

*European Association for Palliative Care*

**Core competencies for education in  
Paediatric Palliative Care**

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***Report of the EAPC Children's Palliative Care  
Education Taskforce***

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## FOREWORD

Improving the education of all people involved in paediatric palliative care is a high priority goal for both the Fondazione Maruzza Lefebvre D'Ovidio Onlus (Maruzza Foundation) and the European Association for Palliative Care (EAPC). We therefore warmly welcome this report which makes recommendations for a core curriculum. It is the result of a sustained effort by the authors and the contributions of a multi-disciplinary working group of international paediatric palliative care experts. This initiative, realised through the active participation and support of the Maruzza Foundation, is an approved EAPC Task Force project.

Paediatric palliative care involves many skills but perhaps the most important is the ability to listen to and empathize with the children and parents whose lives are impacted by serious illness. For each of them, their experiences will be unique. We cannot fully understand what they are thinking or how they feel but we can attempt to appreciate and value their worldview, their priorities and their complex needs. In education it is helpful to take these many experiences and build them into a body of knowledge, rigorously searching for evidence that may be relevant and critically appraise all that we offer in terms of wider knowledge systems, tempered by compassionate communication with the individual child and family. This requires health professionals that are able to hold in balance their cognitive skills (such as learning about the most recent techniques in symptom assessment and treatment) and their emotional engagement with the child and family. Developing just one set of skills is not sufficient. The core curriculum presented here demonstrates how this balance can be achieved through planned and purposeful education and reflective practice.

Care provided by well-educated, questioning and continuously updated health and social care professionals offers children and parents the best options that are available in whatever setting they are currently living in. The authors of this report have drawn upon their work experiences in many different parts of Europe. We hope that it contributes to improving all aspects of the care of children facing life-limiting illness and their families, in Europe and further afield.

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## EXECUTIVE SUMMARY

Education is an essential component in the development of paediatric palliative care, thus all health and social care professionals need to be trained to provide high quality palliative care for children and their families. This report provides recommendations and guidelines for the ongoing development of initiatives in paediatric palliative care training and education for healthcare professionals.

Education programmes for paediatric palliative care should be aimed at: a) the acquisition of knowledge, b) the development of specific skills, c) the capacity of interdisciplinary thinking, d) the cultivation of attitudes that promote quality of life, and e) the ability for self-awareness and reflective practice (Liben et al 2008, Papadatou 2009).

Education programmes need to develop practitioners who are *'fit for practice'* and *'competent'* to provide children's palliative care. Core competencies are identified within the three-tiered approach to education proposed by Gamondi et al (2013) i.e.: (1) The palliative care approach; (2) General palliative care; and (3) Specialist palliative care.

*Basic education on the palliative care approach* focuses on the general principles and practices of palliative care, rather than the specifics of paediatric palliative care, although it is important that the differences between paediatric and adult palliative care are highlighted.

*General paediatric palliative care education* is aimed at those who come from a paediatric background who need to learn about palliative care, and on occasions those from an adult palliative care background who need to learn about palliative care for children. Minimum competencies are identified under the following twelve domains:

1. Core aspects of paediatric palliative care and its application
2. Developmental aspects of infants, children and adolescents
3. Physical care
4. Psychosocial and spiritual care and educational needs
5. Family support

6. Clinical and ethical decision making
7. End-of-Life care
8. Interdisciplinary teamwork and inter-professional collaboration
9. Communication issues with the child and family
10. Bereavement support
11. Reflective practice, self-awareness and self-care
12. Raising community awareness

For healthcare professionals who are working in specialist paediatric palliative care and who are undertaking *specialist paediatric palliative care education* the competency framework is broader and encompasses competencies in areas such as collaborative practice, leadership, service development, research, education and professional practice.

Whilst a growing number of courses and curricula are available on paediatric palliative care, provision of courses does not meet the need, therefore it is important to extend education opportunities for everyone involved in paediatric palliative care.

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## **1.0 INTRODUCTION**

Education is an essential component of the development of palliative care (EAPC 2004). All health care professionals need to be able to provide appropriate palliative care and therefore need to be trained to provide the highest possible standards of care in order to meet the needs of the patient and their family (Gamondi et al 2013). The provision of paediatric palliative care across Europe is at varying stages of development. A recent systematic review identified that out of 43 European countries, 33% had no known paediatric palliative care activity, and in just 12% of countries was paediatric palliative care reaching a measure of integration with mainstream service providers (Knapp et al 2011). Therefore, in many countries, paediatric palliative care is still a relatively new field and, as a result, appropriate and ongoing education and training is particularly important, and a key component of the WHO public health strategy for palliative care development (Stjernsward et al 2007, Downing and Ling 2012).

This report offers key recommendations from a multi-disciplinary group of European paediatric palliative care professionals and educators and is intended to provide guidelines for the ongoing development of paediatric palliative care education initiatives. It seeks to set out core competencies and provides links to sample curricula that can be used for teaching students and care providers with different levels of experience and expertise. The report identifies key components that can be applied to individual cadres. Materials have been drawn from existing competency frameworks and curricula, to complement other EAPC documents on education and/or paediatric palliative care such as the IMPaCCT Standards for paediatric palliative care in Europe (Craig et al 2007), the Education and Training Curriculum in Paediatric Palliative Care (NHPCO, 2003), the White paper on core competencies in palliative care (Gamondi et al 2013) and the White paper on standards and norms for hospice and palliative care in Europe (Radbruch et al 2009, 2010).

