might have been able to care for them when they were dying. However, they had all now realised that, just as they had aged, so had their siblings and they were not in a position to take on the role of carer. Transfer to a nursing home was, for many interviewees, the thing they feared most. As many of the interviewees had been in institutions when they were young, they did not wish to be sent to one at the end of their lives. Others had worked in nursing homes and institutions and spoke of observing older people having no one to speak up for them when they were not being treated very well.

End of Life Care for People Who are Homeless

The absence of a formal national system for recording the number, cause and nature of death and tenancy type of people who are homeless in Ireland means that significant gaps exist in our understanding of the experience of dying and death for those people. This is compounded by that fact that we do not know how many, if any, people who are homeless present for hospice care. The research undertaken for Simon Communities found that in the UK few, if any, people who are homeless tend to present for hospice care because of a high level of non-engagement with services and the prevalence of perceived problematic behaviour⁴.

Delivering high quality end of life care for people living in hostels or on the streets presents particular challenges for housing and healthcare. This is for a number of reasons, including the fact that the average age of death is lower (47 for men and 43 for women according to the most recent study) and because of their age may be thought to not have a need for end of life care. It is also the case that the admissions to hospital among this group tend to be crises admissions which require longer stays and which sometimes result in the individuals being discharged and sent back to the hostel. This in turn can be problematic because the individuals may, as a result of their illness, have additional care needs. The intermediary care model⁵ (proposed in an Irish context by Dr. Austin O'Carroll and others) offers a potential solution to this problem if some of the beds provided in this type of facility could be provided for individuals with palliative care needs. It is also the case that a small number of palliative care (level II) beds may be available in community hospitals around the country⁶. The exact number of beds available is unclear, as is the capacity of these

⁴ Interview with Peter Kennedy, Palliative Care Coordinator St. Mungos 27 January 2012

⁵ O'Carroll, A. O'Reilly, F. Corbett, M & Quinn, L. (2006) Homelessness, Health and the case for an Intermediate Care Centre Report by Mountjoy Street Family Practice

⁶ Communication (29/3/2012) Caroline Lynch, Communications/Advocacy Manager, The Irish Hospice Foundation

hospitals to deal with individuals who may present with both complex needs and challenging behaviour. The willingness of individuals who are homeless to present to these hospitals is also unknown.

There is strong evidence to suggest that there is a need for end of life care for people who are, or formally were, homeless and to facilitate staff to offer the best possible palliative care and advice for friends, family and other staff. Providing appropriate end of life care is clearly important not only for those who die, but for other residents, staff and the wider homeless community⁷.

Recommendations for End of Life Care for People who are Homeless

The research carried out for the Simon Communities made recommendations on End of Life Care for people who are homeless. These recommendations include:

- 1. Awareness needs to be raised at policy, statutory and NGO level of the importance of end of life care for people who are homeless:** Awareness needs to be raised on this issue and the need for particular provision to be made within the health sector for end of life care for older people who are homeless. And that they do have a lower life expectancy with health care needs similar to older people in the general population. Under the current system, these individuals (aged 50-65) are not eligible to avail of services for older people and generally have a history of non-engagement with services.
- 2. Provide staff working with people who are homeless with end of life care training:** Staff working in this sector need to be more aware of the role and purpose of end of life care and support, including bereavement). They also need training and support in order to enable them to identify signals that individuals need to be assessed in relation to the provision of end of life care. Two initiatives (developed by the Irish Hospice Foundation) offer very useful sources of training materials which could be adapted for use by staff working in the homeless sector. The 'think ahead' initiative promotes discussions on care planning (which would be beneficial for staff and ultimately for service users), while the 'final journeys' programme is a model that could be adopted to raise awareness and improve staff members confidence in approaching and ultimately discussing end of life care issues with service users. Another useful source of materials is the work done by Richard Lakeman in Dublin City University. Where staff are trained sufficient time needs to be able to be allocated within their schedules to engage with service users.
- 3. Enhance access to end of life care for people who are homeless through the appointment of a Palliative Care Coordinator** Palliative and end of life care are very sensitive areas that need careful handling. The appointment of a Palliative Care Co-ordinator (shared between different services and organisations) would ensure the necessary skills are available to support and train staff to be able to deal with the issues.
- 4. Ensure that Palliative Care Beds are accessible to people who are homeless** Palliative care beds (Level 2) are available in a number of community hospitals around the country. Work needs to be done to determine to what extent these beds are currently accessible to people who are homeless and to identify what needs to be done to make these beds more accessible.

⁷ Puckett, Katie, Dignity in Death article in e-magazine Inside Housing printed on 28th January 2011
<http://www.insidehousing.co.uk/analysis/best-practice/dignity-in-death/6513430.article>

Simon Communities in Ireland

The Simon Communities throughout Ireland provide the best possible care, accommodation and support for people experiencing homelessness and those at risk. Together, with people who are homeless, we tackle the root causes, promote innovative responses and urge the government to fulfil their commitments. Simon delivers support and service to between 4,500 and 5,000 individuals and families throughout Ireland who experience – or are at risk of – homelessness. The Simon Communities of Ireland is an affiliation of local Communities in Cork, Dublin, Dundalk, Galway, the Midlands, the Mid West, the North West and the South East.

Services range from

- **Housing provision, tenancy sustainment & settlement services, housing advice & information services** helping people to make the move out of homelessness & working with households at risk;
- **Specialist health & treatment services** addressing some of the issues which may have contributed to homelessness occurring or may be a consequence;
- **Emergency accommodation & support** providing people with a place of welcome, warmth & safety;
- **Soup runs & rough sleeper teams** who are often the first point of contact for people sleeping rough.

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Presentation to the Joint Oireachtas Committee on Health and Children

Public Hearings on End of Life Care

November 7th 2013

On behalf of Specialist Children's Palliative Care

Dr Maeve O'Reilly, Consultant in Palliative Medicine, St Luke's Hospital and Our Lady's Children's Hospital Crumlin

Introduction

Definition

Palliative care for children and young people with life limiting conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child / young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (ACT & RCPCH 2009).

As in adult palliative care services, the aim is to enable every child with a life limiting illness to live as well as possible until he/she dies. End of life care is only a small part, although an important part of what palliative care is. Children's palliative care is an important aspect of medical care for children with life limiting or life threatening conditions or who need end of life care. Its core aims are to relieve suffering, improve quality of life (QOL), facilitate informed decision making and assist in coordination of care between clinicians and across sites of care.

Life Limiting Illness

The term Life Limiting Illness (LLI) 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 their family or carers. Such illnesses have been categorised into four categories (ACT & RCPCH 2003) ranging across a broad spectrum from children where imminent death is likely eg 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, eg severe cerebral palsy.

The definition and four categories were developed intending to be broad and inclusive, to raise awareness of how children with a wide variety of conditions would benefit from a palliative care approach, from the point of their diagnosis

Epidemiology

In Ireland the most recent figures available show that approximately 563 children die each year (mortality rate 5.4/10,000). Of these 370 have a pre existing life limiting illnesses (3.6/10,000)(Quin et al 2005). Of these children, the majority of deaths occur in the first year of life. Of all childhood deaths, 57% were infant deaths (<1 year age) and 32% occurred in the first week of life. Congenital anomalies are a leading cause of death in this age group. These children all have palliative care needs.

It is more difficult to determine the numbers of children living with life limiting illnesses. Ireland has no national database, but by extrapolating from UK data it had been estimated that prevalence was 12/10,000, giving Ireland a figure of 1369 children living with life limiting illnesses. In the UK more recent work however, has shown that prevalence rates are much higher at 32/10,000 and increasing, making Irish figures a significant underestimate (Fraser et al 2012).

It is important in planning services to recognise that although the absolute number of deaths amongst children is less than with adults, children tend to have more unpredictable end of life episodes and many children may have several episodes where it appears that they are at end of life. The same level of support needs to be available at each of these episodes whether or not the child actually dies. Services therefore need to be planned based on numbers of children living with a potentially life threatening condition, rather than the number of children who die.

Principles

Despite an obvious overlap in the principles, children's palliative care differs significantly from adult palliative care in several ways

- Numbers of patients dying are relatively small, from conditions often rare and specific to childhood
- Children may live for many years with a LLI making it difficult to estimate a prognosis and plan for end of life (EOL) care. Children may experience several apparently "terminal" phases as their illnesses progress
- Parents require adequate resources to support them with the weighty responsibility of personal and nursing care of their sick child
- Care needs to embrace the whole family including siblings
- Children are continually developing physically, emotionally and cognitively through their illness so that their care needs and palliative care needs change over time

Similarities do exist however

- The focus is always on improving and maintaining the QOL of the child at all times
- The preferred place of care and ultimately death for the majority of families is in the home, although this is not always possible or appropriate given the complexity of the conditions involved. Families may choose hospital or hospice as their desired place of care at end of life.
- Palliative Care support can be given alongside active treatments aimed at prolonging life
- Palliative care needs are best met through an integrated coordinated approach involving hospital based teams, community and primary care teams and specialist palliative care where necessary
- Care requires multidisciplinary team input to meet all the patient and family needs (fig 1)



fig 1. People involved in the provision of care to the child and family

Providers of children’s palliative care need to be able to deliver or access a wide ranging set of services and skills across their multidisciplinary team as well as providing access to consultant level medical expertise.

As described in previous submissions on adult palliative care, palliative care (PC) for children is the responsibility of the whole healthcare system and not just specialist palliative care services. All health care professionals should be familiar with the principles of a palliative care approach and be able to recognise palliative care needs in young patients (level 1). All physicians and nurses involved in caring for children should be trained in basic approaches to symptom management and in clear compassionate communication with children and families (level 2). They also need to be able to recognise when referral to a specialist service is necessary (level 3).

All three levels of PC should however be available to all children with life limiting illness in all care settings as necessary. Children will use the range of services available differently and at different times over the course of their illness from the generalist support of their GP or PHN, care from a paediatrician all the way to a specialist palliative care consultant. The ideal scenario is to have the full range of services and access to a high level of expertise.

POLICY

There have been several key documents published in recent years relating to children's PC in this country. These include:

(1)

The National Advisory Committee Report (2001) focused mainly on adult services but with regard to children made the following recommendations

- PC for children was best provided at home except in extraordinary circumstances
- Medical and nursing care should be the responsibility of paediatrically trained staff
- There should be close cooperation between generalist and specialist children's PC services
- Respite should be provided as close to home as possible
- Local needs assessments should be carried out to assess need for PC services including respite

(2)

The Palliative Care Needs Assessment for Children (2005) was a national needs assessment which identified issues which needed to be addressed in order to provide appropriate PC services for children in Ireland. It followed extensive consultation with all the key stakeholders, including families. It recommended that their needed to be

- Equity in service provision
- Better coordination of and access to services
- Homecare and community services to be developed
- Accurate data collection on prevalence and mortality
- A "key worker" for each family to improve coordination and access to services
- Education and training of health care professionals
- Ready access to locally based respite
- Improved hospital facilities particularly for dying children and their families
- Planning of the development of services
- Specific needs of adolescents to be recognized and considered
- A broader range of bereavement supports to be available

It concluded that the future development of services needed to be underpinned by 4 key principles

- 1) Inclusiveness (all children regardless of diagnosis, geography, culture or age should be able to access appropriate care and all providers should have access to specialist services when necessary)
- 2) Partnership (all stakeholders including the child should be included in the planning of care and decision making)
- 3) Comprehensiveness (care should include a focus on the psychological, emotional and educational needs of the child and the family)
- 4) Flexibility (care should be adaptable to the changing needs of the child and its family, with an identified key worker to facilitate this)

3)

Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy (2010) was published with the aim of addressing the above issues raised in the needs assessment in order to develop a responsive PC service for children and their families. This policy has provided a foundation for the development of services and has given clear direction for the future. A total of 31 recommendations were made several of which have already been achieved. There remains a heavy dependency on voluntary organisations in the provision of care in the community and also of respite to families.

