

---

# European Journal of Palliative Care

---



THE JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

## IMPACT: standards for paediatric palliative care in Europe



An EAPC Taskforce document promoted and sponsored by the FONDAZIONE MARUZZA LEFEBVRE D'OVIDIO ONLUS, working to provide care for children and adults with incurable diseases, for the improvement of in-home palliative care, for dignity and quality of life

# IMPACT: standards for paediatric palliative care in Europe

A document prepared by the Steering Committee of the EAPC task force on palliative care for children and adolescents

In March 2006, a group of healthcare professionals from Europe, Canada, Lebanon and the USA met in Trento, Italy to discuss the current situation of paediatric palliative care in Europe. The group was called the International Meeting for Palliative Care in Children, Trento (IMPACT) (see Box 1) and is sponsored by the Maruzza Lefebvre d'Ovidio Foundation (Rome), Fondazione Livia Benini (Florence) and the No Pain for Children Association (Trento). In 2007 the IMPACT group became an EAPC task force.

Over three days, paediatric palliative care services in different countries were compared, paediatric palliative care was defined, best practices identified and minimum standards agreed. The result is a united document for Europe, defining and identifying standards of care for children with life-limiting and terminal illness. IMPACT recommends that these standards be implemented in all European countries.

### Definition of paediatric palliative care

The World Health Organization (WHO) definition of paediatric palliative care was adopted by IMPACT and these principles apply to cancer and other paediatric disorders.<sup>1</sup>

- 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.

- Healthcare 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.

**Life-limiting illness** is defined as a condition where premature death is usual, for example, Duchenne muscular dystrophy.

**Life-threatening illness** is one where there is a high probability of premature death due to severe illness, but there is also a chance of long-term survival to adulthood. For example, children receiving cancer treatment or admitted to intensive care after an acute injury.

The use of the term 'terminal illness' can often be confusing. It is most frequently used to describe all children with life-limiting illness, in addition to those with life-threatening illness, when death becomes inevitable. Some groups use the term 'terminal illness' only to describe children who are in the process of dying, as it is difficult to consider the well child with cystic fibrosis or Batten disease, for example, as being terminally ill.

### Children who should receive palliative care

These children can be considered in four categories, based on *A Guide to the Development of Children's Palliative Care Services* produced by the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health in the UK.<sup>2</sup>

### Key points

- In March 2006, a group of healthcare professionals from Europe, Canada, Lebanon and the USA met in Trento, Italy to discuss the current situation of paediatric palliative care in Europe.
- It is essential that the core standards for paediatric palliative care recommended in this document now be implemented.

## Box 1. Members of the International Meeting for Palliative Care in Children, Trento

■ <b>Huda Abu-Saad Huijer</b> – Beirut, Lebanon	■ <b>Stefan Friedrichsdorf</b> – Minneapolis, USA	■ <b>Luca Manfredini</b> – Genoa, Italy
■ <b>Ann Armstrong-Dailey</b> – Alexandria, USA	■ <b>Brian Greffe</b> – Denver, Colorado, USA	■ <b>Momcilo Jankovic</b> – Monza, Italy
■ <b>Franca Benini</b> – Padua, Italy	■ <b>Maria Jasenkova</b> – Stupova, Slovakia	■ <b>Maeve O'Reilly</b> – Dublin, Ireland
■ <b>Paolo Cornaglia Ferraris</b> – Rome, Italy	■ <b>Leora Kuttner</b> – Vancouver, Canada	■ <b>Manuela Trapanotto</b> – Padua, Italy
■ <b>Finella Craig</b> – London, UK	■ <b>Julie Ling</b> – Dublin, Ireland	■ <b>Chantal Wood</b> – Paris, France
■ <b>Franca Fossati Bellani</b> – Milan, Italy	■ <b>Gioulia Mammis</b> – Athens, Greece	■ <b>Boris Zernikow</b> – Datteln, Germany

