Palliative Medicine
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# The Budapest Commitments: setting the goals A joint initiative by the European Association for Palliative Care, the International Association for Hospice and Palliative Care and Help the Hospices

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*Palliat Med* 2007; 21; 269
DOI: 10.1177/0269216307080189

*Palliative Medicine*; 2007 **21:** 269–271

# Editorial

# The Budapest Commitments: setting the goals A joint initiative by the European Association for Palliative Care, the International Association for Hospice and Palliative Care and Help the Hospices

Palliative care has expanded tremendously in the last decade in most European countries. A change in the law was recently adopted in Germany, introducing the right for specialist palliative care at home; in Norway, palliative care has been included in the national health plan. Three years ago, the National Institute for Clinical Excellence guidance on improving supportive and palliative care for adults with cancer led to action plans in all of the 34 cancer networks in England to implement this guidance over the ensuing years. Similar milestones were reported from other countries.

However, in spite of this tremendous engagement of palliative care specialists, as well as volunteers and advocates of the hospice and palliative care movement, many patients in Europe with advanced disease still do not receive even a minimum of symptom relief or psychosocial care. The provision of palliative care is far below an acceptable standard in many regions of Europe. The Task Force on the Development of the European Association for Palliative Care has recently surveyed 42 European countries[1] and reported wide differences. The number of services reported in this survey range from more than 20 services per million population in Iceland or 16 in the UK, to zero in Estonia. Even in countries with higher ratios, access to palliative care varies and is greater in urban areas and for selected patient groups, such as cancer patients. As a result, access is limited to patients in rural areas or with non-cancer diagnoses.

Whereas the middle-aged adult with cancer has a good chance of receiving hospice and palliative care services if needed, and sometimes may even choose from a range of services, other populations such as paediatric patients do not have access to appropriate care. Palliative care for children remains a challenge in most European countries. The provision of palliative care for the elderly, especially in nursing homes, is far from adequate even in resource-rich countries. Expanding the scope from end-of-life care for cancer patients to palliative care for other conditions and patient groups such as the elderly and children is a major challenge that we will face in the next decade.

A few countries have formulated national standards of palliative care (for an overview visit: http://www.hospicecare.com/standards/), and in even fewer countries, these standards have been supported or implemented by the national authorities (such as the standards on hospice and palliative care from the Austrian Ministry of Family and Health,[2] or the guidelines from the Scottish Home Office[3]).

Palliative care is now recognized as a public health issue, but it is not yet a priority in health policy reform. To address this challenge, the European Association for Palliative Care (EAPC) in close collaboration with the International Association for Hospice and Palliative Care (IAHPC) and the Worldwide Palliative Care Alliance is launching a 2-year campaign for and with the national palliative care associations in European countries. The campaign will start at the 10th Congress of the EAPC in Budapest (7–9 June 2007, www.eapcnet.org/budapest2007/welcome.html) with the presentation of the Budapest Commitment framework. Representatives of the national associations have been invited to participate in this meeting to develop a consensus for the campaign. The representatives will be asked to define clear goals within a common framework and commit themselves to reach these goals in the next 2 years. The campaign will receive continuous support from an EAPC Task Force on National Associations, chaired by David Praill. The Task Force will support the national associations in their advocacy activities throughout the campaign.

At the 5th EAPC Research Forum in Trondheim in 2008, there will be a forum to present countries' priorities and commitment. The results of the campaign will be presented at the EAPC Congress in Vienna in 2009. Barriers to the development of palliative care are not only a European issue, other pan-national associations from other continents will also be invited to participate in the process and in the development of the framework. We may learn a lot about political advocacy from developing countries, which face far more challenges due to their limited resources.

In Budapest, we will provide a framework, including examples of potential commitment goals that the national associations may use to set their national goals according to their own priorities. The framework covers five areas. The development of palliative care is not a uniform stepwise process, but we believe that these areas might correspond to five distinctive steps that the development of palliative care

10.1177/0269216307080189

has to ascend in any country or region (not necessarily in the same order) until full coverage with high-quality palliative care is available for all those who need it.

For the framework, we will present a list of potential commitments, using five areas in the development of palliative care:

1) Access to medications
2) Policy
3) Education
4) Quality
5) Research.

*Access to medications.* Without access and availability of drugs for symptom relief, such as opioids for the treatment of severe pain or dyspnoea, the delivery of effective palliative care is not possible. The IAHPC recently developed a list of essential drugs with 33 medications for 23 symptoms,[4,5] which should be available and accessible in every country.

*Policy.* Even when essential drugs are available, legislative or regulatory barriers can prevent patients from receiving palliative and hospice care and may even compromise dignity at the end of life. In Italy, the case of Piergiorgio Welby has provoked high emotion, as discontinuation of treatment is not covered by Italian law, which does not differentiate between the prohibition of passive and active euthanasia. Palliative care needs to be integrated into national health plans and health systems to allow mechanisms for service delivery and service provision that are operational. To effect changes in policy, palliative care professionals need to create a national association (if none exists) to advocate for policy reforms in their country. Several policy documents are available for guidance and advocacy.[6]

*Education.* In order for palliative care to be incorporated into the medical care of the patient, the introduction of palliative care in the medical and nursing curricula is critical. Existing curricula can provide a template and model for national development.[7,8] Specialist training, as well as basic knowledge in palliative care has to be implemented to ensure a broad education of all professionals who care for severely sick and dying patients in all types of health care services. There is a wide gap in educational opportunities in palliative care among EAPC members. At the 9th Congress of the EAPC in Aachen 2005, only 90 delegates from central and eastern European countries participated, compared with 2344 participants from western Europe. The organization of the 10th EAPC Congress in Budapest in June 2007 offers a unique opportunity to facilitate participation for specialists in central and eastern Europe.

*Quality.* With the dissemination of palliative care and the related educational programmes, quality assurance and quality improvement measures have to be developed and implemented. Coming from specialist pioneers towards a broad landscape of palliative care providers can lead to a loss of orientation, and it is important that landmarks for high quality are provided early on in this development.[9]

*Research.* Research is essential to create the evidence base for the field of palliative care. Randomized trials may not always be the best option for palliative care trials, and systematic efforts to develop the methodology for palliative care research are an integral part of palliative care research. This need for research was highlighted by the Venice Declaration of EAPC and IAHPC in May 2006 (http://www. eapcnet.org/latestnews/VeniceDeclaration.html), which identified research priorities in developed and developing countries, taking into consideration regional, socio-economic and cultural contexts.

These five areas are not meant as a mandatory path that has to be followed by a country or a national association. For example, research is mandatory in the early stages of the development to provide a needs assessment, to set priorities or to cover cultural or regional topics such as spiritual care with different ethnicities.

Different settings or services for specific patient groups may also set their priorities differently. The provision of palliative care for cancer patients is more developed than for non-cancer patients. Paediatric palliative care is underdeveloped in most European countries; however, in Belarus, 10 services for children have been established, compared with only two services for adults (http://www.eapcnet.org/Policy/CountriesReport.htm).

All countries have potential areas for improvement. We believe that there should be excellent palliative care for those who need it with policy, legislation, education and drug availability in place and with a high level of competence in the provision of care and research. We have a serious challenge before us. We invite the national associations and all their members to participate in this discussion, regardless of the level of development of palliative care in their country. Come and join us in Budapest in this important initiative – commit yourself to your own goals for progress!

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