

A CHARTER OF RIGHTS FOR THE DYING CHILD

The tragic loss of a child is a devastating event for everyone involved. From addressing the needs of distraught family members, to meeting the needs of the health-care providers who are called upon to handle a terminally ill child's complex issues, providing professional, compassionate, and ethical care practices to terminally ill children can sometimes overwhelm even the most experienced of caregivers.

For children who are suffering and coping directly (often in solitude), with the burden of an incurable illness and imminent death; the trauma of separation; and the loss of their future, a Charter provides them with a means by which their rights can be acknowledged and respected.

When those closest to a child refuse to accept the negative progression of a disease or condition, and consequently are unable to recognize/comprehend that the terminal illness and death are real and imminent, many times the child is tragically subjected to unrealistic decision and treatment choices. More often than not, those caring for a dying child will try to protect the child from the truth that they consider too difficult and painful to cope with, by either avoiding any discussions about the topic, or by just blatantly denying what has become the obvious state of affairs. Either way, the child becomes the object of treatment, care, and love, and depending on age, is deprived of his or her role as a person, to be able to speak out, decide, express, and discuss personal feelings, wishes, hopes, and deepest fears.

Based on a 2012 Italian project that was supported and promoted by the Maruzza Lefebvre D'Ovidio Foundation, the Trieste Charter of Rights for Dying Children was formulated, with the goal that the generated (widely-accepted) document could be applied in any clinical situation or circumstance, and be used as a guide by professionals and families caring for children in the terminal stages of an illness.

As such, Cedar Rock is providing the proposal with the intent to help comfort and assist those individuals who are facing difficult quality of life issues during the untimely loss of a child.

Charter of Rights For The Dying Child

A child is:

- *To be considered a person until death, irrespective of age, location, illness, and care setting
- *To receive effective treatment for pain, and physical and psychological symptoms causing suffering through qualified, comprehensive, and continuous care
- *To be listened to and properly informed about his or her illness with consideration for his or her wishes, age, and ability to understand
- *To participate, on the basis of his or her abilities, values and wishes, in care choices about his or her life, illness, and death
- *To express and, whenever possible, have his or her feelings, wishes, and expectations taken into account
- *To have his or her cultural, spiritual, and religious beliefs respected and receive spiritual care and support in accordance with his or her wishes and choices
- *To have a social and relational life suitable to his or her age, illness, and expectations
- *To be surrounded by family members and loved ones who are adequately supported and protected from the burden of the child's illness
- *To be cared for in a setting appropriate for his or her age, needs, and wishes and that allows the proximity of the family
- *To have access to child-specific palliative-care programs that avoid futile or excessively burdensome practices and therapeutic abandonment.