## **2.0 DEFINITION OF PAEDIATRIC PALLIATIVE CARE**

As paediatric palliative care has developed, organisations or countries have different working definitions of palliative care (Together for Short Lives 2013). This ambiguity in the terminology has at times led to uncertainty and confusion (Chambers 2013). Thus,

the accepted definition for this paper is that of Together for Short lives which states that *“Palliative care for children and young people with life-limiting conditions is an active and total approach to care from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement”* (Together for Short Lives 2013). This is linked closely to that of the WHO (2002) which states that *“Palliative care for children represents a special, albeit closely related field to adult palliative care and 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.”*

### **3.0 EDUCATION IN PAEDIATRIC PALLIATIVE CARE**

In-line with other documents, it is recommended that a three-tiered approach to education in children's palliative care is considered (De Vlieger et al 2004, Gamondi et al 2013) according to which, all healthcare professionals working with children, receive education on the principles and practice of paediatric palliative care. Those whose work is more focused on paediatric palliative care will require a more specialist level of knowledge. The three tiered approach seen in Table 1, sets out the levels of education currently adopted by the EAPC.

**Table 1: Agreed levels of education adopted by the EAPC to reflect the scope and focus of professionals involved in the delivery of palliative care (Gamondi et al 2013 p.87).**

Agreed level	Description
The palliative care approach	A way to integrate palliative care methods and procedures in settings not specialised in palliative care. Should be made available to general practitioners and staff in general hospitals, as well as to nursing services and nursing home staff. May be taught through undergraduate learning or through continuing professional development.
General palliative care	Provided by primary care professionals and specialists treating patients with life-threatening diseases who have good basic palliative care skills and knowledge. Should be made available to professionals who are involved more frequently in palliative care, such as oncologists, but do not provide palliative care as the main focus of their work. Depending on discipline, it may be taught at an undergraduate or postgraduate level or through continuing professional development.
Specialist palliative care	Provided in services whose main activity is the provision of palliative care. These services generally care for patients with complex and difficult needs and therefore require a higher level of education, staff, and other resources. Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options. Usually taught at a postgraduate level and reinforced through continuing professional development.

### 3.1 Levels of education covered by these guidelines

Central to the provision of paediatric palliative care are the sick newborn, infant, child or adolescent, along with his or her family and friends. It is also important to address the palliative care needs of unborn children with conditions incompatible with life. Education of family members and other caregivers is essential and a key component of the health professionals' role. Such education is beyond the remit of this report, which is focused only on education for health professionals.

This report touches briefly on the professional competencies needed for the first level of care (i.e. the palliative care approach for children), which focuses on the general principles and practices of palliative care, rather than the specifics of paediatric palliative care. Readers are directed to existing EAPC guidelines for undergraduate medical education (EAPC 2007) and the guide for the development of palliative nurse education in Europe (De Vlieger et al 2004) for information regarding what should be included at this level. Therefore, the guidelines within this report focus mainly on *General education in paediatric palliative care*, and *Specialist education in paediatric palliative care*.

### **3.2 Current status of education in paediatric palliative care**

Education and training are crucial to the provision of quality palliative care for children with life-limiting and life-threatening conditions (Smallman 2007) and globally there are a growing number of courses and curricula available on paediatric palliative care, which can be completed either in person or through a range of distance learning options (Ferguson et al 2012). However, with over 7 million children world-wide in need of palliative care (Field and Behrman 2003) there is a need to increase educational opportunities for all involved in paediatric palliative care.

The EAPC children's education task force, comprised of eight members from different countries<sup>1</sup>, undertook a survey in 2010/11. The questionnaire aimed to identify where paediatric palliative care courses and education programmes are currently being provided and whether national curricula exist. The survey also assessed whether there were core elements of the programmes that could be adopted by other countries/organisations. Eighteen countries responded to the initial contact requesting basic information on key personnel working in paediatric palliative care. Those identified as being involved in education in paediatric palliative care were subsequently sent a more detailed questionnaire requesting details of all educational activities available to health professionals working in paediatric palliative care, categorised as 'sensitisation',

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<sup>1</sup> Ling, J. (Ireland), Herkle W (Germany), Schell M (France), Papadatou, D. (Greece), Garchakova A (Belarus), Hain R (UK), Benini F (Italy) and Downing J (Serbia/Uganda)

‘education’ and ‘specialisation’ of health professionals. Full details were provided by 16 countries<sup>2</sup> and educational programmes were identified in fourteen of these countries (87.5%), although since then at least one other country has begun training. Eleven countries (69%) reported they had educational initiatives in paediatric palliative care at all three levels, and the majority of courses were provided for the multi-disciplinary team (Downing and Ling 2012).

### 3.3 Principles underpinning education in paediatric palliative care

Every educational programme in paediatric palliative care needs to be aimed at: a) the acquisition of knowledge, b) the development of specific skills, c) the capacity of interdisciplinary thinking, d) the cultivation of attitudes that promote the human dignity, quality of life and death acceptance, and e) the ability for self-awareness and reflective practice (Liben et al 2008, Papadatou 2009).

