

# White Paper on standards and norms for hospice and palliative care in Europe: part 1

## *Recommendations from the European Association for Palliative Care*

In this official position paper of the European Association for Palliative Care (EAPC), Lukas Radbruch, Sheila Payne and the Board of Directors of the EAPC outline and explain the association's recommendations for a common terminology and common quality norms

### **1. Background**

The modern hospice movement was introduced by Cicely Saunders with the opening of St Christopher's Hospice in London in 1967. However, as early as 1975, Balfour Mount found a confusion of terms when he looked for a designation for his new inpatient unit in Montreal, as in French-speaking Canada 'hospice' was already used in a different context, leading to the introduction of the term 'palliative care'.

The struggle for a common language has been going on since then in hospice and palliative care throughout the world and has hampered the development of international standards and norms. Recently, the European Association for Palliative Care (EAPC) commissioned a survey on the development of palliative care in European countries. The Task Force on the Development of Palliative Care in Europe, led by Carlos Centeno and David Clark, has just published the results in the *EAPC Atlas of Palliative Care in Europe*, providing for the first time valid data for comparison of the state of palliative care across European countries.<sup>1,2</sup> This evaluation showed some common structures, but also a wide variety in the structure of service development and care delivery. These differences are at least partly related to different understanding of the underlying concepts and the terms of palliative medicine. The development of a common terminology has been claimed as a prerequisite for meaningful comparisons.<sup>3</sup>

Following this lead, the EAPC is now putting forward suggestions for a common European

terminology following a consensus process with the national associations. Norms will be defined on the basis of this consensual terminology. Guidance on norms and standards are necessary not only for healthcare professionals working in hospice and palliative care settings, but also for decision-makers in healthcare who are responsible for adequate access to palliative care for patients.

With the ongoing development of palliative care throughout Europe, decision-makers are challenged not only to decide where and when palliative care services should be developed, but also how they should be equipped and configured. Adequate structural quality is a prerequisite for high quality of care. Administrative and political decision-makers will aim for cost-effectiveness, and try to reduce costs by allocating a minimum of staff or reimbursement. Care providers will negotiate for adequate staff resources necessary for high quality of care. In this conflict, both sides will seek guidance on structural quality.

In this paper, the EAPC presents norms on structural quality for the provision of palliative care with in- and outpatient services in different settings. This *White Paper* takes into account the different concepts in the European countries and regions. This is acknowledged by the description of norms rather than the definition of standards. Whereas standards would imply an absolute limit below which quality palliative care is not possible (minimal standards), norms represent a consensus on quality goals that have to be aimed for (aspirational norms). If (or

when) norms are achieved, high quality can be safely expected.

## 2. Methods

This *White Paper* is designed to provide guidance and recommendations for service providers, stakeholders and decision-makers. The first draft was presented at a cancer conference in February 2008 during the Slovenian presidency of the European Union.

As previously stated, the EAPC presents norms and working definitions rather than standards. Standards set rigid limits with cut-off values, implying that units not achieving them would lose their specialist status. EAPC norms affirm how things ought to be to provide high-quality palliative care, but services that do not meet one or more of these norms due to local or regional differences will not be discriminated against. Taking into account the differences in the healthcare systems as well as different cultural backgrounds, it does not seem possible to agree on standards with national associations in more than 20 countries. However, a consensus on norms does seem realistic.

The Board of Directors of the EAPC gave the remit of preparing this paper to a writing committee (Saskia Jünger, Sheila Payne and Lukas Radbruch). The draft manuscript was reviewed by experts within the EAPC (Franco De Conno, Carl-Johan Fürst, Geoffrey Hanks, Irene Higginson, Stein Kaasa, Phil Larkin, Friedemann Nauck). The draft was revised with the feedback from these experts and this revised draft was circulated to the Board members of the national member associations of the EAPC. Feedback from the national associations was elicited with a Delphi procedure, asking for the level of agreement or disagreement with each norm suggested. Representatives of 35 different national hospice and palliative care associations from 22 European countries have participated in the consensus procedure. Using the feedback from the Delphi process, a final revision of the paper was prepared. This final version was submitted to the Board of Directors of the EAPC and adopted as an official position paper.

### 2.1 The purpose of norms

Norms can be developed on a national and a regional/local level. The national level represents a uniform strategy for development and control; it can save time and energy. At the regional or local level, the national norms are adapted to the specific characteristics of the

### Box 1. Aims/goals of palliative care norms<sup>5</sup>

- Promote quality and reduce variation in new and existing programmes
- Develop and encourage continuity of care across settings
- Facilitate collaborative partnerships among palliative care programmes, community hospices and a wide range of other healthcare delivery settings
- Facilitate the development and continuing improvement of clinical palliative care programmes
- Establish uniformly accepted definitions of the essential elements in palliative care that promote quality, consistency and reliability of those services
- Establish national goals for access to quality palliative care
- Foster performance measurement and quality improvement initiatives

respective regions or institutions. Evidently, the best approach results from a combination of both.<sup>4</sup> The introduction of norms presumes a far-reaching consultation and agreement with all involved participants, in order to ensure validity, as well as relevance. The aims and goals of palliative care norms are outlined in Box 1.

### 2.2 Key areas of norms in palliative care

This paper is not based on a systematic review, but rather on a scoping of publications and other sources from acknowledged official institutions such as the Council of Europe. The key areas outlined in this paper have been derived from existing documents on norms and standards in palliative care from different organisations, associations, nations and committees.<sup>4-7</sup> This paper covers the following key elements of palliative care:

- Definition and terminology of palliative care and hospice care
- Common values and philosophy
- Levels of care
- Patient groups
- Services and settings.

Other key areas – such as availability of, and access to, services; education for healthcare providers; clinical audit and documentation standards; public education and awareness; and research – are not included in this paper and will be covered separately.

### 2.3 Sources of bias

The consensus-building process on norms for quality palliative care in the European Union

**An effective European approach to quality palliative care demands an unambiguous use of terms**

bears several challenges due to the considerable heterogeneity of service provision in the different countries. Some types of services have been developed only in certain countries.<sup>1</sup> For example, the results of the study of the EAPC Task Force revealed that, among 52 European countries, only five countries have a well developed and extensive network of inpatient hospices. In contrast, other countries have a much higher proportion of home-care teams. This leads to the question of whether a common approach will do justice to the different regional, geographical and cultural focuses regarding the provision of palliative care. The same is true for the issue of terms and definitions. Herein, the task of attaining consensus might be even more challenging than in North America. After all, the European Union consists of countries with millennia of history and language that keep them separated – and it must be acknowledged that there is a lot of pride in the differences.<sup>3</sup>

Therefore, the consensus building process has to take into account whether European norms of care provision can be dovetailed to the respective demographical and cultural aspects in the different countries and regions.

Palliative care policy is a rapidly evolving field; since the start of the European consensus process, two important government reports have been published. In July 2008, the *End of Life Care Strategy* for England was published by the Department of Health;<sup>8</sup> in April 2009, the second edition of the consensus guidelines of the National Consensus Project of the USA was released.<sup>9</sup> The updates of this second edition, as well as specific guidelines of the *End of Life Care Strategy*, could not be considered in the European consensus process. By means of a post hoc validation, the writing committee has verified that the statements in this *White Paper* are still in accordance with the recommendations in these recent documents.

### 3. Terminology

The attempt to examine and compare palliative and hospice care in Europe revealed a heterogeneous terminology.<sup>1,10</sup> The differences in terminology did not only appear in the scientific literature, but also in texts of law, government bills and expert statements of relevant associations.<sup>10</sup> For example, by means of a discourse analysis of palliative care definitions, Pastrana *et al* have noticed the use of different terms referring to overlapping medical fields

such as ‘hospice’, ‘hospice care’, ‘continuing caring’, ‘end-of-life care’, ‘thanatology’, ‘comfort care’ and ‘supportive care’.<sup>11</sup> Moreover, different terms may trace back to different cultural backgrounds. For example, in the German language, there is no direct equivalent for the term palliative care, and thus ‘Palliativmedizin’ is used both for palliative care and palliative medicine.<sup>11</sup> However, the synonymous use of ‘Palliativmedizin’ (palliative medicine) with palliative care has led to concerns about a medicalisation of palliative care in Germany.<sup>11</sup> Therefore, some experts even used the English term ‘palliative care’ to differentiate from palliative medicine. Only in the last year has the term ‘Palliativversorgung’ been accepted as synonymous with palliative care. Similarly, in other European languages, it is not evident in how far the same concepts are intended by the term officially used for palliative care (see Table 1).

It is obvious that an effective European approach to quality palliative care demands an unambiguous use of terms, which implies, as a prerequisite, the mutual agreement on the definitions of these terms. The Task Force on the Development of Palliative Care in Europe has compared service development and provision of care in 42 European countries in the *Atlas of Palliative Care*.<sup>2</sup> In a critical appraisal of the *Atlas*, the importance of a common language was underlined, as comparative charts will only have leverage when they are based on a shared language where the same word will have the same meaning in each country where it is used.<sup>3</sup>

Realising that full consensus will not be possible within the scope of languages and cultures in Europe, the EAPC will use the following working definitions of palliative care and hospice care.

