

**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.

Appendix 1. References:

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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.