

# RELIGIONS OF THE WORLD CHARTER FOR CHILDREN'S PALLIATIVE CARE

## AUTHORS

*Zaid Ayoub*  
Zaid Ayoub

*Zeenath Ayoub*  
Zeenath Ayoub

*Maddalena Bano*  
Maddalena Bano

*Stefano Bellon*  
Stefano Bellon

*Franca Benini*  
Franca Benini

*Myra Bluebond-Langner*  
Myra Bluebond-Langner

*John Collins*  
John Collins

*Izzedin Elzir*  
Izzedin Elzir

*Mounir Farag*  
Mounir Farag

*Kathleen Foley*  
Kathleen Foley

*Bruno Giussani*  
Bruno Giussani

*Ann Goldman*  
Ann Goldman

*Richard Hain*  
Richard Hain

*Mia Hilborn*  
Mia Hilborn

*Jyh-Gang Hsieh*  
Jyh-Gang Hsieh

*Al-Sayer Margaret*  
Al-Sayer Margaret

*Ruxi Kiman*  
Ruxi Kiman

*Orlinda Leppne*  
Orlinda Leppne

*Diederick Lohman*  
Diederick Lohman

*Joan Marston*  
Joan Marston

## WHEREAS

- Millions of children in the world are affected by serious illnesses that threaten or shorten their lives.
- Each child has full value as a person.
- Children's Palliative Care is a commitment to act in the best interests of those children by focusing on improving the child's and family's quality of life and dignity, and preventing or relieving their physical, psychological, emotional and spiritual suffering. It is not directed either to hasten or postpone death.
- Children are often denied access to good palliative care on the basis of sex, age, ethnicity, religion, diagnosis, or on other grounds such as resource availability.
- In many parts of the world there are challenges in the provision of palliative care, leading to millions of children suffering needlessly.
- Spiritual leaders and leaders of religions and faith-based organisations must take responsibility to influence the culture, customs and choices to address these challenges for the integration of palliative care into national health systems.

Children's Palliative Care (CPC) aims to ensure relief of suffering and the best possible quality of life for seriously ill children and their families from the time of diagnosis, throughout life, dying and bereavement. 'Serious illnesses' are those that are life-threatening and/or life-limiting. CPC includes prenatal care and care for neonates, children and young people with serious illnesses.

## THEREFORE

We, the undersigned, having diverse life-experiences, with different perspectives and expertise, from varied personal, professional, cultural, religious and spiritual backgrounds, have gathered today in Rome, to affirm the essential right of all seriously ill children and their families to receive palliative care appropriate for children. We give strong support to the representatives of faith organisations and religions using different voices – clinical, patients and family, human rights and religious and spiritual – to call for the broadest possible dissemination of Children's Palliative Care.

We believe that everyone involved in the care of these children, as well as governments, policy makers and spiritual and religious leaders, should engage with and support the development, promotion and dissemination of Children's Palliative Care in order that children and their families in all parts of the world have access to Palliative Care.

### The Clinical Voice

Children and families are partners in care. We should respect and support their dignity, human rights, culture, personal beliefs, values, preferences and need for information. CPC is framed by identifying the goals of care of children and their families. Choices and decisions in CPC are also influenced by societal values, health care systems, available resources and access to essential medicines. CPC can be achieved through access to compassionate and well-functioning interdisciplinary teams, which may be supported by volunteers, traditional and community health care providers. All those caring for seriously ill children and their families should hold basic competencies in CPC. Learning should be on going, involve reflective practice, regular assessment, and include supervision and self-care.

### The Voice of Patients and Families

Quality of life flows from the individual himself/herself; living life with his/her family and in his/her community or society and needs should be respected, regardless of the person's condition, length of life or age. Living and growing with dignity has the same requirements as does enjoying a good quality of life: to be able to live to the fullest that one can as others do, to love and to be loved by one's family in a chosen place, to be a member of a larger inclusive community, that is accepting and supportive, to receive the care one needs and be relieved of pain and to have one's family supported; regardless of cultural, religious, spiritual or socio-economic background. Dying with dignity means living one's life with quality and dignity throughout its course, until its very end. Faith-based, religious and social organisations should recognise and support families and children when palliative care is the appropriate approach to care and treatment. They should facilitate the practical support which ill children and their families need in their everyday lives. They should promote the inclusion of ill children in community, religious life and activities as well as develop an understanding of the ill child as a person like all others. Faith-based, religious and social organisations should promote the understanding that illness, suffering and death together constitute a mystery which judges no one and which all must face together with mutual respect, compassion and without pity.