#### 3.1 Palliative care

**Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor**

**Table 1. Conventional terms for 'palliative care' in different European countries**

Country	Terms for 'palliative care'	Other terms
Austria	Palliativ(e) Care; Palliativmedizin; palliative Betreuung / Palliativbetreuung; Palliativversorgung	Lindernde Fürsorge (relief and comfort)
Belgium (Flemish)	Palliatieve zorg	
Belgium (Walloon)	Soins palliatifs	
Republic of Croatia	Paljativna skrb	
Cyprus	Anakoufisiki frontitha / frontida	Paragoritikes agogis (relief or comfort)
Czech Republic	Paliativni pece	
Denmark	Palliative indsats; palliative behandling (og pleje)	
France	Soins palliatifs	Accompagnement de fin de vie (accompaniment at the end of life)
Germany	Palliativmedizin; Palliativversorgung	Hospizarbeit ([volunteer] hospice work)
Greece	Anakoufistiki frontida	
Hungary	Palliatv ellts	
Iceland	Líknarmedferd / líknandi medferd	
Ireland	Palliative care	
Israel	Tipul tomeh / tomech; tipul paliativi	Palliative care
Italy	Cure palliative	
Latvia	Paliativa aprupe	
The Netherlands	Palliatieve zorg	Terminale zorg (terminal care)
Norway	Palliativ behandling; palliativ omsorg; palliativ madisin; palliativ pleie	Lindrende behandling og omsorg (relief and comfort); palliative care
Portugal	Cuidados paliativos	
Spain	Cuidados paliativos	
Sweden	Palliativ vård; palliative medicin	
Switzerland	Palliative Care; Palliative Betreuung	
UK	Palliative care; palliative medicine	Supportive and palliative care; end-of-life care

postpones death. It sets out to preserve the best possible quality of life until death.<sup>12</sup>

Despite the cultural differences regarding the palliative care approach across Europe, the EAPC definition of palliative care has had a unifying impact on the palliative care movements and organisations of many European countries.<sup>13</sup> The EAPC definition is slightly different from the definition of the World Health Organization (WHO), given below.

**Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.**<sup>14</sup>

This WHO definition has replaced an older definition of the WHO that was restricted to patients 'whose disease is not responsive to curative treatment'.<sup>15</sup> The new and modified WHO definition from 2002 extends the scope

of palliative care to patients and families 'facing the problems associated with life-threatening illness'.<sup>16</sup>

### 3.2 Hospice care

**Hospice care is for the whole person, aiming to meet all needs – physical, emotional, social and spiritual. At home, in day care and in the hospice, they care for the person who is facing the end of life and for those who love them. Staff and volunteers work in multi-professional teams to provide care based on individual need and personal choice, striving to offer freedom from pain, dignity, peace and calm.**<sup>17</sup>

The definition of hospice care meets with much less consensus than the definition of palliative care. There seem to be fundamental differences in the understanding of hospice care, which probably reflect the different ways that hospices are used in Western Europe. In some countries, there is a clear distinction between hospice and palliative care, whereas in

other countries, the terms are used synonymously. If a distinction is made, it can be related to the institutional framework, describing a palliative care unit as a ward within a general hospital versus an inpatient hospice as free-standing service.

However, the distinction can also relate to the indications for admission or the type of interventions offered. Using this framework, in Germany, for example, a palliative care unit as part of a hospital primarily aims at crisis intervention and medical stabilisation, whereas an inpatient hospice provides end-of-life care for patients who can not be cared for at home. This categorisation would not be used in other countries.

In some countries, a similar distinction is made for outpatient services. In Germany, palliative home-care services focus on nursing, whereas home-care hospice services mainly provide volunteer psychosocial support.

In some countries, the meaning of hospice represents the philosophy of care more than a certain type of setting where care is provided.<sup>18</sup> In Germany, for example, hospice work has been used predominantly for the provision of care that has developed as a community movement, depending strongly on volunteer engagement, whereas palliative care and, more specifically, palliative medicine are seen as a medical field.

However, as the underlying philosophy as well as the definitions of palliative care and hospice care overlap to a large extent, we will use the term 'palliative care' throughout this paper to represent both hospice and palliative care.

### **3.3 Supportive care**

**Supportive care is the prevention and management of the adverse effects of cancer and its treatment. This includes physical and psychosocial symptoms and side-effects across the entire continuum of the cancer experience, including the enhancement of rehabilitation and survivorship.**<sup>19</sup>

**There is considerable overlap and no clear differentiation between the use of the terms 'palliative care' and 'supportive care'.**

However, most experts agree that supportive care is more appropriate for patients still receiving antineoplastic therapies and also extends to survivors, whereas palliative care has its major focus on patients with far advanced disease where antineoplastic therapies have been withdrawn.<sup>20</sup> However, a national survey

in Germany has shown that 9% of the patients in palliative care units received chemotherapy.<sup>21</sup> Cancer survivors would not be included in the target groups of palliative care. On the other hand, palliative care covers not only cancer patients, but also other patient groups with life-threatening diseases.

**Supportive care should not be used as a synonym of palliative care. Supportive care is part of oncological care, whereas palliative care is a field of its own extending to all patients with life-threatening disease.**

### **3.4 End-of-life care**

**End-of-life care may be used synonymously with palliative care or hospice care, with end of life understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness.**

The term 'end-of-life care' is widely used in North America and it has been picked up by regulatory bodies in European countries, sometimes with the understanding that palliative care is associated predominantly with cancer, whereas end-of-life care would be applicable to all patients. For example, in England, the NHS *End of Life Care Strategy* was published in 2008 to improve dying for all patients wherever they receive care.<sup>8</sup>

**End-of-life care may also be understood more specifically as comprehensive care for dying patients in the last few hours or days of life.**

End-of-life care in the restricted time frame of the last 48 or 72 hours of life is the goal of the Liverpool Care Pathway for the Dying Patient. This approach has been promoted to transfer the hospice model of care to patients dying in non-specialised settings.<sup>22</sup> Used with this connotation, end-of-life care may also be implemented as a standard of care for dying patients not requiring palliative care.

Considering the ambiguity of the term and the degree of overlap between end-of-life care and palliative care, no specific reference will be made to end-of-life care in this paper.

### **3.5 Terminal care**

**Terminal care is an older term that has been used for comprehensive care of patients with advanced cancer and restricted life expectancy.**

More recent definitions of palliative care are not restricted to patients with restricted life

expectancy in the final stage of the disease. The term 'terminal care', therefore, has lost relevance and should not be used any more, or only to describe the care given during the very last stage (the last few days) of illness.

### 3.6 Respite care

**Family members or other primary caregivers caring for a palliative care patient at home may suffer from the continuous burden of care. Respite care may offer these patients and their caregivers a planned or unplanned break.<sup>23</sup>**

Respite care can be provided in day-care facilities, inpatient units or through specialist home-care services.

## 4. The philosophy of palliative care

Despite the differences among national approaches to palliative care, a series of common values and principles can be identified in the literature, which have been recognised and endorsed by hospice and palliative care activities.<sup>11,24</sup>

**Throughout the European countries, a set of common values is acknowledged among palliative care experts. This includes the value of patient autonomy and dignity, the need for individual planning and decision-making and the holistic approach.**

### 4.1 Autonomy

**In palliative care, the intrinsic value of each person as an autonomous and unique individual is acknowledged and respected. Care is only provided when the patient and/or family are prepared to accept it. Ideally, the patient preserves his/her self-determination regarding the power of decision on place of care, treatment options and access to specialist palliative care.**

Patients should be empowered to make decisions if they wish. This requires the provision of adequate information on diagnosis, prognosis, treatment and care options and all other relevant aspects of care.

However, there is an ongoing discussion on the ethical challenge when decision-making capacity is not available or not wanted by the patient, and information and decision-making shift to the family or the palliative care staff. The balance between autonomy and protective care seems to be influenced by cultural factors, as, in some countries, the shift

of decision-making from patient to caregiver is reported more frequently.

### 4.2 Dignity

**Palliative care is supposed to be performed in a respectful, open and sensitive way, sensitive to personal, cultural and religious values, beliefs and practices as well as the law of each country.**

As with quality of life, dignity seems to be an individual concept including different domains and priorities for each patient. Depending on the definition, dignity may be seen rather as an inherent property than as an item that can be damaged or lost. Following this view, palliative care is challenged to provide a setting where the patient can feel and enact their dignity.

### 4.3 Relationship between patient–healthcare professionals

**Palliative care staff should maintain a collaborative relationship with patients and families. Patients and families are important partners in planning their care and managing their illness.**

Palliative care holds a salutogenic view with emphasis on the resources and competencies of patients, and not simply on their difficulties.<sup>11</sup> Herein, a resilience-oriented approach has recently received increasing recognition. Resilience describes the ability of patients to deal with incurable disease and related problems, and with the change of perspective due to a restricted life expectancy. The concept of resilience offers a change of paradigm: whereas the focus on symptoms, risks, problems and vulnerability is deficit-oriented, the focus on resilience is resource-oriented. Resilience emphasises the importance of public health and creates a partnership between patients, professionals and community structures.<sup>25</sup>

### 4.4 Quality of life

**A central goal of palliative care is to achieve, to support, to preserve and to enhance the best possible quality of life.**

Care is guided by the quality of life as defined by the individual. More specifically, biopsychosocial and spiritual quality of life have been named, and standardised questionnaires are used for the assessment of health-related and disease-specific quality of life. However, the meaning of 'quality of life' can only be determined by each palliative care patient individually for themselves.<sup>11</sup> Relevant

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dimensions of the individual quality of life, as well as priorities within these dimensions, often shift in relation to the progression of the disease. Quality of life seems to depend more on the perceived gap between expectations and actual performance status than on an objective impairment of function.

