



**Children's Palliative Care and HIV/AIDS**  
**An ICPCN Position Paper**

ICPCN  
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[www.icpcn.org](http://www.icpcn.org)

## 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 81 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

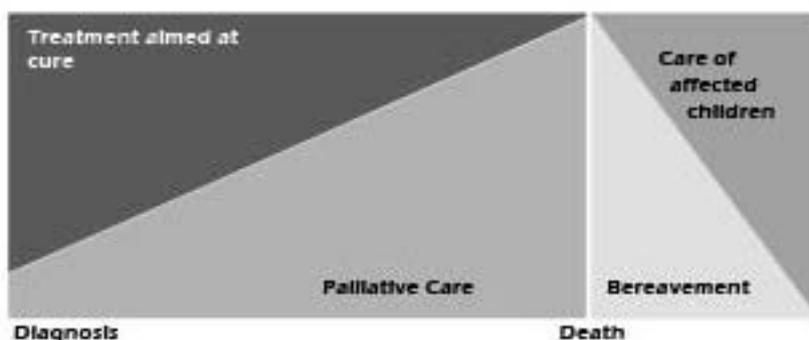
The purpose of this paper is to highlight issues relating to children living with HIV and AIDS and to consider how to develop links between HIV and AIDS health initiatives and the palliative care of babies, children and young people in relation to potential international and national activity.

### 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>

The trajectory of children's palliative care<sup>ii</sup>



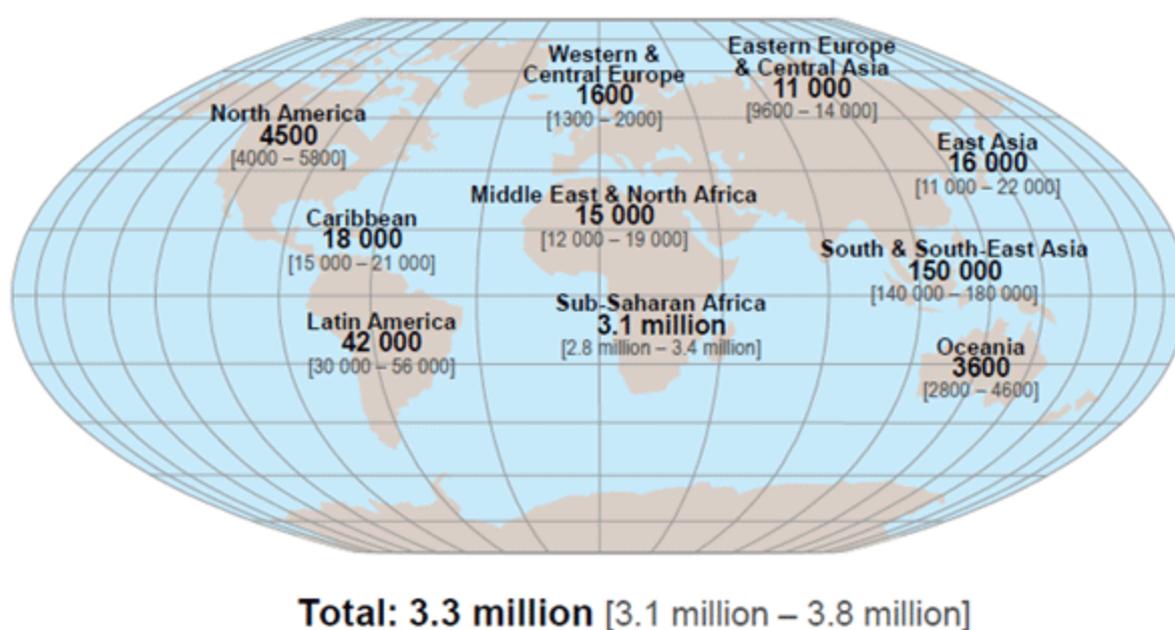
### Global statistics

Globally, in 2011, 34 million people were living with HIV, 3.3 million were children under 15 years. Sub-Saharan Africa accounts for 69% of all people with HIV, 72% of new infections (both adults and children) and 71% of AIDS related deaths worldwide.

8 million people living with HIV had access to antiretroviral therapy, however, 7 million people who need it, still cannot access it. 72% of children living with HIV who are eligible for treatment still do not have access<sup>iii</sup>.

Half of all reduction in new infections in the last two years has been among newborns, which is evidence that elimination is possible. However, among the 2.5 million new infections in 2011, 330 000 were children under 15 years. Of the 1.7 million who died in the same year, 230,000 were children under 15 years.

