



**Palliative Care for Children Living with Non-Communicable  
Diseases (NCDs)**

**An ICPCN Briefing Paper**

ICPCN  
May 2013  
Website: [www.icpcn.org.uk](http://www.icpcn.org.uk)

## **The International Children's Palliative Care Network**

The International Children's Palliative Care Network (ICPCN) was established in 2005 and is the only international organization bringing together individuals and organizations involved in the development and provision of palliative care for babies, children and young people. Present membership is from 90 countries. The vision of the ICPCN is a world where all life-limited children have access to palliative care services. The objectives of the ICPCN are Advocacy; Education and Research; Information- sharing and Networking. The ICPCN is a Registered Charity in England and Wales No: 1143712 and a Registered Company in England and Wales No: 767 172

The purpose of this paper is to highlight issues relating to the need and provision of palliative care for children with non-communicable diseases and what countries need to do to meet those needs.

## **What is children's palliative care?**

The World Health Organization (WHO) defines palliative care for children as a special, albeit closely related field to adult palliative care which includes:

- The active, total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when the illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's own homes.<sup>i</sup>

## **Palliative care in the context of NCDs**

An estimated 36 million deaths, or 63% of the 57 million deaths that occurred globally in 2008, were due to NCDs, comprising mainly cardiovascular diseases (48%), cancers (21%), chronic respiratory diseases (12%) and diabetes (3.5%).<sup>ii</sup> According to World Health Organization (WHO) projections, the total number of annual NCD deaths will increase to 55 million by 2030, if business as usual continues.<sup>iii</sup> NCDs affect children too, they also suffer from cancer, both types of diabetes mellitus, congenital and acquired heart conditions and chronic respiratory diseases e.g. asthma.

Each year an estimated 8 million children (6% of all births worldwide) are born with a serious birth defect or symptomatic genetic abnormality. Heart defects alone contribute about a third or quarter of all birth defects. Many of these children die prematurely due to late diagnosis or lack of access to appropriate treatment. Some face hardships of living with a chronic condition that is not properly managed. It is for these reasons that palliative care should be made available to all children with NCDs.

## **The role of palliative care in children with NCDs**

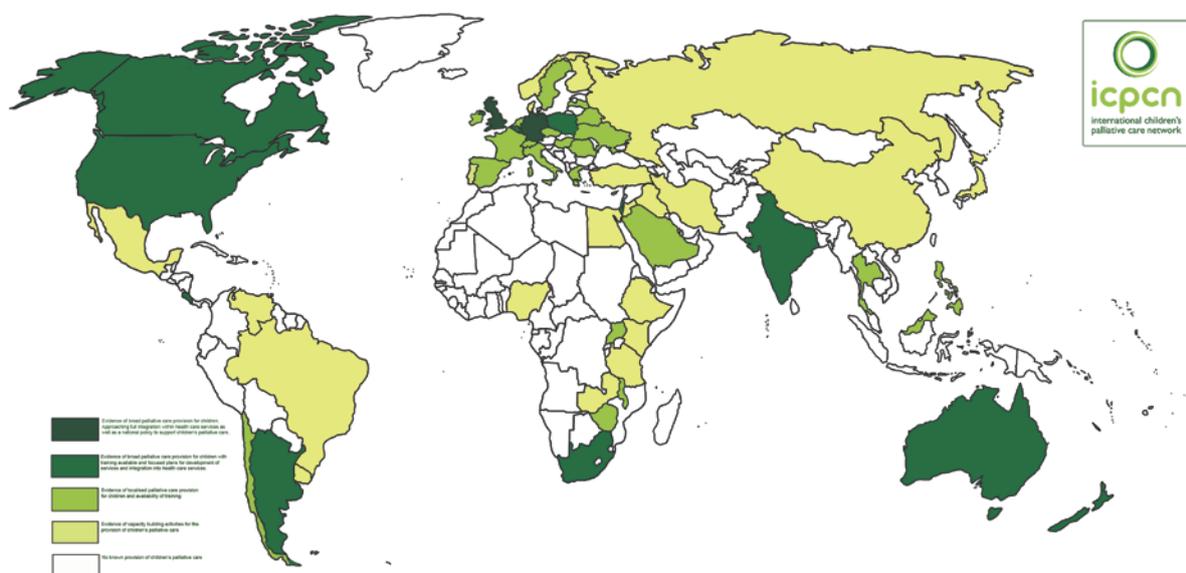
Palliative care offers a holistic approach to the management of NCDs that includes the physical, psychological, social, emotional, spiritual and cultural aspects. Care includes support for caregivers and siblings and the child has a voice in decisions that affect his/her care.

