



## Written submission to the Joint Oireachtas Committee on Health and Children, on behalf of the Irish Association for Palliative Care

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### Introduction:

*“You matter because you’re you, and you matter to the end of your life. We will do all we can not only to help you to die peacefully, but also to live until you die.”*

*(Dame Cicely Saunders)*

This quote from Dame Cicely Saunders, one of the founders of the modern hospice movement, captures the person-centred and life-enabling approach that underpins palliative care. The ultimate aim of palliative care is to enable every person with an illness from which he/she will not be cured, to live as well as possible right up until he/she dies. In its modern sense, this is a relatively new concept, originating in the late 1960s / early 1970s.

There has been intense development of palliative care in Ireland over the past 20 years. In 1995 Ireland became the second country in Europe to recognize palliative medicine as a distinct medical specialty. The Irish Association for Palliative Care (IAPC) was established in 1993, bringing together in a membership body the multidisciplinary professionals involved in the delivery of palliative care, and seeking to build capacity in palliative care through education and research, and with a mission to promote patient-centred, equitable and accessible palliative care for all who need it. ([www.palliativecare.ie](http://www.palliativecare.ie))

The palliative care approach was initially applied to people with cancer, but the last two decades have seen an increasing recognition of the palliative care needs of everyone with a life-limiting illness, irrespective of what that illness is. International literature has demonstrated that patients with many non-

malignant diseases have the capacity to benefit from palliative care services<sup>1</sup>, and have symptom profiles that are comparable to cancer patients<sup>2, 3</sup>). Here in Ireland, the call for “palliative care for all” was made in the mid-2000’s (Irish Hospice Foundation and HSE, 2008<sup>4</sup>), and more recently a global petition seeking for palliative care to be recognised as a human right (The Prague Charter, 2013), was launched. This is an ongoing international campaign to raise the profile of access to Palliative Care.

### How is palliative care delivered?

Palliative Care is delivered in a variety of ways, all with the aim of bringing the service to the patient rather than vice versa, or, as Dame Barbara Monroe (CEO of St Christopher’s Hospice) puts it, “palliative care in the bed you’re in”. Therefore, Specialist Palliative Care (SPC) services will typically have a presence in acute hospitals, in community hospitals, in nursing homes, and in patient’s own homes.

National policy for the provision of palliative care:

- *Report of the National Advisory Committee on Palliative Care (NACPC) (2001)*<sup>5</sup>
- *Palliative Care for Children with Life-Limiting Conditions – a National Policy* (Department of Health and Children, 2010).<sup>6</sup>
- *HSE’s Palliative Care Services - Five Year Medium Term Development Framework (2009 - 2013)*.<sup>7</sup>

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<sup>1</sup> Edmonds P, Hart S, Wei Gao, Vivat B, Burman R, Silber E, Higginson IJ. (2010) Palliative care for people severely affected by MS: evaluation of a novel palliative care service. *Multiple Sclerosis* 16(5): 627-36.

<sup>2</sup> Murtagh FE, Addington-Hall JM, Edmonds PM, Donoghue P, Carey I, Jenkins K, Higginson IJ. (2007) Symptoms in advanced renal disease: a cross-sectional survey of symptom prevalence in stage 5 Chronic Kidney Disease managed without dialysis. *Journal of Palliative Medicine* 10(6): 1266-76.

<sup>3</sup> Higginson IJ, Hart S, Silber E, Burman R, Edmonds P (2006) Symptom prevalence and severity in people severely affected by Multiple Sclerosis. *Journal of Palliative Care* 22(3): 158-65.

<sup>4</sup> Irish Hospice Foundation and Health Service Executive. Palliative Care For All, Integrating Palliative Care into Disease Management Frameworks, Joint HSE and IHF Report of the Extending Access Study, 2008

<sup>5</sup> Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

<sup>6</sup> Department of Health and Children. Palliative Care for Children with Life-Limiting Conditions in Ireland- A National Policy. Dublin: Stationary Office , 2010

The *Report of the National Advisory Committee on Palliative Care (NACPC)* (2001),<sup>8</sup> which was adopted as government policy, recognised that patients with advanced disease have varying levels of need, and therefore require different levels of palliative care expertise. The Report describes three levels of palliative care service provision:

“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: SPC services are those services whose core activity is limited to the provision of palliative care.”

The Report recommended that in each region (which at that time constituted a health board area) “all three levels of service provision should be available and all patients should be able to engage easily with the level of expertise most appropriate to their need.

A team approach is at the very core of the delivery of palliative care. Within specialist palliative care, the combination of medical, nursing, social work, pastoral care / chaplaincy, psychology, physiotherapy, occupational therapy, complementary therapies, dietetics and others work together to meet the multiple and complex needs of patients with advanced disease.