Whilst education programmes vary throughout Europe and across the world, there are key principles that should underpin any training (Downing and Ling 2012) – See Figure 1.

**Figure 1. Principles underpinning training on paediatric palliative care**

- The philosophy of paediatric palliative care
- A relational approach to learning
- Inter-professional and inter-disciplinary education
- Practical experience and expertise
- Competency based education
- Education based on the principles of adult learning
- The need for skilled and experienced facilitators
- The evaluation of the process and outcomes of education

#### 3.3.1 The philosophy of paediatric palliative care

The philosophy of palliative care should underpin all training programmes, with an emphasis on quality of life for the child and their family, who are viewed as the unit of

<sup>2</sup> Belarus, England, Scotland and Wales, France, Germany, Greece, Ireland, Italy, Luxembourg, Northern Ireland, Norway, Romania, Serbia, Spain, and Switzerland.



care, and on providing care from diagnosis through to death and into bereavement as appropriate.

### **3.3.2 A relational approach to learning**

One of the primary challenges in paediatric palliative care education is to design and develop educational programmes that are characterised by a philosophy and approach that is *Relationship-Centered* (Beach et al 2006, Papadatou 2009). So far, the prevailing model of care is family-centered emphasising the importance of addressing the child's physical, psychosocial and spiritual needs along with the psychosocial and spiritual concerns of parents, siblings, grandparents, friends and other significant people. This family-centered approach focuses almost exclusively on one aspect of the caring relationship, i.e. the sick child, the parents and siblings and seeks to identify and respond to their individualised needs. The other aspect of this relationship which involves the clinician, the team, and the service or organisation providing children's palliative care services, is often addressed superficially in education and ignored in clinical practice.

A relationship-centered (or relational) approach emphasises the reciprocal influence among those who provide and those who receive care. Education focuses on relationships and enables participants to become acquainted with the subjective world of the child and family who live with uncertainty and threat of death while helping them to also develop a better understanding of their personal and team responses in the face of serious illness, dying and death situations. The specific culture of the institution or service that provides children's palliative care in the given community should also be understood. Relationship-centered care requires a different kind of learning that has been described by Browning and Solomon (2006) as "relational learning". This learning requires the design of educational experiences which are situated in relationships among trainees, instructors, families and other clinicians all of whom reflect on their partnerships and collaborations. This is particularly helpful in paediatric palliative care.



### **3.3.3 Inter-professional and interdisciplinary education**

Implicit in the philosophy and practice of paediatric palliative care is teamwork amongst the professionals who are providing care for the child and their family (Donaghy and Devlin 2002; Cowley et al 2002, Papadatou et al 2010, Wager et al 2013). Whilst there are some specific areas of knowledge and skills within paediatric palliative care that are unique to different professions, much of the core knowledge and skills can, and should where possible, be taught to an inter-professional group of students and participants. It is assumed that the opportunity of *learning together* increases collaboration among students and participants with a different educational background and leads to better *working together* in the clinical setting (Illingworth and Chekvanayagam, 2007). Moreover, inter-professional course participants are exposed to facilitators who model inter professional working, thus students are able to learn about teamwork most effectively in context. The clinical experience element within the training should demonstrate the benefits of teamwork between the professions and also illustrate the necessary collaboration with the child and family.

Some of the benefits of inter-professional education include:

- A greater understanding of other participants' knowledge, skills and role, which prevents stereotyping or mistrust.
- The prevention of isolation of each discipline along with its perceived supremacy over the care of patients and their families.
- Enhanced communication and mutual respect of different point of views, values or alternative approaches to care.
- The cultivation of interdisciplinary thinking.
- Increased understanding of the differences among multidisciplinary, interdisciplinary and trans-disciplinary levels of team collaboration.
- Increased collaboration on clinical and moral issues through the use of a "shared language" that is free of jargon and misunderstandings, and facilitates shared planning, decision making and problem solving.
- Increased self-awareness, facilitated through group learning and mutual support among participants.



### **3.3.4 Practical experience and expertise**

Ferguson et al (2012) suggest that the practice experience of individual healthcare professionals determines the quality of paediatric palliative care and this is learnt through experiential learning over time, with a large number of children and their families. The most effective way of enabling students to learn this, is through direct interaction with children and their families, under the mentorship and supervision of an expert practitioner who models and teaches clinical care (Sullivan et al 2005). Therefore, a practice component, e.g. a clinical placement, is an important aspect of any training programme, though not always easy to provide, particularly in areas where paediatric palliative care is still relatively new and developing. The relationship between organisations providing education and places of care is therefore crucial (De Vlieger et al 2004).

### **3.3.5 Competency based education**

Education programmes need to develop practitioners who are '*fit for practice*', who are '*competent*' to undertake the role that they are being trained for. Within the EAPC White Paper on palliative care education (Gamondi et al 2013), the recommended definition of a competency, which can be transferred across national settings, is 'a cluster of related knowledge, skills and attitudes that affects a major part of one's job (a role or responsibility), that correlates with performance on the job, that can be measured against well-accepted standards, and that can be improved via training and development' (Parry 1996). When considering paediatric palliative care training we need to be addressing the core questions of 'What is my expectation of the learners following this education programme? How can I facilitate the development of specific skills and attitudes? How do I know that these have been acquired? How well equipped are learners to carry out the duties expected of them by the end of the training?' Are they 'fit for providing paediatric palliative care, according to the level of education they have been exposed to?'

