

*ICPCN is the only international charity dedicated to securing the right of the **twenty million** children worldwide with life-limiting conditions to receive palliative care.*

The International Children's Palliative Care Network (ICPCN) is a global network of organisations and individuals working in the field of hospice and palliative care for children.

We advocate for children's palliative care to be acknowledged and respected as a unique discipline within health care systems and provided by suitably trained and qualified people to all children with incurable or life-threatening conditions and their families, regardless of where they live in the world.

We promote the concept that the care of babies, children, adolescents and young adults who face a shortened life-span should include services, therapies and medications that will reduce pain and suffering and encompass all their physical, social, emotional, spiritual and developmental needs and that of their families, allowing for the best possible quality of life.



## ICPCN C.A.R.E.S.

Key areas in which the organisation is active:

**C**ommunication

**A**dvocacy

**R**esearch

**E**ducation

**S**upport & development

## OUR VISION

*"To achieve worldwide the best quality of life and care for children and young people with life limiting illnesses, their families and carers, through networking, advocacy, information sharing, education and research."*

## ACTIVITIES OF THE ICPCN



Free membership of the network to **individuals** who work or volunteer in children's palliative care or related services.

Free membership for all **organisations** providing children's palliative care.

We provide an international **directory** and mapping of children's palliative care services.

We offer local, regional and international **networking** opportunities for members.

We facilitate the **sharing** of innovations, resources, and research results.

We host an up-to-date **website** providing a comprehensive source of relevant information about international issues related to children's palliative care.

We edit the International children's edition of **ehospice** - a free app and website that provides international news, intelligence, commentary and analysis on hospice, palliative and end of life care.

We develop and **publish** resources and position papers on topics relevant to the international children's palliative care community.

We coordinate and carry out **research** into issues relevant to the global development of children's palliative care.

We provide free online **e-learning** training modules in children's palliative care, endorsed by the University of South Wales and available in 8 languages.

We nurture children's palliative care expertise in developing countries by sending experts to provide face-to-face **training** on the basics of children's palliative care. 'Train-the-Trainer' courses are provided where needed.

We offer strategic **support** and materials to individuals and organisations wishing to start children's palliative care services in their part of the world and help with advice on integration into national health systems.

We **advocate** to member states of the World Health Assembly (WHA) on palliative care for children.

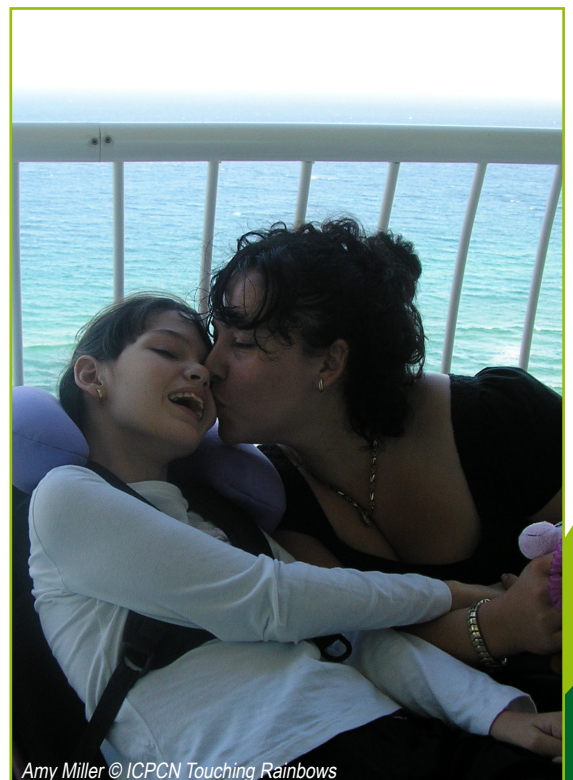
We represent children's palliative care on many **international forums** including the WHO Technical Advisory Group on Palliative and Long-term Care, the UN Social Protection, Care and Support Working Group and the South and East Africa Regional Inter-Agency Task Team.

We hold biannual **conferences** in countries within the developing world to promote the growth and advancement of children's palliative care in that region.

### WHO Definition of Children's Palliative Care

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

*Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate 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 homes.*



Amy Miller © ICPCN Touching Rainbows

## KEY TERMS AND DEFINITIONS

### ***Children's palliative care***

Children's palliative care is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the whole family and includes the management of distressing symptoms, provision of respite and care from diagnosis through death and bereavement.

### ***Life threatening Conditions***

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as children with cancer. Children in long-term remission or following successful curative treatment are not included.

### ***Life-limiting/life-shortening conditions***

Life-limiting or life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

### ***End of life***

The 'end of life' phase ends in death. The definition of its beginning is variable according to the individual child/young person and professional perspectives.

### ***End of life care***

End of life care focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death and immediately afterwards. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

### ***A Children's Hospice***

A children's hospice is an organisation which provides palliative care for a child or young person with a life-limiting condition and their family. It aims to meet all needs - physical, emotional, social and spiritual through a range of services including children's palliative

care, specialist respite care, terminal and emergency care, 24-hour telephone support, practical help, advice and information and bereavement support for all family members

### ***Bereavement support***

Bereavement frequently starts at the moment of diagnosis, so support should be provided throughout the illness. This includes the need to continue and possibly provide intense support to the whole family, during the time of the child's death and beyond.

