Palliative Care for Children
Press release for International Children’s Day

The first day of June is International Children’s Day. On this day that celebrates and honours our children, the International Children’s Palliative Care Network (ICPCN) asks you to take a moment to think about the needs and hopes of those children who are living with a life limiting or life threatening illness and of their families.

The ICPCN estimates that worldwide there are 20 million children living with an illness or condition that could or will significantly shorten their lives and who would benefit from the provision of palliative care. In reality, a very small percentage of this number of children and their families are able to access these essential services. And in more than half the countries of the world, health professionals do not have adequate access to the medications that help to alleviate the needless suffering of their young patients.

A result of this lack of awareness and provision, particularly in the developing world, is an unacceptable number of children burdened daily with the distressing symptoms of their illness and in many instances, dying in severe and unnecessary pain.

How many children are affected?

• Each year more than 160,000 children are diagnosed with cancer worldwide and about 90,000 of these children succumb to the disease. Eighty per cent of children with cancer live in developing nations and more than half of these children will die because they lack access to prompt, effective treatment.¹
• In 2009 there were 2.9 million children living with HIV/AIDS and 260,000 died of AIDS.²
• March of Dimes estimates that around six percent of total births worldwide are born with a serious birth defect of genetic or partially genetic origin. This equates to around 7.9 million children.³
• At least 3.3 million children under five years of age die from birth defects each year and an estimated 3.2 million of those who survive may be disabled for life.
• Every year about 15 million babies are born prematurely. Many require special care simply to remain alive. Newborn deaths account for 40 percent of all deaths among children under five years of age.
• All of these children will have substantial palliative care needs and close family members will be affected, many providing 24-hour complex care and support for their child.

What is children’s palliative care?
Children’s palliative care is a basic human right for any child diagnosed with a life limiting or life threatening illness. It enhances the quality of a child’s life through the effective control of pain and relief from distressing symptoms while giving active and holistic care to the child and members of the child’s family. It begins at diagnosis, continues throughout the duration of the illness and is applicable even during treatment aimed at cure. Palliative care is provided to the 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.⁴

What makes palliative care unique?
Many children and young people who need palliative care are disabled however the risk of or certainty of death in childhood or young adulthood adds a degree of complexity and urgency to their
care and the support that is needed for the family. If the physical, spiritual, emotional and social needs of children with life limiting and life threatening illnesses are to be fully met, these children and their families must be recognised as a discreet group and receive the specialist services that they may require.

ICPCN
The International Children’s Palliative Care Network (ICPCN) is a network of all organisations and individuals working in children’s palliative care and believes that the total needs of life limited children and their families should be met to encompass physical, social, spiritual and developmental aspects of care. To find out more about children’s palliative care worldwide please go to www.icpcn.org.uk

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1 Kids Cancer Care  [www.kidscancercare.ab.ca](http://www.kidscancercare.ab.ca)
2 The Global Report on HIV/AIDS 2010
4 World Health Organization 2002
5 Together for Short Lives  [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)