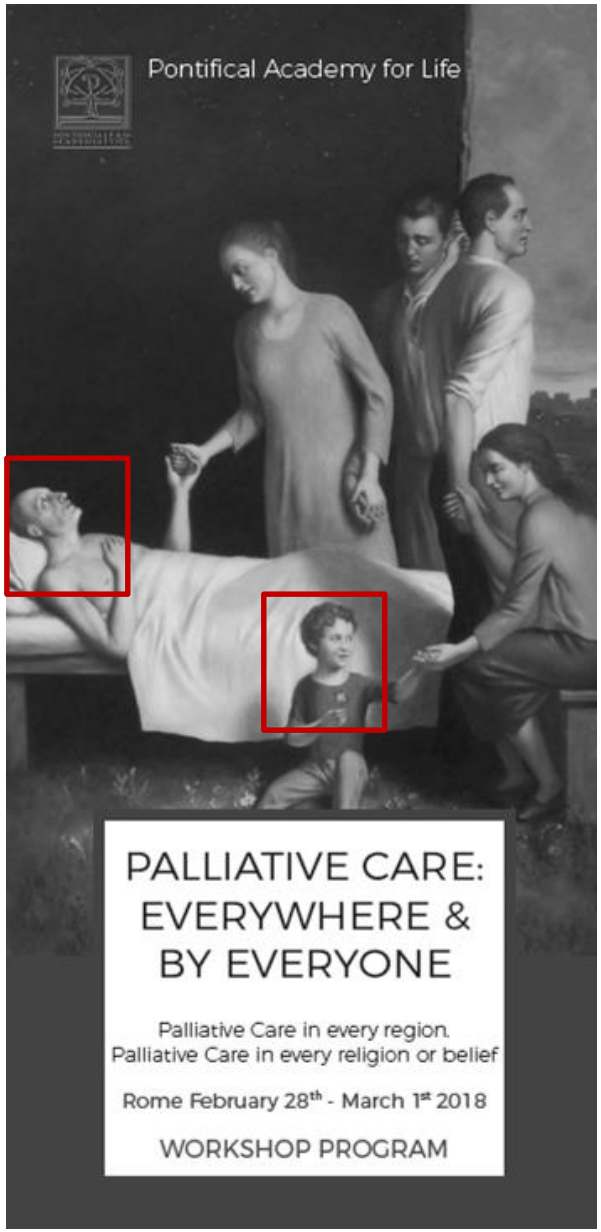
FONDAZIONE MARUZZA ONLUS
CHILDREN'S PALLIATIVE CARE

TOGETHER, FOR A BETTER TODAY.



The vision behind the **Relingions of the World Charters for Palliative Care for Children** and **for Older People** of the Maruzza Foundation

Augustiniaum Institute
Vatican City, Rome, March 1st 2018

Pain - Suffering - Death

Pain - Suffering - Death

The realty of the problem with distressing consequences

The patient


The burden of the illness
Separation
Distress
Anxiety
Anger
Loneliness
Loss of hope
Fear of the future

The two extremes are similar for their vulnerability…

PALLIATIVE CARE

The core values of palliative care concern the holistic approach towards the patient and his or her family, the focus on quality of life and dignity, patient autonomy, coordination and continuity of care.

… give to age what the age needs

Children's Palliative Care

Give Value To Time
Respect The Dignity Of The Person

Original Article

Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis

Stephen R. Connor, PhD, Julia Downing, PhD, and Joan Marston, RN, MA

Worldwide Hospice Palliative Care Alliance and International Children's Palliative Care Network (S.R.C.), Fairfax Station, Virginia, USA; International Children's Palliative Care Network (J.D.), Kampala, Uganda; International Children's Palliative Care Network (J.M.), Bloemfontein, South Africa

Worldwide, there are 20 million children with incurable illness/conditions with complex healthcare needs

Each year, in the United States more than 500,000 children are born with or contract an incurable illness/condition.

In Italy, there are more than 30,000 children eligible for children's palliative care

