



Written submission to the Citizens Assembly on behalf of the Irish Association for Palliative Care

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In order to best address ‘How we respond to the Challenges and Opportunities of an Ageing Population’, it is important to understand what Palliative Care is and what it seeks to do.

Section 1: What is Palliative Care

Introduction:

Palliative care is, an approach to care that is life-affirming and life-enabling.

“You matter because you’re you, and you matter to the end of your life. We will do all we can not only to help you to die peacefully, but also to live until you die.”
(Dame Cicely Saunders)

This quote from Dame Cicely Saunders, one of the founders of the modern hospice movement, captures the person-centred and life-enabling approach that underpins palliative care. The ultimate aim of palliative care is to enable every person with an illness from which he/she will not be cured, to live as well as possible right up until he/she dies. In its modern sense, this is a relatively new concept, originating in the late 1960s / early 1970s.

The World Health Organisation defines Palliative Care as follows:

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.¹

There has been intense development of palliative care in Ireland over the past 20 years. In 1995 Ireland became the second country in Europe to recognize palliative medicine as a distinct medical specialty. The Irish Association for Palliative Care (IAPC) was established in 1993, bringing together in a membership body the multidisciplinary professionals involved in the delivery of palliative care, and seeking to build capacity in palliative care through education and research, and with a mission to promote patient-centred, equitable and accessible palliative care for all who need it.

(www.palliativecare.ie)

¹ <http://www.who.int/cancer/palliative/definition/en/>

The palliative care approach was initially applied to people with cancer, but the last two decades have seen an increasing recognition of the palliative care needs of everyone with a life-limiting illness, irrespective of what that illness is. International literature has demonstrated that patients with many non-malignant diseases have the capacity to benefit from palliative care services², and have symptom profiles that are comparable to cancer patients^{3, 4}). Here in Ireland, the call for “palliative care for all” was made in the mid-2000’s (Irish Hospice Foundation and HSE, 2008⁵), and more recently a global petition seeking for palliative care to be recognised as a human right (The Prague Charter, 2013), was launched. This is an ongoing international campaign to raise the profile of access to Palliative Care worldwide.

What is the Aim of Palliative Care

Palliative care aims to enable people with life limiting illnesses to continue to live their lives for as long as possible in the most satisfying way he or she can, within the limits of their illness. It focuses on adding ‘life to a person’s years’ rather than ‘years to a person’s life’. Recent research has shown that early referral to palliative care not only led to significant improvements in patients’ quality of life and mood, they also survived longer as compared with patients receiving standard care.

When is Palliative Care needed?

The palliative care approach is applicable to all those experiencing the effects of a life limiting illness, all ages, and in some cases, from the time of first diagnosis. The international literature suggests that, “If a clinician answers ‘No’ to the following question: Would you be surprised if your patient died in the next 6-12 months?” then a palliative care approach should be considered. This could provide an opportunity for the treating clinician, the patient and if appropriate, the family, to discuss goals of care and any limitations to further intervention. It is also an opportunity to establish the will and preference of the patient in the event that their condition should deteriorate.

How is Palliative Care delivered?

Palliative Care is delivered in a variety of settings, by a variety of health care professionals.

A number of key documents influence the provision and description of palliative care *and include the following* :

- *Report of the National Advisory Committee on Palliative Care (NACPC) (2001)*⁶
- *Palliative Care for Children with Life-Limiting Conditions – a National Policy* (Department of Health and Children, 2010).⁷
- HSE's Palliative Care Services - Five Year Medium Term Development Framework (2009 - 2013).⁸

² Edmonds P, Hart S, Wei Gao, Vivat B, Burman R, Silber E, Higginson IJ. (2010) Palliative care for people severely affected by MS: evaluation of a novel palliative care service. *Multiple Sclerosis* 16(5): 627-36.

³ Murtagh FE, Addington-Hall JM, Edmonds PM, Donoghue P, Carey I, Jenkins K, Higginson IJ. (2007) Symptoms in advanced renal disease: a cross-sectional survey of symptom prevalence in stage 5 Chronic Kidney Disease managed without dialysis. *Journal of Palliative Medicine* 10(6): 1266-76.

⁴ Higginson IJ, Hart S, Silber E, Burman R, Edmonds P (2006) Symptom prevalence and severity in people severely affected by Multiple Sclerosis. *Journal of Palliative Care* 22(3): 158-65.

