

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

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I am the International Information Officer for the International Children's Palliative Care Network (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

On 11<sup>th</sup> October 2008 the International Children's Palliative Care Network (ICPCN) published a Charter of Rights for children with life-limiting or life-threatening conditions which they wish to see accepted and ratified by governments and health departments around the world. According to the UN Convention on the rights of the child, every child and young person has the right to the enjoyment of the highest attainable standard of health.

Governments are also required to do everything in their power to ensure that children enjoy full and holistic development.

In the spirit of the UN Convention, 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. The Charter calls for all such children to receive appropriate palliative care. This second article expands on the remaining five articles of the Charter, at the same time giving the reader a deeper insight into the field of children's palliative care.

### Introduction

An American father, faced with the diagnosis of his child's life-limiting illness once lamented that there were thousands of books and many people willing to give advice on how to bring a child into the world but, sadly, very little information on how to escort a child out of the world.

In 2008 the ICPCN (International Children's Palliative Care Network) launched its Charter for the Rights of Life-limited and Life-threatened Children. With acknowledgement to the ACT Charter ([www.act.org.uk/](http://www.act.org.uk/)), the ICPCN Charter sets out the *international* standard of support that is the right of all children living with life-threatening or life-limiting illness as well as their families.

ACT defines four classes of children requiring palliative care. The first class encompasses children with life-threatening conditions in which cure is possible but may fail (e.g. children diagnosed with acute lymphoblastic leukaemia, malnutrition, tuberculosis). The second class encompasses children with conditions in which premature death is inevitable, but in which long periods of wellness with reasonable quality of life are possible because of available treatments. (This will include children who are HIV positive but on HAART {Highly Active Anti-Retroviral Therapy} and children with cystic fibrosis.) The third class includes progressive conditions for which there is no known cure and for which treatment is exclusively palliative from the

outset (e.g. some genetic disorders such as trisomy 13 and 18, inoperable congenital heart disease, inborn errors of metabolism, etc). The fourth class includes children with conditions that are irreversible but non-progressive and often associated with disability (e.g. cerebral palsy and Down's syndrome without major heart abnormalities).

In this second part, I would like to discuss Articles 6 to 10 of the charter, expanding on the meaning of each as it affects children with a life-limiting illness and their families in countries around the world.

#### **Article Six**

The sixth article of the Charter states:

**Every child or young person shall have access to education and wherever possible be provided with opportunities to play, access leisure opportunities, interact with siblings and friends and participate in normal childhood activities.**

This article of the charter highlights a significant difference in the provision of adult and paediatric palliative care. Whilst most adults requiring palliative care would have completed their education and tertiary studies, children and young people usually experience the additional burden of having their schooling and tertiary studies interrupted and/or seriously affected by their illness. For this reason it is important that wherever possible the child's teacher/educator be included in the multi-disciplinary team providing holistic care. When it is feasible, and deemed not to be detrimental to the health and wellbeing of the particular patient, children and young people should be both encouraged and enabled to continue with their schooling or tertiary studies in one form or another. This is not only the child's right; it provides purposeful distraction and promotes the child's feelings of self-worth and self-esteem.

Another distressing consequence of a life-limiting or life-threatening illness can be the removal or isolation of the child or young person from normal social interactions and activities associated with childhood and young adulthood. For this reason, where possible, social contact between life-limited children and their siblings and peers will always be encouraged and facilitated by responsible palliative care professionals.

For the younger child, play is not only his or her natural activity, it is the essence of life. Play is the reflection of the child's reality and the means by which they learn, experience the world, give expression to their innermost feelings and emotions, and through which they discover more about who they are and their place in the world. More than most, life-limited children benefit from the distraction and the therapeutic effect of play to assist in coming to terms with their

condition. Play also offers children a vehicle through which they can explore and express their feelings, their concerns and their unspoken fears.

#### **Article Seven**

The seventh article of the Charter states:

**The child and the family shall be given the opportunity to consult with a paediatric specialist with particular knowledge of the child's condition where possible, and shall remain under the care of a paediatrician or doctor with paediatric knowledge and experience.**

A sick child has the right to the very best medical attention available. Children with palliative care needs should have access to medical professionals, including doctors and paediatricians, with specialised knowledge of paediatrics and of their condition or illness as well as to those with training and qualifications in paediatric palliative care. In many parts of the developing world, access to doctors with such specialised training and qualifications is not possible. In these instances, the child should be treated and cared for by the medical professionals who are best suited and available. Medical professionals experienced in working with children should be sought wherever possible.