### The Voice of the Child's Rights

The right to palliative care for children, as well as for every human being with serious illness, is an integral part of the right to health. It flows from other core principles enshrined in international human rights law, especially in the United Nations Convention on the Rights of the Child. This right requires a strong commitment to ensure that children and their families have access to specific and effective palliative care and pain treatment, to allow them to grow and develop to their full potential. This responsibility is shared by governments, health system actors, civil society and religious communities. National governments should develop palliative care plans within the framework of national strategies and universal health coverage, that progressively ensure the availability, accessibility, affordability and acceptability of quality programs. This should happen in an equitable way without discrimination and in all settings where children receive care including community and home-based paediatric care. National governments need to facilitate the accessibility to affordable essential palliative care medicines for children and include paediatric formulations on their national medicines lists. Systemic and regulatory barriers should be eliminated. Palliative care for children and families should be integrated within the curriculum of health care professional training programs. Culturally and age appropriate specific communication training should also be included. National governments should lead a concerted effort for continuing education of all relevant active health professionals in palliative care for children.

### The Spiritual and Religious Voice

The life and flourishing of every child at every stage and age are of intrinsic value. Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices. It is a universal domain; a need which demands the same attention and training in palliative care as physical or psychosocial domains, but which is currently considerably less developed. In paediatric palliative care, it needs to be set in the specific context of the child; a developing being whose understanding is constantly changing. Religion, for many people, is an expression of spirituality. It describes the traditions and practices that provide a means for expressing their beliefs and values. Religion refers to a set of rules or guidelines (including rituals) that are associated with a particular belief-system that can provide a structure and space for emotional energy and intense grief as well as opportunities for socially shared meanings, and affirmation of communal bonds. Dignity reflects the intrinsic value of every child. Every child deserves respect, care and compassion. The aim of palliative care is to enable the seriously ill or dying child to live a dignified life. Religions advocate that preserving dignity is the moral and imperative responsibility of all those caring for the child. The quality of an individual life needs to be understood in the specific child. The seriously ill child is dependent, vulnerable and may lack autonomy. In many parts of the world, faith-based organisations provide healthcare. In any healthcare environment, even non-religious ones, faith leaders can be important members of the healthcare team. With appropriate training, faith leaders could play a number of roles in the practical care of seriously ill children and their families. There are three levels at which faith leaders can contribute to the care of children. They can help care for the individual child, for example by constructively challenging understandings about the nature and value of child suffering. They can sensitise and educate the healthcare team to address issues in the spiritual domain. They can, and always should, influence the culture of their community and society.

Rome, 10<sup>th</sup> November 2015

*Silvia Lefebvre D'Ovidio*  
Silvia Lefebvre D'Ovidio

*Anne Merriman*  
Anne Merriman

*Kshama Metre*  
Kshama Metre

*Mary Ann Muckaden*  
Mary Ann Muckaden

*Marcello Orzalesi*  
Marcello Orzalesi

*Francesco Ostellari*  
Francesco Ostellari

*SARA PAVAN*  
Sara Pavan

*Natasha Kjaerstad Pedersen*  
Natasha Kjaerstad Pedersen

*Renzo Pegoraro*  
Renzo Pegoraro

*Carlo Peruselli*  
Carlo Peruselli

*Christina Puchalski*  
Christina Puchalski

*Lukas Radbruch*  
Lukas Radbruch

*Muttacaud R. N. Rajagopal*  
Muttacaud R. N. Rajagopal

*Traugott Roser*  
Traugott Roser

*Stefano Semplici*  
Stefano Semplici

*Marco Spizzichino*  
Marco Spizzichino

*Avraham Steinberg*  
Avraham Steinberg

*Alexander Tkachenko*  
Alexander Tkachenko

*Chakrapani Vasudevan*  
Chakrapani Vasudevan

*Giovanni Vena*  
Giovanni Vena

*Valentina Vittadello*  
Valentina Vittadello

*Joanne Wolfe*  
Joanne Wolfe

*Antonella Zamboni*  
Antonella Zamboni