Recommendations achieved include

- A national development committee has been established by the HSE involving key stakeholders. Its terms of reference have been established and its role is to oversee the implementation of the policy. Several subgroups have been established to look at different areas including education, governance, Hospice at Home etc.
- Eight regionally based outreach nurses have now been appointed, five are funded by the Irish Hospice Foundation (IHF) on a temporary basis and three by the HSE. Although a very challenging role, this is a very welcome development. These nurses act as key workers for the families as well as supporting primary care teams involved in the care of complex children. The nurses are all paediatrically trained in line with national and international recommendations and provide support for patients and their families in their home, whilst linking with the referring hospitals. They are locally based and supported by the local paediatric team. For complex cases specialist support is also provided by the Consultant in Our Lady's Children's Hospital, Crumlin (OLCHC). Clearly these key workers need ongoing professional support in such a personally challenging role.
- The appointment of a full time paediatrician with a special interest in children's palliative medicine. This post is based at OLCHC and the Coombe Women & Infants University Hospital. It is being funded by the Irish Hospice Foundation for five years until May 2016 after which it is anticipated that the HSE will take over funding. This is a critical post in the development of specialist services nationally. Prior to this appointment service development has been led by adult trained physicians in palliative medicine. In line with best practice and international recommendations however, a paediatrician specialising in this area needs to

lead on the development of services. This post already has seen a 67% increase in referrals in Our Lady's Hospital since the appointment of the consultant in 2011 and with similar increases at the Coombe, where a service is now also being offered antenatally to parents as well as to neonates. The consultant is the clinical lead of the hospital based service but also supports the outreach nurses as necessary depending on the needs of the individual child. She also leads on education and research in this specialist area

- Educational needs of staff have been recognised and training is available through the Centre for Nurse education at OLCHC as well as other postgraduate institutions

There remain many outstanding recommendations which need to be addressed including

- Further development of the Children's Palliative Care team at OLCHC
- Improved facilities in hospital for patients and families, particularly at end of life
- Development of respite services in the community
- Hospice at home teams
- Data collection

WHAT NEEDS TO HAPPEN?

(1) Human resources

Critical to the development of a comprehensive PC service nationally is the development of expertise in the area. The availability of specialist staff is essential so investment in human resources is key. An article this week in the leading journal "Paediatrics" makes recommendations on the future development of children's palliative care and hospice services in the US. In it the American Academy of Paediatrics (AAP) state that "All hospitals and large health organizations that frequently provide care to children with LLI's and routinely provide end of life care should have dedicated interdisciplinary specialty PPC teams" (AAP 2013).

The current consultant Paediatrician post needs to be recognised as critical to the development of services and its funding secured. Currently the consultant and outreach nurse programme are being funded primarily by the IHF. Of the 2.5 million euro invested in the programme, 85% is being provided by the charity. This responsibility needs to be taken over by the HSE after 5 years as per previous negotiations.

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 ie about 1:4 (Hain 2013). 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. Links with maternity hospitals are important given the high prevalence of deaths in the neonatal period (ESRI Perinatal Statistics report 2011)

With the increase in referrals there needs to be appropriate **development of the supporting team** at Our Lady's Hospital Crumlin to include increased specialist nursing support as well as the recommended social worker and secretarial support (DOH&C Policy). Increased specialist nursing support in the PC team is necessary following the increased workload with the appointment of the consultant. The Team needs to be embedded in the New Children's Hospital when it comes on stream.

Further **expansion of the Outreach Nursing Programme** would also help ensure children live and die well. These posts are a significant support to children and families at home. By providing that vital support, and in fulfilling the key worker role for families, these nurses can help keep children at home in many cases and out of the acute hospital services. A single nurse working regionally however is not sustainable in the longterm and we need to look at expanding the programme

Education and upskilling of existing staff working with life limited children would help ensure children live and die well. Those institutions which care for very ill and fragile children, such as respite facilities and children's hospices, need to ensure staff have the skills to deliver specialist care when necessary. Ongoing training and education needs to be undertaken and evaluated for effectiveness. Although training is available it can be difficult for staff to access it in the current climate and this needs to be addressed.

Palliative care is delivered by a range of disciplines therefore children need access to all support services if they are to die well. This includes access to psychology services when necessary and medical social work and counselling services for all families. Psychologists when available play a key role in helping children and families cope with life limiting illnesses. They help with difficult conversations about death and dying, promote coping mechanisms appropriate for the child, manage anxiety etc as well as offering professional support to families. At present psychology services are limited, particularly in the community.

Health Care Staff Support for those working in this difficult area is crucial to the well being and continued ability of staff to meet the needs of families and children. This is particularly true for those who provide essential care on an infrequent basis such as the adult home care teams. This work is physically and emotionally very demanding. Consultants can offer support to other health care professionals on an informal basis but the need for formal support in some cases needs to be recognised

(2) Physical resources

Most families wish to care for their children at home. However for some families this may not be possible due to the specific care needs of the child or other practical barriers. Only 11% of children with non cancer LLI's died at home as reported in the needs assessment. This is in contrast to 67% of children with cancer. This is in part due to the greater physical needs of these children with non-cancer LLIs over a more prolonged period of time In order to address this inequity there needs to be increased practical support for families in the community in terms of respite in the home, easier access to equipment, medical cards etc. This is particularly true at the end of life when the need is often greatest. There is a heavy dependence on voluntary services such as the Irish Cancer Society to

provide night nursing support. This service is not as easily available to children who do not have cancer. Increased nursing support when necessary for children being discharged home for end of life care would facilitate discharge. Currently all children can be referred to local adult PC teams who provide an excellent service. This however is advisory support and not the “hands on” nursing support that some families need.

It needs to be acknowledged however that **not all families choose home** as a desired place of care particularly at the end of life. Hospital may be a more appropriate choice for many as a result of the complexity of some medical conditions requiring intensive ongoing medical input or as a result of complex psychosocial issues, lack of family support, cultural issues etc. In these situations children must have their PC needs met by the hospital based teams with specialist support when necessary. Improved support to children with LLI in hospital would greatly help in improving how children live and die in Ireland. Current facilities are often cramped and challenging particularly when trying to deliver high quality EOL care. It is expected that these limitations will be addressed in the future children’s hospital. National policy states that “Hospitals should provide an appropriate environment for children with palliative care needs. This includes physical environment and professional environment such as staff education and training” (DOH&C)

Conclusions

- Children’s Palliative Care is an established field of medical expertise and practice and is essential in the management of children with life limiting illnesses through their illness and death and into bereavement.
- 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
- Providing appropriate high quality specialist palliative care services to children requires the availability of a broad range of services across a multidisciplinary team. Ideally this broad range of services should be available to all children with life limiting illness, with access to a high level of expertise when necessary.
- Key to development of services is the development of expertise. Funding for the Consultant in post and outreach nurse programme needs to be secured and further expansion of consultant posts is essential.
- The vital contribution made by the voluntary sector in this area is recognized and closer integration with the statutory services needs to be promoted
- Much has been done in recent years to assess the needs of the Irish population and to try to address those needs. Ireland is one of the few countries to have a national policy on the development of children’s palliative care. Adherence to this policy will help ensure that children in Ireland with life limiting illness will get the best possible care throughout their illness, through death and support for families in bereavement.

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Numbers needs and preferences: a children's palliative care perspective

Dr Richard Hain, July 2013

The Future of Hospice care: Implications for the children's hospice and palliative care sector

Key Messages from the Specialist Palliative Care Panel Submissions

to the Joint Oireachtas Committee on Health and Children

on 24th October 2013

- Palliative care is about enabling people to live right up until they die.
- End of life care is only a part of what palliative care is about, and by no means defines it. It can be relevant and effective even from initial diagnosis.
- Palliative care is applicable across all illnesses that cannot be cured, not just cancer.
- Palliative care is for all age groups, including children.
- Palliative care delivers significant health benefits, including improved symptom management, improved quality of life, increased length of life, and reduced care-giver burden.
- Palliative care should be delivered wherever the patient is, whether in an acute hospital, community hospital, nursing home, hospice, or their own home.
- Palliative care works best as an integrated programme, with seamless pathways between care settings, to enable the patient and their family to access the element of care that is most appropriate at any given point in time.
- Bereavement support for families must be factored in when implementing a “money follows the patient” model of healthcare provision
- Demand for palliative care will increase as the population increases and ages.
- There are significant deficits in specialist palliative care beds and in staffing levels, and addressing them should be a funding priority.
- Investment in specialist palliative care makes sense, as it keeps patients who don't need to be there out of acute hospitals.
- Education on palliative care is necessary for all healthcare professionals, at undergraduate and postgraduate levels.
- Investment in research in palliative care should be encouraged, funded and coordinated. The All Ireland Institute of Hospice and Palliative Care is well-placed to promote and coordinate such research.
- Responsibility for the palliative care function and budget should be assigned to designated senior personnel in the emerging healthcare structures.
- The Palliative Care Clinical Programme plays a crucial role in the development and enabling of best practice in palliative care, and must be supported.

Supplementary submission from Specialist Palliative Care providers (further to presentations at End of Life Care Public Hearing 24th October 2013)

Authors: Ms Paddie Blaney, Director, All Ireland Institute for Hospice and Palliative Care
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When providing palliative care to people with advanced incurable illnesses, one of the challenges faced by health professionals is the public's perception that palliative care is about death and that the introduction of a palliative care approach signifies the "end" of their lives. Specialist palliative care professionals are regularly urged by family members and even by other health professionals not to mention the word "palliative" or the word "hospice". This helps to demonstrate just how powerful language can be.

With this in mind, we are interested in the suggestion put forward during the recent End of Life Public Hearings, that Ireland should have an "End of Life Care Strategy". The title of such a strategy will set the scene for its contents so it is important to consider this carefully. By using the words "end of life", there is a possibility this could put an emphasis on death rather than life, and we may also be basing a strategy around something unpredictable and potentially undefinable. The "end" of a person's life is literally the moment they die and no one knows in advance exactly when this will occur. Attempts to define "end of life care" as the last days / weeks / months / year of life have been fraught with difficulties. A strategy for meeting the needs of people with advanced incurable illnesses would need to focus on care before death and no-one knows in advance when this will occur.

We recognise that medical issues are not the only area that requires management for people with life-limiting conditions- lifestyle, family, psychosocial, cultural, and economic issues also need attention. We suggest that the principles of public health may provide a useful framework for a strategy document as this would ensure a population based approach is adopted that addresses social and wider determinants of health, (as well as disease) and emphasises partnership working with all relevant stakeholders.

Within this, and in keeping with public health and health promotion principles, palliative care should be developed so as to achieve "health and wellbeing within disease", as well as empowering communities to provide social, emotional and practical support, alongside and in collaboration with the care provided by health services.

We, as specialist palliative care professionals, would be more than happy to contribute to further developments in this area. In the meantime, we would be delighted to answer any queries the Committee may have.

Travellers and End of Life Care

1 Introduction

In relation to Travellers, end of life care and palliative care, these are a number of areas which may be of some importance to the work of the committee. These include, the status of Travellers as a minority group within Irish population; socioeconomic deprivation within the Traveller population; lower levels of education, including literacy; shorter life expectancy, poorer health status, and different causes of morbidity and mortality; different cultural and ethical approaches to communication and interaction with health services, which will be addressed in this submission.

2 Travellers as a minority group

Travellers are a minority within Irish society. They are recognised by the Government as a separate group and are specifically named in discrimination legislation (Employment Equality Act 1998, Equal Status Act, 2008.) The origin of Irish Travellers is not clear; there are suggestions that they are completely separate to the Irish population; other suggestions are that they are descended from dispossessed Irish who had been made landless during political conflicts. Travellers identify themselves and are identified by settled people as different to each other. Genetic studies suggest that the Traveller population is endogenous rather than as a result of migration e.g. of Roma into Ireland, but the population has become isolated over many years. (North et al, 2000, Murphy et al, 1999, Cavaleri, unpublished, personal communication). At different times in Irish society, the idea of Travellers not being a separate group has led to hostility at times from the settled population rather than the recognition of and respect toward difference.

