ICPCN is a global network of organisations and individuals working in the field of 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 life-limiting 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.

Our Vision
“That all children living with life-limiting or life-threatening conditions, and their families, will have seamless access to palliative care in order to alleviate serious health-related suffering and enhance their quality of life.”

Key areas of strategic focus for ICPCN:
- Communication
- Advocacy
- Research
- Education
- Strategic Development
Activities of the icp cn

- 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 on a wide range of topics, some of which are available in 13 languages.
- We nurture children’s palliative care expertise in developing countries by sending experts to provide face-to-face training on children’s palliative care.
- 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 international forums and work with the Worldwide Hospice Palliative Care Alliance (WHPCA), the International Association for Hospice & Palliative Care (IAHPC) and Palliative Care in Humanitarian Aid Situations and Emergencies (PallCHASE).
- We hold conferences in countries in different regions of the 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. (WHO 2002)
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 holistic multi-disciplinary care for babies and their families following antenatal or postnatal diagnosis of life-limiting conditions, providing integrated ongoing support through pregnancy, delivery, postnatal care, and where appropriate, continuing bereavement care.

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.

“We coordinate and carry out research into issues relevant to the global development of children’s palliative care.”
Where are children’s palliative care services?

ICPCN’s membership reaches into over 140 countries worldwide, and we have had individuals from 170 countries complete our e-learning courses, 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 5 levels of development.

1. No known provision of children’s palliative care.
2. Evidence of capacity building activities for the provision of children’s palliative care.
3. Evidence of localised provision of children’s palliative care.
4. Evidence of broad provision of children’s palliative care, training and plans for development of services and integration into health care services.
5. Evidence of broad provision of children’s palliative care, training and integration into health care services.

Learn More
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