#### **4.5 Position towards life and death**

Many definitions of palliative care include a position towards life and death.<sup>11</sup> The first definition of the WHO in 1990 postulated that 'palliative medicine affirms life and regards dying as a normal process', and other definitions have shared this position. Death is seen on the same level as life, inseparable from it, and as a part of it.

**Palliative care seeks neither to hasten death nor to postpone it.**

The provision of euthanasia and physician-assisted suicide should not be part of the responsibility of palliative care.<sup>13</sup>

'The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualisation' should be acknowledged.<sup>24</sup>

#### **4.6 Communication**

**Good communication skills are an essential prerequisite for quality palliative care. Communication refers to the interaction between patient and healthcare professionals, but also to the interaction between patients and their relatives as well as the interaction between different healthcare professionals and services involved in the care.**

Dissatisfaction and complaints about care can often be attributed to ineffective communication rather than inadequate service delivery,<sup>4</sup> whereas effective communication has been shown to improve patient care.<sup>26</sup>

Communication in palliative care is much more than the mere exchange of information. Difficult and sometimes painful concerns have to be considered, which requires time, commitment and sincerity. For palliative care staff, it can be a challenging task to convey honest and complete information on the one hand, and respect the patient's and their families' hopes for survival despite the oncoming death on the other hand.<sup>27</sup> Adequate prerequisites for effective communication have to be provided,<sup>4</sup> including training and education, appropriate space and accommodation, time for interaction with

patients and their families and for exchange with the team, as well as access to up-to-date information technology.

#### **4.7 Public education**

The Council of Europe claims that it is of utmost importance to create a climate of acceptance for palliative care in the member states of the European Union.<sup>4</sup> Therefore, it is essential to build community capacity and to promote preventive healthcare that will leave future generations less afraid of the dying and bereavement that will confront all of us.<sup>25</sup>

#### **4.8 Multiprofessional and interdisciplinary approach**

Team work is regarded as a central component of palliative care.<sup>28</sup> A multiprofessional team includes members from different healthcare and non-healthcare professions and disciplines who work together to provide and/or improve care for patients with a particular condition. The composition of multiprofessional teams will differ according to many factors, including the patient groups served, the extent of the care provided and the local area of coverage.<sup>29</sup>

**Palliative care is supposed to be provided within a multiprofessional and interdisciplinary framework. Although the palliative care approach can be put into practice by a single person from a distinct profession or discipline, the complexity of specialist palliative care (see under Chapter 5. 'Levels of palliative care') can only be met by continuous communication and collaboration between the different professions and disciplines in order to provide physical, psychological, social and spiritual support.**

There are clear indications that teamwork in palliative care is advantageous for the patient.<sup>4</sup> A systematic literature review on the effectiveness of specialist palliative care teams in cancer care by Hearn and Higginson has revealed evidence that specialist teams in palliative care improve satisfaction, and identify and deal more with patient and family needs, compared with conventional care.<sup>30</sup>

Moreover, multiprofessional approaches turned out to reduce the overall cost of care by reducing the amount of time patients spend in acute hospital settings. A more recent review supported the evidence of the positive effect of palliative care teams, with the strongest effect for patient pain and symptom control.<sup>31</sup> The extension of the team can be dealt with flexibly

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and has to be determined by the patient's needs. The minimal version, therefore, can consist of a general practitioner and a specialised nurse. However, in most cases, social workers, psychologists and/or volunteers are involved in the teams. The Council of Europe recommends that the leadership role of every section in specialised palliative care teams should be adopted by an approved professional qualified in palliative care.<sup>4</sup>

#### **4.9 Grief and bereavement**

Palliative care offers support to family and other close carers during the patient's illness, helps them prepare for loss and continues to provide bereavement support, where required, after the patient's death. Bereavement services are recognised as a core component of palliative care service provision.<sup>4,5</sup>

**Grief and bereavement risk assessment is routine, developmentally appropriate and ongoing for the patient and family throughout the illness trajectory, recognising issues of loss and grief in living with a life-threatening illness. Bereavement services and follow-up support are made available to the family after the death of the patient.**

### **5. Levels of palliative care**

Palliative care can be delivered on different levels. At least two levels should be provided: a palliative care approach and specialist palliative care.

Currently, in most documents, a two-level approach of palliative care can be found; that is, the differentiation between a **palliative care approach** and **specialist palliative care**. The **palliative care approach** would be used in settings and services only occasionally treating palliative care patients. In contrast, **specialist palliative care** applies to a team of appropriately trained physicians, nurses, social workers, chaplains and others whose expertise is required to optimise quality of life for those with a life-threatening or debilitating chronic illness.<sup>5</sup>

#### **5.1 Palliative care approach**

**The palliative care approach is a way to integrate palliative care methods and procedures in settings not specialised in palliative care. This includes not only pharmacological and non-pharmacological measures for symptom control, but also communication with patient and family as well as with other healthcare**

**professionals, decision-making and goal-setting in accordance with the principles of palliative care.**

The palliative care approach should be made available for general practitioners and staff in general hospitals, as well as for nursing services and for nursing home staff. To enable these service providers to use the palliative care approach, palliative care has to be included in the curricula for medical, nursing and other related professionals' basic education. The Council of Europe recommends that all professionals working in healthcare should be confident with the basic palliative care principles and able to put them into practice.<sup>4</sup>

#### **5.2 General palliative care**

This two-step ladder of care levels can be extended to three steps, with a palliative care approach, general palliative care and specialist palliative care. General palliative care is provided by primary care professionals and specialists treating patients with life-threatening diseases who have good basic palliative care skills and knowledge.

**Professionals who are involved more frequently in palliative care, such as oncologists or geriatric specialists, but do not provide palliative care as the main focus of their work, still may have acquired special education and training in palliative care and may provide additional expertise. These professionals can provide general palliative care.**<sup>4</sup>

#### **5.3 Specialist palliative care**

Patients with life-threatening disease, and those important to them, may have complex needs, which require the input of the specialist palliative care team.<sup>29</sup> Specialist palliative care describes 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.<sup>4</sup>

**Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options.**

All patients with progressive incurable diseases should have access to specialist palliative care services, which address proactively all the symptoms of their condition and the effect these symptoms have on them and their families/carers.<sup>29</sup> Patients with complex palliative care

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needs require a wide range of therapeutic interventions for symptom control. The relevant specialist palliative care services must have access to the necessary level of trained staff to safely manage these interventions.

**Specialist palliative care services require a team approach, combining a multi-professional team with an interdisciplinary mode of work. Team members must be highly qualified and should have their main focus of work in palliative care.**

The provision of specialist palliative care services has to be performed by palliative care professionals who have undergone recognised specialist palliative care training.<sup>5,29</sup> The team members are supposed to have expertise in the clinical management of problems in multiple domains in order to meet the patient's complex needs. Their work reflects substantial involvement in the care of patients with life-threatening or debilitating chronic illness, and their families.

**Specialist palliative care services require a team approach**

### *5.4 Centres of excellence*

The ladder can also be extended to a fourth level, that of centres of excellence. Centres of excellence should provide specialist palliative care in a wide variety of settings, including in- and outpatient care, home care and consultation services, and should provide academic facilities for research and education. The role of centres of excellence is still under discussion, and the position of such centres in a multilevel approach will depend on that discussion.

**Centres of excellence in palliative care should act as a focus for education, research and dissemination, developing standards and new methods.**

## **6. Population served**

### *6.1 Patients*

**Palliative care is not restricted to predefined medical diagnoses, but should be available for all patients with life-threatening diseases.**

Palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs and are prepared to accept care.<sup>32</sup> Palliative care may complement and enhance disease-modifying therapy or it may become the total focus of care. Some aspects of palliative care may also be applicable to patients at risk of

developing an illness and their families.

**Each year, 1.6 million patients in the European region will die from cancer and approximately 5.7 million from non-cancer chronic diseases.**

In the European region (as defined by the WHO), 881 million inhabitants are registered. Age-standardised death rates have been calculated for this region, with 9,300 deaths per million inhabitants. Out of these, approximately 1,700 deaths are related to cancer and 6,500 to non-cancer chronic diseases.<sup>33</sup> This calculation is supported by a recent review suggesting that there are 1.7 million cancer deaths per year in Europe.<sup>34</sup>

The vast majority of these patients will suffer from pain, dyspnoea and other physical symptoms or will require support with psychosocial or spiritual problems with the progression of their disease. An Australian workgroup estimated the population for palliative care to be between 50% and 89% of all dying patients, using different approaches in a conceptual framework.<sup>35</sup> Whereas a palliative care approach will provide adequate care for many of these patients, it has been estimated that at least 20% of cancer patients and 5% of non-cancer patients require specialist palliative care in the last year of their life.<sup>36</sup> However, these percentages have been challenged in the consensus procedure, and much higher percentages of cancer as well as non-cancer patients requiring palliative care have been suggested. These estimates will also depend upon specific patterns of disease in different countries. Treatment times will vary from a few days to several years, but, with the advances of modern medicine, many of these patients will need palliative care for longer periods of time and not only in the final year of their life.