There are approximately 36,000 Travellers in Ireland, representing less than 1.0% of the total population. A challenge for health care staff and services is in maintaining awareness, education and training for staff to deal with different groups whom they may encounter infrequently.

Travellers have traditionally had a number of well recognized disadvantages. These include poor education and poor literacy, and socioeconomic deprivation with high levels of unemployment and poverty; these factors are associated in all populations with poorer health outcomes.

The All Ireland Traveller Health Study, *Our Geels*, published in 2010 gathered general data, and health information. 75% of Travellers in the Republic of Ireland lived in family units of 5 or less; 73% lived in a house, 57 % of which was provided by a local authority; and 18% lived in trailer, mobile home or caravan. In the previous year, 78% of families had not travelled. 28% of families reported difficulty reading or filling out forms. Most (98%) are Catholic, and religion is rated as very important by 53%.

40% reported that they often or very often felt discriminated against. Travellers sometimes hid their identity so they could access things they believe may be denied to them if their ethnic origin was clear. This is called 'passing off' and parents reported that their children changed their accent or dress in certain situations to hide their identity.

Traveller societies can be considered collectivist rather than individualist. Collectivist societies value the needs of the family as much, if not more so than the needs of the individual. Families are interconnected and the immediate family can include extended family such as aunts, uncles and distant cousins. The strong emphasis on the importance of families attending for life rituals means that there are large family gatherings, which can cause anxiety for the settled population if for example hundreds of people arrive in a town for funerals, weddings or other family events. This can also cause problems in healthcare settings, as at times of serious illness large crowds can gather in hospitals to provide support for the patient.

3 Travellers, health and health service use

The All Ireland Traveller Health Study showed that Travellers have a higher rate of doctor-diagnosed chronic health problems than the regular population, especially chronic bronchitis and asthma. (A similar, though much smaller study of the health of Gypsies and Travellers in England by Peters et al, shows that Gypsies and Travellers had poorer health than age and sex matched controls from deprived areas and ethnic minority populations. Respiratory illnesses were particularly prevalent; there were no differences between Gypsies and Travellers and the matched populations for cancer, stroke and diabetes.)

This study showed that Travellers had access to health services-for example most had a medical card. However, Travellers are less likely to have complete trust in health care professionals; 41% compared to 82.7% in the settled population. Travellers are more than twice as likely to use the Accident and Emergency Department as the settled population. Travellers are more likely to be admitted via the emergency room than electively (80%vs 35%), are less likely to have a discharge letter written (67% vs. 100%), were less likely to

have OPD follow up appointments (40% vs. 77%) or to be referred to clinical support services (21% vs. 62%) in comparison to the settled population. (Use of Hospital Facilities by the Traveller Community, 2004, Traveller Health Unit, Eastern Region).

Travellers have a higher Standardized Mortality Rate than the majority population. The SMR for the general population has improved in the last twenty years, as has the SMR for Traveller women, but the SMR for Traveller men has worsened.

The cause of excess mortality is reported as respiratory illnesses, followed by external causes such as accidents and suicides. Traveller male life expectancy, at 61 years has not improved since 1987, and is the same as the settled male population in 1945, and is 15 years shorter than the settled population. Female Traveller life-expectancy has improved since 1987, and is now 71 years, the same as the female settled population in 1960.

To quote directly from the All Ireland Traveller Health Study, 'Travellers experience a higher mortality than the general population. The problem is endemic and complex and will not be solved in the short term without considering the wider contextual issues. The picture points to the need for a holistic long term approach to improving the lives of Travellers and reducing their deaths...The fact that an identifiable disadvantaged group in our society is living with the mortality experience of previous generations 50-70 years ago cannot be ignored.

4 Travellers and palliative care

Research by Van Doorsaler and McQuillan, has shown that Travellers have little knowledge of hospice and palliative care. Travellers are fearful of discussing cancer. The word was avoided or when mentioned was accompanied by prayers or blessings. The belief expressed was that by discussing cancer especially or other serious illnesses, bad luck would befall the speakers. Speaking of serious illness and death was considered to invite these.

When a Traveller is seriously ill it is the custom from extended family and friends to visit and spend time supporting the patient and the immediate family. Travellers consider the habits of settled people, when only small numbers of people visit is not appropriate. Traveller custom can mean that large crowds (one hundred would not be unusual) would wish to visit especially as the patient is approaching death. Travellers are demonstrative and the combination of demonstrative behaviour and large crowds can lead to healthcare staff

feeling overwhelmed. Unless staff understand the importance of this behaviour, their response which can include restriction of visiting and calling security to manage visitors, can increase stress and distress. Identifying key people within the family and using clergy can facilitate Travellers visiting and the managing institutional concerns.

When a patient is dying families will often request a priest to attend for prayers and blessings. Healers may also be asked to visit the patient. Items of religious significance such as medals or relics may be placed around the patient and at times placed over the affected area of the body. Staff need to ensure they are not lost during medical and nursing care.

Hospitals are seen as places of hope, where cure is possible. Hospices are seen as a last resort, and although Travellers in Van Doorslaer's research who had experienced hospice care were positive about the experience, it was not an experience that was welcomed, being considered recognition and an acceptance of the terminal nature of an illness.

Travellers were more positive toward community palliative care, (hospice home care) as a way of providing additional help and support for the patient and family. Many respondents saw advantages to the person being cared for at home- surrounded by family, no restriction on visitors, and no disturbance to other patients. Care at home was not considered appropriate if the patient needs medical care which could not be provided at home or was too burdensome for the family. Death at home was usually considered unacceptable, whether the family lived in a house or a trailer. This is because of the feelings of great sadness associated with the death, which can mean that families find it hard to stay in a place where a death has occurred. Traditionally the trailer of a person who died, especially if the death happened in the trailer, would be burned. Families would move away from the site. This happens less frequently now, partly for economic reasons and also because most Travellers live in houses. More commonly now, families may try sell a trailer associated with someone who dies, but it can be difficult to find a buyer for a trailer in which a death has occurred. Travellers who live in houses may, following a death, move out of the house for a period of time, and not return until the house has been redecorated and blessed. For these reasons, families often do not want a family member to die at home.

Research carried out by the Parish of the Travelling People (Travellers Last Rights), found similar results. These included the fear of serious illness and of death, strong religious beliefs and expression, including the importance of religious rituals to support the sick, the centrality of the family and the importance of visiting the sick. Travellers also reported the importance of being present if something were to go wrong, that the sick person be

surrounded by 'their own' and that the sick person has the opportunity to pass on their last wishes.

5 Travellers, deaths funerals, memorialization and bereavement

Funerals are usually organised by men in the Irish Traveller community. For many Irish Travellers having an elaborate coffin and headstone is considered a sign of love and respect. In recent years this has led to greater expense and families may go into debt to pay for a funeral. Traditionally, Travellers are buried in the burial ground associated with their family. Nowadays, especially as more travellers are settled rather than nomadic, Travellers may be buried where their family live. There can be tension in the family if there are different views between the family of origin and the family of marriage about the place of burial and attention and negotiation is needed. Given that many hundreds of people will attend funerals and that it is usual for there to be loud and demonstrative expression of grief, Traveller funerals can cause stress for the settled population. This can lead to intervention by the police which if not appropriately handled can increase tensions.

Traveller families usually have a month's mind, but different families may have other rituals which may include a blessing on the ninth day after the death, which is considered by some that that is the day the soul enters heaven, or the day the person is judged. For other families there may be monthly Masses for a year. Graves are visited on important personal dates such as birthdays or wedding anniversaries. The first anniversary, when the headstone is erected is sometimes called the Blessing of the Cross when what is considered the immediate family will gather; this can be three to four hundred people.

A number of studies, (Brack, Van Cleemput) emphasise the grief and sense of loss experienced when a member of the community dies. This can be so extreme among Irish Travellers as to cause the family to move away from the place of death or burn the trailer, as outlined above. The use of alcohol to cope with bereavement was recognised as not always being helpful (Van Doorsaler and McQuillan, Van Cleemput et al, Brack et al).

6 The dominant discourse-whose voice?

Much is written in health care literature, including the palliative care literature about the importance of open communication and, leading from this, informed consent for treatment. Open acknowledgement and preparation for death is also promoted. These are important

principles that need to be tempered with respect for an individual's coping style and communication wishes. Research with Irish Travellers has shown that they consider disclosure of a diagnosis of a serious illness will cause a patient to give up hope. Travellers can find the communication styles of settled people, including healthcare staff unfeeling in its frankness.

Hope is extremely important in the face of serious illness, including hope for a cure, or a longer life. In the context of palliative care, hospices are avoided as they represent loss of hope, whereas hospitals are considered favourably as places which represent hope of cure. Religious and spiritual help is important to support patients.

Many members of the settled community also cope with serious, life-threatening illness by denial, avoidance and maintaining hope. This can be a useful coping strategy, but is not always sustainable. This coping strategy does make decision making about current and future care, including advance care planning, more challenging. Healthcare staff need to be able to recognize the coping strategy of Travellers (and others who cope in a similar way) and help them deal with serious illness while maintaining realistic hope. This can mean that strategies used in some countries, for example, routinely identifying patients as being in the last year of life, or asking patients about their preferred place of care, or place of death, may be inappropriate.

Travellers in common with many ethnic groups are part of a collectivist rather than individualist society, with a strong emphasis on family involvement. Ekblad's study of palliative care nurses views about caring for patients from different cultures showed that many culture clashes experienced by palliative care staff touched on the differences between group/family and individual orientated thinking.

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. Patients from minority groups, including Irish Travellers subscribe to varying degrees to their own and the majority culture. Healthcare staff who are caring for people from other ethnic groups need to be aware that they may have different beliefs and rituals around serious illness, dying and death and have different experience of how societies work. Cultural mistrust may also impact on the way ethnic

minorities interact with palliative care services. This has been described in relation to the African American community and is also alluded to in this research; a common perceived barrier to accessing care is prejudice. Healthcare staff need to provide culturally appropriate care in so far as is possible, recognizing the importance of hope and the role of the family and different ideas about what constitutes a good death.

7 Recommendations

7.1 To ensure that members of the travelling community die well in Ireland, must in the first instance, consider how to address high premature mortality of Travellers. There are a number of recommendations from the All Ireland Traveller Health Study including

- addressing the causes of respiratory and cardiac disease;
- efforts to improve trust between Travellers and the general population;
- staff training during induction for health services which have a significant Traveller catchment population, including guidelines on how to manage traveller families.

7.2 Accessible information for healthcare staff about caring for Travellers; for example, web-based education, or mobile apps. (These could build on the Intercultural Guide produced by the HSE Social Inclusion Unit, currently being developed as an app.) This may ensure that information is available when needed, rather than being delivered only as an undergraduate or postgraduate module.

7.3 Maintaining a focus the needs of the patient with life-threatening illness and their family, a palliative care approach, rather than focusing on prognosis and approaching death.

7.4 Adoption of the National Clinical Care Programme for Palliative Care clinical competencies, which include the importance of recognising cultural differences, communication skills, and ethics.

7.5 Ensure that any standards introduced to monitor health care delivery, including palliative care are capable of recognizing the needs of minorities, not just the majority culture.

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**Written submission to the Joint Committee on Health and Children,
Public Hearings on End of Life Care.**

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1. Overview

Palliative care is an approach that improves the quality of life of patients and their families facing the 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, psychosocial and spiritual (WHO, 2004). In the last twenty years, the scope of palliative care has broadened to providing palliative care at an earlier stage in the disease trajectory. In 1990, a World Health Organisation expert committee proposed that palliative care should be a gradually increasing component of care from diagnosis to death (WHO, 1990). The emphasis on the early provision of palliative care concurrently with disease modifying treatment has been shown to be feasible and acceptable to clinicians, patients and their families- not only does it ease the transition towards an eventual sole focus on palliation but it also offers improved quality and efficiency of care in the earlier stages of chronic disease management. In fact, the health of the population requires good palliative care, not simply for the benefit of the person dying, but also for caregivers while in the role and after the death, as well as providing substantial benefits for the health system.