In addition, specialist palliative care services aim to work alongside other specialties and primary care teams in a cohesive manner, to ensure that together we are more than the sum of our individual parts.

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<sup>7</sup> Health Service Executive. *Palliative Care – A Five Year/ Medium Term Development Framework (2009-2013)*. Dublin: HSE, 2009

<sup>8</sup> Department of Health and Children. *Report of the National Advisory Committee on Palliative Care*. 2001

**Specialist Palliative Care in the Community:**

*Recommendations of the NACPC report (2001)<sup>9</sup>:*

- Specialist Palliative Care services should be available (seven days a week) to everyone living in the community, whether at home, in nursing homes or in community hospitals.
- Community Specialist Palliative Care teams should be interdisciplinary, containing a consultant(s), nursing staff, and at least a physiotherapist, occupational therapist and social worker, all of whom must be trained in specialist palliative care.

***Current provision of community specialist palliative care services:***

There are currently 35 community specialist palliative care services in Ireland.

There has been an annual increase in patients with non-malignant diseases accessing specialist palliative care. National figures for homecare show an increase for these patients from 17% in 2010 to 24% in 2012 (HSE National Minimum Dataset for Palliative Care).

***Evidence for the effectiveness of home palliative care:***

A Cochrane review, which brought together the results of 23 studies, found that symptom burden amongst patients who received home palliative care services was significantly less than those who did not. In addition, those in receipt of specialist palliative care services at home were more than twice as likely to die in their own homes <sup>10</sup>.

**Specialist Palliative Care in acute hospitals:**

*Recommendations of the NACPC report (2001)<sup>11</sup>:*

- All acute general hospitals should have a specialist palliative care service provided by an interdisciplinary team, to offer advice and support to other professional health care providers regarding the management of patients with advanced and progressive disease.

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<sup>9</sup> Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

<sup>10</sup> Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ (2013) Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database of Systematic Reviews*. 6:CD007760

<sup>11</sup> Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

- Hospital admission policies should be sensitive to the needs of patients with advanced disease.
- Joint outpatient clinics should be established in some acute hospitals so that the specialist palliative care team can become involved in the care of patients early in illness journey as appropriate.

***Current provision of acute hospital specialist palliative care services:***

There are currently 39 acute hospital specialist palliative care teams in Ireland, many of which are unidisciplinary.

***Evidence for the effectiveness of specialist palliative care in the acute hospital:***

A randomised controlled trial was conducted in the USA comparing the early introduction of a specialist palliative care team (alongside standard cancer care) in patients with newly diagnosed advanced lung cancer, with standard cancer care alone. The results showed that patients who received early palliative care had significantly better quality of life scores, less depression and anxiety, and survived an average of 2 months longer than patients in the group who received standard cancer care alone<sup>12</sup>.

**Specialist Palliative Care Units / Hospices:**

*Recommendations of the NACPC report 2001<sup>13</sup>:*

- There should be at least 1 specialist palliative care inpatient unit in each health board area.
- Specialist palliative care units should, where possible, be based close to the acute general hospital with the broadest range of specialist services, including radiotherapy and oncology in the area.

***Current provision of Specialist Palliative Care Units in Ireland:***

There are currently 9 specialist palliative care inpatient units for adults, and 1 children's hospice, in Ireland.

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<sup>12</sup> Temel JS. Greer JA. Muzikansky A. Gallagher ER. Admane S. Jackson VA. Dahlin CM. Blinderman CD. Jacobsen J. Pirl WF. Billings JA. Lynch TJ. (2010) Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*. 363(8):733-42.

<sup>13</sup> Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

Three areas of the country - the north east, the south east, and the midlands - have no specialist palliative care inpatient unit and no access to ring-fenced specialist palliative care beds.

### **Children's Palliative Care:**

A national palliative care needs assessment for children in 2005 estimated that there were 1,369 children living with life-limiting conditions (set to increase to 1,610 in 2021 based on population projections) but warned that this figure may be much higher, given the lack of a system in place to collect this information.

Recent key developments in children's palliative care in Ireland include the national policy - *Palliative Care for Children with Life-Limiting Conditions – a National Policy* (Department of Health and Children, 2010<sup>14</sup>). The policy aims to build a service that is responsive to the needs of children and families, and equitable across the country. Implementation of the policy is being overseen by the HSE National Development Committee for Children's Palliative Care. Under the policy, Ireland's first Consultant Paediatrician with a special interest in Palliative Medicine, was appointed (2011). As of September 2013, 8 Children's Outreach Nurses are in post, as per the recommendations of the National Policy. The Consultant Paediatrician post, and 5 of the 8 Outreach Nurses posts, are funded by the Irish Hospice Foundation (IHF). Ireland's first children's hospice, LauraLynn House at the Children's Sunshine Home in Dublin, which receives no State funding, officially opened in 2011.

