European Association for Palliative Care

EAPC
vzw

European Charter on Palliative Care for Children and Young People

Prepared by the EAPC Children and Young People's Reference Group

The aim of this Charter is to set out standards that can be used as a tool for **empowering** children, families and healthcare professionals, with regards to what they can expect, what should be available and accessible to them, and for **advocating** for the development of children's palliative care services within Europe.

Throughout this Charter, when using the terms 'children (and young people)' we refer to all those aged 0-18 years, including babies in the antenatal and neonatal period.

With over 21 million children and young people globally needing palliative care,(1) yet only 5-10% of them having access to services, there remains much inequity within the field. It is estimated that 2.8% of children needing palliative care globally live in the European region,(2) with around 170,000 children dying every year in Europe with health-related suffering and no access to palliative care.(3)

This Charter, prepared by the **EAPC Children and Young People's Reference Group**, sets out standards for children's palliative care across three areas:

1. **The standards of support the EAPC believes should be the right of all children living with life-limiting or life- threatening conditions and their families.**
2. **The standards of support the EAPC believes all families caring for a child with a life-limiting or life-threatening condition should expect to receive.**
3. **The standards and principles of children's palliative care the EAPC believes should be provided in all European countries.**

Definition of Children's Palliative Care

The EAPC Children and Young People's Reference Group supports the World Health Organization (WHO) definition(4) of children's palliative care:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed and continues regardless of whether or not 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 multidisciplinary 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 even in children's homes.

---

[1] Connor SR, Downing J, Marston J. (2017) Estimating the global need for palliative care for children: A cross-sectional analysis. Journal of Pain and Symptom Management. 53(2):171-177.

[2] Connor SR (Editor) (2020) Global Atlas of Palliative Care. 2nd Edition. London, UK.

[3] Arias-Casais N, Garralda E, Rhee JY, et al. EAPC atlas of palliative care in Europe 2019. Vilvoorde: EAPC Press, 2019.