20% children have cancer disease

Each one of these young patients impacts the life of 300 people

Technological and scientific advancements

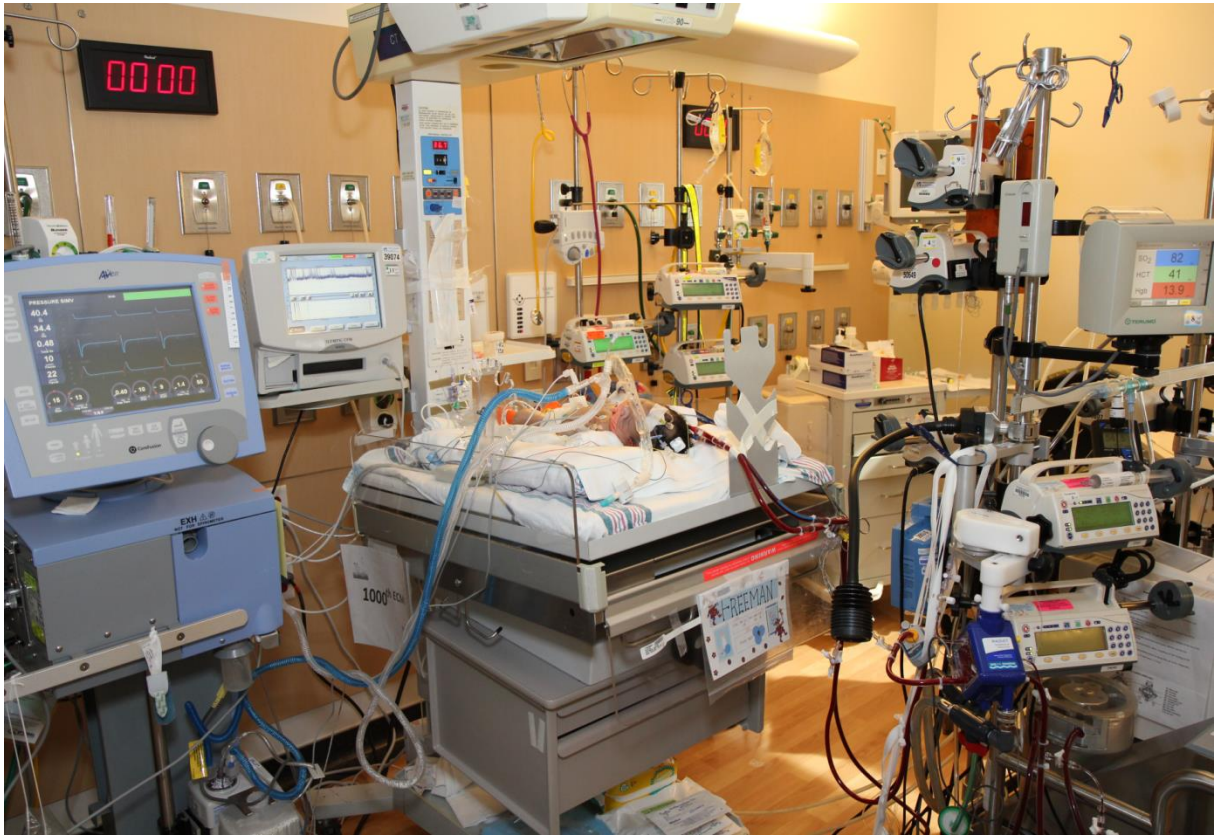
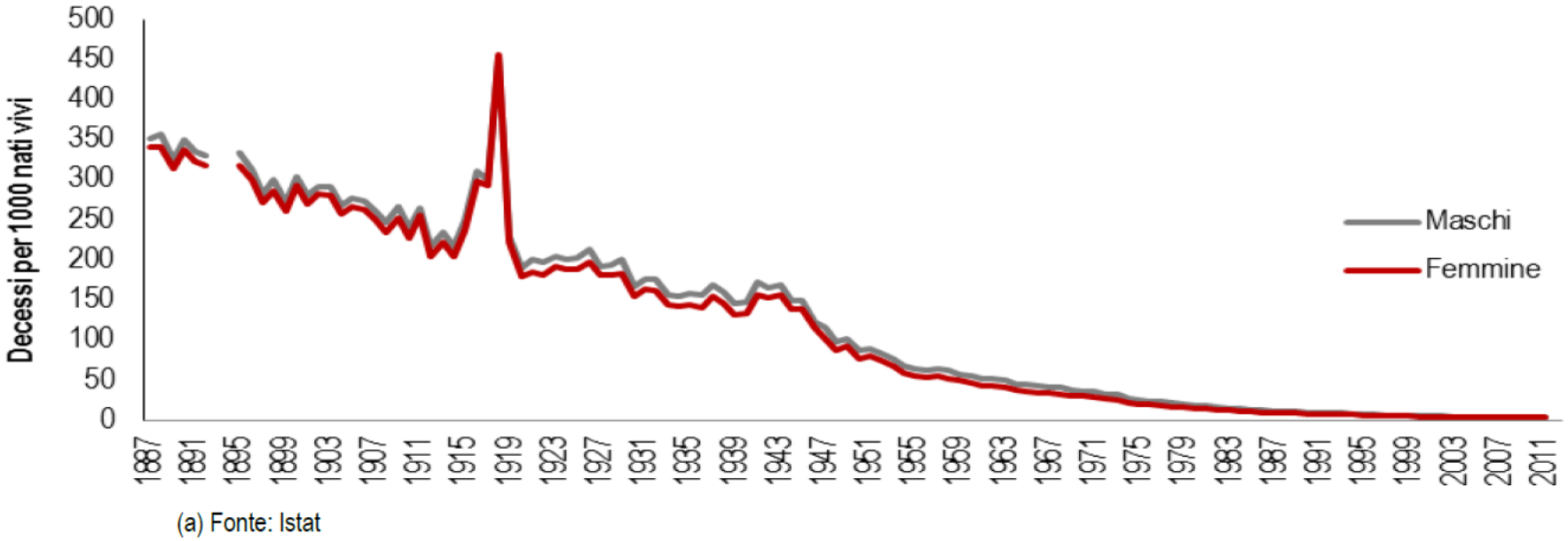


FIGURA 2. MORTALITY RATES IN ITALY FOR CHILDREN UNDER 5YRS FROM 1887 TO 2011



(a) Fonte: Istat

The NEW ENGLAND JOURNAL of MEDICINE

ESTABLISHED IN 1812 FEBRUARY 16, 2017 VOL. 376 NO. 7

Table 2. Survival and Neurodevelopmental Outcomes at 18 to 22 Months of Corrected Age.