### ***Home based care***

Within palliative care, home based care is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment working in partnership with parents and families. It provides hands-on expert nursing care, along with other elements of palliative care.

### ***Perinatal palliative care***

Perinatal palliative care is the support offered to parents who find out during pregnancy that their baby has a life-limiting condition. For parents who choose to continue their pregnancies, this support is provided from the time of diagnosis through the baby's birth and death. Perinatal palliative care helps parents embrace whatever life their baby might be able to have, before and after birth.

### ***Neonatal palliative care***

The planning for and provision of supportive care during life and end of life care for the newborn baby and his or her family when diagnosed with a life-limiting condition. Neonatal palliative care most frequently occurs in a Neonatal Intensive Care Unit. (NICU).

### ***Transition***

Transition is the term used when the child is moving from childhood into adulthood. The transfer of service provision around this time should be well planned and ensure as little disruption to the young person and their family as possible.

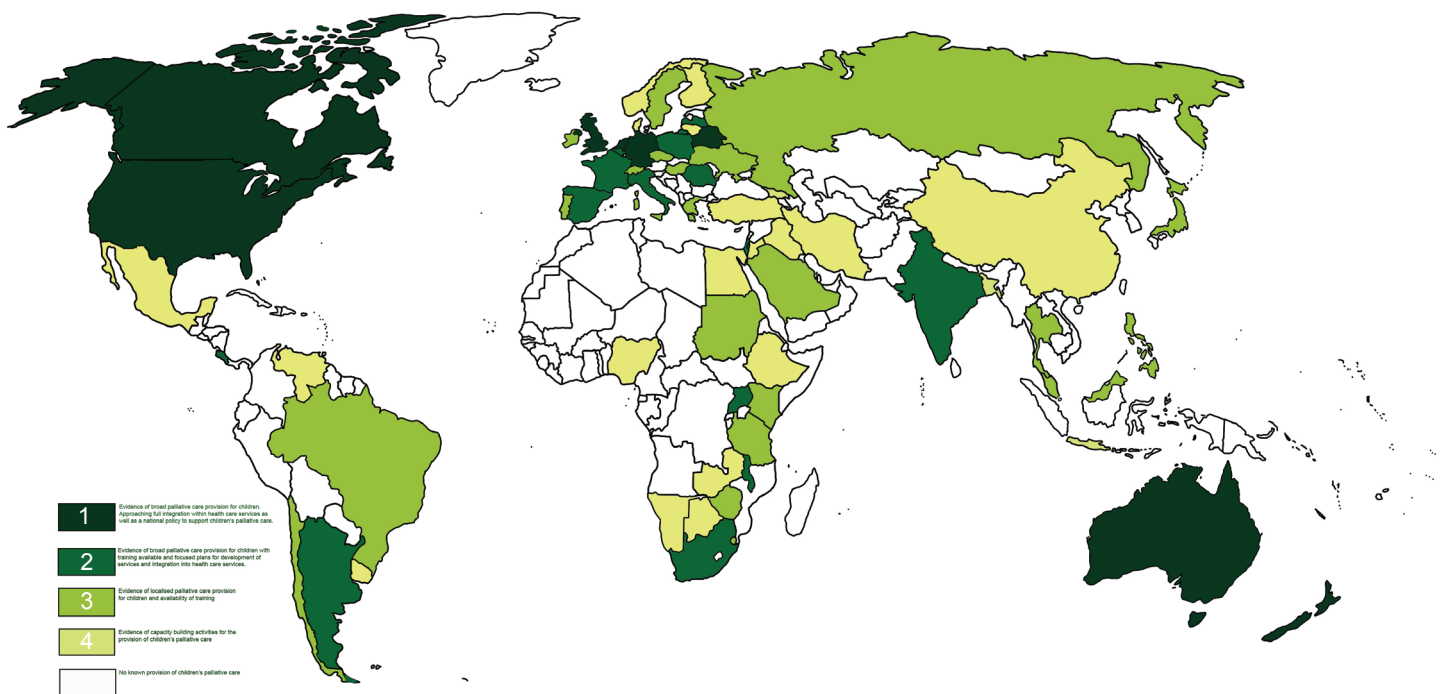


## WHERE ARE CHILDREN'S PALLIATIVE CARE SERVICES?

ICPCN's membership reaches into over 100 countries worldwide, which assists us in estimating the available levels of children's palliative care services. We have created this map as a visual representation of information received from our members and associates and present this as an estimate of the levels of CPC services worldwide. We welcome comment and information that will improve its accuracy. Countries have been categorised according to 4 levels of development.

1. Evidence of broad palliative care provision for children. Approaching full integration within health care services as well as a national policy to support children's palliative care.
2. Evidence of broad palliative care provision for children with training available and focused plans for development of services and integration into health care services.
3. Evidence of localised palliative care provision for children and availability of training.
4. Evidence of capacity building activities for the provision of children's palliative care. Some localised provision may be available.

### ICPCN ESTIMATE OF GLOBAL CHILDREN'S PALLIATIVE CARE PROVISION



### LEARN MORE

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

[www.elearnicpcn.org](http://www.elearnicpcn.org)

[www.ehospice.com](http://www.ehospice.com)

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