- Group 1 – life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary alongside attempts at curative treatment and/or if treatment fails.
- Group 2 – conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, such as cystic fibrosis.
- Group 3 – progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years, for example, Batten disease and muscular dystrophy.
- Group 4 – irreversible but non-progressive conditions with complex healthcare needs leading to complications and likelihood of premature death. Examples include severe cerebral palsy and multiple disabilities following brain or spinal cord insult.
- The services available to children often depend on where they live and on their diagnosis, with the better developed services usually available to children with cancer.
- Communication between professionals involved in the care of children with life-limiting conditions is poor and needs substantial improvement.
- There is an urgent need for better education for all professionals and volunteers involved. Mortality figures are likely to vary between different countries. For example, mortality from life-limiting and terminal illness is 1.2 in 10,000 children aged 0–19 in the UK<sup>2</sup> and 3.6 in 10,000 children aged 0–18 in the Republic of Ireland.<sup>4</sup> To date, no country has a national database identifying all children with life-limiting conditions. Figures on the prevalence of life-limiting conditions may have been underestimated in previous assessments.<sup>2,4</sup>

### Identifying the need for palliative care services

Over the past few years there have been several national paediatric palliative care needs assessments.<sup>3–8</sup> These have provided important information on mortality and place of death, as well as identifying the specific needs of the children and families, carers and service providers. Further needs assessments may not be necessary, because the findings of those already performed have been remarkably consistent.

- Children often want to be at home and families usually want to keep them at home through illness and death.
- Community resources currently provided are inadequate in enabling families to do this.
- Although essential, the provision of respite services is still inadequate.

### ACT Definitions

It is important that there is standardisation of the way in which information on all aspects of paediatric palliative care is collected. The International Classification of Diseases (ICD) codes are the preferred method of collecting data on childhood death, although it can be difficult to use this data to estimate the prevalence of life-limiting conditions. The categories described by ACT<sup>2</sup> are the preferred method of categorising life-limiting conditions. Three levels of paediatric palliative care specialisation are recommended.<sup>9</sup>

- Level 1 – the palliative care approach. Palliative care principles should be appropriately applied by all healthcare professionals
- Level 2 – general palliative care. At an intermediate level, a proportion of patients and families will benefit from the expertise of

healthcare professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care.

- Level 3 – specialist palliative care. Specialist palliative care services are those whose core activity is the provision of palliative care.

## Core standards

IMPaCCT recommends the following minimum core standards for Europe.

### *Provision of care*

- The aim of paediatric palliative care is to enhance quality of life for the child and family.
- Families should be able to refer themselves to a paediatric palliative care programme.
- Palliative care should begin when a child is diagnosed with a life-limiting or life-threatening condition.
- The components of palliative care should be provided at diagnosis and continued throughout the course of the illness.
- Palliative care can be given alongside active treatments aimed at cure or prolonging life.
- Palliative care must be provided wherever the child and family choose to be (for example, home, hospital or hospice).
- Families should be allowed flexibility to move between locations without the child's care being compromised.

### *Unit of care*

- The unit of care is the child and family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship.
- A full range of clinical and educational resources must be available for the child and family, in a format that is appropriate to age, cognitive and educational ability and within a suitable cultural context.
- The child and family must be included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

### *The care team*

- The care team will recognise the individuality of each child and family and uphold their values, wishes and beliefs, unless this exposes the child or carers to avoidable harm.
- The palliative care team should have sufficient expertise to address the physical,

psychological, emotional, spiritual and social needs of the child and family.

- The minimum skills and services provided should include a physician, nurse, social worker, child therapist or psychologist and spiritual adviser.
- Professional resources from the child's own community should be utilised if appropriate.
- Expert paediatric palliative care, support and advice should be available to the child and family 24 hours a day, 365 days a year.
- It is essential that the care team ensures continuity of care at home, in the hospital and in the hospice through planning, sharing strategies and objectives.
- The direct caregivers must be provided with psychosocial support and supervision.

### *Care co-ordinator/Key worker*

- One professional from the palliative care team must be identified as the family's care co-ordinator or key worker.
- The care co-ordinator will help the family to build and maintain an appropriate support system of professionals so the family will be ensured access to social services, practical support (including appropriate aids and home adaptations), spiritual and respite care.
- The care co-ordinator will act as the main link, providing continuity, ensuring that the care provided is consistent with the needs of the child and family.

### *Symptom management*

- Every child should have access to professional pharmacological, psychological and physical management of pain and other symptoms, 24 hours a day, 365 days a year.
- Every child must have their symptoms assessed so that they can receive an appropriate treatment to achieve an acceptable level of comfort.
- Psychological, social and spiritual symptoms must be addressed, as well as physical ones.
- Symptom management must be accomplished through means acceptable to the patient, family and professionals.