It is important to recognise that the provision of palliative care is the responsibility of the whole healthcare system and not just specialist palliative care services. The term ‘generalist palliative care providers’ refers to all those services, health and social care providers who possess ‘palliative care approach’ or ‘general’ palliative skills. Their role is fundamental to the provision of high quality care for people with life limiting illnesses, and the needs of many patients with life-limiting conditions can be appropriately and effectively met with the support of generalist palliative care providers. However, should a patient experience unstable symptoms or problems of high intensity, complexity and/or frequency as a consequence of their illness, then input from specialist palliative care services should be provided. It is essential that systems of care are sufficiently flexible to ensure that specialist services remain aligned to the changes in level of need, respond promptly and collaborate effectively with generalist providers.

Palliative care services may be structured in three levels of ascending specialisation according to the expertise of the staff providing the service (NACPC, 2001).

- Level one – Palliative Care Approach: Palliative care principles should be appropriately applied by all health care professionals.

- Level two – General Palliative Care: At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care.
- Level three – Specialist Palliative Care: Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

The use of terminology regarding levels of expertise of staff is not intended to value contributions of one staff group over another but to assist in differentiating the roles of specialist and generalist providers in ways that clarify the contributions of each and enable a consistent language to be used among planners. Indeed, it is vitally important that the role levels of services are not viewed in a simplistic, one-dimensional manner as the palliative care needs of people and their families will only be met if *all* services are drawn upon if and when necessary. It is not an “either/or” option. Both generalist and specialist palliative care services play a part in the effective treatment and care of people with life-limiting conditions and need to be used in collaboration with each other. This ensures that complexity of needs does not dictate the setting of care. For example, patients with complex needs can be cared for in the majority of settings providing that they have access to appropriate support and expertise from specialist services. National policy states that these three levels of service provision should be available in all HSE areas and all patients should be able to engage easily with the level of expertise most appropriate to their needs regardless of their care setting.

2. Terminology:

Language makes a difference. The Center to Advance Palliative Care carried out a piece of public engagement research in the United States in 2011 and found that the manner in which palliative care is described has a big impact on how people feel about it. Unfortunately, terminology in respect of the care of people who are dying and close to death is potentially confusing and has shown variability over time from ‘terminal care’ to ‘palliative care’ and ‘end-of-life care’ (Prail, 2000).

The HSE Palliative Care Programme has raised concerns about promoting the use of the term ‘end of life care’ in place of ‘palliative care’. In its Glossary of Terms (2102), the Programme noted that:

‘End-of-life care’ is an imprecise term but implies time-defined care. It is a quantitative rather than qualitative descriptor that excludes the purpose of care. In contrast, palliative care is not time-confined but goal-oriented. The discipline of palliative care helps patients to ‘live until they die’ whenever that occurs. The Palliative Care programme is of the opinion that promotion of the term ‘end of life care’ as a descriptor of palliative care practice will send a message to the general public that care is limited to the imminently dying. It is concerned that the phrase will promote among potential referring physicians a transitional ‘discontinuous’ care model rather than a more desirable seamless ‘collaborative’ care with

early referral. Therefore, the programme recommends that the term 'end of life care' is used to describe the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less. 'Palliative care' is the preferred term of the programme when describing care which is focused on improving the quality of life of patients and their families facing the problems associated with life-threatening illness.

3. Key elements that form the basis of the best practice model of care for palliative care

It is important to note that the model of best practice in palliative care must, by definition, be flexible enough to adapt to various social and cultural settings and meet the specific needs and values of individual patients and their families. This is because there is no single definition of what constitutes quality of life for people with life-limiting conditions or, indeed, what constitutes a 'good' death.

Philosophy:

- Palliative care is an approach that improves the quality of life of patients and their families facing the 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, psychosocial and spiritual (WHO, 2002).

Structure:

- Palliative care is provided on the basis of needs and should be a gradually increasing component of care provided to all people with life-limiting conditions from diagnosis to death.
- Palliative care services are structured in three levels of ascending specialisation according to the National Advisory Committee Report on Palliative Care (2001). These levels refer to the expertise of the multidisciplinary teams providing services.
- Specialist palliative care services are organised according to the National Advisory Committee Report on Palliative Care (2001). The specialist palliative care unit is regarded as the core essential element of the specialist palliative care service and the unit acts as a co-ordinating centre for the delivery of specialist palliative care services in all care settings, including hospitals and the community. Specialist palliative care services are, therefore, uniquely configured along patient pathways- they involve services which are managed from the central hub of the palliative care unit and which cross-hospital and community boundaries.

Process:

- The provision of palliative care is the responsibility of the whole healthcare system and palliative care services should be integrated into the existing health system in all areas of care, especially community and home-based care. The three levels of

multidisciplinary service provision should be available in all HSE areas and all patients should be able to engage easily with the level of expertise most appropriate to their needs regardless of their care setting.

- If generalist palliative care providers are unable to provide relief for patient and/or family distress, input from specialist palliative care services should be provided. Systems of care must be sufficiently flexible to ensure that specialist services remain aligned to the changes in level of need and respond promptly and effectively. Episodes requiring specialist support may be of variable duration but should the problem resolve then patients may be discharged from the specialist palliative care service and return to less intensive care arrangements with the generalist palliative care provider.
- A range of services, spanning multiple sectors and settings, are typically involved in the provision of palliative care in order to satisfy the population's diverse needs. Care must be carefully coordinated in order to avoid the delivery of disjointed and fragmented care and to ensure that services that are flexible and responsive to the variations in the palliative care needs of individuals, their carers and their families.

Outcomes:

- Outcome measurement has a major role to play in improving the quality, efficiency and availability of palliative care. However, outcome measurement in palliative care is not without its difficulties due to the unique needs of patients receiving palliative care. The illness trajectory in palliative care, for example, poses a challenge to outcome measurement as patients' health will deteriorate and symptoms will probably worsen. This deterioration makes the detection of health-related outcomes challenging. These challenges influence what type of outcome measure can be used, whom they can be used with and when they can be used.

4. Palliative care and demographic pressures

As a result of the Ireland's ageing population, the annual number of total deaths in Ireland is projected to increase annually from an estimated 27,000 per year at present to 34,000 per year by 2030 (CSO, 2012). This represents an increase of 26% over the coming two decades. In addition, many more people will be dying at an older age and will therefore be likely to have more complex needs and multiple co-morbidities as they near the end of their lives. These demographic changes will lead to an increasing need for palliative care service provision. Historically, palliative care has been associated with those suffering from cancer, but future provision must also cater for other chronic diseases such as neurodegenerative, cardiovascular and respiratory disease.

5. What needs to happen to ensure that people die well in Ireland?

Achievements to date:

Ireland has a long and proud tradition of providing palliative care that extends back to the nineteenth century when the Irish Sisters of Charity established St Patrick's Hospital in 1870 in Cork and Our Lady's Hospice in Dublin in 1879. The Irish Government's commitment to developing palliative care services was first reflected in the national health strategy entitled 'Shaping a Healthier Future – A Strategy for Effective Healthcare' in 1994. The 2001 health strategy, 'Quality and Fairness – A Health System for You', reaffirmed the Government's commitment to the development of a national palliative care service. However, the most fundamental policy commitment to palliative care was the establishment of the National Advisory Committee on Palliative Care (NACPC) in 1999. This resulted in the publication of the NACPC Report in 2001, which highlighted deficiencies in palliative care provision and made recommendations based on quality evidence for the future of palliative care services in Ireland. Further commitment to the development of paediatric palliative care services was made with the publication of 'Palliative Care For Children With Life-Limiting Conditions In Ireland- A National Policy' in 2010.

As a result of the implementation of these policies, there has been significant advancement in palliative care service provision that has been recognized internationally. The Economist Intelligence Unit, well-known for its Quality-of-Life Index (Ireland ranked No. 1 as the best country in the world to live in, in 2005), has now devised a 'Quality of Death Index' to rank countries according to their provision of end-of-life care. Commissioned by the Lien Foundation, the Index measures the current environment for End-of-Life Care services across 40 countries in 2010. At the top of the table is the UK. Australia and New Zealand are ranked second and third, respectively. Ireland is ranked 4th in the overall score, scoring 6.8 out of 10, ahead of countries like the US, Norway, Luxembourg and Canada.

Persistent deficits:

The international acknowledgement of Ireland's achievements to date in the field of palliative care provides an indication of what can be achieved by a visionary and universally accepted palliative care strategy, leadership on a national and local level and community engagement. However, significant deficiencies in palliative care provision remain and the following issues have been noted in clinical experience, reports and research studies:

1. *Needs assessment:* the problem of inadequate recognition of palliative care needs persists.
2. *Inequity in service provision and outcome:* access to community supports, generalist and specialist palliative care services and experience of care can vary according to geographic location and diagnosis.
3. *Communication and coordination of care:* care can be fragmented and inefficient with patients experiencing significant difficulties in care transitions.

4. *Community supports and out of hours service provision:* there can be variability the availability of community supports, and of out of hours service provision.
5. *Services for patients with life-limiting conditions with slow or fluctuating progression and prognosis of longer than 3 months:* it can be difficult to access medium to long-term care, particularly for younger patients.
6. *Carer support:* carers report suboptimal financial assistance, difficulties accessing equipment, care packages and respite care.
7. *Carer education:* there can be a lack of knowledge and skills in palliative care provision (experienced by both formal and informal carers).

Strategies to strengthen the health system and provide optimal palliative care:

Health system strengthening can be defined as any array of initiatives and strategies that improves one or more of the functions of the health system and that leads to better health through improvements in access, coverage, quality, or efficiency (Health Systems Action Network, 2006). The World Health Report 2000 (WHO 2000) identifies the four key functions of the health system: (a) stewardship (often referred to as governance or oversight), (b) financing, (c) human and physical resources, and (d) organization and management of service delivery. Levers for strengthening palliative care provision in each of these areas are considered below:

A. Stewardship:

The stewardship, or governance, function reflects the fact that people entrust both their lives and their resources to the health system. A variety of levers may be exercised to improve palliative care service provision including:

- Maintaining alignment of Palliative Care across policy, commissioning and services. This principle should be reflected in the assignment of the palliative care function to designated senior personnel in the relevant organisations.
- Ensuring that a strong accountability mechanism that clarifies Palliative Care budget allocation, expenditure and funding requirements exists.
- Providing support to raise awareness for specific palliative care messages and behaviours.
- Ensuring that palliative care is part of all health and social care policies for non-communicable diseases, including care delivery, education for the community and clinical staff, optimising models of service delivery, and research.

B. Financing:

Health financing is a key determinant of health system performance in terms of equity, efficiency, and quality. Health financing encompasses resource mobilization, allocation, and distribution at all levels (national to local), including how providers are paid. Systematic reviews of palliative care provision have noted that specialist palliative care is more effective than conventional care in terms of improving outcomes (e.g. controlling pain and other symptoms, increasing satisfaction) and reducing direct costs (e.g., due to reductions in length of stay, ICU utilisation). The move towards Money Following the Patients accompanied by opportunity to strengthen health financing systems and mobilize resources, advocate how resources should be allocated, and appropriately configure health service delivery. However, the application of activity based funding to the palliative care service is challenging as current models of activity based funding do not adequately account for the complexity of palliative care (such as the different disease trajectories associated with life-limiting illnesses, the different settings in which palliative care can be provided and the key role that multidisciplinary teams, including allied health professionals, play in the provision of care). There is merit in palliative care being considered as a separate funding category and with specific consideration as to how funding mechanisms ensure that care is delivered in accordance with the WHO definition of palliative care. The following levers may be applied to ensure adequate funding for modern, responsive palliative care services that allow for quality service provision matched to service user need and in the service user's preferred place of care.