Outcome	Epoch 1 (2000–2003)		Epoch 2 (2004–2007)		Epoch 3 (2008–2011)		P Value†
	no./total no.	*% (95% CI)**	*no./total no.*	*% (95% CI)**	*no./total no.*	*% (95% CI)**	
All infants‡							
Survival without neurodevelopmental impairment	217/1391	16 (14–18)	250/1535	16 (15–18)	276/1348	20 (18–23)	0.001
Survival with neurodevelopmental impairment	207/1391	15 (13–17)	209/1535	14 (12–15)	211/1348	16 (14–18)	0.29
Death	967/1391	70 (67–72)	1076/1535	70 (68–72)	861/1348	64 (61–66)	<0.001
Survival without neurosensory impairment	340/1380	25 (22–27)	391/1533	26 (23–28)	395/1348	29 (27–32)	0.01
Survival with neurosensory impairment	73/1380	5 (4–7)	66/1533	4 (3–5)	92/1348	7 (6–8)	0.01
Infants born at 22 wk							
Survival without neurodevelopmental impairment§	2/241	1 (0–3)	4/274	1 (1–4)	3/234	1 (0–4)	0.80
Survival with neurodevelopmental impairment§	4/241	2 (1–4)	9/274	3 (2–6)	5/234	2 (1–5)	0.46
Death	235/241	98 (95–99)	261/274	95 (92–97)	226/234	97 (93–98)	0.39
Infants born at 23 wk							
Survival without neurodevelopmental impairment	34/496	7 (5–9)	55/489	11 (9–14)	59/450	13 (10–17)	0.005
Survival with neurodevelopmental impairment	63/496	13 (10–16)	41/489	8 (6–11)	51/450	11 (9–15)	0.08
Death	399/496	80 (77–84)	393/489	80 (77–84)	340/450	76 (71–79)	0.11
Infants born at 24 wk							
Survival without neurodevelopmental impairment	181/654	28 (24–31)	191/772	25 (22–28)	214/664	32 (29–36)	0.007
Survival with neurodevelopmental impairment	140/654	21 (18–25)	159/772	21 (18–24)	155/664	23 (20–27)	0.44
Death	333/654	51 (47–55)	422/772	55 (51–58)	295/664	44 (41–48)	<0.001

* Unadjusted binomial confidence intervals were determined with use of the Wilson method.
† P values were determined using chi-square tests.
‡ Included are 4274 infants who had data available on the primary outcome.
§ Among the 27 surviving infants born at 22 weeks, the median (interquartile range) gestational age was 22 weeks 5 days (22 weeks 4 days to 22 weeks 6 days) and birth weight was 570 g (510 to 620).

Specialist paediatric palliative care services: what are the benefits?

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Received 18 September 2016
Accepted 3 February 2017
Published Online First
4 April 2017

ABSTRACT

Background The number of children and young people (CYP) living with life-limiting and life-threatening conditions is rising. Paediatric palliative care is a relatively new aspect of healthcare, the delivery of which is variable, with a wide range of healthcare and voluntary sector providers involved. Policy recommendations are for Specialist Paediatric Palliative Care (SPPC) services to be supported by a physician with specialist training.

Aim To examine the research evidence regarding the distinct benefits of SPPC services, with 'Specialist Paediatric Palliative Care' defined as palliative care services supported by a specialist physician.

Method Systematic review of studies of SPPC services published in English from 1980 to 2016. Keyword searches were carried out in medical databases (Cochrane, PubMed, EMBASE, CINAHL and AMED) and a narrative synthesis.

Results Eight studies were identified, most of which were retrospective surveys undertaken within single institutions; three were surveys of bereaved parents and three were medical notes reviews. Together they represented a heterogeneous body of low-level evidence. Cross-cutting themes suggest that SPPC services improve the quality of life and symptom control and can impact positively on place of care and family support.

Conclusions Current evidence indicates that SPPC services contribute beneficially to the care and experience of CYP and their families, but is limited in terms of quantity, methodological rigour and

What is already known on this topic?

- The number of children and young people (CYP) living with life-limiting and life-threatening conditions is rising with continuing advances in clinical medicine.
- There are international recommendations and standards for Specialist Paediatric Palliative Care (SPPC) services, but this is a relatively new subspecialty and is inconsistently available.
- The more universal adoption of recommendations and standards requires significant investment of resource, which is difficult to achieve.

What this study adds?

- This is the first systematic review of research related to the evaluation of SPPC.
- The review identifies a summary of the evidence that suggests that SPPC provides benefit to CYP and families.
- Key themes have been identified to inform future service development and research in paediatric palliative care.


Ministero della Salute

COMITATO TECNICO SANITARIO

Sezione O

"Sezione per l'attuazione dei principi contenuti nella Legge 15 marzo 2010, n.38 recante disposizioni per garantire l'accesso alle cure palliative e terapia del dolore" D.M. 20 maggio 2015

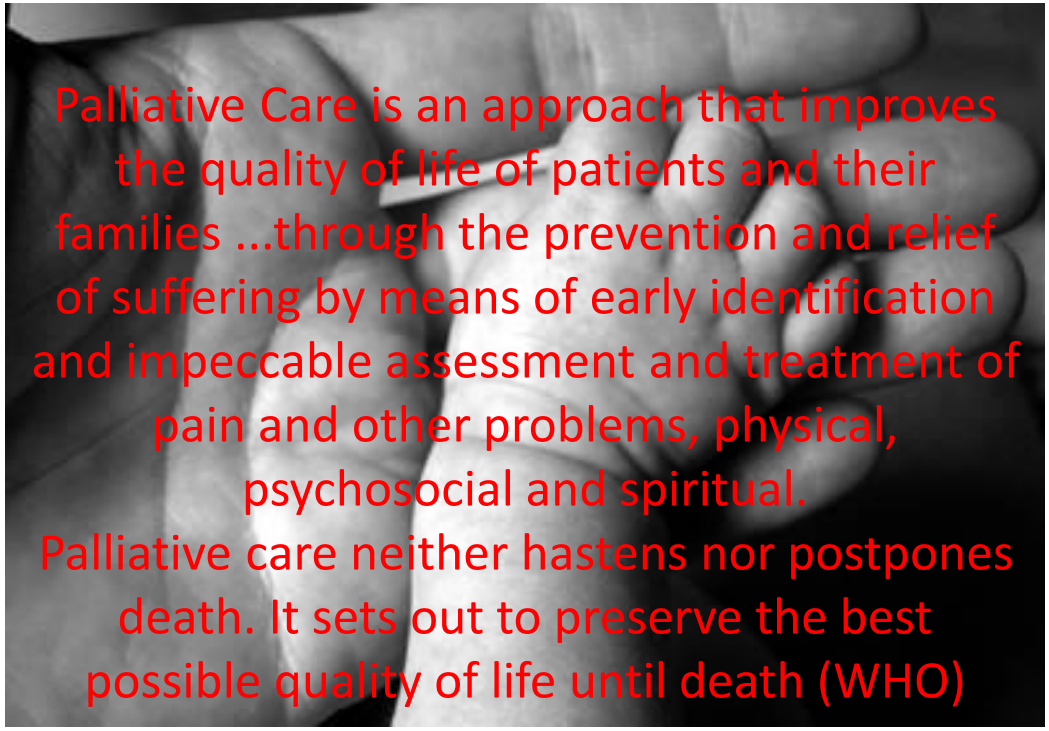
TAVOLO TECNICO TERAPIA DEL DOLORE
E CURE PALLIATIVE PEDIATRICHE

Monitoraggio ed analisi dello stato di realizzazione e sviluppo delle Reti regionali di Terapia del Dolore e Cure Palliative Pediatriche