### *Respite care*

- Respite for family carers and the child is essential, whether for a few hours or a few days at a time.

Every child must have their symptoms assessed so that they can receive an appropriate treatment to achieve an acceptable level of comfort

- It should be possible to provide respite in the family home and away from home; for example, in an inpatient children's hospice.

### *Bereavement*

- Bereavement support must commence at diagnosis and continue through the disease process, through death and beyond, for as long as it is needed.
- It must be available to the family, carers and others who are affected by a child's disease and death.
- It is essential that sibling support is an integral part of paediatric palliative care.

### *Age-appropriate care*

- Parents are central to a child's wellbeing. They should be present and involved in all aspects of their child's care, guided by the age and wishes of the child.
- The healthcare team and the care environment must meet the needs of children of different ages, developmental stages and with different communicative and cognitive abilities.
- Children and young adults should have access to recreational opportunities that are appropriate to both their age and their cognitive ability.

### *Education and training*

- All professionals and volunteers working in paediatric palliative care should receive comprehensive training and support.
- Palliative care training must be a core part of the curriculum for all paediatric healthcare professionals, as well as related subspecialties.
- Each country should develop a national curriculum for all professionals working in paediatric palliative care.
- There must be designated centres of excellence that can provide formal teaching and postgraduate training in all aspects of paediatric palliative care.

### *Funding for palliative care services*

- Palliative care services should be available to all children and families who require them, regardless of their financial or health insurance status.
- Governments need to commit to sustained adequate funding to provide holistic, multidisciplinary palliative care in a variety of settings, including home, schools, hospitals and children's hospices.

- There should be sufficient funding available for the teaching and training of service providers.

### *Euthanasia*

The practice of physician-assisted suicide or euthanasia for children or teenagers with life-limiting, life-threatening or terminal diseases is not supported.

## **Pain and symptom management in paediatric palliative care**

### *Symptom recognition and assessment*

- Every child must have their psychological, social, spiritual and physical symptoms assessed on a regular basis so that they can receive appropriate treatment to achieve an acceptable level of comfort.
- The use of a multidisciplinary team in the assessment and management of symptoms is paramount. Healthcare professionals must be provided with support and training in using appropriate communication techniques.
- Information on symptoms must be elicited from all relevant sources. This includes gaining information from:
  - The child, using appropriate prompting techniques
  - Parents and other family members (such as siblings or grandparents)
  - Healthcare workers and others such as carers and teachers.
- Communicating with non-verbal and/or cognitively impaired children requires specific planning and co-ordination.
- Cultural differences in the way suffering is expressed must be respected.

### *Core principles of symptom management*

- Treating the underlying cause of a symptom may be equally as appropriate as providing symptom control.
- Practical, cognitive, behavioural, physical, and supportive therapies should be combined with appropriate drug treatment.
- Persistent symptoms should be treated with medication given at regular intervals.
- Severe and uncontrolled symptoms should be regarded as a medical emergency and active interventions may be appropriate.
- Inappropriately invasive and painful routes of drug administration should be avoided whenever possible.
- Side-effects of medication must be anticipated and actively treated.

**Treating the underlying cause of a symptom may be equally as appropriate as providing symptom control**

The appropriate opioid dose is the dose that effectively relieves pain

## *Core principles of pain management*

Pain is a major symptom in paediatric palliative care, both in children with cancer<sup>10</sup> and those with non-malignant life-limiting or life-threatening conditions.<sup>11</sup>

- Unnecessary painful procedures should be avoided. Procedural pain prevention should be anticipated and actively treated.
- The WHO 'analgesic ladder' approach should be used, recognising that starting at step three may be appropriate according to the pain pathophysiology and intensity.<sup>12</sup>
- Adequate doses of analgesics should be administered 'by the clock', that is at regularly scheduled intervals. Additional doses should be given on an 'as needed basis' to treat breakthrough pain.
- A sufficient dose and an appropriate pharmacological formulation (for example, sustained-release preparation or continuous infusion) should be chosen to enable children and their families to sleep through the night, without waking in pain or to take their medications.
- The appropriate opioid dose is the dose that effectively relieves pain.
- Opioid pain therapy in children with life-limiting or life-threatening conditions does not lead to addiction but may lead to physical tolerance. When dose reduction is appropriate, the dose should be reduced slowly in order to avoid the physical symptoms of withdrawal.
- Non-pharmacological therapies are an integral part of pain management.