⁵ Irish Hospice Foundation and Health Service Executive. Palliative Care For All, Integrating Palliative Care into Disease Management Frameworks, Joint HSE and IHF Report of the Extending Access Study, 2008

⁶ Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

⁷ Department of Health and Children. Palliative Care for Children with Life-Limiting Conditions in Ireland- A National Policy. Dublin: Stationary Office , 2010

The *Report of the National Advisory Committee on Palliative Care (NACPC)* (2001),⁹ which was adopted as government policy, recognised that patients with advanced disease have varying levels of need, and therefore require different levels of palliative care expertise. The Report describes three levels of palliative care service provision:

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: SPC services are those services whose core activity is limited to the provision of palliative care.”

The Report recommended that in each region (which at that time constituted a health board area) “all three levels of service provision should be available and all patients should be able to engage easily with the level of expertise most appropriate to their need.

It is however important to recognize 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.

Palliative Care can be provided by GP’s (working with the palliative care team); public health nurses and trained nurses and staff in residential and nursing homes and in general hospitals can provide a general level of palliative care.

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.

⁸ Health Service Executive. *Palliative Care – A Five Year/ Medium Term Development Framework (2009-2013)*. Dublin: HSE, 2009

⁹ Department of Health and Children. *Report of the National Advisory Committee on Palliative Care*. 2001

A team approach is at the very core of the delivery of palliative care. Within specialist palliative care, the combination of medical, nursing, social work, pastoral care / chaplaincy, psychology, physiotherapy, occupational therapy, complementary therapies, dietetics and others work together to meet the multiple and complex needs of patients with advanced disease. In addition, specialist palliative care services aim to work alongside other specialties and primary care teams in a cohesive manner, to ensure that together we are more than the sum of our individual parts.

Where should Palliative Care be delivered?

Palliative care is an approach to caring for people with life limiting illnesses, it is not about a geographical place. In Specialist Palliative Care (SPC) we aim to provide a service without walls, going to wherever the patient is, literally, as Dame Barbara Monroe (former CEO of St Christopher's Hospice) suggests, to deliver "palliative care in the bed you're in", whether that bed is in an acute hospital, community hospital, nursing home, hospice, or indeed your own bed in your own home.

Specialist Palliative Care (SPC) works best as an integrated programme – this means combining inpatient (hospice) beds with hospital-based inpatient and outpatient services, community services, bereavement care, and education and research services, with seamless pathways between one care setting and another, so that the patient and their family can access the element of care that is most appropriate at any given point in time.

An example would be a SPC programme providing in-reach to community hospitals and nursing homes, so as to avoid situations that necessitate sending elderly patients to the Emergency Department inappropriately and, if and when these patients are admitted to hospital, that their discharge back to a more appropriate setting is expedited. Similarly, SPC services work alongside Paediatric and primary care teams in enabling children with life-limiting illnesses to be cared for in their own homes. A core value of palliative care is 'the prevention and relief of suffering'. Support provided to family caregivers by the inter-disciplinary team throughout the patient's journey, and bereavement support after the patient's death, helps to prevent potential physical and mental ill health resulting from having lost a loved one. (It is important that after-death bereavement support for families is factored in when implementing a "money follows the patient" model of healthcare provision).

Who should deliver Palliative Care?

Palliative care is everybody's responsibility.

For complex patients, specialist palliative care services will be directly involved in delivering care to a patient at any point, and sometimes throughout, the patient's illness journey, working alongside generalist services and all other specialties. However, there are other patients whose needs are such that they don't require the SPC team to provide care directly to them; rather the need is for the SPC team to provide on-going education and support to the primary care team or other specialist team looking after them.

Who can benefit from Palliative Care?

Anyone of any age with a life-limiting illness can benefit from palliative care. Ideally palliative care should begin at the time of diagnosis and continue across the trajectory of the life limiting illness or condition.

Traditionally palliative care was connected with the treatment of cancer patients. Nowadays increasingly, people with other kinds of advanced life limiting illnesses such as neurological diseases, heart failure, renal conditions, chronic obstructive pulmonary disease ect., are being seen by palliative care teams. Palliative care can be given at the same time as curative treatments such as chemotherapy and radiation. The palliative medicine physician and team often provide patient care in an integrated and supportive way with other specialist doctors in areas such as oncology, cardiology, neurology, nephrology, in order to manage the symptoms and side-effects of curative treatment and therapies provided in these areas of care.

Where is Palliative Care Available?

Palliative care is provided in hospitals (delivered by the Specialist Palliative Care team and often in conjunction with other therapies and treatments) through in-patient and out-patient services; in the community, in hospices (often called Specialist In-patient Units) which also provide Day Care (outpatient) and in the patient's own home (delivered by home care teams attached to Specialist In-patient units). Palliative Care can also be delivered in residential care settings such as nursing homes. The aims of palliative care are the same regardless of where the patient receives it.

How can Palliative Care be Accessed?