5% of children with incurable illness in Italy have access to children's palliative care services (15% of children with cancer)

Access to children's palliative care is conditioned by the child's pathology, age and place of residence

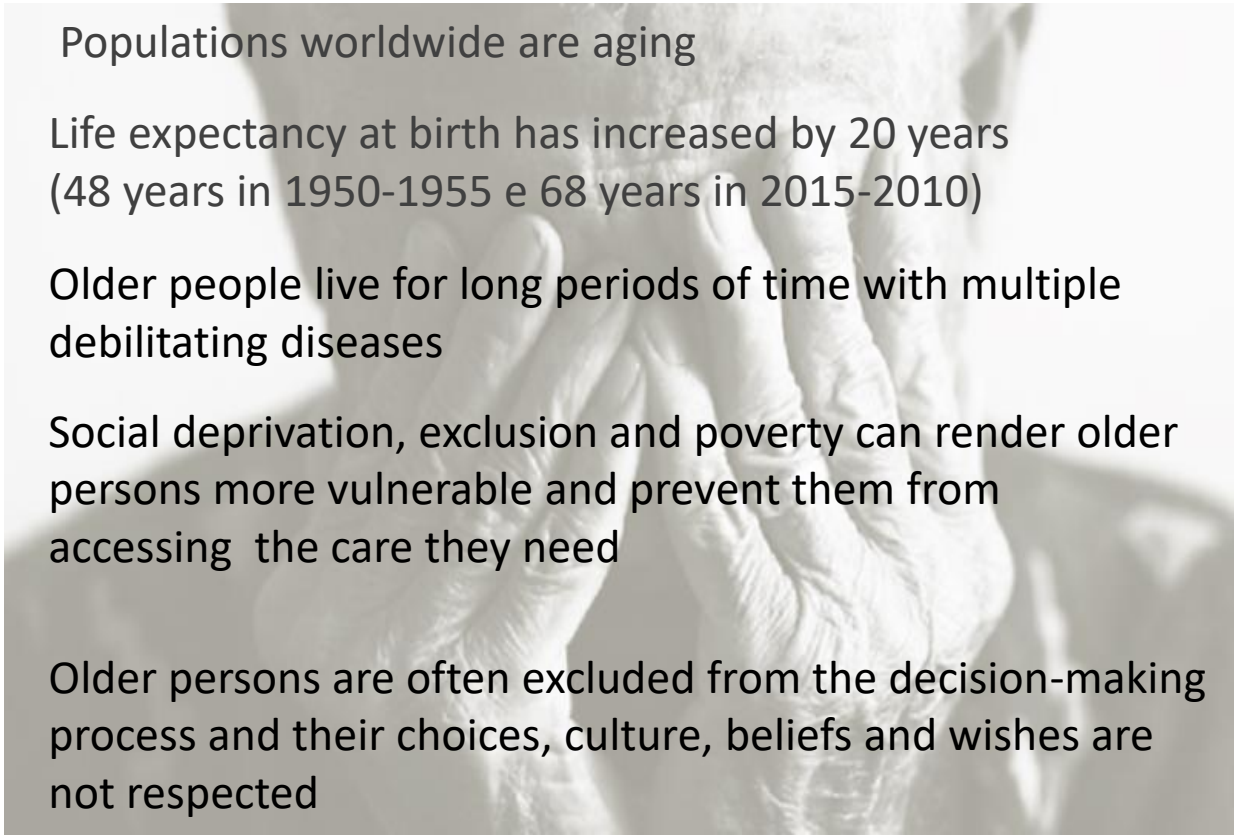
Palliative care for Older People



Give Value To Time

Respect the Dignity Of The Person

Palliative care for older people



Populations worldwide are aging

Life expectancy at birth has increased by 20 years
(48 years in 1950-1955 e 68 years in 2015-2010)