- Reviewing the specialist palliative care budget in order to address deficiencies in service provision and ensuring that palliative care is made a funding priority.
- Ensuring 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.

C. Human and physical resources:

The third function of the health system is the recruitment, training, deployment, and retention of qualified human resources; the procurement, allocation, and distribution of essential medicines and supplies; and investment in physical health infrastructure (e.g., facilities, equipment). The following levers may be applied to achieve improved palliative care provision:

- Developing a generalist workforce with appropriate palliative care skills by:
 - Engaging in workforce planning and review of undergraduate and continuing professional development curricula with teaching and training bodies.
 - Ensuring that appropriate education and practice and professional development opportunities are provided to generalist and specialist palliative care staff, across whole of career pathways.

- Developing and creating additional funded education and training opportunities in palliative care in nursing, medicine and allied health.
- Facilitating health care services to support working practices that allow staff to most effectively use their skills to provide quality palliative care including dedicating sufficient time to patients and their carers.
- Recognising the role of the volunteer workforce in palliative care.
- Ensuring affordable access to aids, equipment and medications necessary to provide quality palliative care in the community.
- Supporting the appropriate re-design of the infrastructure healthcare facilities to ensure accessibility, comfort and dignity for service users.
- Investing in Palliative Care Health Information Systems as a current lack of capacity in measurement and analysis in serves as a constraint to national policy making and resource allocation.

D. Organisation and management of service delivery:

The final function of the health system is in the organization and management of service delivery. Health services are the most visible function of any health system, both to users and the general public and a number of opportunities exist in this area to improve palliative care provision, such as:

- Addressing the deficits in palliative care bed provision and shortages in specialist palliative care staffing in order to ensure that there is sufficient specialist palliative care capacity to provide care for patients who are currently receiving inappropriate or sub-optimal care in acute and community care settings.
- Increasing access to in-home support, including access to 24/7 on call support and support for carers.
- Increasing access to rehabilitation and respite care as required.
- Increasing recognition of and service development for bereavement care for families and carers.
- Realising continuity of care by integrating existing resources and systems to provide for coordinated case management systems and promoting linkages between specialist palliative care services and other parts of the health system.
- Supporting palliative care practice through the promotion of the Palliative Care Clinical Programme and the development and implementation of clinical practice guidelines, pathways and decision support tools.

- Supporting research that examines the most appropriate way to assess and monitor quality, efficiency and effectiveness of palliative care service provision.

Conclusion:

The ultimate goal of palliative care is to improve quality of life for patients and families facing life-limiting illness. It is not dependent on prognosis and can be delivered at the same time as disease-modifying treatment. National and international achievements to date provide an indication of what can be achieved by a visionary and universally accepted palliative care strategy, leadership on a national and local level and community engagement. Palliative care represents a paradigm shift in the management of life-limiting conditions, providing interdisciplinary coordination and team-driven continuity of care while efficiently utilizing healthcare resources and delivery systems. Addressing outstanding deficiencies in palliative care provision offers a key solution to current challenges facing Irish healthcare system.

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Appendix 2. Summary of recommendations:

1. That alignment of Palliative Care across policy, commissioning and services is maintained. This principle should be reflected in the assignment of the palliative care function to designated senior personnel in the relevant organisations.
2. That a strong accountability mechanism that clarifies Palliative Care budget allocation, expenditure and funding requirements is ensured.
3. That the specialist palliative care budget is reviewed in order to address deficiencies in service provision and ensure that palliative care is made a funding priority.
4. 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.
5. That support is provided to raise awareness for specific palliative care messages and behaviours.
6. That palliative care is part of all health and social care policies for non-communicable diseases, including care delivery, education for the community and clinical staff, optimising models of service delivery, and research.
7. That a generalist workforce with appropriate palliative care skills is developed by:
 - a. Engaging in workforce planning and review of undergraduate and continuing professional development curricula with teaching and training bodies.
 - b. Ensuring that appropriate education and practice and professional development opportunities are provided to generalist and specialist palliative care staff, across whole of career pathways.
 - c. Developing and creating additional funded education and training opportunities in palliative care in nursing, medicine and allied health.
8. That health care services are facilitated to support working practices that allow staff to most effectively use their skills to provide quality palliative care including dedicating sufficient time to patients and their carers.
9. That the role of the volunteer workforce in palliative care is recognised.

10. That affordable access to aids, equipment and medications necessary to provide quality palliative care in the community is provided.
11. That the appropriate re-design of the infrastructure healthcare facilities to ensure accessibility, comfort and dignity for service users is supported.
12. That investment is made in Palliative Care Health Information Systems as a current lack of capacity in measurement and analysis serves as a constraint to national policy making and resource allocation.
13. That deficits in palliative care bed provision and shortages in specialist palliative care staffing are addressed in order to ensure that there is sufficient specialist palliative care capacity to provide care for patients who are currently receiving inappropriate or sub-optimal care in acute and community care settings.
14. That increased access to in-home support, including access to 24/7 on call support and support for carers is provided
15. That increased access to rehabilitation and respite care is provided as required.
16. That increased recognition of and service development for bereavement care for families and carers is provided.
17. That continuity of care is realized by integrating existing resources and systems to provide for coordinated case management systems and promoting linkages between specialist palliative care services and other parts of the health system.
18. That palliative care practice is supported through the promotion of the Palliative Care Clinical Programme and development and implementation of clinical practice guidelines, pathways and decision support tools.
19. Research that examines the most appropriate way to assess and monitor quality, efficiency and effectiveness of palliative care service provision is supported.

The role of specialist palliative care: establishing what needs for happen to ensure that people die well in Ireland.

Dr Karen Ryan,
Consultant in Palliative Medicine, St Francis Hospice and Mater Misericordiae
University Hospital.
Clinical Lead, Palliative Care Programme, HSE.

vigorous treatment of
pain and other symptoms

treatment

relief from worry,
anxiety and depression

relief

close communication
about their care

information

well-coordinated care
and transitions

coordination

support for family
caregivers

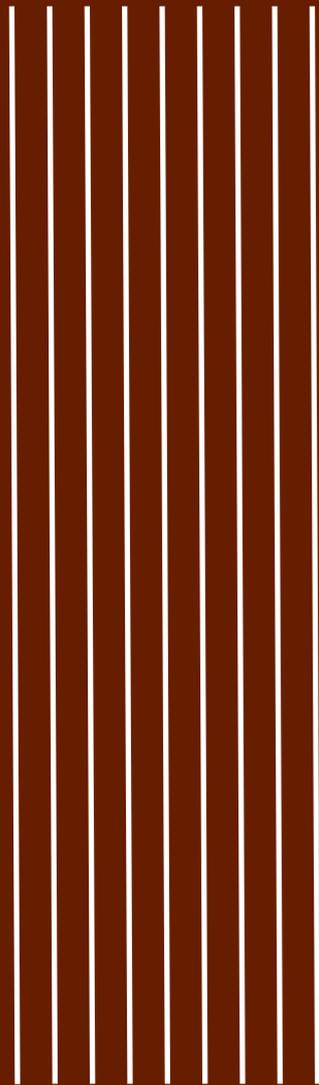
support

a sense of safety in
the healthcare system

safety

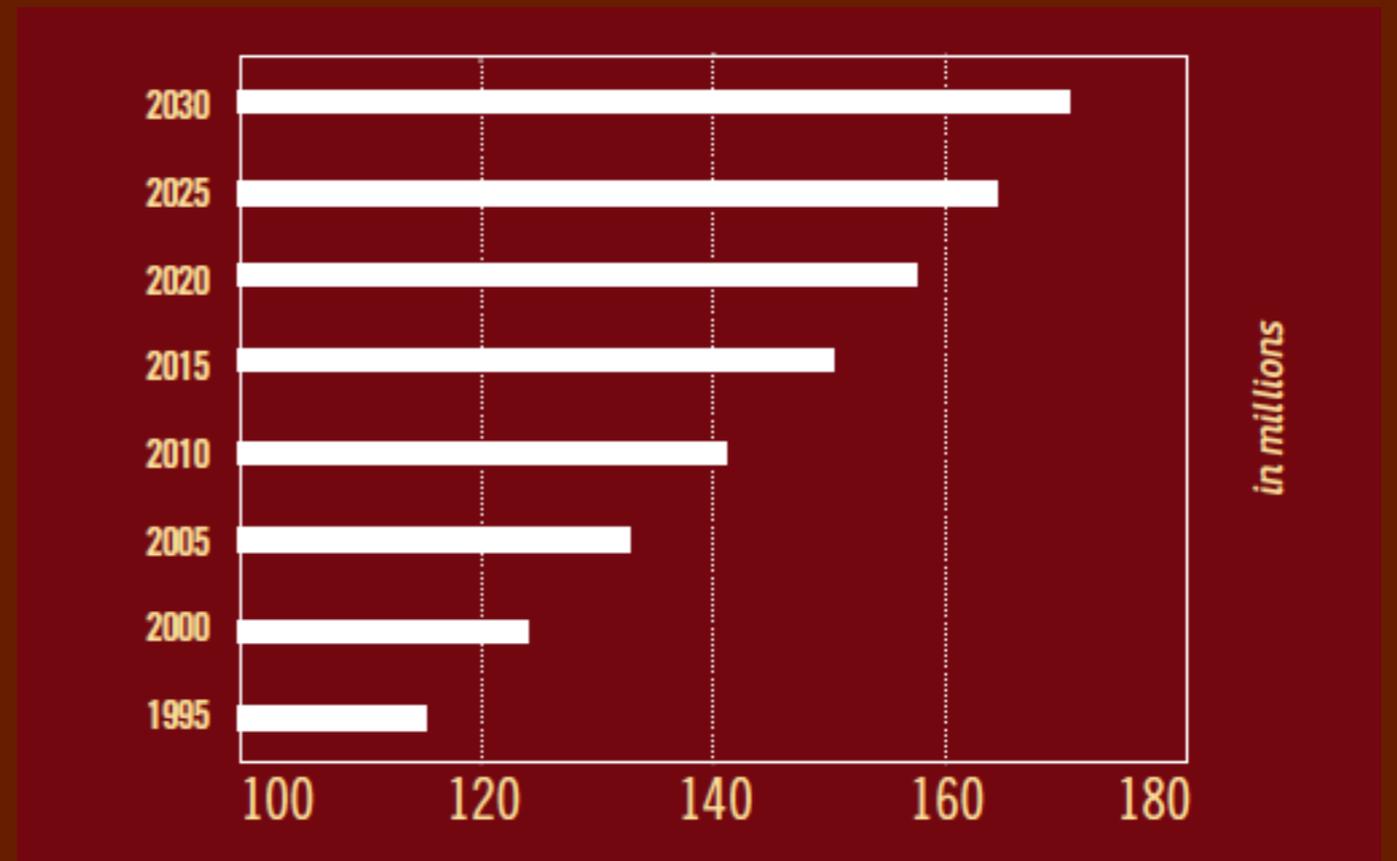


**PALLIATIVE CARE:
PROVIDING QUALITY CARE
THAT PATIENTS WANT**

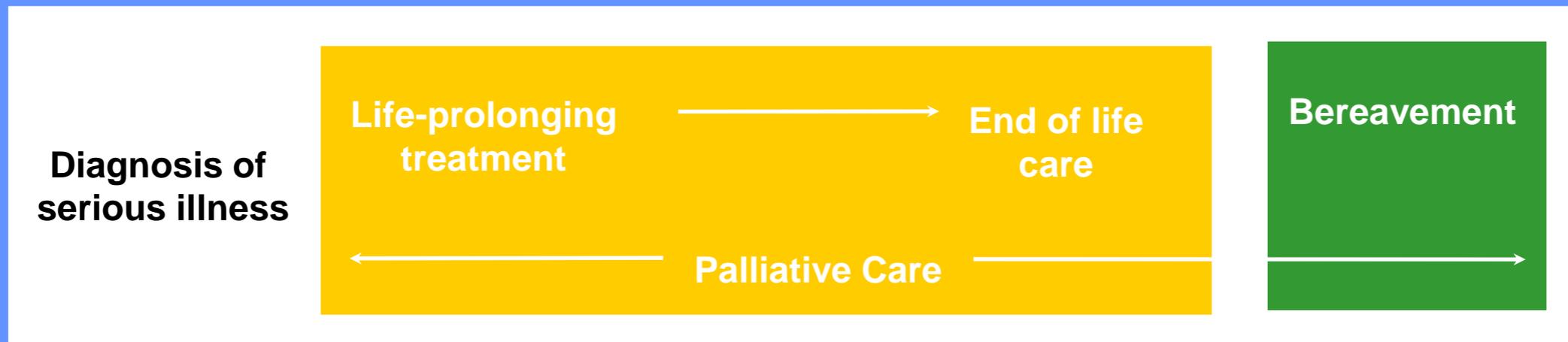


THE NUMBER OF PEOPLE WITH CHRONIC CONDITIONS IS INCREASING RAPIDLY

Source: Shin-Yi and Green, RAND, October 2000.



