



Position paper on need of palliative care for children living with non-communicable diseases

Purpose	Raise awareness for the need for palliative care for children and young adults with non-communicable diseases
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Summary	This statement explains the need for palliative care for children with non-communicable diseases.
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Introduction

The International Children's Palliative Care Network (ICPCN) is a network of individuals and organisation working in children's palliative care worldwide. The vision of ICPCN is to live in a world where children's palliative care is acknowledged and respected as a unique service, and every child and young person with a life-limiting or life-threatening condition and their families can receive the best quality of life and care regardless of which country they live in. We believe that the total needs of life limited and life threatened children should be met to encompass physical, emotional, spiritual and developmental aspects of care. To achieve this, children's palliative care must be acknowledged as a unique and specialist service.

ICPCN aims to:

- Assist services across the world to develop and meet the total care and support needs of life-limited children and their families.
- Advocate for and raise awareness of children's palliative care and the specific needs of life-limited or life-threatened children and their families.
- Campaign for the global development of children's palliative care services.

- Increase the international evidence base for children's palliative care.

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.ⁱ

Palliative care in the context of Non-Communicable Diseases (NCDs)

NCDs are currently the leading cause of death worldwide and include cancer, cardiovascular disease, chronic lung disease and diabetes. 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%).ⁱⁱ According to the World Health Organization (WHO) projections, the total number of annual NCD deaths will increase to 55 million by 2030, if business continues as usual.ⁱⁱⁱ

Approximately 1.2 million deaths from NCDs occur in people under 20 years of age, which represents over 13% of all NCD mortality.^{iv} More than one million children and adolescents are living with type 1 diabetes. 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 and disability of living with a chronic condition that is not properly managed^v.

NCD rates are increasing faster in low and middle-income countries, with worse outcomes than in high income countries.^{vi} Children living with NCDs will likely have lower educational attainment and poorer access to employment opportunities. Therefore, the approach to care for them should be one that includes an affordable diagnosis, access to disease specific medication, pain management, psychosocial care and education. Palliative care encompasses all these necessary elements of care.

The need for palliative care for children with non-communicable diseases has been largely ignored though it is an essential element of universal health coverage. The Lancet Commission on '*Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage*' states that every year nearly 2.5 million children die needing palliative care and pain relief and more that 98% of these children are from developing countries.^{vii}

The role of palliative care in children with NCDs

The goal of palliative care is to relieve suffering and improve quality of life. It 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 or young person has a voice in decisions that affect his/her care. Pain control is of paramount importance in children with cancer and other conditions, whilst management of dyspnoea forms the core of management activities in children with cardiac and chronic respiratory illnesses. A chronic illness has been shown to result in emotional and psychosocial distress in families and all members of the family need to be included in care provision. Such comprehensive care is provided by a multidisciplinary team trained in children's palliative care. Where needed, end-of-life care ensures a pain free and dignified death and the family are supported throughout the period of bereavement, for however long that may last.

Palliative care a human right to health for children

Children's palliative care is a basic human right for all children living with chronic and life-threatening 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".^{viii}*

According to the Global Action Plan for the prevention and control of non-communicable diseases, *"comprehensive care for non-communicable 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".^{ix}*

Call to Action

In May 2014, the World Health Assembly adopted a resolution which called for member states to:

- Develop, strengthen and implement palliative care policies.
- Support palliative care initiatives including education and training, quality improvement and availability of medicines essential for the provision of palliative care.
- Provide support to caregivers.
- Include palliative care as a part of integrated training for all healthcare workers who routinely work with people with serious illnesses.
- Ensure access to essential medications.
- Foster partnerships between government and civil society to increase access to palliative care.

World Health Assembly - WHA 67.19^x

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

1. Integrate palliative care into national health care systems.
2. Integrate palliative care into universal health coverage.
3. Include children's palliative care in relevant health, welfare and educational policies.
4. Ensure training for health care workers in children's palliative care and development of mentor programmes to support these professionals in their work settings.
5. Ensure equitable access to pain-relieving, particularly opioids, and other palliative medicines. This may necessitate a review of the Essential Medicines Lists to include palliative medicines.
6. Make available adequate funding for the provision of children's palliative care services. The use of the Essential Package of palliative care which has been developed by the Lancet Commission is strongly recommended. The Essential Package includes medicines, equipment and human resources which are affordable even in low income countries.

ⁱ World Health Organization 2002

ⁱⁱ http://www.who.int/healthinfo/global_burden_disease/cod_2008_sources_methods.pdf

ⁱⁱⁱ Updated revised draft. Global Action Plan for the prevention and control of non-communicable diseases: 2013-2020

^{iv} www.ncdchild.org/media/1128/ncd-child-call-for-action-electronic.pdf

^v NCD Alliance Briefing Paper on Children and NCDs. Children in Every Policy: Recommendations for a Life Course Approach to NCDs. 2011

^{vi} www.ncdchild.org/media/1128/ncd-child-call-for-action-electronic.pdf

^{vii} The Lancet Commissions. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage. Published online October 12 2017.[http://dx.doi.org/10.1016/S0140-6736\(17\)32513-8](http://dx.doi.org/10.1016/S0140-6736(17)32513-8)

^{viii} Convention on the Rights of the Child. General Comments no 15 (2013) on the right of the child to the enjoyment of the highest attainable standard

^x Sixty-Seventh World Health Assembly: Strengthening of palliative care as a core component of comprehensive care throughout the life course. Geneva. 2014