Table 2 gives an overview of the competencies that are proposed as the core competencies for paediatric palliative care and build on and expand those identified within the EAPC White Paper on education (Gamondi et al 2013).

**Table 2: Core competencies in paediatric palliative care education**

1.	Demonstrate and apply the core aspects of palliative care in the setting where children and families are based.
2.	Demonstrate the range of knowledge on infants', children's and adolescents' development and family functioning, and how these are affected by a life-threatening illness.
3.	Enhance physical comfort throughout the child's disease trajectories including end-of-life care.
4.	Identify and respond to the child's psychosocial, educational and spiritual needs in palliative care.
5.	Assess and respond to the needs of family carers.
6.	Respond to the challenges of clinical and ethical decision-making in children's palliative care.
7.	Facilitate communication and decision making during crisis and end-of-life care.
8.	Demonstrate capacity for interdisciplinary teamwork and inter-professional collaboration.
9.	Develop interpersonal and communication skills appropriate to children and adolescents, including demonstrating capacity to break bad news and teaching parents how to provide care for the seriously ill child.
10.	Assess the grief process, respond to the distinct needs of bereaved parents, siblings and significant others and provide appropriate support.
11.	Practise reflective practice, self-awareness, and self-care.
12.	Raise community awareness about palliative care for children and adolescents.

### ***3.3.6 Education based on the principles of adult learning***

Across Europe, exposure to educational opportunities varies widely. However learning should be viewed as a life-long process based upon individual interest, motivation, need, values and competency (De Vlieger et al 2004). Principles of adult learning suggest that adults are motivated by learning that:

- Is perceived as relevant



- Builds on previous experience
- Is participatory and actively involves them
- Focuses on problems
- Engenders personal responsibility
- Is immediately applicable to practice
- Involves reflection
- Is based on mutual trust and respect (Spencer and Jordan 1999, De Vlieger et al 2004).

Implicit within adult education is the philosophy of mutual trust, respect, personal responsibility and experience. Whilst there are numerous adult-learning theories (e.g. constructivism, experiential theory and reflective practice, andragogy, hierarchical taxonomies of learning, and problem based learning), in paediatric palliative care education, what is more important than the theory used, are the following: (Ferguson et al 2012):

- The facilitation of learning rather than the mere transmission of knowledge
- The development of habits of learning that result in understanding, rather than simply knowing
- A clear and evolving connection between learning and practical experience, going in both directions as practice is the basis for learning and learning informs and modifies practice.

In facilitating any programme in paediatric palliative care education, there is often a tension between the need for a didactic approach that lends structure and focuses on knowledge, and a more explorative, reflective and interactive approach. Facilitation should be varied, relative to the content, and targeted appropriately to the group of participants in order to ensure the best outcome (De Vlieger 2004). Methods of teaching may include lectures, group work, case studies, critical incident analysis, reflection, sculpting, role-play, experiential activities that enhance self-awareness and attitude development, practical demonstrations, sharing of practical experience, self-directed learning, videos, mentored clinical placements, and site visits.



### ***3.3.7 The need for skilled, experienced educators***

It is important that those facilitating paediatric palliative care courses are professionals experienced in paediatric palliative care as well as in education and training. Educators need to be skilled not only in the practice of paediatric palliative care, but in facilitating the change of attitudes and perceptions depending on condition from cure to care, an approach that 'consists of searching for underlying meaning and structure leading to superior performance' (Fordham and Dowrick 1999), as well as from patient to relationship-centered care (Beach et al 2006, Papadatou, 2009). Expertise and clinical practice reveals a 'kind of knowing' which does not stem just from knowledge but from experience (MacLeod 2004), and enables facilitators to teach 'from the heart'.

### ***3.3.8 Evaluation of the process and outcomes of education***

In order to ensure that programmes are equipping professionals with the competencies needed within paediatric palliative care, evaluation must play a key part. Evaluation should be concerned with the assessment of both the *process* through which education was offered and of the *outcomes* of what has been achieved (Papadatou 1997). Ideally its focus is educative and aims to find out what has gone well and what not so well in order to learn from it, but it is also likely to address the need for accountability and determine whether the investment has been worthwhile (Somekh and Lewin 2005). Evaluation should aim for action as well as reflection (Stronach 1986), thus ensuring that it looks to the future as well as to the past and the present. Any evaluation should be addressing not only issues around knowledge and skills, but also change in attitude and practice, thus a clear strategy for evaluation should be implemented from the start of any education programme.

Assessments should, where possible, be based on the competencies demonstrated by participants and should aim to assess that participants have acquired the necessary level of expertise. Evaluation of knowledge can be done through a variety of methods (e.g. knowledge tests), while evaluation of values and beliefs of paediatric palliative care can be achieved through the use of objective measures (e.g. scales on professional attitudes). Simulations and OSCEs (Objective Structured Clinical Examinations) can form the basis of evaluations of the competencies of paediatric palliative care,

particularly clinical competencies and communication. However, the provision of paediatric palliative care is complex, with many competencies being utilised in real-life situations, therefore the best place for assessment of such competencies is in the workplace itself (Ferguson et al 2013).

