

ICPCN KEY ADVOCACY MESSAGES

1. Access to good health care, including palliative care, is every child's right.
2. Every child should receive good pain and symptom management, using paediatric formulations when appropriate.
3. Universal Health Coverage must include palliative care for children, provided by skilled health care workers.

For the purposes of these messages, the term 'child' refers to neonates, infants, adolescents and young adults in every country of the world, including those displaced and affected by war and other humanitarian situations and 'palliative care for children' refers to a specialised field to be provided by healthcare workers with the relevant training and skills.

EXPLANATORY NOTES

Children's palliative care enhances the quality of a child's life through the effective control of pain and relief from distressing symptoms while simultaneously giving active and holistic care to the child and members of the child's family. It should begin at diagnosis, continue throughout the duration of the illness and can be provided alongside treatment aimed at cure. It supports the child and family at the time of death and into the bereavement period for as long as it is needed. Effective palliative care makes use of available community resources and is provided by a multi-disciplinary team of trained practitioners. It can be provided anywhere, including the child's own home.ⁱ

Preliminary data from an ICPCN study reveals that more than 21 million children globally are in need of palliative care. The vast majority (98%) of children in need of palliative care live in low and middle income countries and almost half are concentrated in Africa.ⁱⁱ

1. Access to good health care, including palliative care, is every child's right.

The ICPCN believes that children's palliative care is the right of any child diagnosed with a life-limiting or life-threatening illness. This belief is supported by the UN Convention on the Rights of the Child, which states that the best interest of the child should be the primary consideration in all interactions with the childⁱⁱⁱ. It further refers to palliative care as a component of the child's right to health^{iv}.

The Human Rights Committee of the UN also recognises children's palliative care as an obligatory part of health care services to be provided by adequately trained professionals^v.

The World Health Assembly, in its 2014 Palliative Care Resolution 67.19, urges countries to integrate palliative care into their national systems and make opioids and other palliative medicines available to effectively manage pain and other symptoms in children^{vi}.

2. Good pain and symptom management, making use of paediatric formulations when needed, is every child's right.

Pain is the most prevalent symptom, experienced by 80% of children with cancer, 67% of those with progressive non-malignant diseases and 55% of those with HIV/AIDS.^{vii} Our experience has shown that pain in children is often inadequately treated due to a lack of practitioner skill in assessing a child's pain and the

fear of using opioids by medical professionals working with children. Morphine is the drug of choice for treating moderate to severe pain, preferably using the oral route as it is safe and inexpensive. The WHO two-step ladder should be used as a guide and medications need to be provided in paediatric formulations. Other physical symptoms as well as psychosocial and spiritual pain should be appropriately managed to ensure relief of suffering and good quality of life for the child and family.

3. Universal Health Coverage must include palliative care for children by skilled healthcare workers.

The World Health Organization^{viii} defines Universal health coverage (UHC) as access by people of all ages to the promotive, curative, rehabilitative and palliative health services they need and that these services should be affordable and of sufficient quality to be effective. We therefore call on every government to actively ensure that palliative care for children is included as an integral part of Universal health coverage.

ⁱ World Health Organization 2002

ⁱⁱ WPCA and WHO, Global Atlas of Palliative Care at End of Life, London, 2014.

ⁱⁱⁱ UNCRC article 3

^{iv} UNCRC, General Comment No 15, 2013

^v Report of the UN Special Rapporteur on torture and other cruel or degrading treatment or punishment, March 2015

^{vi} WHA Resolution “Strengthening of palliative care as a component of care throughout the life course,”

^{vii} Ibid , p 95

^{viii} World Health Organization http://www.who.int/health_financing/universal_coverage_definition/en/