**This means that, at any given time, more than 320,000 cancer patients and 285,000 non-cancer patients require support or care from specialist palliative care services in the European region (as defined by the WHO).**

These numbers are rather conservative estimates, as symptom load and palliative care needs are often not recognised and consequently may be much higher than estimated. These estimates also assume that general palliative care is well developed and generally available, which is true only for few European countries. Other reports from the UK have used higher numbers of cancer and non-cancer deaths and estimated considerably

higher percentages of patients requiring specialist palliative care.<sup>37</sup>

**In all European countries, palliative care is predominantly delivered to patients with far advanced cancer. Patients with other diseases, such as neurological diseases, HIV/AIDS, or with cardiac, pulmonary or renal failure, may have the same palliative care needs as cancer patients, but will find it much harder to access palliative care.**

Prevalence of physical symptoms as well as psychological, social and spiritual needs are as frequent in patients with chronic neurological, cardiac, cerebrovascular, pulmonary or renal disease or HIV/AIDS. The pattern of symptoms and the disease trajectory may be different from those of cancer patients.<sup>38,39</sup> However, many of these patients require either a palliative care approach or even specialist palliative care, as intensity and complexity of symptoms and problems may be similar to those of cancer patients.

**Providing access to high-quality palliative care for non-cancer patients should be a priority of national and European health policy development.**

Today, more than 95% of all patients currently treated in specialist palliative care services suffer from cancer.<sup>40</sup> However, the low percentage of non-cancer patients is primarily related to higher barriers preventing access of these patients to palliative care providers, as palliative care in the public and medical opinion is often perceived to be restricted to cancer patients.

**Adequate provision of palliative care for non-cancer patients requires additional resources. If non-cancer patients were to have equal access to palliative care compared to cancer patients, the percentages of patients requiring palliative care are estimated at 40% (non-cancer patients) and 60% (cancer patients) respectively.**

With the demographic changes of aging populations, the pattern of mortality also changes.<sup>41</sup> More people are now living longer and the proportion of those living beyond 60 years has increased, and will increase further over the next 20 years.<sup>41</sup> With increasing life expectancy, more people die as a result of severe chronic diseases, such as heart disease, cerebrovascular disease and respiratory disease, as well as of cancer. As more people live to older ages, and as chronic diseases become more common with older age, the numbers of people

in the population living with, and suffering from, these diseases will increase as well. With ongoing medical progress, patients will survive longer with chronic disabling disease, and in consequence will require palliative care over a longer period of time.

The number of cancer patients requiring palliative care will also increase in the years to come, as the number of patients living with cancer is expected to increase, due to earlier diagnosis, improved treatment and longer survival.<sup>40</sup>

National health strategies should include plans to cover an increasing demand. A recent analysis of past trends and future projections in mortality in England and Wales underlined the urgent need to plan for a large increase of aging and deaths, requiring either substantially more inpatient facilities or extensive development of community care.<sup>42</sup>

### 6.2 Disease stage

**There is no predefined time point in the course of the disease marking the transition from curative to palliative care.**

Palliative care is appropriate for all patients from the time of diagnosis with a life-threatening or debilitating illness.<sup>5</sup> The term 'life-threatening or debilitating illness' here is assumed to encompass the population of patients of all ages with a broad range of diagnostic categories, who are living with a persistent or recurring condition that adversely affects daily functioning or will predictably reduce life expectancy.

Most patients will need palliative care only with far advanced disease, but some patients may require palliative care interventions for crisis management earlier in their disease trajectory. This can be a period of several years, months, weeks or days.<sup>4</sup>

The transition from curative to palliative care is often gradual rather than a clear time point, as the treatment goal shifts more and more from life prolongation at all costs to preservation of quality of life, with a need to balance between treatment benefit and burden.

### 6.3 Children and adolescents

**Palliative care for children represents a special, albeit closely related field, to adult palliative care.<sup>43</sup>**

The Council of Europe points to the specific challenge of palliative care for children with incurable and life-threatening diseases.<sup>4</sup>

**Providing access to high-quality palliative care for non-cancer patients should be a priority**

**Palliative care for children begins when the illness is diagnosed, and continues regardless of whether or not the child receives treatment directed at the disease.<sup>44</sup> The unit of care is the child and family.**

Life-limiting illness in children is defined as a condition where premature death is usual; for example, Duchenne muscular dystrophy.<sup>44</sup> Life-threatening illnesses are those with a high probability of premature death due to severe illness, but where there is also a chance of long-term survival into adulthood; for example, children receiving cancer treatment or admitted to intensive care after an acute injury.

Paediatric palliative care is characterised by a heterogeneous range of conditions and a higher proportion of non-cancer diagnoses than adult palliative care. Palliative care for children and adolescents can be summarised in four categories, based on a guide to the development of children's palliative care services produced by the Association for Children's Palliative Care (ACT) and the Royal College of Paediatrics and Child Health in the UK.<sup>45</sup>

- 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, such as cystic fibrosis, where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.
- 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.

**Specific paediatric palliative care services for inpatient treatment and home care should be implemented. A full range of clinical and educational resources must be available for the child and family, in a format that is appropriate to age and to cognitive and educational ability.<sup>44</sup>**

The document on standards for paediatric palliative care in Europe prepared by the Steering Committee of the EAPC Task Force on

Palliative Care for Children and Adolescents (IMPaCCT) reveals that palliative care services are insufficiently available for children and their families.<sup>44</sup> For example, a lack of community resources enabling families to care for their child at home has been noticed, as well as a shortage of services for respite care.

**The family home should remain the centre of caring whenever possible. Every family should have access to a multi-disciplinary, holistic paediatric palliative care team at home.<sup>44</sup>**

**The bold type in this text highlights the recommendations made by the EAPC. Part 2 of this EAPC White Paper will be published in the *European Journal of Palliative Care* 17.1.**

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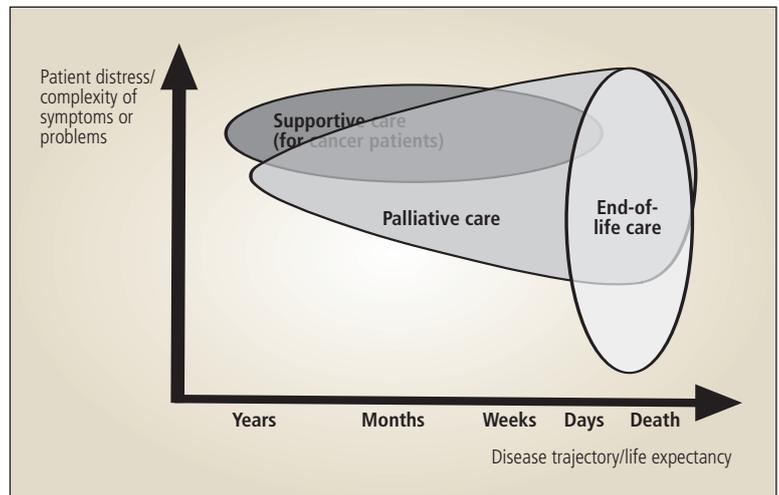
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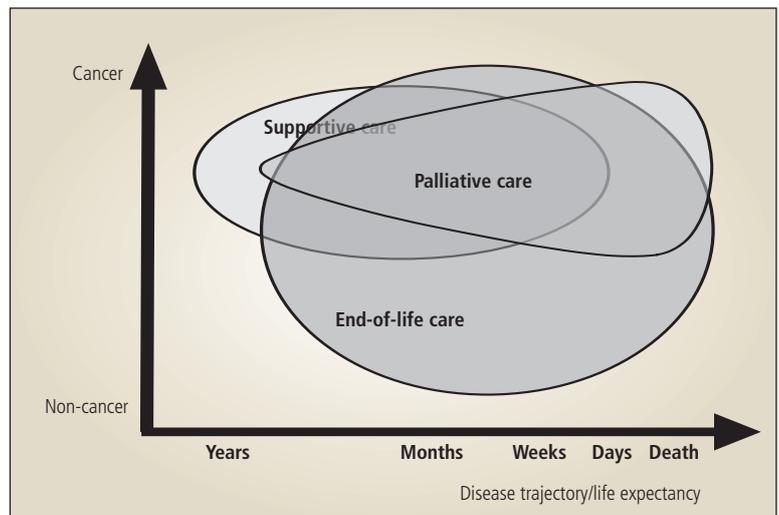
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Main area of care provision for palliative care, supportive care and end-of-life care (using a narrow definition of end-of-life care)



Main area of care provision for palliative care, supportive care and end-of-life care (using an extended definition of end-of-life care)

**Graded system of palliative care services\***

		Palliative care		
	Palliative care approach	Specialist support for general palliative care	Specialist palliative care	
Acute care	Hospital	Volunteer hospice service	Hospital palliative care support team	Palliative care unit
Long-term care	Nursing home, residential home		Home palliative care teams	Inpatient hospice
Home care	General practitioners, community nursing teams			Home palliative care teams, day-care centre

\*Adapted from: Nemeth C, Rottenhofer I. *Abgestufte Hospiz- und Palliativversorgung in Österreich*. Wien: Österreichisches Bundesinstitut für Gesundheitswesen, 2004

# White Paper on standards and norms for hospice and palliative care in Europe: part 2

## *Recommendations from the European Association for Palliative Care*

In part 2 of this official position paper of the European Association for Palliative Care (EAPC), Lukas Radbruch, Sheila Payne and the EAPC Board of Directors outline general requirements for palliative care services and the specific requirements for each service type

... continued from the *European Journal of Palliative Care* (EJPC) 16.6

### **7. Palliative care delivery**

This chapter focuses on the way in which palliative care is provided in the community. Basic assumptions and general requirements for palliative care services will be outlined. Thereafter, in Chapter 8, different types of services will be presented with the specific requirements for each service type.