### 3.4 Challenges to paediatric palliative care education

The provision of education for paediatric palliative care is not without its challenges. These challenges have been outlined by a variety of authors (e.g. Ferguson et al 2013, Liben et al, 2008, Papadatou, 1997, 2009, Wager et al 2013, Downing and Ling 2012) and include those described in Box 1. Specific challenges in Europe were identified through the EAPC children's taskforce survey (Downing and Ling 2012) and include a lack of recognition of paediatric palliative care as a specialty; a reluctance of staff to be involved in educational initiatives; the small numbers attending training, therefore making them not financially viable or sustainable. Despite these challenges, training in paediatric palliative care must be provided across the region, therefore it is important to find ways of addressing these challenges.

**Box 1: Challenges to the provision of paediatric palliative care education**

1. Accessibility and affordability of courses
2. Large numbers of people to be trained
3. Education in geographically remote areas
4. Shortage of competent educators and mentors for clinical practice.
5. Lack of recognition or accreditation of courses
6. Limited sites to gain clinical experience
7. Culturally appropriate training
8. Development of interdisciplinary thinking and collaboration
9. Limited resources
10. Translation from theory to practice
11. Evaluation of training
12. Sustainability of courses.

#### **4.0 1<sup>st</sup> LEVEL OF EDUCATION: THE PALLIATIVE CARE APPROACH**

This level of education aims to educate students and professionals with the purpose of integrating palliative care methods and procedures in settings not specialised in either palliative care for adults or children. It is made available to undergraduate students, general practitioners and staff in general hospitals, as well as to nursing services.

At the undergraduate level, education is often focused on the general principles and practices of palliative care, rather than the specifics of paediatric palliative care, however it is important that differences between paediatric and adult palliative care are identified and examples of various applications for infants, children, adolescents, and adults are offered. Examples of these can be found at the EAPC website [<http://www.eapcnet.eu>].

#### **5.0 2<sup>nd</sup> LEVEL of EDUCATION: GENERAL PAEDIATRIC PALLIATIVE CARE EDUCATION**

This level of education is made available to students in health care, as well as to professionals who are involved more frequently in palliative care, such as paediatric oncologists, neurologists and neonatologists but do not provide palliative care as the main focus of their work. Depending on discipline, it may be taught at an undergraduate or postgraduate level or through continuing professional development.

At this level education is aimed at those who come from a paediatric background who need to learn about palliative care, and also on occasions those who are working in paediatric palliative care and come from an adult background and need to learn about children. Whilst the core competencies for both groups of professionals is the same, there may be some additional content that both groups of professionals need in order for them to provide quality paediatric palliative care.

Curricula have been developed which vary in terms of length, format and content. Examples of these can be found at EAPC website [<http://www.eapcnet.eu>]. The table in Section 5.1 outlines the minimum competency level, and the emphasis should not be on the length of time of the programme but on the achievement of the competencies.

### 5.1 Domains and Competencies for ‘General Paediatric Palliative Care’ education programmes

Domain	Competencies
<p>1. Core aspects of paediatric palliative care and its application</p>	<ul style="list-style-type: none"> <li>• Acquire knowledge on the history of the palliative care movement and principles of paediatric palliative care, as distinct from adult palliative care.</li> <li>• Acquire knowledge on children with life limiting or life-threatening conditions benefiting from paediatric palliative care.</li> <li>• Acknowledge the holistic approach to care by identifying the physical, psychological, educational, spiritual, social and cultural needs of children, adolescents, and their family.</li> <li>• Understand the value of a relationship-centered approach to paediatric palliative care.</li> <li>• Ability to work closely with those involved in the child’s care (professional and non-professional).</li> <li>• Ability to identify the challenges, obstacles and benefits of applying the principles of paediatric palliative care in the hospital, in perinatal and neonatal units, in the intensive care environment, in the community and at home.</li> <li>• Initiate and monitor the provision of paediatric palliative care as part of the continuum of care including referrals.</li> <li>• Identify gaps in collaboration and referral systems.</li> </ul>
<p>2. Developmental aspects of Infants, Children and Adolescents</p>	<ul style="list-style-type: none"> <li>• Describe normative, developmental tasks in childhood and adolescents and identify how these are affected by life-threatening conditions.</li> <li>• Outline the development of children’s and adolescents’ concepts of illness, dying, and death.</li> </ul>