Older people live for long periods of time with multiple debilitating diseases

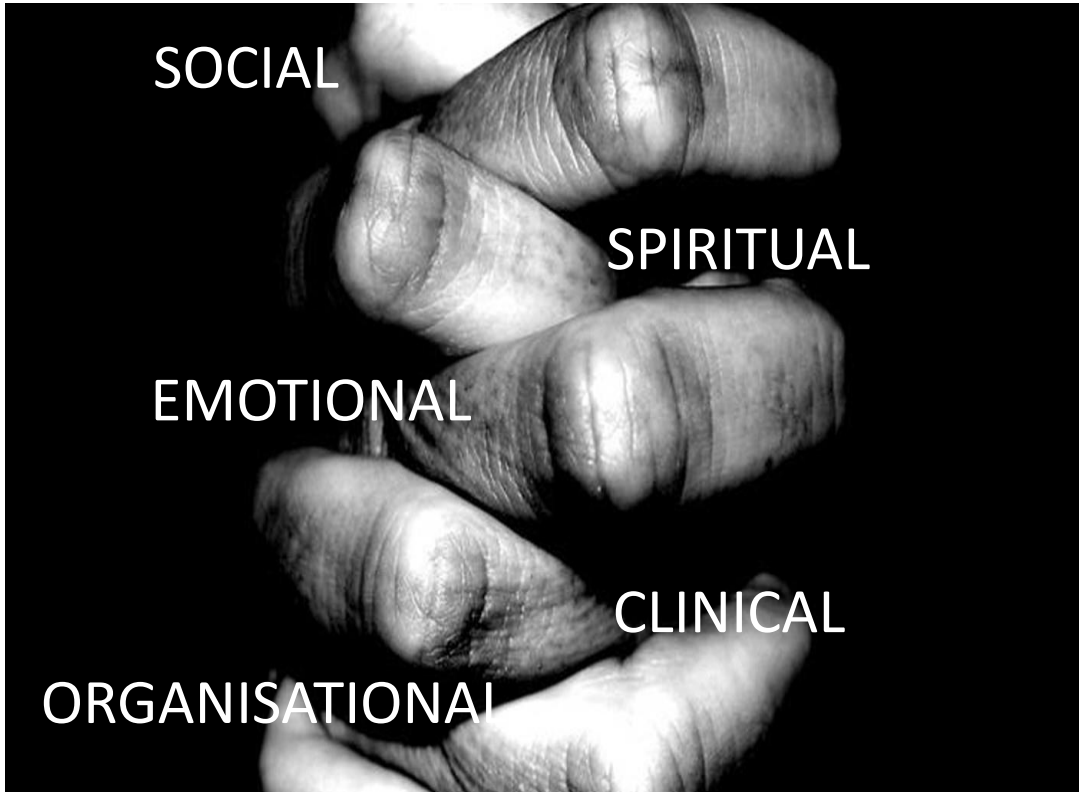
Social deprivation, exclusion and poverty can render older persons more vulnerable and prevent them from accessing the care they need

Older persons are often excluded from the decision-making process and their choices, culture, beliefs and wishes are not respected

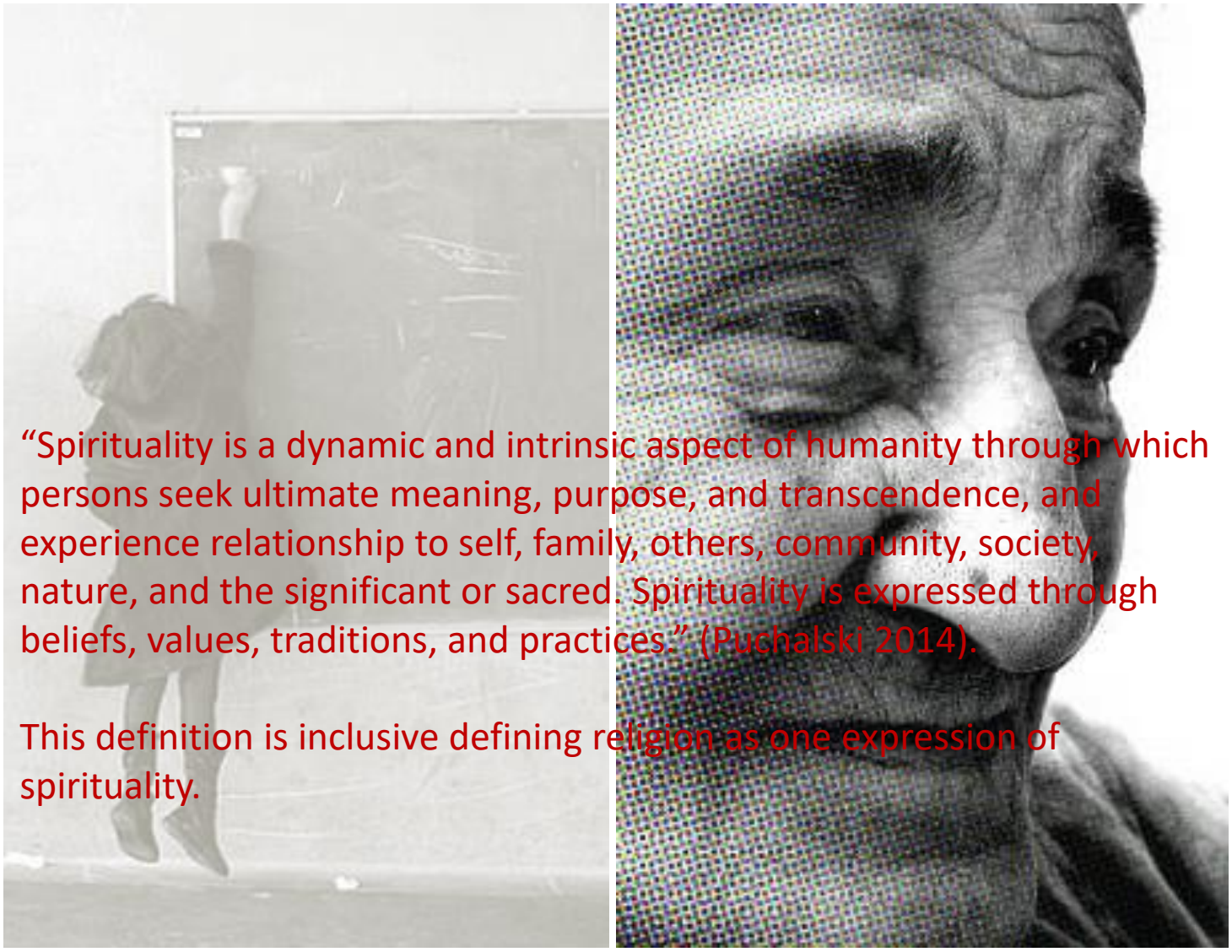
Palliative care for older people

Often older people have limited access to palliative care

NEEDS



Spiritual Needs



"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." (Puchalski 2014).

This definition is inclusive defining religion as one expression of spirituality.