### Children under 5 years living with HIV globally, 2011<sup>iv</sup>



### Palliative Care for children HIV

Children with HIV who have no access to antiretrovirals and co-trimoxazole prophylaxis, will suffer from a great deal of pain and various distressing symptoms related to HIV/AIDS. Most of those living in low and middle-income countries will eventually succumb to death. Together with their families they will also suffer from emotional, social, spiritual and cultural pain. These children and their families would benefit from the comprehensive approach offered by palliative care. Palliative care is provided by a multidisciplinary team of health professionals including doctors, nurses, social workers, various therapists, community caregivers and family members.

### Pain in the context of HIV

Antiretrovirals have brought about significant relief to the suffering of people with HIV but many including children continue to experience pain due to the following factors:

- Effects of HIV itself or the body's immune response to it e.g. peripheral neuropathy, cardiomyopathy, myelopathy, etc.<sup>v</sup>

- The effects of opportunistic infections e.g. pneumonia, meningitis, herpes zoster, mouth ulcers, etc.
- Repeated painful procedures e.g. venesection, lumbar puncture, tube feeding, etc.
- Effects of medications used to treat the disease e.g. nausea and vomiting, diarrhoea, skin rashes, etc.
- Psychosocial stressors e.g. emotional pain due to living with a chronic illness, long periods of hospitalisation, clinical depression, etc.

**It is important note that pain is often not adequately treated in children because:**

- Some of the children are often unable to express their pain due to their age, lack of verbal skills or disability.
- Few health care professionals are trained and skilled at evaluating children’s pain and suffering, and therefore pain is left unrecognised, ignored and untreated.
- The majority of health professionals lack competence in prescribing opioids in children.
- There is fear of using opioids for pain management due to common belief that it will lead to addiction.
- Acknowledgement and support for spiritual pain and conflict, and the impact of culture and language, is mostly ignored in children.

**The role of palliative care in children with HIV**

It is a misconception that palliative care is end of life care. End of life care is one but important component of palliative care. Palliative care begins at diagnosis, continues throughout the duration of the illness and is applicable even during treatment aimed at cure. It is not a substitution for HIV treatment but part of care and should be given alongside such treatment. Care includes proper control of pain using effective analgesics especially opioids. Morphine is an effective, versatile yet inexpensive analgesic for use in cases of moderate to severe pain. The “WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses” is a good tool to use for adequate pain control. Distressing symptoms such as dyspnoea, wasting, adverse effects of drugs and other debilitating symptoms, should be managed properly. Important areas that are often overlooked in children with HIV and their families (siblings included) are emotional, spiritual, cultural and educational aspects. A multidisciplinary team provides commendable outcomes resulting in enhanced quality of life for the child and family. Planning for end of life should take place well in advance where death is imminent to ensure a dignified death. Bereavement care should be extended to include siblings and provided for as long as it is necessary.

**Key Points In Children’s Palliative Care**

- It provides comfort in the form of pain relief and the management of unpleasant symptoms
- It relieves suffering and addresses the needs of the child and family
- It requires an interdisciplinary team who have specific skills and experience
- It can run concurrently with curative treatment
- It is applicable from diagnosis and continues into bereavement
- It provides supportive, physical, psycho-social and spiritual care which includes members of the child’s family

## Integration of palliative care into HIV care programmes for children.

1. FHI 360 developed a toolkit to help HIV programmes integrate palliative care into their services. ***Integrating palliative care into HIV services: A practical tool for implementers***. This toolkit:

- Reviews the many benefits of integration for the patient and health system
- Presents key issues to consider when planning for integration
- Offers clear, succinct ways to initiate and sustain integration
- Provides clinical and organisations tools to guide integration

It is available at: [www.fhi360.org/en/Publications/index.htm](http://www.fhi360.org/en/Publications/index.htm)<sup>vi</sup>

2. In 2012 the WHO developed pain treatment guidelines for the proper management of physical pain in children. ***WHO guidelines for the pharmacological treatment of persisting pain in children with medical illnesses***.

This document is available at: [www.who.int](http://www.who.int)

## Recommendations

Children's palliative care is a basic human right for all children living with life threatening and life limiting illnesses including HIV/AIDS. 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*".

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 Essential Medicine Lists to include palliative medicines.
5. Make available adequate funding for children's palliative care

Until we achieve 100% coverage of treatment for children with HIV worldwide, palliative care will remain an absolute necessity in care provision.

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

<sup>ii</sup> Children's Palliative Care in South Africa. The facts: Why should children suffer? ICPCN.2010

<sup>iii</sup> Global Fact Sheet. World AIDS Day 2012: UNAIDS

<sup>iv</sup> [www.childinfo.org/hiv\\_aids.html](http://www.childinfo.org/hiv_aids.html)

<sup>v</sup> Children's Palliative Care in Africa edited by Dr Justin Amery: Oxford University Press. 2009

<sup>vi</sup> Fact Sheet. Palliative Care and HIV. UK Consortium on AIDS and International Development. February //2013