The following basic requirements are highly relevant for the provision of palliative care:

- Advance care planning
- Continuity of care
- Availability of care
- Preferred place of care.

#### **7.1 Advance care planning**

Ideally, the patient, family and palliative care team discuss the planning and delivery of palliative care, taking into account the patient's preferences, resources and best medical advice. Changes in the patient's condition or performance status will lead to changes in the treatment regimen, and continuous discussion and adaptation will forge an individual plan of care throughout the disease trajectory.

However, with the progression of disease and deterioration of cognitive and physical function, some patients' decision-making capacity will be reduced and they may not be able to participate in decision-making any more. Palliative care should integrate means for advance care planning, so that these patients

can receive palliative care according to their preferences, if they wish.

**Advance directives allow patients to retain their personal autonomy and provide instructions for care in case the patients become incapacitated and cannot make decisions any more.<sup>1</sup>**

The legal standing of advance directives differs between the European countries. Only a few countries have authorised these documents by state laws.

There has been an ongoing discussion on how binding advance directives should be. Patients' preferences may change with the progression of the disease, and it is not always clear whether patients have been informed adequately or have understood that information. Advance directives, therefore, may not be relevant any more, or may never have been meant for the situation at hand.

**Advance directives may be supplemented with, or substituted by, a healthcare proxy (or durable power of attorney). This document allows the patient to designate a surrogate, a person who will make treatment decisions for the patient if the patient becomes too incapacitated to make such decisions.<sup>1</sup>**

Adequate use of a surrogate decision-maker as well as of an advance directive requires that the patient and proxy have discussed the patient's preferences in recognition of the specific disease and have had adequate information from the palliative care team on the projected disease trajectory. In some European countries, the legal basis for this is not yet established.

### 7.2 Access to services

**Services should be available to all patients, wherever and whenever they require them, without delay.<sup>2,3</sup>**

Palliative care teams should work towards equitable access to palliative care across all ages and patient populations, all diagnostic categories, all healthcare settings (including rural communities) and regardless of race, ethnicity, sexual preference or ability to pay.<sup>4</sup>

**Equity of access to palliative care should be guaranteed in all European countries, assuring provision of palliative care according to needs and regardless of cultural, ethnic or other background.**

There should be equal access to services for patients with equivalent needs. The access should not depend on the ability to pay.<sup>3</sup>

**Access to high-quality palliative care should not depend on the ability of patients or carers to pay.**

### 7.3 Continuity of care

**Continuity of care throughout the disease trajectory and across the different settings in the healthcare system is a basic requirement of palliative care.<sup>4</sup>**

This applies to continuity of care throughout the illness trajectory as well as across settings. Continuity of care will help to avoid errors and needless suffering of patients with a life-threatening illness; it can prevent patient and family from feeling abandoned, and ensure that patient choices and preferences are respected.

Palliative care is integral to all healthcare delivery system settings (hospital, emergency department, nursing home, home care, assisted living facility, outpatient service, and non-traditional environments such as schools and prisons). The palliative care team collaborates with professional and informal carers in each of these settings to ensure co-ordination, communication, and continuity of palliative care across institutional and home-care settings. Preventing crises and unnecessary transfers is an important outcome of palliative care.<sup>4</sup>

### 7.4 Preferred place of care

**Most patients want to be cared for in their own homes, if possible until the time of death. In contrast to this, the place of death for most patients is the hospital or nursing home.**

A growing body of evidence from both population and patient surveys shows that the

majority of cancer patients would prefer to die in their own home. Studies have found that around 75% of respondents desire to experience their last phase of their life at home.<sup>5</sup> However, this is linked to the presence of a strong social and family network; the percentage of younger, single or widowed patients preferring to die at home seems to be well below that percentage.

Nonetheless, in contrast to patients' preferences, in Europe, the place of death is most often the hospital or nursing home. In a review on the state of palliative care in Germany, the place of death was reported with considerable variation depending on the different authors' approaches, but dying in institutions was summarised with a frequency of 60–95%. Based on different studies with varying percentages, the authors report the following estimations with respect to the place of death in Germany: hospital 42–43%, home 25–30%, nursing or residential home 15–25%, hospice 1–2%, other 3–7%.<sup>6</sup>

Many patients are able to spend most of the final year of life at home, but are then admitted to the hospital to die. The fact that many dying people are admitted to hospital for terminal care because of inadequate support in the community has been criticised.<sup>3</sup>

**The preferred place of care and place of death should be acknowledged and discussed with the patient and family, and measures taken to comply with these preferences, wherever possible.<sup>7</sup>**

It is important to recognise, however, that the place of death may be determined by factors other than patient preference. In the final stage of the disease, the medical condition may deteriorate to the extent that it may necessitate admission to hospital or specialist inpatient unit for intensive medical and nursing care, which could not be provided in the home-care setting.

### 7.5 Locations of care

**Palliative treatment, care and support are provided at home, in nursing homes, in residential homes for the elderly, in hospitals and in hospices, or in other settings if required.<sup>2</sup>**

It is currently recognised that palliative care in the community should be provided along a 'continuum of specialisation'.<sup>8</sup> It is supposed to reach from primary healthcare to services whose core activity is limited to the provision of palliative care. Palliative care can be provided as a palliative care approach or general palliative

Considering the reduced life expectancy of palliative care patients, fast-tracking care pathways should be implemented in medical services

care in non-specialist services as well as in specialist palliative care services.<sup>2</sup>

Non-specialist palliative care services are:

- District nursing services
- General practitioners
- Ambulant nursing services
- General hospital units
- Nursing homes.

Specialist palliative care services are:

- Inpatient palliative care units
- Inpatient hospices
- Hospital palliative care support teams
- Home palliative care teams
- Community hospice teams
- Day hospices
- 'Hospitals at home'
- Outpatient clinics.

**Now, as in the future, a major part of palliative care will be provided by non-specialist services. Consequently, non-specialist professionals must have easy access to specialist consultation for advice and support.**

Non-specialist services need specific guidance to implement a palliative care approach or provide general palliative care. Integrated care pathways are useful to facilitate implementation.<sup>9</sup> The Liverpool Care Pathway for the Dying Patient (LCP) has been named, in the UK's National Institute for Health and Clinical Excellence (NICE) guidance for supportive and palliative care,<sup>7</sup> as a mechanism to identify and address the particular needs of patients dying from cancer.

**Integrated care pathways, such as the Liverpool Care Pathway for the Dying Patient, are recommended as an educational and quality assurance instrument to improve care of dying patients in settings that are not specialised in palliative care.**

In some non-specialist services (for example, radiology, radiotherapy or surgery), limited resources may lead to the implementation of waiting lists. These waiting lists are particularly disadvantageous for palliative care patients because of the limited remaining life-span in which they could benefit from the service. Therefore, fast-tracking pathways have been suggested to give priority access to palliative care patients.<sup>2</sup>

**Considering the reduced life expectancy of palliative care patients, fast-tracking care pathways should be implemented in medical services, ensuring adequate priority for these patients, to prevent disproportional burden from lost time.**

The provision of specialist palliative care should be structured in a way that permits patients to change from one service to another according to clinical needs or personal preferences. This implies that specialist palliative care services are not isolated entities and that co-ordination of services is essential.

**A comprehensive system of services, including inpatient services, home-care services and support services, should be available to cover all care needs and treatment options.<sup>10</sup>**

In a graded system of palliative care services (as shown in Table 1), the different needs of patients and carers can be matched with the most suitable service.<sup>10</sup> With such a system, the right patients can be treated at the right time in the right place.

### 7.6 Palliative care networks

**Regional networks integrating a broad spectrum of institutions and services, and effective co-ordination, will improve access to palliative care and increase quality as well as continuity of care.**

Relevant experts' reports on quality palliative care argue that the specialist palliative care inpatient unit should be the centre of a regional palliative care network.<sup>2,3</sup>

**There should be at least one specialist palliative care inpatient unit within each healthcare service area.**

The specialist palliative care inpatient unit should be the core element of the specialist palliative care service. Specialist palliative care services in all other settings, including general hospitals and the community, should be based in, or have formal links with, the specialist palliative care inpatient unit.<sup>3</sup> This connection not only warrants support and continuing education of the teams, but also improves continuity in patient care.<sup>2</sup>

In its recommendations, the Council of Europe states that the quality of care in a certain region does not depend only on the quality of the single institutions and services, but also on the co-ordination of specialist services and the co-ordination between specialist services and primary care services.<sup>2</sup> If the services are organised within a coherent regional network, this will improve access to palliative care and increase quality as well as continuity of care.<sup>9,11-13</sup> If such a network is to function well, two conditions have to be fulfilled: an effective

**Table 1. Graded system of palliative care services\***

Palliative care				
	Palliative care approach	Specialist support for general palliative care		Specialist palliative care
Acute care	Hospital	Volunteer hospice service	Hospital palliative care support teams	Palliative care unit
Long-term care	Nursing home, residential home		Home palliative care teams	Inpatient hospice
Home care	General practitioners, community nursing teams			Home palliative care teams, day-care centre

\*Adapted from: Nemeth and Rottenhofer<sup>10</sup>

co-ordination and a broad spectrum of institutions and services.