#### **Article Eight**

The eighth article of the Charter states:

**The child and the family shall be entitled to a named and accessible key-worker whose task it is to build, co-ordinate and maintain appropriate support systems which should include a multi-disciplinary care team and appropriate community resources.**

Coping with the day-to-day maintenance and medical needs of a child with a disability and/or a life-limiting or life-threatening condition can be an overwhelming experience for both the affected child and his or her primary caregivers. A keyworker should be assigned in order to support the child and family and be the link by which all other necessary services are accessed and used effectively. Often this keyworker will be a social worker or an auxiliary social worker. Depending on the condition and diagnosis, some children need more complex medical and therapeutic interventions than others, from a range of professionals. Apart from the paediatrician and medical specialist, these could include physiotherapists, occupational therapists, speech therapists, psychologists, dieticians, counsellors and educators. Specific roles of a keyworker include:

- provision of important information to the child and to the family as well as to other members of the inter-disciplinary team

- responsibility for identifying and assessing the specific needs of the child and his or her family
- provision of emotional support to the child and his or her family
- organisation and co-ordination of timely support
- willingness to act as an advocate for the patient when this should be necessary.<sup>1</sup>

Caregivers should be led to understand that although desirable, it is not always possible to have the same keyworker throughout the trajectory of the child's illness. The specific and changing needs of the patient as well as limited resources may play a role in determining the assignment or reassignment of a keyworker.

#### Article Nine

The ninth article of the Charter states:

**The child's home shall remain the centre of care whenever possible. Treatment outside of this home shall be in a child-centred environment by staff and volunteers, trained in palliative care of children.**

The WHO definition of paediatric palliative care states:

**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.<sup>2</sup>**

It is always preferable and desirable to keep the child in an environment which is familiar and in which he or she will suffer the least distress. Usually, this will be the child's own home, but it is important that the palliative care team are aware of the particular child's living conditions in order to assess its suitability. If a child lives in unsanitary conditions, or in a home where access to clean water is limited, these factors will obviously be detrimental to their care. In some cases small and affordable changes and additions to the home are all that will be needed, in others the family may have to buy or hire expensive equipment in order to keep the child at home.

#### Article Ten

The tenth article of the Charter states:

**Every child and family member, including siblings, shall receive culturally appropriate, clinical, emotional, psychosocial and spiritual support in order to meet their particular needs. Bereavement support for the child's family shall be available for as long as it is required.**

Children and their families coping with life-threatening illness and the end of life are exposed to a range of factors that may affect their psychological health. They often have to adjust to a huge amount of change, which demands a certain amount of emotional maturity and strength. Some of the aforementioned events can be the most stressful faced in one's life and it is important to have support from others at this time.<sup>3</sup>

Siblings should not be forgotten in all the drama that surrounds the illness of a young child. When parents are expending all their energies looking after the sick child, siblings can often feel as if they are in the way and are not loved as much. Sometimes they do not have a clear understanding of the illness which has affected their family and may have fears which need to be addressed. The most effective management of this is for the social or care worker to ensure that there are open lines of communication within the family and to persuade its members to find suitable strategies to manage any problems that may occur as a result. If possible, parents should be encouraged to spend focussed time alone with the siblings of a sick child. The UK charity, Sibs, is specifically for people who grow up with a brother or sister with any disability, long-term chronic illness, or life-limiting condition. They recognise that siblings have specific needs requiring attention at different stages of their lives and aim to provide information and support to this group. Find out more about Sibs at [www.sibs.org.uk](http://www.sibs.org.uk)

Another group of family members who need consideration during the illness of a child are grandparents. Grandparents will often hide their own pain in an attempt to provide comfort and support for the parents of the sick child. In some countries, especially those ravaged by HIV/AIDS, it is often the grandmother of the child who will be left looking after HIV-infected grandchildren as a result of the death of the child's mother from an AIDS-related illness.

The length of bereavement is different for everyone. Some families have their own community and faith-based support systems and do not need the same amount of support from the hospice staff or care workers as others. A good palliative care programme offers bereavement support to all members of the family for as long as it is needed, whether this is for a month, a year or a number of years. The hospice may offer therapeutic support sessions for family members which run for a finite number of sessions, after which individual members of the family are encouraged to make contact whenever they feel the need.

**References**

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