FONDAZIONE MARUZZA ONLUS
CURE PALLIATIVE PEDIATRICHE

Maruzza Foundation - Pontifical Academy for Life

To influence culture, habits and choices to encourage the integration of dedicated palliative care services for children and older people to all national healthcare systems

THE ROLE OF THE RELIGIONS

Religions have the capacity to:

- **go beyond borders and prejudices**
- **listen to and support the most vulnerable and needy**
- **speak to everyone in a common language**
- **respect the value and dignity of life at every phase, regardless of age, sex, social status, place and time**

Religions can offer sanctuary and provide guidance to the patient and family in making their care choices

The Religions of the World Charters For Palliative Care for children

Clinical Perspectives
Patients and Families Perspectives
Human Rights Perspectives
Spiritual and Religious Perspectives

Soliciting ideas

Discussion document

Revised document

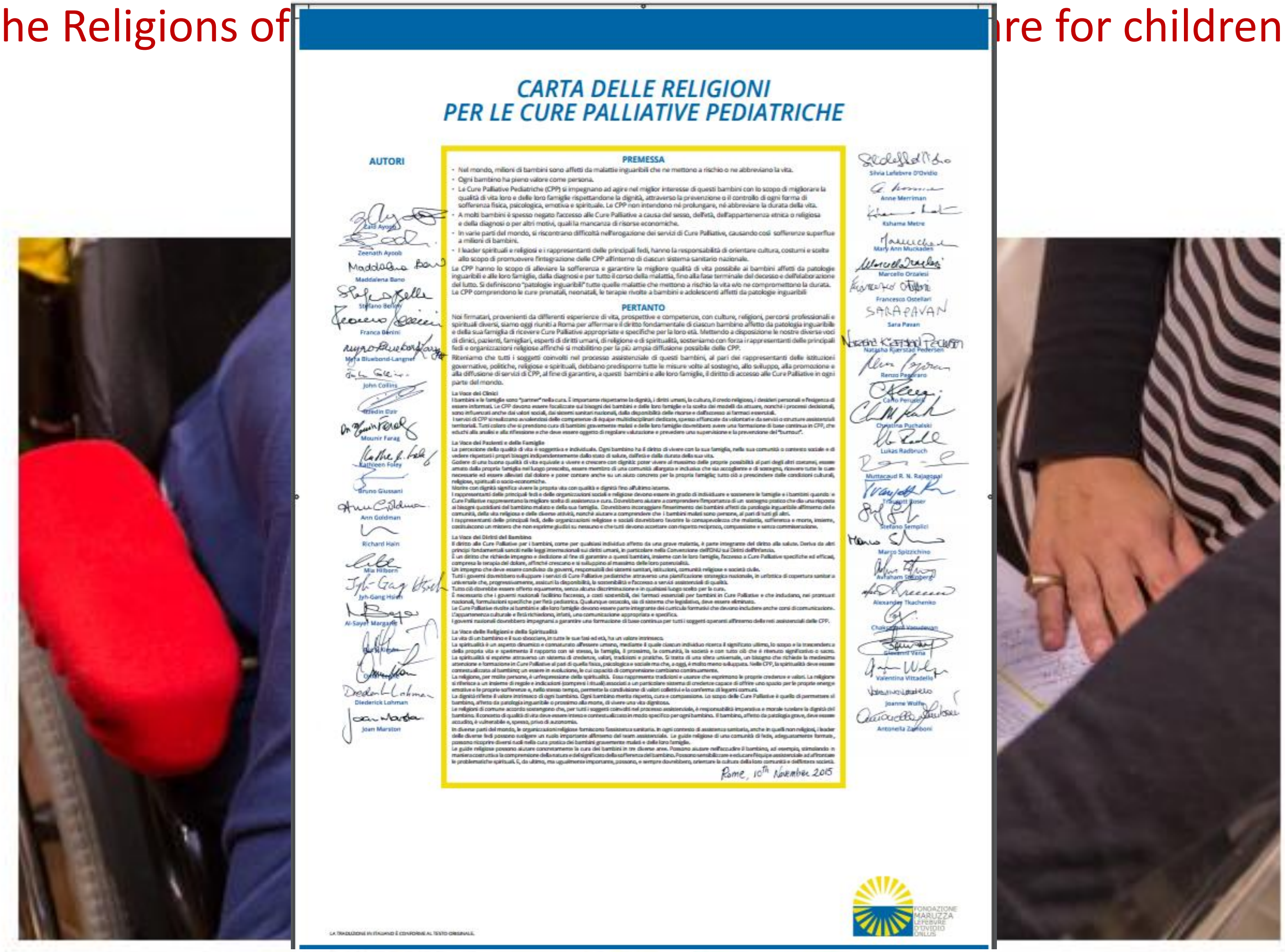
The Religions of the World Charters For Palliative Care for children

The Roman Catholic Church
The Lutheran Evangelical Church
The Anglican Church
The Eastern Orthodox Church
Hinduism
Buddism
Islam
Judaism

Soliciting ideas → Discussion document → Revised document

Maruzza Foundation - Pontifical Academy for Life
Vatican City ,Rome, 10th November 2015

The Religions of … re for children



CARTA DELLE RELIGIONI
PER LE CURE PALLIATIVE PEDIATRICHE

AUTORI

PREMESSA

PERTANTO

Rome, 10th November 2015

To formulate and underwrite a document that highlighted the role and commitment of the main world religions in the support and endorsement of dedicated palliative care provision for babies, children and adolescents with serious and incurable illness

It is the fundamental right of every child and family affected by incurable illness to receive dedicated palliative care appropriate to the child's age

By uniting the different voices of experts in palliative care and human rights, of patients and their families with those of theologian, religious and spiritual leaders, we fervently support the main world religions in their actions directed at the promotion, development and expansion of access to palliative care for all eligible children worldwide

IL VIAGGIO DELLA CARTA

The World Religions Charter For Children's Palliative Care has been translated into 11 languages