## **Ethics and legal rights of children in paediatric palliative care**

IMPaCCT has adopted and revised the ACT Charter, with some additional ethical and legal rights.<sup>2</sup>

### *I. Equality*

- Every child shall have equal access to palliative care, irrespective of the family's financial capability.

### *II. Best interests of the child*

- The best interests of the child shall be the primary consideration in decision-making.
- Children will not be subjected to treatments that impose burden without benefit.
- Every child has the right to receive adequate pain relief and symptom management, using pharmacological and integrative methods, 24 hours a day for every day needed.

- Every child shall be treated with dignity and respect and shall be afforded privacy, whatever the child's physical or intellectual ability.
- The needs of adolescents and young people shall be addressed and planned for, well in advance.

### *III. Communication and decision making*

- An honest and open approach shall be the basis of all communication, which shall be sensitive and appropriate to the child's age and understanding.
- Parents shall be acknowledged as the primary carers and shall be centrally involved as partners in all care and decisions involving their child.
- Information shall be provided for the parents, for the child and for siblings according to age and understanding. The needs of other relatives shall also be addressed.
- Every child shall be given the opportunity to participate in decisions affecting his or her care, according to age and understanding.
- Situations posing a high risk of conflict should be anticipated and procedures for early communication, therapeutic intervention or ethics consultation should be established.
- Every family shall be given the opportunity of a consultation with a paediatric specialist who has particular knowledge of the child's condition, including the treatment and care options available.

### *IV. Care management*

- The family home shall remain the centre of caring whenever possible.
- If admitted to a hospital or inpatient hospice, children shall be cared for by paediatric trained staff in a child-centred environment, together with children who have similar developmental needs. Children will not be admitted to adult hospitals or adult hospices.
- Children shall be cared for by paediatric healthcare professionals, whose training and skills enable them to respond to the physical, emotional and developmental needs of children and their families.
- Every family shall have access to a multidisciplinary, holistic paediatric palliative care team in the home, which includes a nurse, paediatrician, social worker, psychologist, and a spiritual/religious worker.
- Every family shall be entitled to a named key worker, who will enable the family to build and maintain an appropriate support system.

## V. Respite care

- Every family shall have access to flexible respite care in their own home and in a home-from-home setting, with appropriate paediatric multidisciplinary care.

## VI. Family support

- Sibling care, commencing at diagnosis, must be an integral part of paediatric palliative care.
- Bereavement support shall be available to the whole family for as long as it is required.
- Every child and family shall have access to spiritual and/or religious care.
- Every family shall have access to expert advice in procuring practical aids and financial support, and have access to domestic help at times of stress at home.

## VII. Education

- Every child shall have access to education and be supported to attend their usual school.
- Every child shall be given the opportunity to engage in play and childhood activities.

## Summary

The needs of children and families living with life-limiting and life-threatening illness are similar across Europe. Meeting these needs

requires a comprehensive and integrative approach from a skilled multidisciplinary team. It is essential that the core standards for paediatric palliative care recommended in this document now be implemented across Europe.

### Acknowledgement

We deeply appreciate Professor Vittorio Ventafridda's advice and support in developing this document.

### References

For a full list of references, please email: [edit@hayward.co.uk](mailto:edit@hayward.co.uk)

*Authors and members of the EAPC Taskforce Steering Group: Finella Craig, Consultant in Paediatric Palliative Care, Great Ormond Street Hospital for Children, London, UK; Huda Abu-Saad Huijjer, Professor of Nursing Science, American University of Beirut, Lebanon; Franca Benini, Consultant in Paediatric Pain and Palliative Care, University of Padua, Italy; Leora Kuttner, Clinical Psychologist and Clinical Professor of Paediatrics, British Columbia's Children's Hospital and University of British Columbia, Vancouver, Canada; Chantal Wood, Consultant in Paediatric Pain and Palliative Care, Hôpital Robert Debré, Paris, France; Paolo Cornaglia Ferraris, Scientific Director, Maruzza Lefebvre d'Ovidio Foundation, Rome, Italy; Boris Zernikow, Director of the Vodafone Foundation Institute of Children's Pain Therapy and Paediatric Palliative Care, Datteln, Germany*

