

Oral Presentation to the Joint Committee on Health and Children,

Public Hearings on End of Life Care

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Thanks to modern medicine, people are living longer with serious, chronic and complex illness. But our healthcare system is fragmented and difficult to navigate—just when the needs of chronically ill patients are growing at a rapid rate. Also, service users are ageing- and their needs are placing additional demands on healthcare provision.

The major challenges that face today's healthcare system are clear. The need for effective and inclusive solutions to these growing problems is urgent.

Palliative care can help in meeting these demands. It is concerned with preventing, treating and relieving pain and other debilitating effects of serious illness. It is not dependent on prognosis and can be delivered at the same time as disease modifying treatment. It has the ultimate goal of improving quality of life for patients with life-limiting conditions and their families.

People with serious illness want the types of services that palliative care provides- and they expect today's healthcare system to deliver those services. Forward-looking jurisdictions understand that palliative care is a 'triple win'- as beneficial to the patient as it is for the healthcare team as it is for the healthcare system. They recognize that the provision of palliative care is the responsibility of the whole healthcare system and not just specialist palliative care services. Both generalist and specialist palliative care services have a part to play in the effective treatment and care of people with life-limiting conditions. It is vitally important that responsibility for palliative care service provision is 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. There is no 'either/or' option.

When considering the question of what needs to happen to ensure that people die well in Ireland, it is important to remember that uncertainty is an integral part of dying. Contrary to popular belief, the transition towards dying is often not a clear-cut or linear process, and protocols or pathways that utilize so called 'prognostic triggers' are often imprecise, lack clinical nuance and fail to reflect the complexity of decision-making in this area. Indeed, the very term 'end of life' is one that is ambiguous as it may be variously interpreted to cover the last year of life of a person with a chronic and progressive disease, the last months, the last weeks or indeed the last days and hours of life.

End of life care is not the same as palliative care. 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 is goal-oriented. The discipline of palliative care helps patients to 'live until they die' whenever that occurs. Both comfort promoting and appropriate disease modifying interventions can co-exist in the integrated model of palliative care provision. This encourages a needs based approach to palliative care provision rather than depending on a clinician's uncertain ability to make a diagnosis of 'dying'.

It is important to recognize the significant work that has been done to date in Ireland in developing palliative care and improving the care provided to people at the end of life and to use this as a firm foundation for moving forward. We have a long and proud tradition in this area that extends back to the nineteenth century and there has been international acknowledgement of our achievements to date. The Economist Intelligence Unit has 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 measured the environment for End-of-Life Care services across 40 countries in 2010. Ireland was ranked 4th in the overall score.

This acknowledgement provides an indication of what can be achieved by visionary and universally accepted palliative care strategy, leadership on a national and local level and community engagement. We are indebted to all of those politicians, civil servants, managers, health and social care professionals, service users, advocacy organisations and members of the public who have made such efforts to promote, develop and provide palliative care services.

However, significant deficiencies in palliative care provision remain and the following issues have been noted in clinical experience, reports and research studies:

1. The problem of inadequate recognition of palliative care needs persists.
2. Access to community supports, generalist and specialist palliative care services and experience of care can vary according to geographic location and diagnosis.
3. Care can be fragmented and inefficient with patients experiencing significant difficulties in care transitions.
4. There can be variability the availability of community supports, and out-of-hours service provision.
5. It can be difficult to access medium to long-term care for those with slow or fluctuating progression of disease and prognosis of longer than 3 months, and this problem particularly affects younger service users.
6. Carers report suboptimal financial assistance, difficulties accessing equipment, care packages and respite care.
7. There can be a lack of knowledge and skills in palliative care provision (experienced by both formal and informal carers).

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. The World Health Report 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 in turn:

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 possible 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.

B. Financing:

Health financing is a key determinant of health system performance in terms of equity, efficiency, and quality. 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 regardless of setting 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.

- 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.
- 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:

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 the healthcare system and will help people to die well in Ireland.