



Opening Statement to Joint Oireachtas Committee on Health and Children in relation to Specialist Palliative Care

Thursday 24th October 2013

Good afternoon Chairman and members of the Committee.

Thank you for inviting me here today, as Chairperson of the Irish Association for Palliative Care. Whilst I am a specialist working in Palliative Care, I am here on behalf of the Board of the IAPC, a representative organisation of all healthcare professionals involved in the delivery of palliative care across the country, and a collective and expert voice driving patient-centred, equitable and accessible palliative care for all who need it.

What is palliative care?

Let me start by saying that palliative care is, first and foremost, about life. It is an approach to care that is life-affirming and life-enabling. I once looked after a gentleman who had developed a pressure sore on his right hip because he was in such dreadful pain from a pelvic tumour that the only position he could tolerate was sitting or lying on his right side. He said it felt like someone was “sticking a hot poker into him”. On admission to the hospice, he said it felt like his life was over and he just wanted to die. After two weeks of intensive pain management, of his physical, psychological, social and spiritual pain, with contributions from all the members of the inter-disciplinary team, he was discharged home a changed man, with follow-up from the community SPC team. On discharge, he said that he now felt he could live again and “enjoy the simple things in life”. He subsequently attended his daughter’s wedding, and died many months later in his own home.

We’re delighted that you are asking the question “what needs to happen to ensure that people die well in Ireland?” indeed to ensure that people live as well as possible right up until they die. “Access to palliative care” is the answer and we propose to elaborate this under the headings of “when, where, how and by whom”.

When is palliative care needed?

Although the gentleman I've just described had cancer, the palliative care approach is applicable across all illnesses that cannot be cured, all ages, and in some cases, from the time of first diagnosis. Most deaths in Ireland (other than RTAs, accidents, poisonings and suicide) can be anticipated by the treating clinicians. 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 be the entry point to an informed discussion between the treating clinician, the patient and if appropriate, the family.

Where should palliative care be delivered?

Palliative Care is an approach to caring for people with illnesses that will not be cured - it is not about a geographical place. In SPC we aim to provide a service without walls, going to wherever the patient is, literally, as Dame Barbara Monroe (CEO of St Christopher's Hospice) puts it, 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.

Unfortunately significant inequalities currently exist in SPC service provision across the country, and the range of services that people with advanced disease can access is hugely variable according to their "postcode".

How should palliative care delivered?

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?

The short answer is 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.

The future / Increasing need:

There is no doubt that very significant progress has been made in recent years with regard to palliative care in Ireland. Even as recently as 30 years ago, the gentleman with the pelvic tumour that I mentioned earlier would simply not have been able to access the service that, in his words, “gave him his life back”. However, inequalities in service provision remain, and over the next 10 years we are going to see an exponential increase in the number of people with palliative care needs, because of the increasing number of elderly people living longer with ill health and multiple illnesses, and the increasing recognition of the number of children with palliative care needs. Therefore, we need to work together, using an integrated approach, so that we can provide both quality *and* quantity (and equity) to future – proof palliative care, so that everybody with a life-limiting illness can live the lives they want to lead right up until they die. **That concludes my opening statement. I will be delighted to answer any questions you may have.**