Effective co-ordination is best achieved through a case manager (case co-ordinator, key worker) who can provide transfer of information and continuity of care across different settings.<sup>5</sup> An effective co-ordination of services will allow a higher proportion of people to die at home if they so wish. To be effective, these co-ordination services must be available 24 hours a day, seven days a week.

**Co-ordination can be accomplished by a team or a person. Case management and co-ordination can be performed by an interdisciplinary expert group representing the various services within the network, or by a palliative care unit or an inpatient hospice.**

The spectrum of services is supposed to cover all the different levels of care needed by the patients (see Table 1).<sup>10</sup> Additionally, liaison services are strongly recommended (support services in hospitals as well as ambulant palliative care services).

A palliative care network has several tasks. Apart from the co-ordination of care, the components of a smoothly functioning network are:

- Consensual definition of goals and quality standards
- Uniform criteria for admission and discharge at all levels of care
- Use of common evaluation methods
- Implementation of common therapeutic strategies based on available evidence.

Beyond the provision of care, the network should evaluate its own efficiency, for example using audit methods, and should organise and supervise education and research activities.<sup>14</sup>

**7.7 Staff in specialist palliative care services**  
**Services that are not specialised in palliative care can use a palliative care approach or**

**deliver basic palliative care, even when this can only be done by one professional category, or even by one individual (for example, a general practitioner working alone), if they have access to support from an interdisciplinary team.**

Palliative care is most effectively delivered by an interdisciplinary team of healthcare professionals who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice.<sup>15</sup> However, in the non-specialised setting, multidisciplinary team work is the exception rather than the rule. Care should be taken that non-specialised services maintain adequate communication links with specialist facilities.

**Specialist palliative care service delivery requires a multiprofessional team with an interdisciplinary work style.**

The Council of Europe<sup>2</sup> and the National Advisory Committee on Palliative Care<sup>3</sup> list staff requirements for specialist palliative care services. According to these, the following professionals – in addition to nurses and physicians – should be available full-time, part-time or at regular times:

- Social workers
- Professionals skilled in psychosocial support
- Adequate numbers of office workers, administration secretaries and general assistants
- Physiotherapists
- Professionals skilled in bereavement support
- Coordinators for spiritual care
- Co-ordinators for voluntary workers
- Chaplains
- Wound management specialists
- Lymphoedema specialists
- Occupational therapists
- Speech therapists
- Dietitians
- Pharmacists

Specialist palliative care services should include volunteers or collaborate with volunteer services

- Complementary therapists
- Trainers/instructors
- Librarians.

The core palliative care team should consist of nurses and physicians with special training as a minimum, supplemented by psychologists, social workers and physiotherapists if possible. Other professionals can be members of the core team, but more frequently will work in liaison.

Differences between European countries, regions and settings have to be considered in the balance between core team and extended team. For example, in some countries, psychologists are regarded as essential members of the core team, whereas, in other countries, this profession does not have relevance for the clinical work with patients and their families.

Children need specialised services that are to be provided by paediatrically skilled staff. This applies especially to the paediatric palliative care nursing service. Palliative home care for the support of children and their families should be available.<sup>2</sup>

### 7.8 Voluntary work

Specialist palliative care services should include volunteers or collaborate with volunteer services.

Volunteers provide an indispensable contribution to palliative care. The hospice movement, as a civil rights movement, is based on volunteer work. The Council of Europe points out the importance of voluntary work for the provision of quality palliative care in the community.<sup>2</sup> To adequately fulfil the role of a partner in the palliative care network, several prerequisites have to be met:

- Voluntary workers have to be trained, supervised and recognised by an association
- Training is indispensable and demands a diligent selection of voluntary workers
- Voluntary workers act within a team under the responsibility of a co-ordinator
- The co-ordinator is the link between the voluntary workers and the carers, between the hospital and the association
- In the interdisciplinary team, voluntary workers do not substitute for any staff member, but supplement the work of the team.

For more detailed staff requirements for different palliative care services, see Chapter 8 ('Palliative care services').

### 7.9 Palliative care leave

Legal regulations for palliative care leave for carers are available only in Austria and France. Similar regulations should be introduced in other European countries to enable family members to provide care for their relatives at home for as long as required.

Leave of absence from work for people who have to care for seriously ill or dying spouses, parents, children or other close relatives would allow many patients to remain in their home until the time of death. However, legal regulations for palliative care leave exist in only two European countries. Introduction of similar legislation in other countries would be a major step in the development of palliative care. Legal recognition of reimbursement claims for palliative care leave would further reduce the burden of care for family members and other carers.

## 8. Palliative care services

In this section, guidelines are provided on the minimum resources required to meet the population's needs for palliative care in a community. The different kinds of services are presented according to the following characteristics:

- Definition and purpose of the service
- Demand in the community
- Requirements (staff and spatial requirements).

### 8.1 Palliative care unit

#### 8.1.1 Definition and purpose

Palliative care units (PCUs) provide specialist inpatient care. A palliative care unit is a department specialised in the treatment and care of palliative care patients. It is usually a ward within, or adjacent to, a hospital, but it can also exist as a stand-alone service. In some countries, palliative care units will be regular units of hospitals, providing crisis intervention for patients with complex symptoms and problems; in other countries, PCUs can also be freestanding institutions, providing end-of-life care for patients where home care is no longer possible. The aim of palliative care units is to alleviate disease- and therapy-related discomfort and, if possible, to stabilise the functional status of the patient and offer patient and carers psychological and social support in a way that allows for discharge or transfer to another care setting.

PCUs admit patients whose medical condition (physical, psychological, social and spiritual) necessitates specialist multiprofessional palliative care.<sup>2</sup> Patients can be admitted to these units for specialist care for a few days or for a number of weeks; medical, nursing, psychosocial or spiritual problems can determine the priority.

These units may also provide day hospice facilities, home care, support for appropriate patients cared for in care homes, and bereavement support, together with advice services and education.<sup>16</sup>

Essential services should be available 24 hours per day and seven days per week.<sup>15</sup> If possible, there should be 24-hour telephone advice for healthcare professionals and 24-hour telephone support service for known outpatients and their carers.

PCUs are supposed to collaborate with various services in the ambulant and inpatient sector.<sup>2</sup> They work in a network with medical centres, hospital units, general practitioners, ambulant nursing services and hospice services, as well as other appropriate services.<sup>6</sup>

### 8.1.2 Demand

**It is estimated that 50 palliative care beds are needed for 1,000,000 inhabitants. With an optimal size of 8-12 beds per unit, this would correspond to five PCUs per million inhabitants. Recent estimations have upgraded the number of palliative care and hospice beds needed to 80–100 beds per 1,000,000 inhabitants.**

Until recently, the need for palliative care beds for cancer patients was estimated to be 50 beds for one million inhabitants. However, this rate does not take into account the needs of non-cancer patients, nor does it consider the rising prevalence of chronic diseases resulting from the European population growing older.<sup>2</sup> The actual need probably amounts to twice the number of beds.

Generally speaking, the respective number of palliative care beds needed in a certain region will depend on the region's demographic and socioeconomic development and on the availability of other specialist palliative care services, providing, for example, respite care or home care. For Austria, 60 beds for one million inhabitants have been recommended, distributed according to the regional conditions.<sup>10</sup> For Ireland, the Report on the National Advisory Committee on Palliative

Care recommends that at least 80–100 palliative care beds for one million inhabitants should be available.<sup>3</sup>

The *EAPC Atlas of Palliative Care in Europe* sheds light on the existing number of palliative care beds in different European countries.<sup>17</sup> The number of palliative care beds in Western Europe was estimated to range from 10–20 beds per million inhabitants (Portugal, Turkey) to 50–75 beds per million inhabitants (Sweden, UK, Iceland, Luxembourg). Consequently, the number of beds has to be increased even in many Western European countries – and the situation in most Eastern European countries is even worse.

### 8.1.3 Requirements

**PCUs require a highly qualified, multidisciplinary team.<sup>2</sup> Staff members in palliative care units are supposed to have specialist training. The core team consists of doctors and nurses. The extended team comprises relevant associated professionals, such as psychologists, physiotherapists, social workers or chaplains.**

A central feature of PCUs is a multiprofessional team with specially trained members from different healthcare professions, completed by voluntary workers.<sup>6</sup>

The core team consists of doctors and nurses as a minimum and comprises dedicated input from psychologists, social workers, physiotherapists and spiritual care workers. In addition, there should be ready access to other professionals. All staff members of the core team are supposed to have specialist training in palliative care accredited by the national professional boards.