It has been presented in events in Argentina, Germany, Russia, Scotland and Ireland

It has been endorsed by over 1000 supporters

The Religions of the World Charters For Palliative For Older People

Clinical Perspectives
Patients and Families Perspectives
Human Rights Perspectives
Spiritual and Religious Perspectives

Soliciting ideas

Discussion document

Revised document

The Religions of the World Charters For Palliative Care for Older People

The Roman Catholic Church
The lutheran Evangelical Church
The Anglican Church
The Eastern Orthodox Church
Hinduism
Buddism
Islam
Judaism

Soliciting ideas → Discussion document → Revised document

Maruzza Foundation - Pontifical Academy for Life
Vatican City, Rome, 31st March 2017

RELIGIONS OF THE WORLD CHARTER
PALLIATIVE CARE FOR OLDER PEOPLE

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Giovanni Gambassi
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WHEREAS

- Between 2000 and 2050 the proportion of the world's population aged over 60 years will double and the number of persons aged 80 years or over is projected to increase by almost fourfold.
- Each older person has full value and human rights, and contributes to society including when fragile and in need of care.
- Serious chronic conditions, end of life, death and bereavement affect every aspect of peoples' lives, including the family, friends and community in which they live.
- Older persons frequently have poor access to appropriate health care services and Palliative Care is no exception to this. They often report symptoms less, problems are put down to 'age'. Psychological, social and spiritual issues are less recognised.
- Older persons can have multiple chronic conditions over a long period of time, but health care is often fragmented, crisis based and not organised in ways to facilitate their timely access to care. Therefore, the cumulative problems of multimorbidity and their Palliative Care needs are frequently missed.
- Social deprivation, isolation, poverty can render older persons more vulnerable in accessing the care they need.
- Older persons are often excluded from decision-making processes, without respect for their choices, culture, beliefs and prior preferences.
- Symptoms, including pain and suffering, are often under-recognised and undertreated in older persons.
- Spiritual leaders and leaders of religions and faith-based organisations can cooperate with health care workers in respect of beliefs, culture, customs and choices to address these challenges. They can promote the integration of Palliative Care and the relief of suffering into national health systems.

The World Health Organisation has defined Palliative Care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative Care affirms life and regards dying as a normal process, intends neither to hasten nor to postpone death and uses a team approach to address the needs of patients and their families, including support in bereavement if indicated. Modern Palliative Care, including established interventions and multiprofessional services integrated with existing care, is proven and cost-effective in helping older people to live well, even with their illness, as well as providing better care towards the end of life.

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 older persons and their families to receive Palliative Care appropriate for them. We give strong support to the representatives of faith organisations and religions using different perspectives - clinical, patients and family, human rights and religious and spiritual - to call for the broadest possible dissemination of Palliative Care for older persons.

We believe that everyone involved in the care of these persons, as well as governments, policy makers and spiritual and religious leaders, should engage with and advance the awareness, development, promotion, improvement and dissemination of Palliative Care for older persons in order that these persons and their families in all parts of the world have access to Palliative Care.

Clinical Perspectives

Older persons have a right to be informed about and to have early access to high quality Palliative Care. This can help them to live well when they face the problems associated with multiple or complex illnesses.
Older persons should be offered Palliative Care on the basis of need, in terms of physical, emotional, social, spiritual and/or caregiver concerns. These concerns should be monitored routinely in health care, using validated tools, and can be used to trigger Palliative Care provision.
Outcomes, quality of life and needs should be assessed using measures that meet the internationally accepted criteria for outcome measures.
Priority should be given for research to improve Palliative Care therapies, services, tools and educational approaches for older persons, including those with frailty.
All workers in all care settings, including health, social, spiritual care and community workers and volunteers need to be appropriately trained and educated in Palliative Care, with capacity building in communities and developing leaders and specialised expertise.

Patients and Families Perspectives

Quality of life, beliefs and needs of older persons are highly subjective and should be respected in the context of family, significant others and culture. These should be upheld regardless of age or condition. Dignity, self-determination, reconciliation, and peace are important.
Older persons should be enabled to live their life to the full and be respected as individuals in every aspect of care. Wherever possible this should be within the family or with significant others, with respect, acceptance and support, having their needs timely and systematically assessed and met within an holistic approach.
Irrespective of setting it is important that there is respect for individual cultural norms and beliefs. Good knowledge of his/her biography, identification of the person's wishes and preferences, is important in all aspects of care and should be included in planned and integrated care.
Communities and organisations should support patients and those close to them, whatever the care setting. They should foster social relations, ensure an awareness of Palliative Care and other resources, work to overcome loneliness, isolation and barriers to good care.

Human Rights Perspectives

Palliative Care for older persons is a human right and is implicated in the rights to health, non-discrimination, freedom of religious belief, and freedom from cruel, inhuman, and degrading treatment, as enshrined in human rights law.
Governments must ensure the accessibility of Palliative Care interventions for life threatening and life limiting illness. Governments must include essential medicines for Palliative Care, including controlled medicines, such as oral morphine, on their national medicines lists and remove unnecessarily restrictive barriers.
Older persons have the inalienable right to free and informed consent at all times. They have the right to freely consent to, refuse, or suspend medical or surgical treatment, and to be given clear and timely information about the potential consequences and risks of such a decision. When a person has impaired capacity for a particular decision, those acting on their behalf must respect the person's human rights and consider their previously expressed preferences.
Education in Palliative Care should include human rights and the knowledge, skills, attitudes and behaviors to provide Palliative Care to older persons and their families.
Older persons' right to justice includes the elimination of ageism, regulations facilitating a person's right to receive appropriate and timely care to live well in their preferred place, and support to manage their affairs. Government and community leaders must provide resources and supportive networks for all aspects of Palliative Care.