PALLIATIVE CARE IS APPROPRIATE AT ANY POINT IN A SERIOUS ILLNESS

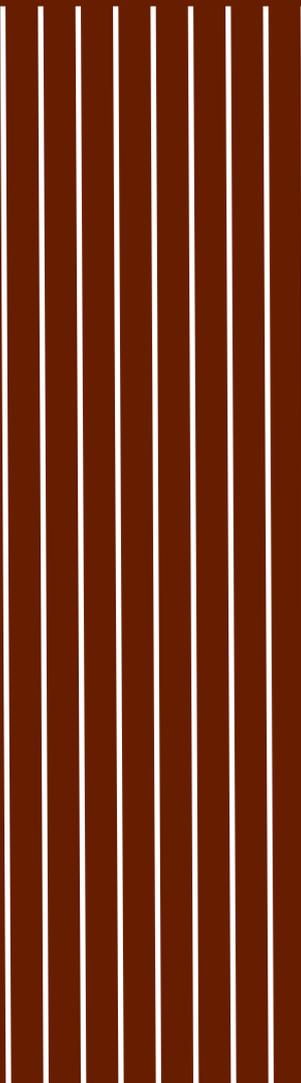


Palliative Care

**is the responsibility
of the entire health
system.**

It is provided by specialist and generalist
practitioners

**working in
partnership.**



Report of the National Advisory Committee on Palliative Care, 2001

The Palliative Care Needs Assessment for Children, 2005

Palliative Care for All- Integrating Palliative Care into Disease Management Frameworks, 2008

National Quality Standards for Residential Care Settings, 2008

Palliative Care - A Five Year/Medium Term Development Framework, 2009

Palliative Care For Children With Life-Limiting Conditions In Ireland- A National Policy, 2010

Establishment of the Palliative Care Clinical Programme, 2010

**THERE HAVE BEEN SIGNIFICANT
ADVANCES IN PALLIATIVE CARE
PROVISION IN IRELAND**

needs assessment

inadequate

communication and
coordination of care

deficits

service provision

inequitable

community supports &
out of hours provision

variable

carer support

suboptimal

carer education

deficits



**HOWEVER,
GAPS IN SERVICE PROVISION
REMAIN**

**whole systems
approach**

STEWARDSHIP

FINANCING

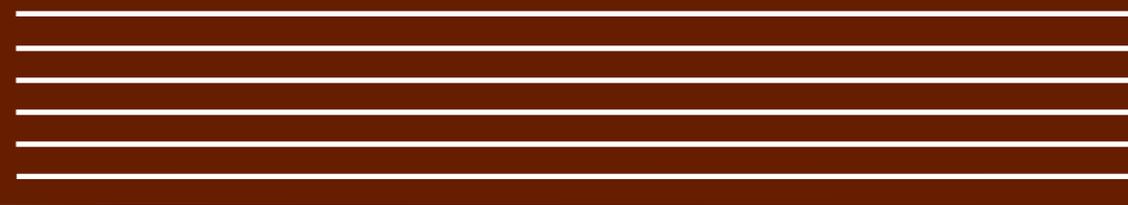
HUMAN RESOURCES

PHYSICAL RESOURCES

**ORGANISATION AND
MANAGEMENT OF
SERVICE DELIVERY**

**OPPORTUNITIES
TO PROVIDE THE QUALITY
CARE THAT PATIENTS WANT**

Conclusions:



Palliative Care:

Is not dependent on prognosis and can be delivered at the same time as disease modifying treatment.

Has the ultimate goal of improving quality of life for patients and families facing serious illness.

Represents a paradigm shift for managing life-limiting conditions, providing interdisciplinary coordination and team-driven continuity of care while efficiently utilizing healthcare resources and delivery systems.

Achievements to date provide an indication of what can be achieved by a visionary and universally accepted palliative care strategy, leadership on a national and local level and community engagement.

Addressing outstanding deficiencies in palliative care provision is a key solution to challenges facing Irish healthcare system.

Submission to the Oireachtas Committee on Health End of Life Care in Ireland

Introduction

St Patrick's Mental Health Services is Ireland's largest independent mental health service provider established over 260 years ago to provide treatment and protection for those experiencing mental illness. Today, St Patrick's Mental Health Services is driven by a commitment to provide the highest quality mental health care, to promote awareness of mental health and to protect the rights of those who experience mental health difficulties. Based on a strong human rights framework and a recovery model of service delivery, we are committed to developing a Later Life Mental Health Wellness Campus, to become a more active advocacy voice for those experiencing mental health difficulties and drive awareness within Irish society. We are committed to empowering those who experience mental health difficulties to be active citizens in shaping the legislation and services which impact on their lives and in determining the treatments they receive. We welcome the opportunity to provide a submission to the Oireachtas hearings on End of Life Care in Ireland.

Dr Miriam Kennedy is a consultant psychiatrist with experience and higher training in models of care in dementia in UK and Ireland. In addition, she has both initiated and collaborated in training programmes for staff working in nursing homes, and psychiatric units caring for people in the final stages of dementia and ran workshops on empathy and communication skills for medical and nursing staff (including those working in palliative care). She is an interpersonal psychotherapist (IPT, which emphasises psychosocial treatments for depression) and her research area is in capacity to consent to treatment. Mary O'Hora is currently the manager of the Information Centre in St Patrick's Mental Health Services and acts as the service user liaison with the Hospital's Consumer Council. She is the current Chair of the Hospital's Advocacy Committee.

St Patrick's Mental Health Services provide holistic, person centred recovery focused care and treatment of mental illness. The Hospital's ethos is grounded in human rights and it recognises the right of service users to autonomy and self-determination regarding decisions about their care and treatment. The Hospital assumes that an individual has capacity to make decisions about his / her treatment unless a formal assessment of capacity deems that this is not the case. In the event of a lack of capacity an Advance Healthcare Decision policy has been approved and implemented in the Hospital.

Service users have the right to respect, dignity, self-determination, autonomy, reciprocity, justice and confidentiality in all aspects of their care and treatment including those end of life care decisions where mental capacity may be impaired. The Hospital would like to ensure that these guiding principles are upheld in all healthcare decisions and the will and preferences of the individual take precedence in the decision making process for end of life care treatment options.

Recommendations

1. It is recommended that any individual who may wish to do so to have an advance healthcare decision expressing their will and preferences adhered to regardless of their capacity to make choices at the end of their life.
2. Where specialist care is being provided for persons suffering with advanced dementia or a medical illness which is in the terminal stages, the emphasis of care needs to be on providing quality of life at each stage of illness. Our aim is that care is a collaborative work between health care professionals, patients and their relatives/carers/loved ones. Generally aggressive interventions (unless in the case of necessity) are not undertaken which are burdensome and cause distress rather than relief from suffering.
3. The aim of care for a person with dementia who is in a specialised unit is to provide a care plan which can look after physical, social, emotional, psychological, spiritual, cultural needs and proved specialised expertise in mental health including treatment and care for behavioural and psychological disturbance. Nursing care appropriate to those needs is a key part of the service. Comfort and dignity in dying is seen as core work. To provide this the care plan needs to address these needs a long time before the actual phase where death is imminent. We recommend a care plan which integrates medical, nursing, diagnosis and stage of illness, mental health risk , psychological and behavioural functioning, medication, activities the person enjoys , personality, cultural needs including spiritual and religious needs, palliative care liaison and quality of life issues (eg peg tube feeding or not, not necessarily routine) next of kin input and regular review of this care plan ,signed and dated each time and accessible easily by all staff, and reviewed regularly with all parties involved,
4. Resource allocation and service development must reflect the needs of people with dementia and identify unmet need.
5. Training of staff is required across a range of skills and competencies, including communication, legal, ethical duties of care, identification of common cause of distress and pain, end of life issues and skills to act in the patients best interests with professional competence and skill. Competency based training is key..
6. All health professionals should be able to practise palliative care and we recommend this be a core skill fo all hospital staff (including careassistants, catering staff, nutrition input, etc). It should be possibl that patients with advancde illness have their care needs met comprehensively and satisfactorily without necessarily being referred to specialist palliative care units.
7. Decisions around appropriate investigations, and the effect of interventions or not are key. Professional competencies in end of life care, legal and ethical awareness of the decision making process, advocacy and the acceptance of death and focus on death with dignity are all key to the care of the person through the life continuum. Continuing professional training as part of the culture of car, with evidence of same, can ensure that our patients receive a quality service.
8. Audit of care plans, with focus on the integration of medical nursing, multidisciplinary inputs, legal, ethical, spiritual, cultural roles in the care plan are all important in achieving these goals of truly person centred end of life care. Audit of training and collaboration of services can identify where improvements are needed and where centres

of excellence exist the evidence of same through audit and information sharing can lead to replication and improvement elsewhere.

Submission Ends

SUBMISSION

1. INTRODUCTION

My name is Bernadette Halpenny and I have worked as a Registered Nurse for Intellectual Disability (R.N.I.D.) in Sunbeam House Services (SHS) since 2003. For the last eight years I have worked as Clinical Nurse Manager (CNM2). In this role a palliative care approach has been used in working with an ageing population residing in SHS residential locations.

It is the experience of SHS staff that in view of the increased lifespan of this client group, there is a greater need for the development of a palliative care approach, particularly in the context of providing end-of-life care for people with an intellectual disability.

I have recently completed a Masters in Palliative Care from Trinity College Dublin and in so doing was sponsored by my employing Organisation SHS.

2. EXECUTIVE SUMMARY

The lifespan of people with an intellectual disability has increased over recent decades. Terminally ill people with an intellectual disability have the same rights as other individuals to be treated with dignity and respect as they approach end-of-life.

In order that the needs of this client group can be met in a professional, sensitive and caring manner it is recommended that medical, nursing and allied professionals receive education with regard to how best to meet the needs of terminally ill people who have an intellectual disability.

It is also recommended that professionals working in the intellectual disability sector be included in any care plan for clients with an intellectual disability

3. RECOMMENDATIONS

Recommendation No. 1

The concept of a terminally ill person with an intellectual disability, who lives in residential care, receiving end-of-life care within their residential location need to be supported.

It is recommended that education and training be offered to community palliative care teams in respect of how best to work with, and meet the needs of clients with an intellectual disability. It is also recommended that staff working in the intellectual disability sector be offered education and training with regard to providing end of life care. This will facilitate the provision of high quality end-of-life care for people with an intellectual disability.

Recommendation No. 2

It is recommended that hospital staff be offered some education as to how best to communicate with a person with an intellectual disability.

