

Opening Statement by Dr Brian Creedon
Chairman of the Irish Palliative Medicine Consultants Association (IPMCA)
to the Joint Committee on Health and Children
Public Hearings on End of Life Care
24th October, 2013.

I'd like to thank you Deputy Buttimer and the Committee for the opportunity to meet with you today to discuss "What needs to happen to ensure people die well in Ireland?"

I would respectfully suggest that we should be asking a much more important question, that is "what needs to happen to ensure people live well until they die?"

The Irish Palliative Medicine Consultants Association represents the 35 consultant physicians in palliative medicine in Ireland. These consultants are members and the clinical leaders of the nation's specialist palliative care services delivering care to patients and their families across all settings, including the home, acute hospitals and other settings throughout Ireland.

It is important to set out that Ireland has a long and proud tradition in pioneering the development and provision of palliative care. Ireland was only the second country globally to recognise Palliative Medicine as a medical speciality. In 2001 Ireland was the first country to produce a national plan for palliative care service development & integration, which was subsequently adopted as government policy. There are many aspects of this plan which have not been implemented. The National Clinical Programme for Palliative Care was established in 2010 and has developed many work streams to benefit the quality of care provided to patients in all care settings throughout the country. The principals of palliative care are being taught across all disciplines, at both undergraduate and post graduate level. Frameworks are being currently developed by the Palliative Care Clinical Programme to ensure the essential elements of the palliative care approach are embedded in healthcare professional training.

Our use of **language** and **terminology** in this area is extremely important. End of life care refers to that care offered to an individual when death is imminent, when life expectancy is days or even hours. End of life care is only a PART of what palliative care is and by no means defines palliative care. It cannot be over emphasised that Palliative care aims to be life enabling and life enriching. It strives to help patients to "live until they die".

A patient never forgets how he is told of a serious diagnosis; the family never forget how the patient dies; the most important bereavement care is provided before a patient dies.

Palliative care has been a leader in the development of services that are truly integrated and stretch across boundaries of care settings to reach the patient, in the right place, at the right time. This integrated approach enables our patients to transfer between care settings, depending on their individual clinical needs and personal preference, for example supporting a patient who wishes to be cared for at home and/or facilitating early discharge from an acute hospital to a hospice bed or community setting. When adequately resourced, we are a service without barriers.

Palliative care works closely alongside all specialities, looking after patients of all ages and in all settings. Traditionally associated with cancer care, the principles of palliative care have been seen to benefit patients with diverse pathologies and now our expert skills are supporting other physicians in caring for patients with heart, kidney and lung disease, dementia and other neurological conditions such as motor neuron disease. There is a growing level of service provision to children with life limiting and life threatening conditions.

Healthcare systems in Canada, Argentina, and Catalonia have demonstrated that palliative care services are cost effective (even reducing overall cost of care) yet greatly enhance the quality of life for patients. This is largely achieved by avoiding inappropriate hospital admissions which are often traumatic for the patient and family, and costly for the health service as a whole. At the same time, early evidence in lung cancer patients is showing that patients receiving palliative care are living longer, despite (and perhaps because of) receiving less aggressive active treatments near the end of life. It is perhaps worth contemplating for a moment the impact on a patient, perhaps in their last weeks of life, and their family of being admitted through a busy emergency department in the present day. Is this always needed? Surely there must be a way to prevent this happening so frequently?

Our population is ageing and by 2031, the population of those aged over 65 years of age will have doubled. This will increase the numbers of death per year, and also significantly increase the number of people living with life limiting illness, all of which will further increase the demand for palliative care.

Palliative care services are readily placed to empower the patient and their family by maximising the quality of life and offering choice of care setting.

“What needs to happen to ensure people live well until they die?”

1. The work of the Palliative Care Clinical Programme is focused on improving quality, equity of access based on the need of the individual and efficient use of resources. **This programme must continue to be resourced.**
2. The emergent new governance structures of healthcare in Ireland must recognise the enhanced value of palliative care as an integrated service and the need to manage and finance it on this basis. **A dedicated budget for palliative care nationally and a single entity responsible for palliative care services country-wide would be significant steps to achieve this.**
3. It must be ensured that services are resourced adequately (as per the National Advisory Committee on Palliative Care, 2001) to ensure that geographical inequities do not continue and effective care is available to those who need it. As a core essential element of a comprehensive service, the ongoing gross deficits of specialist palliative care inpatient hospice beds and required staffing in the Midlands, the North East and the South East must be addressed urgently. **National Service Plans to include these and other such deficits to ensure equity of access**