

The ICPCN (International Children's Palliative Care Network) Charter

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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 un-chartered 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 11th 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 article expands on the first five articles of the ICPCN 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 (Association for Children's Palliative Care) Charter (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 and future writing for IQJ, I would like to discuss the ten articles 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 One

The first article of the Charter states:

Every child should expect individualised, culturally and age-appropriate palliative care as defined by the World Health Organization. The specific needs of adolescents and young people shall be addressed and planned for.

The World Health Organization (WHO) defines palliative care for children as follows:

Paediatric palliative care is a special, albeit closely related field to adult palliative care; the following principles apply to all chronic disorders:

- Palliative care for children is the active, total care of the child's body, mind and spirit, and also involves giving care to the family
- It begins when the illness is diagnosed, and continues regardless of whether 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 multi-disciplinary 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 in children's homes
- A paediatric palliative care service's main purpose is patient care. Providing the most appropriate care in a setting that supports and responds to each patient's unique needs requires a high level of planning and co-ordination.

What is culturally and age-appropriate palliative care?

Caring for children in a manner which is respectful and culturally appropriate can be challenging for health

care providers and often requires that this person step out of their own comfort zone. It is not unusual for grief-stricken families to seek answers from alternative medicine or look for miracles from within their own religions and cultural belief systems. The health worker needs to allow families the space to make the journey through this period of hope and uncertainty in a way that is completely supportive and non-judgemental. Utmost respect for the culture of the child and his or her family is not optional within good paediatric palliative care.

Age-appropriate palliative care takes into consideration not only the chronological age of the child, but the developmental stage through which the child is passing at the time of diagnosis and throughout the treatment. All children develop, and sometimes regress, at a unique rate through physical, cognitive, social, emotional and spiritual developmental stages. The rate at which they progress through these stages will be determined by factors such as genetics and circumstance as well as the illness or condition with which the child is afflicted. For example, a child's understanding of death is normally determined by his or her cognitive development and ability to think in abstract terms – but will to an even greater extent be affected by the child's personal experience. Many children in Africa and India have a deeper understanding of the permanence of death at a younger age than their western counterparts due to repeatedly experiencing the deaths of friends and family members as a result of the AIDS pandemic. It is also not unusual for a child with limited mobility to have an advanced cognitive ability from greater exposure to adult company as well as games and toys requiring mental problem solving skills rather than movement. Accordingly, this child is also more likely to demonstrate a mature understanding of the ultimate consequences of his or her illness. It is the task of the health care provider to accurately assess and regularly reassess the child's levels of development in all areas and provide appropriate palliative care for him or her accordingly. Members of the paediatric palliative care team are trained to make a thorough and accurate assessment not only of the child's clinical condition but also his or her developmental levels in order to tailor individualised treatment and care. These assessments are on-going.

Adolescents and young adults have very specific palliative care needs which are related to their age, the physical changes in their bodies and their own personal stages of development – along with a more complete understanding of their illness, condition or diagnosis. Adolescence is a time when a child wishes to assert independence but often the illness or condition does not allow this natural separation from parents or primary caregivers to take place. Adolescents have a very strong urge to 'belong' to a group of like-minded peers and the life-limited adolescent

constantly struggles with feelings of isolation, and of being different. During this time some may begin to feel the effects of stigmatisation, especially if afflicted with a disease such as HIV/AIDS. It is also a time of rebellion and the palliative care team will need to make every effort to give the adolescent opportunities to make decisions relevant to his or her own treatment and care.

Young adults may also have to face the transition from child-centred health services into those catering for adults which can mean the traumatic severing of ties that have been forged over many years. This process of transition needs to be carefully planned for in advance and carried through with a great deal of sensitivity.

Article Two

The second article of the Charter states:

Palliative care for the child and family shall begin at the time of diagnosis and continue alongside any curative treatments throughout the child's illness, during death and in bereavement. The aim of palliative care shall be to relieve suffering and promote quality of life.