Domain	Competencies
	<ul style="list-style-type: none"> <li>• Perform an effective developmental assessment.</li> <li>• Ability to interact with children according to stage of cognitive, social, emotional, physical or spiritual development.</li> <li>• Recognise the importance of play and it's appropriate therapeutic intervention.</li> </ul>
3. Physical Care	<ul style="list-style-type: none"> <li>• Acquire knowledge of common physical symptoms in paediatric palliative care.</li> <li>• Recognise common misconceptions regarding pain in children and explain how these impede optimal pain management.</li> <li>• Identify and utilise suitable assessment tools.</li> <li>• Demonstrate effective documentation of pain and symptoms.</li> <li>• Demonstrate safe and effective use of widely use of medications in paediatric palliative care.</li> <li>• Demonstrate effective use of analgesic ladders in managing pain and of adjuvant drugs in symptom control.</li> <li>• Identify non-pharmacological approaches to symptom management.</li> </ul>
4. Psychosocial and Spiritual Care and Educational Needs	<ul style="list-style-type: none"> <li>• Identify how serious illness and dying affects psychosocial and spiritual development in childhood and adolescence.</li> <li>• Be aware of how childhood and adolescent's psychological concerns and difficulties can be manifested.</li> <li>• Identify and utilise suitable psychosocial and spiritual assessment tools.</li> <li>• Help children cope with anxiety and relax.</li> <li>• Recognise the importance of children's education needs.</li> </ul>
5. Family Support	<ul style="list-style-type: none"> <li>• Understand families as systems and how they are affected by the impact of life limiting or life threatening conditions.</li> <li>• Utilise tools such as genograms to understand the family structure and their needs.</li> <li>• Discuss common responses, concerns and needs that parents, siblings, grandparents experience when living with a child with a life-limiting or life-threatening condition.</li> <li>• Provide family support in a culturally appropriate manner.</li> </ul>
6. Clinical and Ethical	<ul style="list-style-type: none"> <li>• Facilitate discussions with the child and family to achieve a common</li> </ul>

Domain	Competencies
decision-making	<p>goal.</p> <ul style="list-style-type: none"> <li>• Facilitate family involvement in clinical decision making.</li> <li>• Be aware of children's capability to be involved in decision-making.</li> </ul>
7. End-of-life Care	<ul style="list-style-type: none"> <li>• Acquire knowledge of common physical symptoms at the end of life.</li> <li>• Acquire knowledge about advance care planning for end of life care.</li> <li>• Identify distressing acute terminal events and clinical emergencies.</li> <li>• Identify common responses, concerns and needs of seriously ill children, siblings, parents and grand parents in the face of impending death.</li> <li>• Recognise manifestations of anticipatory grief and provide support.</li> <li>• Discuss interventions that promote quality of life for the child or adolescent who is dying.</li> <li>• Describe the role of school in coping with the dying and death of a student.</li> </ul>
8. Interdisciplinary Teamwork and Inter-professional Collaboration	<ul style="list-style-type: none"> <li>• Recognise the importance of viewing problems from an interdisciplinary perspective.</li> <li>• Ability to understand team dynamics in the face of serious illness and death.</li> <li>• Ability to identify personal and team coping patterns to manage anxiety, dying and death.</li> </ul>
9. Communication Issues with the Child and Family	<ul style="list-style-type: none"> <li>• Utilise 'child friendly' communication skills.</li> <li>• Demonstrate basic communication skills such as active listening, use of silence reflecting, challenging and discussion of emotionally difficult topics.</li> <li>• Ability to understand non-verbal communication.</li> <li>• Ability to break bad news in a sensitive and culturally appropriate manner.</li> <li>• Ability to deal with denial, strong emotions and difficult questions.</li> <li>• Ability to communicate with children about illness, dying, and death according to their level of awareness and understanding.</li> </ul>
10. Bereavement Support	<ul style="list-style-type: none"> <li>• Recognise unique features of sibling and parental bereavement.</li> <li>• Identify and apply available grief theories in supporting bereaved</li> </ul>

Domain	Competencies
	<p>parents and siblings.</p> <ul style="list-style-type: none"> <li>• Facilitate rituals and use of memory work.</li> <li>• Identify manifestations of complicated grief and make appropriate referral.</li> </ul>
11. Reflective Practice, Self-awareness, and Self-care	<ul style="list-style-type: none"> <li>• Ability to self-analyse critically and constructively personal responses in the caregiving relationship.</li> <li>• Be aware of own areas of vulnerability and resilience and helpful resources in coping with childhood loss.</li> <li>• Structure healthy and holistic support system suited to own personality and circumstances.</li> </ul>
12. Raising Community Awareness	<ul style="list-style-type: none"> <li>• Describe and explain the principles of paediatric palliative care.</li> <li>• Advocate for children's rights for palliative care.</li> <li>• Sensitise others to paediatric palliative care.</li> </ul>

## 6.0 3<sup>rd</sup> LEVEL of EDUCATION: SPECIALIST PAEDIATRIC PALLIATIVE CARE EDUCATION

This level of education is made available to students at post-graduate level and is available to professionals whose main activity is the provision of paediatric palliative care.

Those undertaking this level of education are specialised in paediatric palliative care and ideally have had prolonged experience in the field prior to undertaking specialist paediatric palliative care education. At this level of education, the competency framework is broader and includes additional competencies in collaborative practice, networking, leadership, service development, research and audit, education and professional practice. It is envisaged that professionals trained at this level will be the paediatric palliative care leaders of the future, and as a result, it is essential that they be equipped not only to care, but also to lead, develop an evidence base through research, provide education and advocate for paediatric palliative care in their region.