Spiritual and Religious Perspectives

The dignity of older persons, as they continue to have meaning and value, is core to religious faiths. Older persons deserve respect, by our being a compassionate presence, by showing empathy and by accompanying older persons in the midst of their suffering, and celebrating their lives.
Religious faiths can inspire Palliative Care to create space for intergenerational connectedness so that older persons can pass on their legacy and wisdom about living until the end of their life.
Religious faiths can help transform aging and dying as meaningful living throughout all of life, even in the midst of chronic and serious illness.
Religious faiths support the principles of Palliative Care in the relief of pain and suffering, approaching a natural end of life.
Faith communities can advocate for Palliative Care with older persons within their communities, government and with media. They can integrate the spiritual dimension within patient and family resources. Religious leaders can address Palliative Care in their teachings and counselling, promoting a greater awareness of the preciousness of human life and experience, and the shared vulnerability of human existence.
Religious leaders can encourage dialogue and collaboration between science and religion to develop models of care and an evidence base for spiritual care interventions and outcomes, to ensure that all older persons have their beliefs, values and preferences addressed and respected.
Religious faiths can contribute to the support and training of religious leaders, spiritual care professionals and other members of the healthcare team and communities at large; training particularly in compassionate listening, eliciting spiritual values and beliefs, supporting the spiritual life of professionals and family caregivers and emphasizing the development of the inner life and inner strength.

Rome, 30th March 2017

Suresh Kattierath Kumar
Philip Larkin
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Carlo Leget
Emmanuel Luyirika
Andrea Manto
Federico Nicoli
Vincenzo Paglia
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Renzo Pegoraro
Carlo Peruselli
Katherine Pettus
Bethany Brown
Christina Puchalski
Rasoul Rafoulipour
Abbas Shouman
Peter Speck
Mimi Tse
Anne Vandenhoeck
Yingwei Wang
Barbro Westerholm

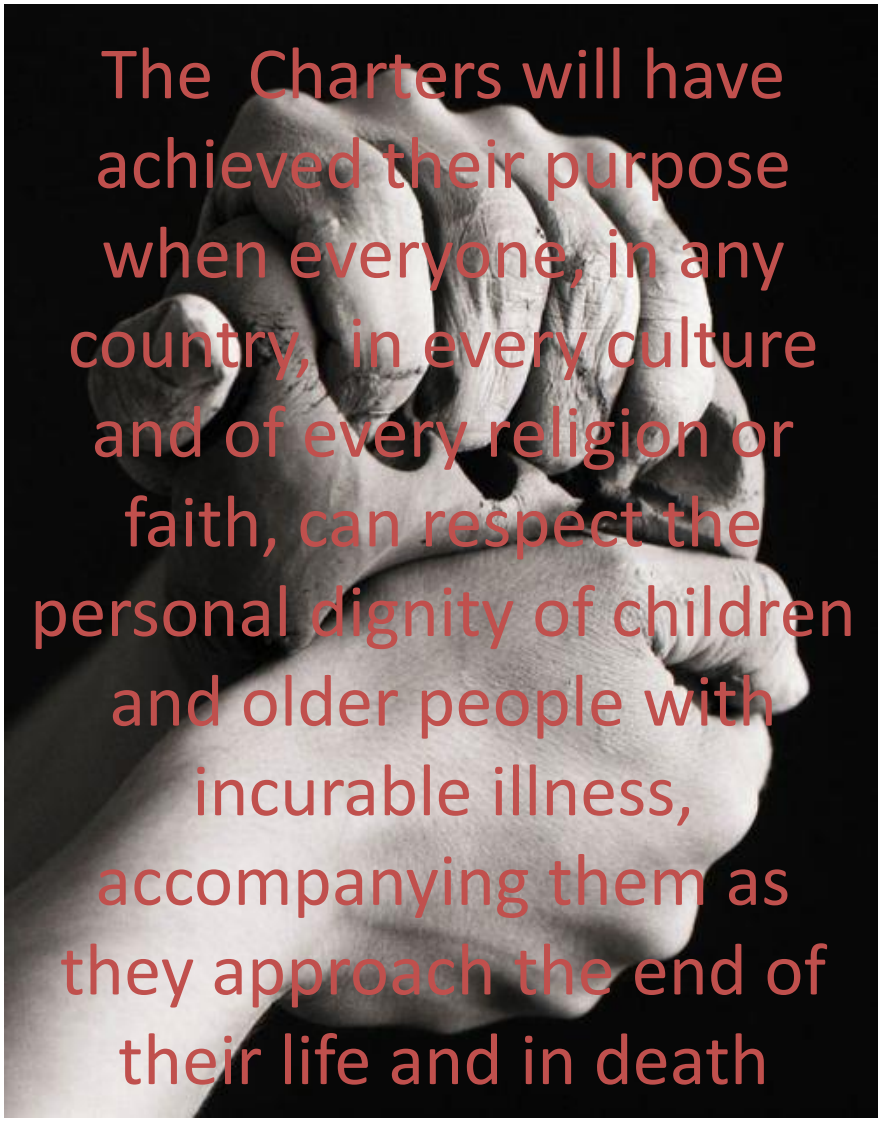
FONDAZIONE MARUZZA
PALLIATIVE CARE
TOGETHER, FOR A BETTER TODAY.

Support and share the universal right to palliative care: the best solution to guarantee dignity and a better quality of life to older people with advanced chronic conditions or approaching the end of their life

THE OUTCOME

Access to dedicated and appropriate palliative care for older persons with incurable and chronic illness is a basic Human Right

We strongly support the representatives of faith organizations and religions by uniting different perspectives: patients and their families, palliative care experts, human rights advocates, religious and spiritual leaders , to call for the broadest possible dissemination of palliative care for older persons


The Charters will have achieved their purpose when everyone, in any country, in every culture and of every religion or faith, can respect the personal dignity of children and older people with incurable illness, accompanying them as they approach the end of their life and in death

Paediatric Palliative Care
Palliative Care for Older People

Challenging field