Medical staff should include consultants with special knowledge and skills in palliative medicine. Nurses are supposed to have post-basic professional training in palliative care. Voluntary workers should have participated in a course of instruction for voluntary hospice workers.<sup>10</sup>

**PCUs require a dedicated core team of nurses and physicians. PCU nursing staff should encompass a ratio of at least one nurse per bed, and preferably 1.2 nurses per bed. PCUs require physicians with special training, with a ratio of at least 0.15 physicians per bed.**

**In a setting where children are being cared for, there should be at least one nurse on each shift with a special paediatric qualification.**

A number of recommendations are made on

**Recent estimations have upgraded the number of palliative care and hospice beds needed to 80–100 beds per 1,000,000 inhabitants**

**An inpatient hospice requires a multi-professional team that cares for patients and their relatives using a holistic approach**

the staffing level of specialist palliative care nurses working in different care settings. There should be no less than one full-time specialist palliative care nurse for each bed.<sup>3</sup> It is recommended that there should be at least one whole time physician specialised in palliative medicine for every five to six beds.

**PCUs require an extended team of relevant associated professionals, such as psychologists, social workers, spiritual care workers or physiotherapists. These professions should be included in the team or work in close liaison with it. There should be dedicated input from these professionals, or at least ready access to them should be warranted.**

National reports on norms for palliative care staff agree that relevant professions to be included in a PCU's extended team are: speech and language therapists, psychologists, chaplains, occupational therapists, clinical nutritionists, pharmacists, physiotherapists, wound management specialists, lymphoedema specialists, speech and language therapists, social workers, bereavement specialists, and psychologists. Moreover, there should be voluntary workers available with a professional volunteer co-ordinator.

**Palliative care units should offer a homelike atmosphere with quiet and private areas. They should be separate areas with a capacity of 8–15 beds. The units should be equipped with single or double patient rooms, facilities for relatives to stay overnight and rooms for social activities, such as kitchens or living rooms.**

The patient areas should be accessible for people with disabilities. Every room should have a bathroom. In the unit, one room for viewing the deceased, taking leave from them and meditating, as well as for multifunctional use, should be available. Access to a chapel or prayer room (multi-faith room) is desirable.

The setting of care should be arranged so that it conveys safety and comfort and provides ample opportunity for privacy and intimacy.<sup>15</sup> Where possible, care settings should be homelike, with access to the outdoors.

### **8.2 Inpatient hospice**

#### **8.2.1 Definition and purpose**

**An inpatient hospice admits patients in their last phase of life, when treatment in a hospital is not necessary and care at home or in a nursing home is not possible.**

The central aims of an inpatient hospice are the alleviation of symptoms and achievement

of the best possible quality of life until death, as well as bereavement support.<sup>10</sup>

**In many countries, the function of an inpatient hospice is similar to that of a PCU, whereas, in other countries, a clear distinction can be observed.**

In Germany, for example, patients will be admitted to a PCU for crisis intervention and to an inpatient hospice for end-of-life care. In some countries, a hospice, in contrast to a PCU, is a free-standing service with end-of-life care as its main focus of work.

#### **8.2.2 Requirements**

**An inpatient hospice requires a multiprofessional team that cares for patients and their relatives using a holistic approach. Nursing staff should encompass at least one, preferably 1.2 nurses per bed. A physician trained in palliative care should be available 24 hours a day. There should be dedicated input from psychosocial and spiritual care workers as well as voluntary workers.**

The core team of an inpatient hospice consists of nurses and requires ready access to a trained physician. The extended team comprises social workers, psychologists, spiritual carers, physiotherapists, dietitians, speech and language therapists and occupational therapists, as well as voluntary workers.<sup>10</sup>

**An inpatient hospice requires a homelike atmosphere with access for people with disabilities, single or double patient rooms and a capacity of at least eight beds. The hospice should be equipped with rooms for social and therapeutic activities.**

The inpatient hospice is supposed to be an autonomous organisational unit with its own team and at least eight beds.<sup>10</sup> The patient rooms should be equipped with a bathroom. Facilities for overnight stay of relatives should be provided.

### **8.3 Hospital palliative care support team**

#### **8.3.1 Definition and purpose**

**Hospital palliative care support teams provide specialist palliative care advice and support to other clinical staff, patients and their families and carers in the hospital environment.**

**They offer formal and informal education, and liaise with other services in and out of the hospital.**

Hospital palliative care support teams are also known as hospital supportive care teams or

hospital mobile teams.<sup>17</sup> Hospital palliative care support teams, in the first instance, offer support to healthcare professionals in hospital units and polyclinics not specialised in palliative care.<sup>10</sup>

**One central aim of a hospital palliative care support team is the alleviation of multiple symptoms of palliative care patients on different hospital wards by mentoring the attending staff and by supporting the patients and their relatives. Furthermore, expertise in palliative medicine and palliative care shall be made available in the respective environments.**

Support and education is offered on pain therapy, symptom control, holistic care and psychosocial support. This involves attending to patients on a variety of different wards and providing advice to other clinicians. However, decisions on, and implementation of, therapies and interventions remain the responsibility of the attending medical staff. The hospital palliative care support team contributes at the request of medical and nursing staff, the admitted patient and his relatives.<sup>2</sup> The team is supposed to act in close collaboration with other specialists.

**The aims of a hospital palliative care support team are the improvement of care to foster discharge from an acute hospital unit and the facilitation of the transfer between inpatient and outpatient care.**

Measures taken by the team can be a well-directed transfer of patients to palliative care units or co-ordination between inpatient and outpatient care. Close co-operation with other services and the contribution to a sustainable palliative care network is an important function of a hospital palliative care support team. Within this context, additional tasks can be the provision of a hotline to give advice to medical and nursing staff on difficult palliative questions, or of regional education and training in selected topics of palliative care.<sup>6</sup>

### 8.3.2 Demand

**A hospital palliative care support team should be affiliated to every PCU and should be available for every hospital in case of need. There should be at least one team available for a hospital with 250 beds.**

It would be desirable to have a hospital palliative care support team associated with every PCU. In case of need, such a team should be available for every hospital.<sup>10</sup> However, in the

majority of European countries, this model of support and care delivery is still very poorly represented.<sup>17</sup> Countries with a high proportion of hospital palliative care support teams are Belgium, France, Ireland and the UK. In most of the other European countries, a considerable dearth can be observed in the availability of these teams.

### 8.3.3 Requirements

**A hospital palliative care support team is composed of a multiprofessional team with at least one physician and one nurse with specialist palliative care training.**

The core team should include dedicated input from doctors and nurses.<sup>10,16</sup> Medical and nursing staff are supposed to have specialist training accredited by the national professional boards. The team should have ready access to other professionals working in liaison with it, including bereavement specialists, chaplains, dietitians, therapists, oncologists, pharmacists, physiotherapists, psychiatrists, psychologists, social workers and speech and language therapists. All clinical staff should be supported by administrative staff. Staff support such as supervision should be available for the team.

**A hospital palliative care support team should have a room for staff meetings and administrative support at its disposal.**

## 8.4 Home palliative care team

### 8.4.1 Definition and purpose

**Home palliative care teams provide specialised palliative care to patients who need it at home and support to their families and carers at the patient's home. They also provide specialist advice to general practitioners, family doctors and nurses caring for the patient at home.**

The home palliative care team is a multiprofessional team that, in the first place, supports people at home or in a nursing home (for example, relatives, medical staff, nurses, physiotherapists). It offers support with a graded approach. Most often, the home palliative care team has an advisory and mentoring function, and offers its expertise in pain therapy, symptom control, palliative care and psychosocial support. Advice and support by the home palliative care team can also be provided directly to the patient. Less frequently, the home palliative care team may provide 'hands-on', direct care in collaboration with the general practitioner and other primary care workers. In selected cases with highly complex

**One central aim of a hospital palliative care support team is the alleviation of multiple symptoms of palliative care patients on different hospital wards**

symptoms and problems, the home palliative care team may take over treatment from the general practitioner and the nursing service, and provide holistic palliative care. The mode of action also depends on the local model of care delivery and the level of involvement of primary carers. The home palliative care team also assists the transfer between hospital and home.<sup>10</sup>

### 8.4.2 Demand

**There should be one home palliative care team available for 100,000 inhabitants. The team should be accessible 24 hours a day.<sup>10</sup>**

Home palliative care teams have to be available seven days a week and 24 hours a day.<sup>6</sup>

According to the *EAPC Atlas of Palliative Care in Europe*, the UK, Poland and Sweden have a high proportion of home-care services, with a ratio of approximately one service for 160,000 to 180,000 inhabitants.<sup>17</sup> Italy and Spain also show a noteworthy number of home-care services, with a ratio of approximately one service for 310,000 to 380,000 inhabitants. However, in other European countries, the number of home-care services is much smaller. In some regions, there is hardly any palliative home care available at all (for example, in Germany, there are 30 services in total for a population of more than 80,000,000).

In rural areas, home-care services have to cover a greater catchment area in order to work cost-effectively.<sup>18</sup> Therefore, regional networks have to be developed in order to provide ambulant palliative care in rural areas with poor infrastructure.