The Consultant Paediatrician with a special interest in Palliative Medicine is based at Our Lady's Children's Hospital, Crumlin (OLCHC). Since her appointment in 2011, there has been a 67% increase in referrals to the specialist palliative care service at OLCHC <sup>15</sup>. In addition, a broader range of other paediatric specialist services are now referring children to the specialist palliative care service. This may reflect the benefit of having an on-site palliative medicine paediatrician, and her role in education /

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<sup>14</sup> Department of Health and Children. *Palliative Care for Children with Life-Limiting Conditions in Ireland- A National Policy*. Dublin: Stationary Office , 2010

<sup>15</sup> Clifford M, O'Donoghue L, Jennings V, Hurley I, Delaney L, O'Reilly M, Twomey M, Devins M. Review of referral patterns to a children's palliative care service. European Association for Palliative Care Congress abstracts.

empowerment may be responsible for bringing about a greater recognition of the palliative care needs of children with life-limiting illnesses.

**Bereavement:**

*Recommendations of the NACPC report 2001<sup>16</sup>:*

- Bereavement support should be available in all settings where specialist palliative care is offered, and should begin early in the disease process, long before the death of the patient.
- All specialist palliative care staff can provide a general level of bereavement support to individuals and families. For those who require extra support, appropriately trained staff such as social workers, psychologists or professionals' counsellors should be available. An appropriate member of staff should act as bereavement service co-ordinator.

**Education and Research:**

*Recommendations of the NACPC report 2001<sup>17</sup>:*

- The culture of continuing professional education and development should be promoted among health care professionals in all disciplines that are involved in the delivery of palliative care.
- Academic departments of palliative medicine should be established in each medical faculty to support and develop education and research in all disciplines.
- There should be a major public funding allocation to promote palliative care research in Ireland.

*Current role of SPC in Education and Research:*

The role of SPC services in education is four-fold: 1. On-going education and continuing professional education of specialist palliative care professionals. 2. Providing or facilitating formal education courses for healthcare professionals involved in delivering palliative care. 3. Education / support / advice to healthcare professionals in primary care and other specialist services, in delivering palliative care to individual patients. 4. Promoting public awareness of palliative care / involvement in "health promoting palliative care" initiatives.

In times of scarce resources, research assumes an even more important role, as it assesses the effectiveness of services and various components of care, which helps guide resource allocation. It is

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<sup>16</sup> Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

<sup>17</sup> Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

essential that interventions, that require both time and funding to implement and maintain, are impacting positively on patient outcomes.

**Future need / Changing demographics:**

There are challenging times ahead, both for palliative care services and for the healthcare system as a whole. Projected changes in demography over the next 10-15 years present a significant challenge. According to Ireland's Central Statistics Office, the Irish population is gradually ageing with a predicted doubling of numbers for those aged 85 years by 2021<sup>18</sup>. This is predicted to coincide with an increase in disease prevalence between 2007 and 2021 for diseases including cancer as well as chronic conditions such as cardiovascular and respiratory diseases<sup>19</sup>. Such data has great implications on palliative care service provision as estimates show that each year, 1.6 million cancer patients in Europe experience pain related to their disease, one third of them will require complex treatment and a significant number also experience distressing symptoms<sup>20</sup>.

**Recommendations:**

1. Specialist Palliative Care services should be integrated with other healthcare services in each region, so that the service can be brought to where the patient is, and patients and families can access the element of care most appropriate at any given time.
2. Everyone with an illness which cannot be cured should have access to the palliative care approach, which may be delivered by the primary care or other specialist team with ongoing education and support from the SPC team, or directly by the SPC team in the case of more complex patients.
3. The benefit to patients of early referral to Palliative Care needs to be recognised. Patients not only benefit from a better quality of life, but may also survive longer and with a good quality of life.

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<sup>18</sup> Central Statistics Office. Vital statistics: Fourth quarter and yearly summary 2010, <http://www.cso.ie/en/newsandevents/pressreleases/2011pressreleases/vitalstatisticsfourthquarter2010/>

<sup>19</sup> Layte R, Barry M, Bennett K, et al. Projecting the impact of demographic change on the demand for and delivery of healthcare in Ireland. Report for the Economic and Social Research Institute (ESRI). October 2009

<sup>20</sup> Higginson IJ and Costantini M. Dying with cancer, living well with advanced cancer. *Eur J Cancer* 2008;44:1414–24



