

**ORAL PRESENTATION**  
**TO THE**  
**JOINT COMMITTEE ON HEALTH AND CHILDREN**  
**PUBLIC HEARINGS ON END OF LIFE CARE**

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My colleague Dr. Tony O'Brien introducing the Report of the National Advisory Committee on Palliative Care in 2001, wrote 'As a society, perhaps the most sensitive measurement of our maturity is the manner in which we care for those who are facing the ultimate challenge - the loss of life'. It is timely, 12 years on from the adoption of this Report as Government Policy, that the Joint Committee on Health and Children would again revisit this subject. I would like to take this opportunity to thank you Deputy Buttimer and the Joint Committee for considering this issue and to lend my support to your deliberations of this vital topic.

You have asked me 'specifically to comment on the role of Specialist Palliative Care, establishing what needs to happen to ensure that people die well in Ireland'. In considering this question I would like to borrow some words from the Tibetan Book of the Living and Dying:

'Often we forget that the dying are losing their whole world: their house, their job, their relationships, their body and their mind – they are losing everything. All the losses we could experience in life are joined in one overwhelming loss when we die'.

I use these words to contextualize the work of Specialist Palliative Care because death is not an event, a moment in time, but a deeply personal experience for every person and their family and friends. For many the losses

that may be experienced in dying begin at the time when they are diagnosed with a life –threatening illness.

This, the most intimate of life experiences is both physical, emotional, spiritual and is lived by the patient and all who feel close to them. Irrespective of how close to death I am asked to see a patient, whether that be hours, days, weeks or months; my experience is that people want to be able to live well, without suffering until they start to die.

It is worth reflecting on the World Health Organization's definition of Palliative Care where it states "Palliative Care is required for many patients early in the course of their disease, sometimes from the time of diagnosis"

**RECOMMENDATION: In considering how people can be enabled to 'die well' the Joint Committee would not confine their deliberations to care in the last days and weeks of life.**

I am conscious in addressing the committee that there may be members of the public, who have not experienced specialist palliative care, who may not understand what in fact we do. Cicely Saunders, whom you will have heard much of this morning, wrote: 'I once asked a man who knew he was dying what he needed above all in those who were caring for him. He said, 'For someone to look as if they are trying to understand me'.

Palliative Medicine, the science that informs specialist palliative care attempts to do this. In accompanying patients and their families to a place where few clinicians are comfortable, we have developed a body of medical science and expertise that enable us to:

- Undertake detailed, specialised and holistic assessments of the needs of the patient across physical, psychological, social and spiritual domains to anticipate, in some cases prevent and in others relieve suffering.
- Provide expert management of complex symptoms
- Provide advice in situations of ethical complexity
- Deliver direct clinical care in partnership with colleagues in primary, secondary and social care

- May provide care in any setting, including: hospital; community (including nursing homes); hospice inpatient units; hospital inpatient units; day therapy; outpatient clinics
- May undertake case management/case leadership (if this is not already and appropriately undertaken by another professional)
- Attend the range of multidisciplinary team meetings in secondary care (for example, lung and other specific cancer type meetings)
- Attend multidisciplinary community meetings to contribute and guide in the care of patients with complex life threatening illness
- Support colleagues, patients and carers with advice and information on palliative care issues
- Facilitate education and training across a variety of topics and according to local need, such as symptom control, advance care planning, support for the use of tools such as integrated care pathways for the last days of life, communication skills training, etc.
- Support/undertake research

**RECOMMENDATION: The Government would maintain an ongoing awareness campaign informing the public of the health benefits of ‘specialist palliative care’ to people of all ages with life limiting illness.**

This expertise delivered by a multi-disciplinary team should be available to all who require it, 24/7, on the basis of need alone. Yet my experience is that, some patients are unable to access this expertise because of constrained resources that results in access being limited on the basis of age, diagnosis, post-code or due to lack of services out of hours and weekends. Patients are disadvantaged as a consequence this is inexcusable.

**RECOMMENDATION: The Government would ensure that resources proscribed for palliative care are applied for the purposes intended and that they would be distributed in a manner that eliminates the inequities that currently exist.**

## **The Integration of Palliative Care into Standard Care**

Until recently, data from clinical trials demonstrating the benefits of palliative care in patients with life-threatening illness has not been available. As a consequence some clinicians, patients and their families were understandably reluctant to suggest palliative care as part of the care plan. There is now increasing evidence from randomized control trials (the highest level of clinical evidence) by potentially increasing the Quality of Life, improved survival and reduced cost of care in patients with metastatic cancer.

Last year the American Society of Clinical Oncology provided provisional clinical opinion i.e. timely clinical direction of potentially practice changing data from major studies indicating ‘substantial evidence demonstrates that palliative care—when combined with standard cancer care or as the main focus of care—leads to better patient and caregiver outcomes. These include improvement in symptoms, QOL, and patient satisfaction, with reduced caregiver burden’. They further qualified their comments saying ‘While evidence clarifying optimal delivery of palliative care to improve patient outcomes is evolving, no trials to date have demonstrated harm to patients and caregivers, or excessive costs, from early involvement of palliative care’.

This year the American Society of Clinical Oncology further qualified their guidance suggesting ‘There is a need to change the paradigm for advanced cancer care to include an earlier and more thorough assessment of patients’ options, goals, and preferences, and to tailor the care that we deliver to these individual needs throughout the continuum of care.’ They advocated the rationale, evidence and clinical implications of benefit to patients from an earlier discussion of palliative care as an approach for some patients with advanced cancer.

While there is no data from randomized control trials in non-cancer illnesses to support a similar approach as yet, there is an increasing amount of

evidence to support a similar approach for some patients with advanced heart failure, chronic obstructive lung disease and advanced renal failure.

We also know that patients are more likely to receive end of life care that is consistent with their preferences when they have had the opportunity to discuss their wishes for end of life care with a physician.

**RECOMMENDATION: The Government would ensure through the National Clinical Programmes that Palliative Care is incorporated into Standard Care for Advanced Cancer and other illnesses as appropriate.**

**Capacity and Capability:**

There are clear benefits to the patient; family and the healthcare system with the earlier introduction of palliative care into the standard care approach to a number of life-threatening illnesses.

This will invariably result in an increased demand for specialist palliative care. The Joint Committee has heard that there are existing issues with capacity throughout the country. This increased need will not be managed by expanding existing capacity alone.

Palliative Care needs to be incorporated into mainstream medical and surgical care of patients of all ages. The core skills of caring for people at the end of life should be within the capability of all clinical staff. However currently palliative care is not part of all medical, nursing and allied health professional curricula at under-graduate level. Apart from physician training, it does not form part of the basic specialist training of other junior doctors.

Given that 80% of all people who die in Ireland will spend some part of their last year of life in acute hospital, there should be a focused emphasis on increasing capacity of hospital based palliative care services. These services are well placed to integrate with standard medical approaches to care within the hospital and extending into all community settings.

**RECOMMENDATION:** The Government would direct that education in palliative care be part of the under-graduate core curriculum of all health care professionals. It should also form part of the curriculum for basic specialist training of all medical, surgical and paediatric trainees such that they obtain the basic knowledge about palliative care and are able to provide it to patients regardless of where in the healthcare system they work.

**RECOMMENDATION:** The Government would require all Hospital Groups to provide a comprehensive specialist palliative care service that is integrated with all services within the hospital and in the community appropriate to the needs of patients with life-threatening illness.

#### **REFERENCES:**

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**Ends.**