Palliative care ideally begins at the time of diagnosis of a life-limiting or life-threatening illness or condition with the aim to provide comfort and support for the family, and symptom control and pain relief for the child. Provided alongside curative treatment, it allows a less distressing transition into end-of-life care and planning should treatment fail. Care workers are always ready to celebrate with the child and family in the case of a cure, rehabilitation or remission. 'I flunked hospice three times!' one young man battling a heart condition announced proudly before finally succumbing to his illness many years after medical professionals had expected he would. When providing end-of-life care for the child and the family, palliative care workers do everything possible to make this difficult time as meaningful and free from unnecessary stresses as possible. For this to happen, careful prior planning is needed, taking into account the desires and wishes of both the child and the child's family. At the time of death and after death, the palliative care team provide bereavement care to the family for as long as it is needed.

Palliative care for the family may include counselling and therapy sessions with siblings, relatives and grandparents where necessary. The illness and anticipated death of a child has a very large ripple effect and the multi-disciplinary team takes cognisance of the needs of the entire family while caring for the sick child. In some countries, including UK, there are support groups specifically for the siblings of children

with life-limiting and life-threatening conditions to help them deal with feelings they may have such as isolation, helplessness, jealousy and grief. (Sibs www.sibs.org.uk)

Article Three

The third article of the Charter states:

The child's parents or legal guardians shall be acknowledged as the primary caregivers and recognised as full partners in all care and decisions involving their child.

There is a helplessness which all parents feel when faced with the diagnosis of their child's life-shortening illness. This is exacerbated by any medical professionals who do not involve them in both major and minor decisions regarding treatment and care. Trained and responsible palliative care professionals will always provide parents or primary caregivers with all the necessary information in order that they may participate in making informed decisions regarding the treatment and care of their child. This leads naturally to the fourth article:

Article Four

The fourth article of the Charter states:

Every child shall be encouraged to participate in decisions affecting his or her care, according to age and understanding.

Children have the right to be consulted and must be given opportunities whenever possible to make decisions regarding their own care and treatment. The level of participation in decision-making is based on the palliative care worker's on-going assessment of the child's ability to understand the issues and complexities of the situation.

A simple example of the importance of this concept was brought home to a palliative care worker who was having great difficulty getting her six-year-old patient to take a very necessary pain medication orally. When the child spat out the first medication, repeated this with another medicine and refused to even try a third, an injection seemed the only alternative. Trying something different, the nurse lined up the three bottles of medication in front of the child and explained, 'You do need to have this medicine but you get to choose which one you will have.' The child carefully considered the three alternatives and then pointed to one of them, which she proceeded to swallow without any further struggle. She had been empowered by being given a simple choice.

Article Five

The fifth article of the Charter states:

A sensitive but honest approach will be the basis of all communication with the child and the child's family. They shall be treated with dignity and given privacy irrespective of physical or intellectual capacity.

It is completely normal for parents to initially want to protect both themselves and their sick child from the truth about the illness and the probability or even certainty of death at some time in the future. The sick child may also feel the need to protect his or her parents by not talking about death as they sense it is taboo or too difficult for their parents to discuss. It can become 'the elephant in the room' that everyone is trying to ignore. In some African cultures it is believed that talking of death attracts it to you – so it is never mentioned. Palliative care-trained professionals are sensitive but honest when communicating with the child and will encourage the same honesty between the child and his or her parents. Palliative care workers have found that children are frequently underestimated by their parents and by the health care professionals and tend to know and understand a great deal more than they are given credit for. A responsible professional trained in palliative care will allow the child to ask the difficult questions and will reflect these back to the child in a sensitive way in order to understand exactly what it is the child knows and how much they really want to know.

The issue of dignity and privacy is central to all good paediatric palliative care. While children may not always be as sensitive to issues involving privacy as an adult this does not mean that they do not deserve or have the right to be treated with exactly the same respect and given the same degree of privacy during treatment and consultation as would an adult. No matter what the child's mental or physical abilities, circumstances, culture, beliefs and clinical condition, all care given and treatment carried out is done so with great respect for the child's humanity and ultimate frailty.

The ICPCN charter is available in 21 different languages and can be downloaded from the ICPCN website at www.icpcn.org.uk