[4] https://www.who.int/

European Charter on Palliative Care for Children and Young People

Prepared by the EAPC Children and Young People's Reference Group: September 2022

European Association for Palliative Care

	For Children and Young People	For Parents & Carers*	For Health and Social Care Professionals**
	The standards of support the EAPC Children and Young People's reference group believes should be the right of all children living with life-limiting or life- threatening conditions and their families.	**The standards of support the EAPC Children and Young People's reference group believes all families caring for children with a life-limiting or life-threatening condition should expect to receive.**	**The standards and principles of children's palliative care the EAPC Children and Young People's reference group believes should be provided in all European countries.**
Dignity & Respect	Every child should be treated with dignity and respect irrespective of physical or intellectual capacity, and should expect individualised, culturally, and age-appropriate palliative care.	Every family should be treated with dignity and respect and expect to have an individualised support plan that is built around their unique needs.	Funding and resources should be made available for the development of age and developmentally appropriate palliative care for children, that can be built around their individual needs.
Communicating diagnosis and prognosis	Every child should receive sensitive and honest communication about their condition, according to their age, understanding and choice.	A sensitive and honest approach will be the basis of all communication with the child's family. Parents should be informed about their child's prognosis with honesty, whether this is during pregnancy, neonatally or later in their child's life.	Children's palliative care education, in particular communication training, should be a core part of all paediatric healthcare professionals' education. Specific training should be available for those working within core and specialised children's palliative care services.
Supporting communication	Every child should be provided with information in a language and a format that they can understand.	Every parent should be provided with accurate and relevant information in language that they can understand, throughout their child's illness, from diagnosis through to death and bereavement.	Standardised information and assessment tools should be available, validated for the specific language and culture of the child and family.
Keeping children, young people and their families at the centre of decision making	Every child should be supported to be heard and involved in decision-making, taking account of their wishes and abilities.	Parents should be acknowledged as the primary caregivers, empowered to carry out this caring role and recognised as full partners in all care and decisions involving their child and family. They should be supported to think about Advance Care Planning.	Advance Care Planning should start early in the disease trajectory, with a focus on parallel planning***, for the best and for the worst outcome. The child's best interest should be respected. Futile or excessively burdensome practices and therapeutic abandonment should be avoided.
Location of Care	Every child should live as well as possible in the setting that they choose, including at home. If location of care is away from the home, they should be able to stay in touch with the people and things that matter to them.	Parents should have the option to care for their child at home and, if that is not possible, in a 'home-away-from-home' environment, keeping them close and involved. When caring for their child at home, they should be able to contact services 24h a day for support.	The necessary workforce, equipment and transport resources should be available to ensure families have a choice in location of end-of-life care. This should include options of home, hospice, and hospital care.
Symptom Management	Every child should be helped by professionals to be as well as they can. Their pain and symptoms must be managed by professionals experienced in providing symptom management, alongside experts in their underlying condition. They should have access to all the medications they need.	Parents should be reassured that their child will remain under the care of specialists with particular knowledge and experience of their child's condition, as well as those experienced in symptom management. Medications must be available for their child whenever needed.	Essential palliative care medicines for children should be accessible and free, with paediatric formulations on national medicines' lists. Systemic and regulatory barriers should be eliminated.
Psycho-social and Spiritual Needs	Every child should have their emotional, psychosocial, and spiritual needs assessed and supported.This care should be provided in a way that minimises disruption to their daily lives.	Parents, siblings, and the wider family should have the full range of their psycho-social, emotional, and spiritual needs assessed and supported. They should receive emotional and, where appropriate, bereavement support, before and after the death of the child, for as long as it is needed. A keyworker should be identified whose task it is to build, co-ordinate and maintain appropriate support systems.	Children's palliative care professionals should be encouraged to work in partnership with others to provide a multi-disciplinary and multi-agency joined-up approach to the child and family care.
Everyday Life	Every child should be supported to participate in normal childhood activities, including access to education, play, leisure, friends, and maintaining their special relationships with siblings and other family members.	Parents should be offered respite so they can take short breaks from caring when needed. They should be helped to support all their children to undertake normal childhood activities.	Children's palliative care services should be regulated at national level, and tools developed to objectively measure their effectiveness and impact on meeting the child and family's needs.
End of life care	Every child, where possible and appropriate, should be helped to talk about their hopes and special wishes for their future, their choices about care at end of life and how they wish to be remembered. They should be supported to have as good a death as possible.	Parents, siblings, and the wider family should be given time to discuss their wishes for their child's end of life care and care after death, revisiting their Advance Care Plan and revising it as appropriate. They should be supported to be involved at their child's end of life and after their death, according to their wishes.	Children's palliative care professionals should be confident about providing end of life and post-death care for children. They should know the practicalities of processes after death and be able to support families through this difficult time.
Public Awareness	Society in general should be aware of the reality of death occurring in childhood. This should include public health initiatives to raise awareness that children's palliative care is focused on maximising comfort and quality of life, sometimes over a long time (even years to decades). It also includes, but is not limited to, providing care at the time of death.		

**When using the terms 'parents/carers' we refer to parents, carers, family members, legal guardians, etc.*

***When using the terms 'health and social care professionals' we refer to all those who work with children needing palliative care, including doctors, nurses, allied health professionals, social workers, counsellors, play therapists, teachers, religious leaders, etc.*

***Parallel planning is planning for and offering palliative care alongside treatments aiming to cure or prolong life so that the child has as good a quality of life as possible, whilst also acknowledging the need to plan for a good death (Together for Short Lives 2018. A guide to children's palliative care (fourth edition), UK)

European Charter on Palliative Care for Children and Young People

This charter draws on a range of existing documents, including, but not limited to, the following documents:

- The ICPCN Charter of Rights for Life Limited and Life Threatened Children (2008)
- The Together for Short Lives Charter (2012)
- The Maruzza Foundation Religions of the World Charter for Children's Palliative Care (2015)
- The Maruzza Foundation Trieste Charter of the Rights of the Dying Child (2016)
- The Bambino Gesú Hospital Charter of the Rights of the Incurable Child (2018)
- The Spanish Paediatric Palliative Care Society Charter (Manifesto de Madrid) (2020)
- The European Association for Children in Hospital (EACH) Charter (2016)

In addition to these the EAPC Children and Young People's Reference Group endorses the International Standards for Paediatric Palliative Care - Global Overview – PPC Standards 2021 (GO-PPaCS Standards).

Prepared by the EAPC Children and Young People's Reference Group

September 2022

EAPC vzw

European Association for Palliative Care