Recommendation No. 3

It is recommended that when a person with an intellectual disability avails of hospital treatment whether on an inpatient or outpatient basis that the role of the intellectual disability nurse and/or carer in supporting the patient be acknowledged and that they would form part of any care plan.

4. MAIN BODY OF SUBMISSION

Introduction

The academic literature has noted that the life expectancy of people with intellectual disability has increased resulting in the need for the development of various services to meet the needs of this ageing population (Walsh, 2003; Fahey-McCarthy et al 2008).

The goal of palliative care is to improve the quality of life for people and their families in the context where the person has been diagnosed with a terminal illness. It is holistic in its approach and attends to the physical, psychological and spiritual needs of the person (European Association of Palliative Care 2010). Palliative care accepts the terminal nature of the person's illness provides relief from pain and attends to the care of the whole person and the person's quality of life.

Palliative care as an approach can be delivered at three levels. At level one the principles of palliative care can inform the practice of medical, nursing and allied professionals. At level two palliative care can be delivered by professionals with some level of training and experience in this area. At level three palliative care is provided by specialist palliative care teams working in specialist units or in the community supporting other agencies or people in their homes (O'Brien 2001, Fahey-McCarthy et al 2008).

Point 1.

It is the experience of SHS staff that terminally ill clients in SHS residential care, who are aware of their terminal condition, have a marked wish to die in their residential location which they regard as their own home. These clients have expressed a wish to stay within the familiar surroundings of their residential location and not to be transferred to either a hospital or hospice setting.

In this context therefore, palliative care is delivered to terminally ill clients in SHS residential locations, by SHS nursing and support staff working in co-operation with community palliative care teams. This is in accordance with the wishes of the clients and avoids using hospital resources.

The academic literature indicates that whilst staff working in the intellectual disability sector often lacks confidence in delivering palliative care, staff working in the palliative care sector often lack confidence in working with people with an intellectual disability. The building of relationships between intellectual disability sector and palliative care services is essential to ensure the provision of high quality palliative care for this client group (Ryan et al 2010).

Point 2.

In the continuum of providing palliative care the area of communication is often fraught with difficulties. Thus, because of their limited understanding a person with an intellectual disability will have difficulty in understanding information. Terminally ill people with an intellectual disability will often have to avail of hospital treatment for other illnesses. Medical and diagnostic information whether in relation to the person's terminal illness or any other illness can often be difficult to understand and the academic literature states that such information needs to be communicated in a simple and sensitive way to a person with an intellectual disability (Tuffrey-Wijne & McEnhill 2008; Hardy et al 2011).

Point 3.

Similarly medical staff can often fail to understand the utterances and/or the meaning of the body language of the person with an intellectual disability (Read 1998). SHS staff have helped medical staff to achieve a better understanding of the patient with an intellectual disability and have played an important role in facilitating communication between medical staff and patients. It is the experience of SHS staff that a person with an intellectual disability can find a stay in a hospital to be a distressing experience which in turn has been a source of both distress and disruption to other patients and hospital staff. It has been found that the presence of SHS staff in supporting their clients in a hospital setting has helped to ensure not only that the person with an intellectual disability receives maximum benefit from medical care but also has helped to ensure that disruption to other patients is minimised.

18th November, 2013.

Bernadette Halpern

Recommendations for Review and Development of Palliative Care Undergraduate Medical Education in Irish Universities

Dr Catherine Sweeney

Lecturer Clinical Science and Practice,
Medical Education Unit,
University College Cork

Dr Margaret Clifford

Clinical Tutor,
Graduate Entry Medical School
University of Limerick



Executive Summary

To meet the needs of a growing number of patients living with advanced incurable illnesses, newly qualified doctors must be proficient in the basic principles and practice of palliative care. The need for palliative care education of medical students has been highlighted by several key organisations, including the World Health Organisation, and by the Prague Charter, a global petition calling for palliative care to be recognised as a human right. The European Association for Palliative Care (EAPC) has produced recommendations for a Curriculum in Palliative Care for Undergraduate Medical Education, including seven key domains that need to be addressed in undergraduate medical curricula to achieve basic competency in palliative care. We recommend that:

1. All undergraduate medical curricula in Ireland should be reviewed and content relevant to palliative care identified.
2. Minimum requirements for undergraduate palliative care education for medical students should be agreed, in line with the EAPC recommendations and the HSE Palliative Care Competency Framework.
3. An implementation strategy and an assessment framework should be established and agreed by all relevant stakeholders across diverse medical specialties.

Background

Patient and Societal Needs

Patients with life-threatening illnesses have complex multidimensional needs. These needs are well summarized in the World Health Organisation's definition of palliative care as "an approach that improves the quality of life of patients and their families facing the 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, psychosocial and spiritual".¹ Evidence of the impact of palliative care on quality of life is substantial.² Recent evidence suggests that along with improving quality of life, palliative care can confer a survival benefit in some patients.³

Almost a half of Irish deaths occur in acute hospitals and 75% of these deaths are

expected.⁴ Junior doctors are actively involved in the care of these patients. In the UK it has been estimated that on average in the year after qualification a doctor cares for 40 people who will die in hospital (including 10 from cancer, 18 from heart disease and stroke, 4 from a respiratory cause) and another 120 with advanced disease who are not dying at the time.⁵ Most of these patients and their families would benefit from a palliative approach to their care. Hence, basic palliative care competencies are vital in the practice of junior doctors from the time of qualification and will be important for the majority throughout their professional lives.

The Central Statistics Office has predicted that the number of those over 65 in Ireland will rise from 462,364 in 2006 to approximately 765,000 by 2016 and 1,381,000 by 2041.⁶ As our population ages it is anticipated that there will be increasing numbers of patients with palliative care needs related to both malignant and non-malignant diseases. This change in population demographics will put an increased emphasis on the need for doctors with palliative care competencies.

Education Needs of Medical Students

The need for palliative care education of medical students has been highlighted by several key organizations, including the World Health Organisation, The General Medical Council, and the Liaison Committee on Medical Education.⁷⁻⁹ In 2013, a worldwide petition known as The Prague Charter was launched, calling for palliative care to be recognized as a human right. One of the key domains of this petition relates to education, stating that “Governments should adopt the necessary changes in the training curricula for healthcare providers (medical, nursing, pharmacy, psychology, etc) at undergraduate levels to ensure that all healthcare workers obtain basic knowledge about palliative care and are able to provide it to patients regardless of where in the healthcare system they work.”¹⁰ As this global initiative gains momentum, there will be an increasing expectation that all newly qualified healthcare workers are proficient in the delivery of palliative care.

The Report of the National Advisory Committee on Palliative Care¹¹ commissioned by the Department of Health and subsequently adopted as government policy made detailed recommendations regarding both undergraduate and postgraduate education for healthcare professionals. This included the development of a core

curriculum in palliative care for medical students and the establishment of academic departments of palliative medicine. In 2003 a report on the Organisation of Palliative Care (COE 144/153) by an international committee of experts chaired by Dr. Tony O'Brien (Consultant in Palliative Medicine, Marymount Hospice, Cork) was published and adopted by the Council of Europe.¹² In response to this report the European Association for Palliative Care (EAPC) produced recommendations for a Curriculum in Palliative Care for Undergraduate Medical Education.¹³ Seven key domains were identified that need to be addressed in undergraduate medical curricula to achieve basic competency in palliative care:

- Palliative Care, Palliative Medicine (definitions etc.)
- Pain
- Neuropsychological symptoms (agitation, confusion etc.)
- Management of other symptoms (dyspnoea, nausea, etc.)
- Ethics and law
- Patient/family/ non-clinical caregivers perspectives
- Clinical communication skills

The need for experiential learning through appropriate clinical exposure and multidisciplinary education was also highlighted, as well as the importance of multi-professional learning and the need for some members of the faculty of medicine to have professional backgrounds other than medicine (e.g. nursing, pastoral care). A cohesive approach is needed in order to provide comprehensive education covering these domains.

There is evidence that lack of a formal palliative care curriculum at undergraduate level impacts negatively on the development of students' palliative care skills. In a comparison of 6 US medical schools, students in those schools whose curricula had formal palliative care content were more likely to feel competent in the delivery of end of life care than their counterparts.¹⁴ Another recent US study of 1445 fourth year medical students from 62 medical schools found that lack of a formal curriculum and informal educational experiences through bedside teaching impacted negatively on preparedness to carry out end of life care.¹⁵ In a German university without compulsory palliative care curriculum content, assessment of a number of core palliative care competencies (accompaniment of dying patients, breaking bad news

and integration of spiritual aspects of care) were unchanged in a comparison between 1st and 5th year medical students and overall palliative care knowledge was poor.¹⁶ In a study carried out in University College Cork, medical students' (4th and 5th year) and interns' (in last 3 months of internship) perceived competency in 3 key areas of palliative care (symptom management, teamwork and communication) were assessed using a validated tool. When compared by amount of palliative care education received, those who had had more than 6 hours of education (the majority of whom had completed a special study module in palliative care) scored significantly higher in all 3 areas than those who had no formal palliative care education.¹⁷

Previous studies have found that senior medical students and newly qualified doctors feel ill equipped to deal with patients palliative care needs.^{18,19} Similar findings are suggested by studies in Irish interns.^{20, 21} In a qualitative study looking at the reasons why newly qualified doctors did not feel ready to meet the needs of patients at the end of life, the participants highlighted lack of exposure to dying patients prior to qualification as an important factor.¹⁷ The need for clinical exposure to patients at the end of life is supported by findings of an earlier US study where clinical experience in palliative care was found in senior medical students to be associated with preparedness to discuss end-of-life issues with patients and to treat common symptoms.¹⁴

Education including clinical experience is key to addressing these deficits. Students' attitudes to palliative care, knowledge and perception of competency in key areas of palliative care can be significantly improved by well thought out educational initiatives.²²⁻²⁵

Added Value of Palliative Care Education:

A well-designed palliative care education programme for medical students has the potential to deliver key general educational benefits along with the 7 domains highlighted in the EAPC Recommendations. These include increased understanding and appreciation of the importance of holistic and collaborative patient and family care, interdisciplinary teamwork and the need for self-care.²⁴ Palliative care is a specialty where all these areas are integrated into everyday practice and students

can observe the real world application of theoretical knowledge gained in other areas of the curriculum. Advanced communication skills and ethical problem solving are other key aspects of practice where students can gain invaluable insight and integration of theoretical knowledge gained in the classroom with real world clinical practice. International literature demonstrates the positive effect that structured palliative care communication skills training can have on healthcare professionals' competence and confidence.²⁶ Competencies developed during palliative medicine education such as communication skills, breaking bad news, pain and symptom control are transferrable to many other medical specialties and are relevant to all newly qualified doctors. In addition, a clinical attachment in palliative care provides an opportunity to learn clinical and practical skills that can be overlooked in medical education such as, identification of dying, how to commence an opioid, prophylactic prescribing for dying patients, pronouncement of death and completion of death certificates and cremation forms.

Recommendations:

1. A "curriculum mapping" exercise should be carried out across all the universities to identify all undergraduate medical curricular content relevant to palliative care, with a view to identifying areas for improvement, and to facilitate sharing and co-operation between universities.
2. Minimum requirements for undergraduate palliative care education for medical students should be agreed, in line with the EAPC recommendations and the HSE Palliative Care Competency Framework.
3. An implementation strategy and an assessment framework should be established and agreed by all relevant stakeholders across diverse medical specialties.

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PRESENTATION

ON BEHALF OF

THE VOLUNTARY HOSPICES GROUP

TO THE OIREACHTAS COMMITTEE ON HEALTH AND CHILDREN

24TH OCTOBER 2013

1. INTRODUCTION

The Voluntary Hospices Group (VHG) is a membership group, representative of the major voluntary specialist palliative care service providers in Ireland.

Currently the VHG membership comprises the following providers:

- Galway Hospice
- Marymount University Hospice, Cork
- Milford Care Centre, Limerick
- North West Hospice, Sligo
- Our Lady's Hospice & Care Services (including Blackrock Hospice)
- St. Francis Hospice (Raheny & Blanchardstown)

The VHG's vision is that high quality palliative care will be available to all who may need it, in all care settings, and in line with national policy and best practice.