A person's own GP or hospital doctor normally makes a referral. Referral to palliative care can be organized as soon as a diagnosis is made. Palliative Care is funded by the health service in partnership with the voluntary sector. Services are free to patients and family. Further details on accessing Palliative Care Services is available through the HSE National Clinical Programme for Palliative Care.

Is Palliative Care the same as End of Life Care?

While palliative care is often equated with end of life care, and end of life care is integral to palliative care there are differences:

- A person can access palliative care services over an extended period of time and can lead an independent life during that period
- End of life care is the period where the person's condition has deteriorated to the point where death is imminent or life expectancy is limited to a short period of weeks or days
- Palliative care can be given simultaneously with curative treatments, often managing the symptoms caused by the treatments
- End of life care usually precludes any curative treatments
- The palliative care programme (HSE, 2012) however, suggests that end of life care should not be used as a descriptor of palliative care as it implies time defined care, palliative care as presented previously may be provided to anyone with a life threatening illness over a prolonged period of time.

Section 2: 'How we respond to the Challenges and Opportunities of an Ageing Population':

Future need / Changing demographics:

There are challenging times ahead, both for palliative care services and for the healthcare system as a whole. Projected changes in demography over the next 30 years present a significant challenge. According to Ireland's Central Statistics Office, the number of people aged over 65 is projected to double from 624,183 in 2016 to over 1.4 million in 2046. The very old population (those aged 85 and over) is projected to quadruple from 69,873 in 2016 to 266,900 in 2046¹⁰. This is predicted to coincide with an increase in disease prevalence between 2007 and 2021 for diseases including cancer as well as chronic conditions such as cardiovascular and respiratory diseases¹¹. Such data has great implications on palliative care service provision as estimates show that each year, 1.6 million cancer patients in Europe experience pain related to their disease, one third of them will require complex treatment and a significant number also experience distressing symptoms¹². With increasing age, demand for long-term care and support will grow. Approximately 10-11 percent of people aged 65 years and over in Ireland require some form of home care.¹³

It is very difficult to access home care and support. Provision of these services is discretionary and there is a lack of transparency in the allocation of hours. Being able to access this vital support is dependent on the resources available at a given time and in a particular area.¹⁴ However we are at a point where we have an opportunity to plan for the future to ensure that older people can age in their communities, according to their wishes.

Palliative Care and Older Person Care

The demographic changes related to the ageing population, longer life expectancies, changing illness trajectories, and advances in medical, pharmacological and surgical interventions have challenged the historical view of palliative care. While the philosophy that most commonly underpins older person care is person centred care, its core values and beliefs are aligned with those of palliative care and providing a palliative care approach.

The term palliative care has traditionally been associated with malignant disease and terminal care. It is worth exploring how it now might be understood in older person care. It has been suggested that the period during which older people live in residential homes can be considered the end of life period, so there is a need for a palliative approach to care in this care setting (Frogatt and Payne, 2006; Parker et al, 2005). In keeping with the principles and philosophy of palliative care and the principles and philosophy of older person care, there is evidence to support the argument that the provision of palliative care in nursing homes improves the quality of care received by residents (Baer and Hanson, 2000).

¹⁰http://www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016_2046.pdf

¹¹ Layte R, Barry M, Bennett K, et al. Projecting the impact of demographic change on the demand for and delivery of healthcare in Ireland. Report for the Economic and Social Research Institute (ESRI). October 2009

¹² Higginson IJ and Costantini M. Dying with cancer, living well with advanced cancer. *Eur J Cancer* 2008;44:1414–24

¹³ <https://www.hse.ie/eng/services/publications/planningforhealth.pdf>

¹⁴https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_Ir_for_web_2.pdf

The following two definitions of palliative care are related to older people regardless of setting. Palliative care is described as: *'active, compassionate approach that treats comforts and supports older individuals who are living with, or dying from, progressive or chronic life threatening conditions. Such care is sensitive to personal, cultural, and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement* (Ross et al, 2000:9).

In the second definition, Pautex et al (2010:790) describe the merging of the care of the older person and palliative care as Geriatric Palliative Medicine (GPM).

'[GPM] is the medical care and management of older persons with health related problems and progressive, advanced disease for which the prognosis is limited and the focus of care is quality of life. GPM combines principles of geriatric medicine and palliative care; focuses on comprehensive geriatric assessment; relief of pain and other symptoms; and management of physical and psychological problems; integrating social, spiritual and environmental aspects. It recognises the unique features of symptom and disease presentation, the interaction between diseases, the need for safe drug prescribing, and the importance of a tailored multidisciplinary approach for older patients receiving palliative care and their family; it emphasises the importance of autonomy, the involvement in decision making and the existence of ethical dilemmas. It calls for good communication skills when discussing and giving information to older people and their families; addresses the needs of older patients and their families across all settings; pays special attention to transitions within and between settings of care and offers a support system to help families cope during the patients terminal phase of care'.