Education programmes at this level may be profession specific, such as those training to be a Specialist Paediatric Palliative Care Nurse or Consultant in Paediatric Palliative Medicine, or else, they may be multi-professional, with optional modules specific to the different professions. Programmes are provided at a post graduate level and are normally validated by a University and/or accredited by a professional body, in order for them to receive recognition of the specialty. Programmes vary in length and cover a variety of domains and competencies, examples of these can be found at the EAPC website [<http://www.eapcnet.eu>]. In Table 4 are presented the domains, sub-domains and competencies, (which comprise knowledge, skills, and attitudes) for specialists in paediatric palliative care. Five key domains are identified including:

1. The Caregiving Relationship
2. Clinical Care
3. Collaboration and Interprofessional Practice
4. Leadership
5. Professional Practice

### 6.1 Domains and competencies for ‘Specialist Paediatric Palliative Care’ education programmes

Domain	Sub-domain	Specialist Paediatric Palliative Care Competencies
1. The Caregiving Relationship	a. Philosophy and practice of paediatric palliative care	<ul style="list-style-type: none"> <li>• Demonstrate in depth knowledge of the history, development of paediatric palliative care and future prospects.</li> <li>• Understand the application of holism to the development of palliative care services for children from an inter-disciplinary perspective.</li> <li>• Adopt a relationship-centered approach to paediatric palliative care.</li> <li>• Apply the philosophy of palliative care across the age ranges including the unborn child, the newborn, infants, children and adolescents.</li> <li>• Demonstrate detailed knowledge of specific life limiting and life threatening conditions (e.g. the ACT categories).</li> <li>• Recognise their role within the wider palliative care</li> </ul>

Domain	Sub-domain	Specialist Paediatric Palliative Care Competencies
		community, nationally and internationally.
	b. Communication with the Child and Family	<ul style="list-style-type: none"> <li>• Identify barriers to communication (personal, interpersonal, organisational, and cultural) and strategies to overcome them.</li> <li>• Demonstrate good communication skills that enables one to:               <ul style="list-style-type: none"> <li>○ Break bad news</li> <li>○ Facilitate the expression of feelings, thoughts and needs</li> <li>○ Decode non verbal communication</li> <li>○ Actively listen and elicit concerns across physical, psychological, spiritual and social areas</li> <li>○ Establish extent of awareness of illness and prognosis</li> <li>○ Impart information sensitively, at a pace that suits each child, adolescent, and family according to their needs and wishes</li> <li>○ Facilitate involvement in decision-making</li> <li>○ Enhance self-esteem and promote autonomy.</li> </ul> </li> <li>• Ability to discuss uncertainty and prognosis.</li> <li>• Facilitate open communication among family members.</li> <li>• Discuss advanced care planning in anticipation of the child's death.</li> <li>• Educate the patient and family about care of the child.</li> </ul>
	c. Psychosocial and spiritual care	<ul style="list-style-type: none"> <li>• Demonstrate in depth knowledge of what 'accompanying' families throughout the child's illness and dying entails.</li> <li>• Recognise how specific diagnosis, personal factors, family dynamics, and cultural influences, affect responses to diagnosis and end of life care.</li> <li>• Recognise the multiple losses and associated grief responses that families experience throughout the child's illness and dying process.</li> </ul>

Domain	Sub-domain	Specialist Paediatric Palliative Care Competencies
		<ul style="list-style-type: none"> <li>• Distinguish between functional and dysfunctional coping patterns in children, their parents, and siblings.</li> <li>• Utilise assessment tools for identifying psychosocial and spiritual concerns and resources in children and parents.</li> <li>• Provide appropriate support and/or therapy, and identify when further referral is necessary.</li> <li>• Demonstrate in depth knowledge of the latest research on vulnerability and resilience issues among children and families.</li> <li>• Develop and maintain close links with relevant support services, including local child and adult psychiatric services, psychological services, bereavement counselling and support groups.</li> <li>• Identify how peer relationships are affected by the child's or adolescent's illness or dying.</li> <li>• Provide counselling and guidance to school communities, and facilitate child, educator, and peer communication and support.</li> </ul>
	d. Bereavement support	<ul style="list-style-type: none"> <li>• Support a bereaved parent and recognise unique features of parental bereavement.</li> <li>• Support a bereaved sibling and recognise unique features of sibling bereavement.</li> <li>• Ability to recognise multiple losses following a child's death and their impact upon family adjustment.</li> <li>• Identify prolonged and complicated grief in children and adults.</li> </ul>
	e. Self and team care	<ul style="list-style-type: none"> <li>• Demonstrate insight into one's attitudes towards life-threatening illness, dying, death, and grief</li> <li>• Identify personal suffering that is unavoidable (e.g. grief) and suffering that leads to impairment (e.g. burnout, post-traumatic stress disorder) and recognise professionals at risk or in difficulty.</li> <li>• Identify measures to manage distress and available</li> </ul>

Domain	Sub-domain	Specialist Paediatric Palliative Care Competencies
		<p>support systems for individuals and teams</p> <ul style="list-style-type: none"> <li>• Identify strategies to enhance personal and team resilience</li> <li>• Ability to recognise functional and dysfunctional team patterns in coping with distress, dying and death</li> <li>• Identify individual and team need for bereavement support and facilitate its availability and accessibility</li> </ul>
2. Clinical Care	a. Pain assessment and management	<ul style="list-style-type: none"> <li>• Be knowledgeable of the pathophysiology of pain in children.</li> <li>• Anticipate, assess and manage pain in newborns, infants, children and adolescents.</li> <li>• Evaluate critically and facilitate implementation of the use of new pain assessment scales where appropriate.</li> <li>• Tailor pain management to meet the individual assessed needs of each child using all available methods of pharmacological and non-pharmacological approaches.</li> </ul>
	b. Assessment and management of other symptoms	<ul style="list-style-type: none"> <li>• Be knowledgeable of the pathophysiology of different symptoms.</li> <li>• Anticipate, assess and manage symptoms from a holistic perspective through the use of an interdisciplinary approach.</li> <li>• Develop a plan for symptom management that includes both pharmacological and non-pharmacological interventions.</li> </ul>
	c. End of life care	<ul style="list-style-type: none"> <li>• Develop a comprehensive advanced plan for end of life.</li> <li>• Identify, anticipate and plan for potential emergencies.</li> <li>• Ability to communicate sensitively and appropriately with a child and family concerning anticipation of emergencies.</li> <li>• Facilitate child and family's wishes with respect to preferred place of death, rituals and practices around death and dying.</li> </ul>