The VHG has an operational budget (2013), of **€53.413m**, 69% of which comes from the statutory sector, with the balance coming from fundraising, health insurance and other sources. It provides 91% (139) of the hospice beds in the country (with another 46 beds ready to be opened). In addition, all of the members operate specialist community care and day care services.

In 2012, the VHG cared for 2,449 inpatients, 5,076 patients in the community, and 871 patients in day care. These activity figures actually show a marked increase since 2009, by 271 (12.4%), 731 (16.8%), and 32 (3.8%) respectively, despite significant cuts in statutory funding in the intervening period.

The capital spend by the Group in the last five years was €74.283m, of which €60.403m, (81%) came from fundraising, and €13.880m (19%) from statutory sources.

2. SPECIALIST PALLIATIVE CARE

2.1 Goals of Palliative Care

The goal of palliative care is the achievement of the best possible quality of life for patients and their families. Specifically, palliative care is concerned with the following:

- Providing relief from pain and other distressing symptoms;
- Affirming life and regarding dying as a normal process;
- Neither hastening nor postponing death;

- Integrating the psychological and spiritual aspects of patient care;
- Offering a support system to help patients live as actively as possible until death;
- Offering a support system to help the families cope during the patient's illness and in their own bereavement;
- Using a team-based approach to address the needs of patients and their families, including bereavement counselling;
- Enhancing quality of life and positively influencing the course of illness.

2.2 Changing Patterns in Palliative Care

Palliative care is not confined to end of life care. The early involvement of palliative care helps to dispel the fears and anxieties associated with specialist palliative care programmes, and the benefits for quality of life are felt and appreciated by patients and families over a longer period. Discharge rates from hospices range between 35% and 50%, clear proof of the fundamental change in the delivery and impact of palliative care. Multiple admissions and discharges in the patient's journey are no longer exceptional. Many patients are now admitted for symptom control, and are then discharged home (supported as necessary by the community specialist palliative services), comforted in the knowledge that they will be readmitted if their condition changes and cannot be managed in the community setting.

Specialist palliative care services were often limited to cancer patients in the past, but in recent years, most providers offer their services based on the patient's needs rather than diagnosis. 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), are now being admitted to specialist palliative care services in greater numbers than heretofore, with other developments happening in paediatric palliative care. There is a long way to go, but the sector is aware of the need, and is trying to respond within the limited resources available.

2.3 Economics of Palliative Care

There is clear evidence and international research that demonstrates significant savings when patients have access to comprehensive specialist palliative care services, with greatly reduced admissions and length of stay in expensive, acute hospital care.

For example, the 2009 National Cancer Registry shows that just 19% of all cancer deaths in the Mid-West, where there are well-resourced and developed specialist palliative care services, were in an acute hospital, compared to 50% in the North East, where there is no hospice. (Extracted from a study by the Irish Hospice Foundation (IHF) in 2012.

Earlier studies by the VHG showed that the average bed cost in a hospice was over 20% lower than a bed in an acute hospital. That simple comparison ignores the multiplier impact of the community-based palliative services, which of course minimises the number of patients needing access to either type of bed. The IHF report showed that only 6% of community palliative patients in the Mid-West died in acute hospitals, whereas 30% died in acute hospitals in the North East.

2.4 National Policy Documents

Current national policy on palliative care is based on the principles and recommendations of the Report of the National Advisory Committee for Palliative Care (DoH&C October 2001). This seminal document prompted further reports, which included the following:

- Needs assessments in each of the health boards of the time;
- The 2006 Baseline Study (Irish Hospice Foundation), which measured progress against the recommendations in the 2001 Report
- The 2008 HSE’s Palliative Care Services – Five Year/Medium Term Development Framework , which was a plan for implementing the outstanding recommendations from the 2001 Report.
- The findings of the 2001 Report were fully endorsed by the 2008 Report of the International Expert Advisory Group on Palliative Care.

2.5 Levels of Specialisation in Palliative Care

The report recognised that palliative care services may be structured in three levels of ascending specialisation according to the expertise of the staff providing the service.

- **Level one** – Palliative Care Approach: Palliative care principles should be appropriately applied by all health care professionals.
- **Level two** – General Palliative Care: At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care.
- **Level three** – Specialist Palliative Care: Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

2.6 Organisation of Specialist Palliative Care

Specialist in-patient units (hospices) act as the “Hub” of all palliative care provision in a defined geographical area. Specialist palliative care providers work in two key ways: firstly, by providing direct care themselves, and secondly, by providing education and support to health care professionals working in acute, primary and community settings.

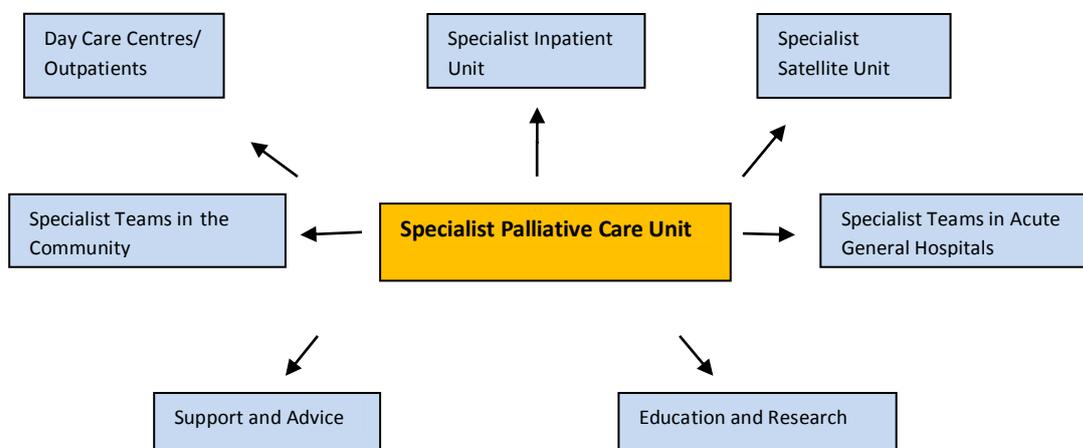


Diagram 1 – The Specialist Palliative Care Unit as the Hub

Services should be sufficiently flexible to allow movement of patients from one care setting to another, depending on their clinical situation and personal preferences. Where specialist palliative care inpatient units exist, services are fully integrated, with easy movement between the acute and community services, enabling the patient to be cared for in the location best-suited to their needs at any particular time, be that their home, the community hospital or nursing home, the acute hospital or the local hospice. Unfortunately there are several parts of the country without this key element of the system, and many of the services operate without the full complement of professionals recommended in the 2001 report.

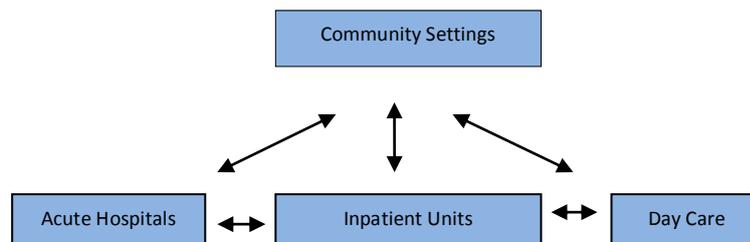


Diagram 2 - Integrated Nature of Specialist Palliative Care

3. Elements of Specialist Palliative Care

3.1 Principles

The 2001 Report recommended that:

- In order to achieve the best quality palliative care for patients and families, each health board should have a comprehensive specialist palliative care programme in its area. This service should be available in all care settings and should support the patient wherever the patient may be: at home, in hospital, in residential care, in day centres, in outpatients, or in a specialist palliative care unit;
- All health care professionals should be able to access advice and support from specialist palliative care service providers when required”.

3.2 Characteristics of a Specialist Palliative Care Service

The key characteristics of a specialist palliative care service as listed in the 2001 Report are as follows:

- The provision of physical, psychological, social and spiritual support, with a mix of skills, delivered through a multi-professional, collaborative team approach;
- At least the lead person in each professional group within the multi-professional team should be a trained and acknowledged specialist in palliative care;
- Patients and families are supported and involved in management plans;
- Patients are encouraged to express their preference about where they wish to be cared for and where they wish to die;
- Carers and families are supported through the illness into bereavement, and the needs of the bereaved are recognised and addressed;
- There is cooperation and collaboration with primary health care professionals, and hospital and home care services, to support patients wherever they might be;
- The contribution of volunteers is recognised and valued;
- The service has either directly or indirectly a recognised academic educational role and in-service education provision;
- Standards are set for the education and training provided;
- Quality assurance programmes are in place and are constantly used to review practice;
- Clinical audit and research programmes exist to evaluate treatment and outcome;

- Staff support arrangements exist which are appropriate to meet the needs of those working in specialist palliative care, whether full time or part time.

3.3 Recommended Bed Numbers

The 2001 Report recommended that there should be at least 8 to 10 specialist palliative care beds per 100,000 population, although this could vary depending on demographic and socio-economic composition of an area. This would suggest that there should therefore be between 367 and 458 beds in Ireland based on the 2011 Census, although changing models of care may reduce this somewhat.

The reality is that there are only 153 currently, with a further 46 ready to be opened. There are no hospice beds in the midlands or northeast, with a token 2 beds in the southeast. It is imperative that the beds waiting to be opened in Cork and Blanchardstown are brought on stream as soon as possible, and that the inpatient units planned for Louth, Laois/Offaly, Waterford, Wicklow, Mayo, Cavan/Monaghan, Kilkenny, and Kerry, and extensions in Donegal, Sligo, Kildare and Galway, are progressed.

3.4 Recommended Staffing Levels

There are major deficits in the staffing levels in the current specialist palliative care services compared with the recommended levels in the 2001 Report, across all disciplines and settings. The IHF Baseline Study in 2006 confirmed that less than 50% of the posts recommended had been filled, and that an additional 744 staff would be needed to implement the recommendations. Many of these posts will not be needed until the capital projects required to redress the bed deficit are delivered, but there are significant deficits in staffing levels in existing services too.

There have been many changes since the Baseline Study was carried out, in population (numbers and location), in practice, in skill mix, in models of care, and in service developments, and it would be extremely useful if a new study were initiated. However, this should not delay efforts to reduce staffing deficits in existing services. The scale of the challenge will require a phased response.

3.5 Specialist Palliative Care Funding

Funding for current specialist palliative care services comes from a combination of statutory and voluntary sources. Over 30% of funding of the VHG inpatient units comes from fundraising and other non-statutory sources (2013), while the 2008 HSE Framework document suggests that the percentage for community-based palliative services may even be higher. One of the recommendations of the 2001 Report was that the State should fund all core specialist palliative care services.

There was a further recommendation that there should be a protected specialist palliative care budget. This is essential to prevent erosion of the funding provided to date for specialist palliative care services, especially in the current economic climate where all budgets have been substantially reduced, and where the health services are undergoing a fundamental restructuring, and to protect future investment in the sector.

4. Conclusions and Recommendations

- The 2001 Report of the National Advisory Committee on Palliative Care is the blueprint for the delivery and development of palliative care services in Ireland.

- Its vision and recommendations were fully endorsed by an International Expert Advisory Group in 2008.
- There must be access to comprehensive, integrated specialist palliative care services for all, irrespective of diagnosis or geographic location, with easy movement between elements of the services depending on patient choice and need.
- The number of inpatient beds needs to be greatly expanded, especially in the parts of the country where there are currently no inpatient units.
- Staffing levels need to be increased to ensure the necessary personnel with the right skills and expertise are available in the required numbers.
- The Baseline Study needs to be updated to take account of changes in demographics, practice, service developments and healthcare structures since the previous study.
- All core services should be funded by the State.
- There should be a protected budget for specialist palliative care.