Pain control is of paramount importance in children with cancer, whilst management of dyspnoea forms the core of management activities in children with cardiac and chronic respiratory illnesses. A chronic illness always results in emotional and psychosocial distress in families and members need to be included in care provision. Such comprehensive care should be provided by a multidisciplinary team trained in children's palliative care.

### Access to children palliative care for children

A systematic review was undertaken by Knapp et al (2011) to help determine the prevalence of palliative care provision for children worldwide and the level of provision for each country. The classification of palliative care provision developed by the International Observatory on End-Of-Life Care was adapted for children (Wright et al, 2008). Based on this classification, 65.6% of countries had no known children's palliative care activities, 18.8% had capacity-building activities, 9.9% had localised provision, and 5.7% had provision that was reaching integration into the health system.<sup>iv</sup> This mapping exercise demonstrates that there is still much work to be done in the development of children's palliative care services globally, with gaps particularly in South America and Africa. There are not many countries where children's palliative care provision is reaching integration into the health system, and a similar map for palliative care for adults would show more countries reaching integration.<sup>v</sup> Based on information from this review and its own information, the ICPCN has produced a map that indicates levels of service provision around the world. Palliative care services for children tend to develop in isolation and there are major disparities in provision, resources, capacity and infrastructure, especially in the developing world. Many only provide palliative care in the home and at the primary care level through home-based care programmes and mainly linked to non-governmental organisations and faith-based organisations with little or no government support.

### ICPCN Estimate of Global Children's Palliative Care Provision



The result of lack of access to palliative care services for babies, children and young people, is unrelieved and unnecessary suffering. Children live and die in pain, pain that could be relieved with simple and inexpensive medications; supportive holistic care; and non-pharmacological interventions such as massage, hypnosis, distraction. A government

response based on education, policies and access to adequate medications would be cost – effective, achievable and compassionate.<sup>vi</sup>

### **Palliative care a human right to health for children**

Children’s palliative care is a basic human right for all children living with chronic illnesses. General comments No.15 (2013)Article 24 paragraph 1 of the Convention on the Rights of the Child, states that *“Children are entitled to quality health services, including prevention, promotion, treatment, rehabilitation and palliative care services. At the primary level, these services must be available in sufficient quantity and quality, functional, within the physical and financial reach of all sections of the child population, and acceptable to all”*.

According to the Global Action Plan for the prevention and control of noncommunicable diseases, *“comprehensive care for noncommunicable diseases encompasses primary prevention, early detection/screening, treatment, secondary prevention, rehabilitation, palliative care and attention and improving mental health as a priority for social development and investment in people”*.<sup>vii</sup>

### **Essentials for children’s palliative care provision**

1. A workforce of health professionals trained in children’s palliative care
2. National policies for the inclusion of children’s palliative care in children’s health programmes
3. Appropriate drugs for the adequate management of pain (especially opioids)and other symptoms
4. Budget for the development and provision of children’s palliative care.

### **Call to Action**

To fulfil the right of making palliative care accessible to all children who need it countries should:

1. Integrate children’s palliative care into all health care services for children.
2. Include children’s palliative care in relevant health, welfare and educational policies.
3. Ensure training for health care workers in children’s palliative care and development of mentor programmes to support these professionals in their work settings.
4. Ensure equitable access to pain-relieving and other palliative medicines, including opioids. This may necessitate a review of the Essential Medicines Lists to include palliative medicines.
5. Make available adequate funding for the provision of children’s palliative care services.

---

<sup>i</sup> World Health Organization 2002

<sup>ii</sup> [http://www.who.int/healthinfo/global\\_burden\\_disease/cod\\_2008\\_sources\\_methods.pdf](http://www.who.int/healthinfo/global_burden_disease/cod_2008_sources_methods.pdf)

<sup>iii</sup> Updated revised draft. Global Action Plan for the prevention and control of noncommunicable diseases: 2013-2020

<sup>iv</sup> Knap et al 2011

<sup>v</sup> Wright et al, 2008

<sup>vi</sup> Palliative care for children: A basic Human Right. An ICPCN briefing paper. Joan Marston. Summer 2012.