



THE CHARTER OF THE RIGHTS OF THE DYING CHILD “The Trieste Charter”

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**Second Congress on Paediatric Palliative Care
A Global Gathering
Rome, November 19-21, 2014**

Pediatric Palliative Care

Worldwide there are 7-9 million children with life-limiting and life-threatening conditions requiring palliative care.

The estimated global number of children in need of palliative care at the end-of-life is almost 1,2 million.

The rights of these dying children are often unrecognized and hence not respected.

These dying children and their families pose special problems: the usual undulatory, unpredictable course, which leaves space for intervention, some possibility for future planning and hope, is substituted by the certainty of imminent death, which cancels any hope and projection for the future, generating complex emotional reactions in the family and in the care givers that can impair their recognition of the real needs of the child.



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The aim of the chart is to highlight the rights of these young patients that age, condition, culture, location and time, cannot, nor should not, undermine and the duties of the care givers to respect those rights.

THE HISTORY OF THE CHARTER

1. Review of the literature and pertinent publications.
2. May 2013 - Compilation of a First Draft of the Charter of the Rights of the Dying Child.
3. September 2013 - a Consensus Conference of 50 Italian experts selected on the basis of their scientific publications, professional background/occupation, institutional role and experience.
4. November 2013 - Second Draft based on outcome of the Consensus Conference.
5. April 2014 - Peer-review by a Panel of International experts.
6. June 2014 - Final version of the Charter of the Rights of the Dying Child.

THE STRUCTURE OF THE CHARTER

Glossary

The 10 rights of the dying child

The duties deriving from those rights

The explanatory notes

The references and documents

RIGHT 1. To be considered as a 'person' until death regardless of age, location, condition and care setting.

To respect the child's personality, individuality, values, life-history and daily routine by providing appropriate support that enables the child to feel alive and present until the end-of-life.

To always safeguard the child's dignity through respectful behaviour even if the child is in a state of partial or complete unconsciousness due to the progression of the disease and/or treatments.

RIGHT 2 . To receive effective treatment, through qualified, comprehensive and continuous care, for pain and for other physical and psychological symptoms causing suffering.

To provide palliative care services delivered by dedicated and appropriately trained multi-professional and interdisciplinary care teams.

To assess the presence and level of pain and other symptoms causing suffering using specific tools adapted to the child's age and condition.

To provide effective prevention for foreseeable symptoms and, with particular attention to pain, effective treatment for those already present.

To propose therapeutic strategies that respect the child's autonomy, dignity, social life, circadian rhythms and privacy and that avoid futile, invasive, painful and burdensome procedures.

RIGHT 3. To be listened to and properly informed about his/her illness with due consideration to his/her wishes, age and ability to understand.

To communicate with the child providing understandable information about diagnosis, prognosis and treatment in a way that permits an on-going dialogue and allows time and space for listening.

RIGHT 4. To participate, on the basis of his/her abilities, values and wishes, in care and treatment choices regarding his/her life, illness and death.

To listen to the child and offer opportunities for verbal and non-verbal expression concerning the possible choices and treatment options regardless of his/her age.

To bear in mind that the child is a member of a family and to be aware of the way in which decisions have been taken by the family and will probably be made in the future.

To consider that, in the case of very young children, if properly supported, parents are an essential aide for understanding the child's wishes and treatment preferences.

To recognize that parental authority gradually diminishes as the child's competence increases.

To endeavour to resolve possible divergences between the child's wishes and those of the family bearing in mind that the child's "best interest" must prevail.

RIGHT 5. To express his/her feelings, wishes and expectations and have these taken into consideration.

For family members: to be able, within their specific aptitudes and competencies, provide the child with emotional support and to recognize both expressed and unexpressed feelings, wishes and expectations.

For the healthcare team: to be trained, according to their professional role, to recognize, value and support the child's feelings and emotions.

For people close to the family: to help them to support the child and protect his/her vulnerability.

To help the child live daily life with his/her own projects and expectations and encourage him/her to express interests and emotions through activities such as art, music, play, etc.

RIGHT 6. To have his/her cultural, spiritual and religious principles respected, and receive spiritual care and support in accordance with his/her wishes and choices .

To consider the best interest of children of all ages and in all circumstances, in a way that respects and sustains the cultural, spiritual, religious and family values, which are the mainstays of individual identity.

To allow the child and family to express their emotions and suffering according to their own culture and religion.

To use cultural mediators to ensure that the child and family of any ethnic group or language can properly express their needs.

To be aware of and support the child and family's spiritual needs according to their cultural models and ethnic traditions.

To create, during the final stages of illness, an environment/setting where the child and family can live and express their practices and rituals linked to death and mourning, in accordance with their cultural and spiritual orientation.

RIGHT 7. To have a social and relational life suitable to his/her age, condition and expectations

To encourage and reinforce the child's interaction with his/her environment through appropriate planning and organization.

To facilitate and maintain the child's relationships through the rehabilitation, support and reinforcement of his/her motor, sensory, cognitive, communicative and social skills.

To offer the child appropriate recreational tools, settings and activities, and create opportunities for play and social interaction.

To allow the child to continue his/her educational process, either through school attendance or other educational and cultural activities.

RIGHT 8. To be surrounded by family members and loved ones who are empowered in the organization and provision of the child's care, and supported in the management of the emotional and financial burdens that arise from the child's condition.

To respond to the child's need for the presence of family members and loved ones, in accordance with his/her wishes.

To provide the family with constant, timely, detailed information about prognosis and the clinical situation.

To listen to, educate and support the parents in caring for their child, helping them to maintain their parental role.

To provide all the family members, including siblings, with the necessary psychological, emotional and spiritual support throughout the disease process, death and into bereavement.

To help the family to overcome any financial, social and employment issues, including access to legal support, even through the involvement of voluntary associations and charities.

RIGHT 9. To be cared for in a setting appropriate for his/her age, needs and wishes, and that enables the family to be close and involved.

To allow the child and family to choose the care setting for end-of-life care.

To ensure the same quality of care and support, regardless of the setting, by providing flexible interventions adapted to the different circumstances.

Whenever possible, to propose and facilitate end-of-life care in the family home with appropriate support for coping with the child's illness and death.

If care delivery in the home is not possible, to ensure that the child is cared for in a setting appropriate for his/her age that permits the constant presence of family members and loved ones.

RIGHT 10. To have access to child-specific palliative care services that respect the child's best interest and avoid futile or excessively burdensome practices and therapeutic abandonment.

To ensure access to palliative care expertise that is specific to the care of children and that continues to provide healthcare support, even when a cure for the underlying condition is no longer possible.

To ensure that medical interventions are only carried out when the benefits to the child plausibly outweigh the adverse effects.

To ensure continuity and quality of care provision between care-settings (home, hospital, hospice).

To avoid inappropriately invasive or burdensome treatments that negatively impact the child's quality-of-life and/or unnecessarily prolong suffering and the dying process.

“The Charter will have achieved its purpose when every person caring for a dying child is capable of staying near to the child until the last moments of his/her life, prepared to accept and embrace his/her death, ensuring due respect and dignity” (F. Benini)

THANK YOU FOR YOUR ATTENTION

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