

## NEW WRITING

### *The International Children's Palliative Care Network (ICPCN)*

*Sue Boucher*



I am the International Information Officer for the ICPCN. Originally from a well-established teaching background and the author of numerous teaching resource materials and children's books, I took up the challenge to become the ICPCN's very first employee

in December 2007. Changing careers at any stage of one's life is never easy and after 30 years as a teacher I never imagined I would find myself in such personally uncharted waters as that of paediatric palliative care. But on reflection it is not such a surprising change, as both careers have the child as the central focus. This move has catapulted me into a world of the most dedicated, compassionate and focused individuals. People who bend over backwards to help you and who are all driven by the same overriding passion – to uphold the rights and fight for the holistic care and the dignity of children afflicted with a life-threatening or life-limiting illness, their families and carers. It is an honour to be counted amongst them.

#### **Summary**

Sue Boucher, International Information Officer for the International Children's Palliative Care Network (ICPCN) describes hospice and palliative care as that which surrounds the child suffering from any life-limiting or life-

threatening illness – and that child's entire family – with a comforting 'cloak' of timely, appropriate and comprehensive care, co-ordinated by one key person. Hospice and palliative care for children follows ten years behind services for adults. In 2005 the new Network was established to advocate for children's palliative care on an international scale, and to be a place where information for both existing and developing children's hospice and palliative care services could be found and shared.

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This article will look at the following issues:

1. What is hospice and palliative care for children?
2. The history and present state of children's palliative care internationally.
3. The development of the ICPCN and the network's growth to date.
4. Some accomplishments and future plans of the ICPCN.

#### **1. What is hospice and palliative care for children?**

For most people the term "palliative care" is either unknown or completely misunderstood – even by workers in health care professions. People tend to associate the word *hospice* with a building where old people, usually with cancer, go for respite and/or end-of-life care.

Understandably it tends to cause a modicum of confusion when you tell people that you work in the field of 'hospice and palliative care for children'. To many it seems unnatural to associate children and teenagers with the concept of hospice care and death. But every year thousands of children are born and live with illnesses or genetic conditions with a poor prognosis for a normal life expectancy. Hundreds of thousands of children are diagnosed with cancers, some more aggressive than others. In developing nations, millions of children die each year from preventable illnesses, including malnutrition, and close to 2.5 million children around the world are HIV positive or have AIDS. Add to that the 15 million bereaved children who have been orphaned as a result of their parents contracting AIDS, the need for hospices and palliative care for children becomes more apparent.

Hospice and palliative care is a 'philosophy of care' rather than a physical location and can include home-based care where trained caregivers pay regular visits to patients in their own homes. There are of course numerous hospice services, including those specifically for children, with in-patient care facilities which are used for both respite and end-of-life care. But hospice and palliative care encompasses far more than this.

Hospice and palliative care for children surrounds the child suffering from any life-limiting or life-threatening illness – and that child's entire family – with a comforting 'cloak' of timely, appropriate and comprehensive care, co-ordinated by one key person. This care is provided by a multi-disciplinary team of professionals which can include doctors, paediatricians, nurses, psychologists, social workers, counsellors, physiotherapists, play therapists, music therapists, educators and any others, according to the individual needs of each child. Ideally, the members of this team will have undergone specific training in children's palliative care in order to be effective in alleviating any physical, social, psychological, emotional or spiritual suffering the child and family members experience, and to do so with sincerity and compassion. Hospice and palliative care is available from the time of diagnosis, even when there is hope for a cure, continues through the trajectory of the illness and, should no cure be possible, supports the child and

family through death and into the bereavement period for as long as necessary.

### **How does children's palliative care differ from that for adults?**

Palliative care for children differs in numerous ways from that provided to adults, the most significant being that children are in a dynamic and continual process of physical, emotional, social and cognitive development, which affects their treatment needs and influences such issues as their understanding of life and death, sickness and health, and their ability to participate in decisions relating to their own treatment and care. As the child grows and matures their specific requirements and their perceptions will change. Carers must have the skills to communicate effectively with children at all these different stages of development.

Other significant differences include the following:

- Children have a *right* to play, to be given every opportunity to participate in leisure activities with their peers and to continue their education, despite their illness or condition. Palliative care for children must take these rights into account.
- There are many childhood-specific diseases and conditions which require very particular knowledge and responses from those caring for them.
- In some cases a child's illness may extend over a period of many years, even into early adulthood, making regular respite for the family from the burden of care an important priority.
- The family, which includes siblings and grandparents, will have diverse and challenging bereavement needs as they come to terms with the loss of a child.
- As a result of improved medical care and treatment in more developed countries, some children need support in making the difficult transition from child-centred to adult hospice services.