Two Irish studies exploring end of life care and palliative care for older people in long stay settings by Payne et al, (2009) and Casey et al (2011) indicate a lack of understanding of the principles of palliative care, a failure to recognise approaching death until it is too late to implement care and uncertainty about how to deal with older people as they are dying. They also suggest that the shift to providing appropriate palliative care services for older people at End of Life has not yet occurred.

Across developed countries the number of patients with palliative care needs is expected to rise in tandem with the ageing population (Gomes et al. 2011). Although less than 15% of older people die of a terminal disease such as cancer, many more die following a slow period of deterioration (Goodman et al., 2003). The challenge lies in the fact that the slow trajectory towards death for these residents is often punctuated by acute and apparently reversible illnesses such as pneumonia, sepsis and dehydration. These episodes of acute illness may occur repeatedly before death (Hanson et al., 2002). Residents will need support and care through these illnesses. The concept of palliative care is above all based on the idea of reinforcing factors that improve quality of life, and decreasing the impact of factors that may reduce quality of life, which seems adequate as a concept for the long term care of older people (Hallberg, 2006).

The World Health Organisation defined palliative care as an approach that is applicable early on in the illness trajectory. The world wide palliative care alliance (2014) affirmed and adapted the definition emphasising that Palliative Care be adopted by all not just professionals specialising in palliative care.

The Work of the IAPC in this area

The IAPC, through its Special Interest Group for Older Person Care seeks to embrace the knowledge and experience of those caring for older people in the acute setting, long term residential care and in the community who seek to embrace that palliative care approach and find ways in which a shared understanding may be developed which impacts on the quality of care that older people receive as they live and die in their older years. It also acknowledges that although a palliative care approach builds on the knowledge and expertise of palliative care it is also apparent that it needs to be adapted to the particular needs of older people with chronic life limiting conditions.

Recommendations:

1. A comprehensive, universal health and social care system, which provides the right care, in the right place, at the right time, is essential for the health and well-being of all, but particularly older people as the main users of our healthcare system
2. Everyone with a life threatening illness should have access to the palliative care approach, which may be delivered by the primary care or other specialist team with ongoing education and support from the Specialist Palliative Care team, or directly by the Specialist Palliative Care team in the case of more complex patients.
3. The benefit to patients of early consideration of a Palliative Care Approach in care, needs to be recognised. Patients not only benefit from a better quality of life, but may also survive longer and with a better quality of life.
4. A Palliative Care approach should be integrated with other healthcare services in each region, so that the service can be brought to where the patient is, and patients and families can access the element of care most appropriate at any given time.
5. As the number of people aged over 65 is projected to double from 624,183 in 2016 to over 1.4 million in 2046, we also must consider home as a place of care and Specialist Palliative Care must be responsive to that need, however older people's preference of staying at home may not be possible without supports in place.
It is very difficult to access home care and support. Provision of these services is discretionary and there is a lack of transparency in the allocation of hours. Being able to access this vital support is dependent on the resources available at a given time and in a particular area.¹⁵ In planning for the ageing population, the introduction of a statutory entitlement to home care, to ensure the services required are funded to meet need, would be most welcome. A statutory entitlement to home care is essential if the service is to attract ring-fenced funding and to meet the needs and preferences of older people. Without certainty in the allocation of home care, an increasing number of people with low to moderate level of

¹⁵ https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf

dependency will have no choice but to go into long-term residential care, with a substantial cost to the State, estimated to be €1.234 billion in 2021.¹⁶

6. High quality health and social services for older people provide continuity of care, integrated between care settings should be a priority so that the ultimate goal to facilitate the older person to lead an independent life, with dignity is respected. Therefore the appropriate services must be available to each person when and where required. Enabling a move away from acute care services to primary and social care services through the provision of ring fenced funding for the development of comprehensive services in the community would be of significant benefit to achieve this.

7. Older people requiring high dependency care waiting to access beds under the Fair Deal Scheme could be prioritised with the aim of enabling them to access residential care in a timely manner and thereby facilitate their final medical care in a more appropriate setting and incorporating a Palliative Care approach which may be most relevant at this point.

In reviewing the current Fair Deal Scheme consideration could be given to extending the definition of Long Term Residential Care Services, and the range of services covered by the Scheme. Further, an evidence-based cost of care model could be used in assessing the real cost of residential nursing home care in Ireland.

This is not to be seen as an exhaustive list, nor does it fully describe all of the challenges for Palliative Care Service delivery. We are available to make further information available to the Assembly if requested.

¹⁶ <https://www.hse.ie/eng/services/publications/serviceplans/nsp16.pdf>