### 8.4.3 Requirements

**The core team of a home palliative care team consists of four to five full-time professionals and comprises physicians and nurses with specialist training, a social worker and administrative staff.**

The core team of a home palliative care team should consist of professionals with specialist training in palliative care accredited by the national professional boards.<sup>10</sup>

In some home palliative care teams, day-to-day care for patients and carers is provided by staff members without specialist training, with palliative care consultants and nurses specialised in palliative care available for guidance and supervision.<sup>7</sup>

In addition, there should be easy access to other professionals such as physiotherapists, psychologists, occupational therapists, speech

therapists, dietitians, spiritual care workers and voluntary workers.

**The home palliative care team works in close collaboration with other professionals so that the full range of multiprofessional team work can be realised in the home-care setting.**

In some countries, multiprofessional teams are not available and palliative care at home is delivered by specialist palliative nursing services and by specialist physicians working in general practice or in home-care support services.

**Palliative care at home requires close collaboration of other professional services, such as specialised nursing services and general practitioners with specialist training, including (but not restricted to) regular meetings at the patient's bedside (and other tasks).**

**The home palliative care team requires a working room at its disposition for nurses, physicians and social workers, as well as a meeting room and a depot for medical aids.**

### 8.5 'Hospital at home'

**The 'hospital at home' provides intensive hospital-like care for the patient at home.**

In some European countries, for example France or Finland, the 'hospital at home' offers an intensive medical and nursing service that allows patients who would otherwise be admitted to a hospital to stay at home. This implies a type of care that is much more similar to inpatient hospital treatment than to the usual home care. Different organisational models can be found, ranging from an expansion of existing resources within the home environment to the allocation of a specialist team that can cover all demands.<sup>2</sup>

### 8.6 Volunteer hospice team

#### 8.6.1 Definition and purpose

**A volunteer hospice team offers support and befriending to palliative care patients and their families in times of disease, pain, grief and bereavement. The volunteer hospice team is part of a comprehensive support network and collaborates closely with other professional services in palliative care.**

Volunteer hospice teams are vital in contributing to the psychosocial and emotional support of patients, relatives and professionals, and foster the maintenance and improvement of patients' and carers' quality of life. The support persists beyond the patient's death and

**There should be one home palliative care team available for 100,000 inhabitants**

continues in the phase of bereavement.<sup>10</sup> Volunteer hospice teams do not only provide an indispensable dimension of palliative care to patients and families, but also act as advocates of palliative care to the general public. In some countries, volunteers contribute to fund-raising, reception and administration duties, and the governance of hospices as trustees.

### 8.6.2 Demand

**There should be one volunteer hospice team available for 40,000 inhabitants.<sup>10</sup>**

However, during the Delphi procedure (see part 1 of this article in the *EJPC* 16.6), the consensus regarding this statement was not as great as it was for other statements. The demand for volunteer hospice teams may vary according to the role of volunteers in the national and local settings. In certain regions, one volunteer hospice team for up to 80,000 inhabitants may be sufficient.

### 8.6.3 Requirements

**The volunteer hospice team comprises specially trained voluntary hospice workers with at least one professional co-ordinator.**

A volunteer hospice team consists of at least ten to 12 voluntary hospice workers and one dedicated professional co-ordinator. The co-ordinator should have an education in the social care and/or the healthcare sector, with additional specialist training in palliative care. The voluntary workers should have participated in an accredited instruction course and take part in regular supervision and self-reflection, as well as in continuing education.<sup>10</sup> The required qualification of volunteer workers and their co-ordinators depends on their tasks in palliative care. Volunteers in administrative or other functions require a different type of training.

## 8.7 Day hospice

### 8.7.1 Definition and purpose

**Day hospices or day-care centres are spaces in hospitals, hospices, PCUs or the community especially designed to promote recreational and therapeutic activities among palliative care patients.**

Patients usually spend part of the day in the day-care centre, either each day or once weekly. Day hospices focus on creative living and social care, offering patients the opportunity to participate in various activities during the daytime outside their familiar surroundings. Formal medical consultations are not usually

part of routine day care, but, in some day-care centres, patients may have some treatments, such as a blood transfusion or a course of chemotherapy, while at the centre.

Central aims are social and therapeutic care, to avoid social isolation as well as to relieve the burden of care on relatives and carers.

### 8.7.2 Demand

Until now, day-care centres have been a characteristic feature of hospice and palliative care development in the UK, with a reported total of more than 200 services, but are only sparsely available in other European countries.<sup>19</sup> In consequence, a clear estimation of the need for day-care centres in European countries is lacking. However, a mid-range prediction of the demand for palliative care services has recommended a catchment area of 150,000 inhabitants for one day-care centre. Because of the lack of evidence, pilot projects are strongly suggested.<sup>10</sup>

It must be noted that, in many countries, day-care centres are not regarded as an essential service and other models of palliative care delivery are offered.

**There should be a day hospice available for 150,000 inhabitants.<sup>10</sup> National pilot projects should be established and evaluated to investigate the need for this type of service.**

### 8.7.3 Requirements

**A day-care centre is staffed by a multiprofessional team supplemented by voluntary workers. It is recommended that there are two nurses present during opening hours, with at least one specialist palliative care nurse for every seven daily attendees. A qualified physician should be directly accessible in case of need. Ready access to other professionals, such as physiotherapists, social workers or spiritual care workers, should be obtained.<sup>3,10</sup>**

A day-care centre is supposed to have patient rooms, a therapy room, staff rooms, a bathroom, a kitchen and a recreation room. All rooms should have access for people with disabilities.

A day-care centre should provide a homelike atmosphere. Patient rooms should be equipped comfortably and suitable for multifunctional use. The centre is an autonomous organisational unit with at least six places and may be associated with an inpatient hospice or palliative care unit.

**Day hospices or day-care centres are spaces in hospitals, hospices, palliative care units or the community especially designed to promote recreational and therapeutic activities**

### 8.8 Palliative outpatient clinic

#### Palliative outpatient clinics offer consultation for patients living at home who are able to visit the clinic.

Palliative outpatient clinics are an important component of a community palliative care programme. Usually, they are affiliated to specialist PCUs or inpatient hospices. Patients with progressive disease and reduced performance status will often no longer be able to visit the outpatient clinic. Therefore, outpatient clinics should be integrated in regional networks, in order to consult with inpatient services, home palliative care team or the primary care team.

### 9. Discussion and future prospects

After a pioneering stage of about four decades, palliative care is still quite a young discipline, and consensus-building processes are a recent development. Ferris *et al*, in their publication on the US-based model to guide patient and family care, state that the 'grassroots movement developed where there were champions'.<sup>15</sup> Approaches to care were usually based on individual opinion. Considerable variability in the services offered by individual programmes as well as inconsistent access to care could be observed.

In their recent publication on the results of the EAPC Task Force on the Development of Palliative Care in Europe, Carlos Centeno and colleagues pointed to the following problems in the evaluation of palliative care services:<sup>19</sup>

- Different types of services in different countries
- Lack of unified standards and universally accepted definitions of each type of available resource
- Different interpretations of what is considered to be a 'specialist palliative care resource'.

Commenting on this publication, von Gunten stated that this inconsistency 'bedevils conversation, comparisons and progress'.<sup>20</sup> He strongly pleaded for a European consensus and pointed to Canada and the USA, which have set a good example.

The need for professional consensus on what constitutes high-quality palliative care is a prerequisite to the effective delivery of such services across the continuum of care. Disseminating and advocating these standards and norms recommended by the EAPC to decision-makers and other stakeholders will

support public awareness about hospice and palliative care in Europe.<sup>4</sup>

The World Health Organization (WHO) strongly advises policy-makers to ensure that palliative care is integral to the work of all healthcare services and is not seen as just an 'add-on extra'.<sup>5</sup> This is in line with the recommendations of the Council of Europe to its member states that palliative care is an indispensable and integral part of healthcare. Therefore, national healthcare strategies should contain measures for the development and functional integration of palliative care.<sup>2</sup> Health organisations must be rewarded for improving quality. Partnerships should be established between geriatric medical teams, nursing homes and palliative care staff.

The EAPC supports the recommendations of the WHO to policy- and decision-makers, which are the following:<sup>5</sup>

- Recognise the public health implications of aging populations
- Undertake a quality audit of palliative care services
- Invest in the development of core data sets
- Invest in audit and quality improvement methods/reward the involvement of health organisations
- Ensure that multidisciplinary services are adequately funded, rewarded and supported
- Ensure that the training of healthcare professionals includes sufficient time devoted to palliative medicine and that professionals are supported to keep up to date
- Act against stereotypes that mean older people are not offered palliative care when they need it.

The focus of this *White Paper* is on norms and standards for hospice and palliative care in Europe as recommended by the EAPC. The content has been restricted to those issues directly related to the distribution of services in the community as well as the material, staffing and personal equipment of these services.

As a matter of course, in addition to the structure of care, other dimensions play an important role in the provision of quality hospice and palliative care – such as treatment methods, quality and outcome measurement, research, education, funding, policy and organisation, and legislation. It is beyond the scope of this *White Paper* to cover those areas in detail. Relevant topics will be examined in more depth in a series of future papers.

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**The bold type in this text highlights the recommendations made by the EAPC. Part 1 of this EAPC White Paper was published in the EJPC 16.6.**

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