## **2. The history and present state of children's palliative care internationally**

There is a 10-year gap between the first modern hospice and palliative care centre for adults, begun by Dame Cecily Saunders at St.

Christopher's Hospice in London, and the start of similar services for children.

Sister Francis Dominica, a nurse who trained at the Great Ormond Street Hospital for Children and at the Middlesex Hospital, London, recognised that children needed very particular palliative care, different to that available to adults. She founded Helen House, the world's first children's hospice, which opened in 1982 in Oxford. From these early beginnings, the children's hospice movement has grown to more than 40 children's hospices within the United Kingdom alone and has spread to every continent – although, sadly, not every country. Only between 25 to 30 countries worldwide have some kind of recognised children's hospice and palliative care services available to their population. The locations of these services tend to be patchy and are often unconnected.

### **3. The development of the ICPCN and the network's growth to date**

In 2005 the International Children's Palliative Care Network was founded by a group of people who had up until then focussed primarily on expanding the reach and effectiveness of palliative care for children within the borders of their own countries. This group of visionaries realised that in order to make a difference in the lives of the millions of children around the world who suffer and die without any form of palliative care, it was imperative to form a network that was a 'one-stop-shop'. This network would not only advocate for children's palliative care on an international scale, but would be a place where information for both existing and developing children's hospice and palliative care services could be found and shared. Their stated vision is as follows:

*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.*

These dedicated individuals who established the Network form the core of the international Steering Group that is the governing body of the ICPCN today, and all volunteer their time and their skills to keep this vision alive. The ICPCN is part of the Worldwide Palliative Care Alliance and is administered from the offices of the

Hospice Palliative Care Association of South Africa in Cape Town. Its Steering Group is made up of 13 members who are recognised leaders in the field of children's palliative care and represent 9 different regions worldwide including South and Central Africa, India, America, Canada, the United Kingdom, South America, East and Western Europe and Russia.

With generous funding from the True Colours Trust in 2007, the ICPCN was able to raise its profile through advertising, the creation of its website and the appointment of an International Information Officer and immediately started forging ahead towards its stated goals. It has not taken long for the ICPCN and its logo to become known and for it to be seen as a trusted and recognised source of information and means of communication and networking amongst members of the international paediatric palliative care community.

### **Some accomplishments and future plans of the ICPCN**

ICPCN has achieved the following:

1. Membership of the ICPCN, which is open and free to both organisations and individuals, has grown rapidly and to date is representative of 34 countries worldwide. All organisations that join are included in the interactive database to be found on our website – [www.icpcn.org.uk](http://www.icpcn.org.uk)
2. The ICPCN website has become a trusted source for news, information on new developments, document downloads, dates and information on relevant conferences, and available training in the field of palliative care for children, and has been visited by thousands of people this past year.
3. The ICPCN accepted the invitation to become the voice for children on the newly constituted Worldwide Palliative Care Alliance, a powerful advocacy body in the field of palliative care.
4. Four quarterly newsletters have been published and disseminated to members and national organisations. These newsletters deal with issues relevant to the field and articles which highlight advances and challenges experienced in both developed and developing countries around the world.

5. Members are sent important information, reminders of upcoming events and conference abstract submission dates on a regular basis.
6. To coincide with the 2008 World Hospice and Palliative Care Day on the 11<sup>th</sup> October 2008 the ICPCN launched its *Charter for the Rights of Life-Limited and Life-Threatened Children*. With acknowledgement to the ACT Charter, the ICPCN Charter sets out the *international* standard of support that is the right of all children living with life-limiting and life-threatening illnesses worldwide, and their families. This Charter is available in 21 languages and can be downloaded directly from the website.
7. Funding has been secured for the initiation of a programme in early 2009 of expertise-sharing through the awarding of scholarships and bursaries, focusing initially on paediatric palliative care leaders in resource-poor countries.

For any queries or for more information, please feel free to contact:

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### **What does the future hold?**

Future plans for the ICPCN include the drawing up of an inventory of available education and training in Paediatric Palliative Care worldwide, an international mapping of hospice and palliative care programmes and research into the unmet needs of people working in the field.

We will continue to be the voice for children who cannot always speak for themselves and we are committed to advocacy work with the ultimate aim of making palliative care recognised as a basic human right for every child and family faced with the distress and the challenges that accompany the diagnosis and progression of a life-limiting or life-threatening illness.

### **Who can join the ICPCN?**

The ICPCN is open to both organisations and individuals who either work in the field of paediatric palliative care or in a related field. Membership is completely free and carries no obligations. You can join via the website at [www.icpcn.org.uk](http://www.icpcn.org.uk)