Domain	Sub-domain	Specialist Paediatric Palliative Care Competencies
		<ul style="list-style-type: none"> <li>• Ability to ensure continuity of care between the home, hospice and hospital at the end of life.</li> <li>• Identify and respond to the specific needs of siblings and other extended family members at the end of life</li> <li>• Recognise and respond to the needs of peers, teachers and other community members</li> </ul>
3. Collaboration and Interprofessional Practice	a. Teamwork	<ul style="list-style-type: none"> <li>• Ability to work as part of an interdisciplinary team.</li> <li>• Demonstrate an understanding of team dynamics and of the functional and dysfunctional patterns used to manage illness, death and dying.</li> <li>• Facilitate inter-disciplinary team meetings.</li> <li>• Recognise the role and benefits of clinical supervision in teamwork.</li> </ul>
	b. Networking	<ul style="list-style-type: none"> <li>• Set up effective communication systems between teams to ensure holistic care for the child and family.</li> <li>• Integrate palliative care into alternative settings through networking and collaboration.</li> <li>• Facilitate 'open teamwork' and create conditions for meaningful interactions among teams.</li> <li>• Demonstrate ability to collaborate effectively with volunteers.</li> </ul>
4. Leadership	a. Leading and developing services	<ul style="list-style-type: none"> <li>• Ability to lead an inter-disciplinary team caring for children with palliative care needs in different settings.</li> <li>• Ability to provide mentorship and supervision to all those involved in paediatric palliative care service provision.</li> <li>• Lead by example and facilitates change in paediatric palliative care.</li> <li>• Ability to plan for and set up a palliative care service.</li> <li>• Initiate new and/ or innovative paediatric palliative care services.</li> </ul>
	b. Advocacy	<ul style="list-style-type: none"> <li>• Advocate for palliative care as a human right, policies</li> </ul>

Domain	Sub-domain	Specialist Paediatric Palliative Care Competencies
		<p>for palliative care and availability and accessibility of essential palliative care medications.</p> <ul style="list-style-type: none"> <li>• Advocate for the development of paediatric palliative care.</li> <li>• Advocate for education in paediatric palliative care.</li> <li>• Advocate for the integration of palliative care into the formal health sector.</li> </ul>
5. Professional Practice	a. Research	<ul style="list-style-type: none"> <li>• Critically appraise the literature and available data on paediatric palliative care to influence practice.</li> <li>• Conduct research and implement new findings to the provision of paediatric palliative care.</li> <li>• Demonstrate knowledge of ethical standards when involving children and parents in research.</li> </ul>
	b. Evaluation of services	<ul style="list-style-type: none"> <li>• Assess, monitor and evaluate the impact of palliative care service provision on children, families and professionals.</li> <li>• Evaluate the short and long term effects of training on the provision of paediatric palliative care.</li> <li>• Utilise audit in order to provide evidence to improve palliative care services for children.</li> <li>• Document, interpret and disseminate evaluation results.</li> </ul>
	c. Policy	<ul style="list-style-type: none"> <li>• Be aware of national and international directives, frameworks, policies and guidelines which govern the development of paediatric palliative care services.</li> <li>• Contribute to the development or revision of laws on paediatric palliative care, when necessary.</li> <li>• Design policy on the establishment and implementation of palliative care services.</li> </ul>
	d. Training and education	<ul style="list-style-type: none"> <li>• Recognise responsibility for training others, and for maintaining own learning and skills.</li> <li>• Assess training and learning needs of the team</li> <li>• Develop training programmes and select appropriate</li> </ul>

Domain	Sub-domain	Specialist Paediatric Palliative Care Competencies
		<p>learning methods for the context and participants.</p> <ul style="list-style-type: none"> <li>• Ability to teach, supervise, and support junior staff sensitively and effectively.</li> <li>• Ability to evaluate a training programme on paediatric palliative care.</li> </ul>

## 7.0 CONCLUSION

The EAPC children’s palliative care education taskforce view these guidelines as a basis for paediatric palliative care education. This report is based on the three-tiered agreed levels of education currently adopted by the EAPC which have been applied to the field of paediatric palliative care. A competency framework for two levels of education – that of general paediatric palliative care education and specialist paediatric palliative care education have been outlined, thus providing the basis and framework for paediatric palliative care programmes. It is hoped that this report and the resulting guidelines will empower those seeking to develop such programmes, such that quality education on paediatric palliative care will be made accessible and available throughout Europe and the world.



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