



International Children’s Palliative Care Network (ICPCN) statement on palliative care and children living with cancer

Purpose	Policy statement
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Audience	Children’s palliative care personnel, national governments, international and regional organisations
Circulation List	Regional and National Hospice and Palliative Care Associations; Government Ministries of Health; Members; INGOS; Faith–Based Organisations
Summary	The purpose of this statement is to highlight issues relating to the need and provision of palliative care for children living with cancer and what is needed to do to meet these needs.
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Introduction

The International Children’s Palliative Care Network (ICPCN) is the only global network working to reach the estimated 21 million children worldwide needing palliative care who have a right to access such care. It is a network of individuals and organisations committed to the development of children’s palliative care worldwide. The vision of ICPCN is 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 enjoy the best quality of life and care regardless of where they live. 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.

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

Children and cancer

Every year approximately 300 000 children develop cancer worldwide. With access to proper care and treatment more than 80% of children with cancer can survive. However, many children in low and middle-income countries do not have access to life-saving treatments and as a result 90% of childhood cancer deaths occur in low resource settings.ⁱⁱ It is also estimated that 80 000 deaths occur due to childhood cancer globally. Survival rates differ according to the socio-economic circumstances of the regions in the world with 80% in high-income countries and as low as 10% in low-income countries. 80% of children with cancer live in middle and low-income countries.ⁱⁱⁱ

Reasons for high morbidity and mortality in low and middle-income countries

- Late diagnosis due to the lack of public and health professional awareness of cancer signs and symptoms.
- Lack of diagnostic capability, resources and trained laboratory staff.
- Paucity of trained nurses and doctors to treat patients plus failure to retain them within low and middle-income countries (LMICs).
- Inadequate facilities and resources in hospitals.
- High rates of co-morbidities e.g. HIV, TB, malaria, diarrhoea and malnutrition.
- Lack of availability, accessibility and affordability of good quality essential medicines which appear on the WHO listing.
- High rates of treatment refusal and treatment abandonment frequently due to non-affordability or the perception of incurability.

Palliative care – a human right for children with cancer

Children with cancer often suffer from moderate to severe pain and other debilitating symptoms as a result of cancer or the side effects of treatment. Not to adequately relieve these symptoms is inhuman and has been sighted in many international documents, reports and declarations. The table below reflects some of these.

No.	Organisation	Document/Report/Declaration	Relevant Text
1.	Committee on the Rights of the Child(2013) ²	Comment No. 15 on the Right of the Child to Enjoyment of the	Children are entitled to quality health, including prevention, treatment,

		Highest Attainable Standard of Health	rehabilitation and palliative care services.(para.25)
2.	Special Rapporteur on the Right to Health (2012)	Submission to the Committee against Torture regarding Drug Control Law	Access to controlled medicines is essential in the management of moderate to severe pain, including as part of palliative care for people with life-limiting illnesses; certain emergency obstetric situations; and management of epilepsy. The right to health requires States to provide essential drugs mentioned in the WHO list of essential medicines. [para. 22]
3.	Special Rapporteur on Torture (2009)9	Promotion and Protection of All Human Rights, Civil Political, Economic, Social and Cultural Rights, including the Right to Development	The Special Rapporteur is of the opinion that the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment. [para. 72] Given that lack of access to pain treatment and opioid analgesics for patients in need might amount to cruel, inhuman and degrading treatment, all measures should be taken to ensure full access and to overcome current regulatory, educational and attitudinal obstacles to ensure full access to palliative care. [para. 74(e)].
3.	Committee on the Rights of the Child (2011)5	Consideration of Reports Submitted by States Parties Under Article 44 of the Convention, Concluding Observations: Belarus	The Committee recommends that the State party establish a funding mechanism for the provision of palliative care for children and support the palliative care services provided by nongovernmental organizations. [para. 56]
4.	Committee on Economic, Social and Cultural Rights (2001)10	General Comment No. 14 on the Right to the Highest Attainable Standard of Health	In particular, States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services. [para. 34]

Building Integrated Palliative Care Programmes and Services.^{iv}

Children's palliative care provides the following interventions:

- prevention, assessment, and treatment of physical symptoms
- culturally appropriate psychological support for the patients and their families about diagnosis, prognosis, and treatment options as well as bereavement support for family members
- intersectoral social supports to alleviate extreme poverty
- support to respond to suffering that is spiritual in nature^v

According to the *Lancet Commission: Alleviating the access abyss of palliative care and pain relief - an imperative of universal health coverage*, nearly 2,5 million children die each year needing palliative care and pain relief and 98% of them are from low-income countries. The Commission stresses that access to paediatric palliative care is imperative everywhere, including and especially in LMICs because of the concentration of cases.

What are the common causes of suffering in childhood cancer?^{vi}

- Pain
- Fatigue
- Dyspnoea
- Poor appetite
- Nausea and vomiting
- Constipation
- Diarrhoea

Integration of palliative care into the response to a cancer diagnosis

Integrating palliative care into the care of children with cancer should be included early, preferably at diagnosis, to discuss:

- the prognosis
- goals of treatment
- suffering

All children should have access to generalist palliative care including basic control of pain and other symptoms, as well as psychological issues such as depression and anxiety. At the specialist level management should include control of refractory pain and symptoms, management of more complex psychological and existential distress. A palliative care approach will also provide assistance with conflict resolution, regarding goals or methods of treatment which could occur:

- within families
- between staff and families
- among treatment teams^{vii}

Recommendations

To fulfil the right of making palliative care accessible to all children who need it, in line with the World Health Assembly Palliative Care Resolution (WHA 67.19)^{viii} and Cancer Resolution (WHA 70.12)^{ix}, the ICPCN calls on governments to:

1. Integrate children's palliative care into all health care services for children, especially within cancer care.
2. Include children's palliative care in relevant health, welfare and educational policies.
3. Ensure training for health care workers working in children's cancer care on children's palliative care.
4. Ensure equitable access to pain-relieving and other palliative medicines, including opioids. (The Lancet Commission has developed an Essential Package of Palliative Care. The 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/cancer/iccd-2018/en>

ⁱⁱⁱ www.internationalchildhoodcancerday.org

^{iv} Gomeze-Batiste X; Connor S. Building Integrated Palliative Care Programs and Services. WHO, WHPCA, “la Caixa” Banking Foundation. 2017

^v 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)

^{vi} Wolfe et al. Symptoms and suffering at the end of life in children with cancer. NEJM Feb 2000.

^{vii} Quill and Abernethy. NEJM March 28, 2013

^{viii} WHA (2014) Strengthening of palliative care as a component of integrated treatment within the continuum of care. 134th Session of the World Health Assembly. EB134.R7 May 2014.

^{ix} WHA (2017) Cancer prevention and control in the context of an integrated approach. Seventieth World Health Assembly. WHA70.12 May 2017.