The Budapest Commitments – a framework for palliative care development

A joint initiative by:

- European Association for Palliative Care (EAPC),
- International Association for Hospice and Palliative Care (IAHPC) and
- Worldwide Palliative Care Alliance (WPCA)

**Background**

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. This definition of the World Health Organisation (WHO) ([http://www.who.int/cancer/palliative/definition/en/, accessed on 27.02.2007](http://www.who.int/cancer/palliative/definition/en/, accessed on 27.02.2007)) shows the full scope that palliative care providers have to cover.

However, in most services the provision of palliative care is far from optimal and in many countries and regions in and out of Europe, the development of palliative care is hindered by barriers and obstacles. In spite of tremendous engagement of palliative care specialists and volunteers, countless patients at the end of life suffer from treatable pain, anxiety and other symptoms, social isolation and existential solitude. Results from a recent survey on development of Palliative Care in Europe show vast differences in the state of development among European countries (Centeno C. EAPC Task Force on the Development of Palliative Care in Europe. European Journal of Palliative Care 2006; 13: 149-151).

Even in countries with an adequate standard of care, access to palliative care is greater in urban areas and for selected patient groups such as cancer patients, while limited to patients in rural areas or with non-cancer diagnoses. Whereas the middle-aged adult with cancer has a good chance for a full scope of hospice and palliative care services, paediatric palliative care remains a challenge in most European countries. The provision of care for the elderly, especially in nursing homes, is far from adequate even in resource-rich countries, and the extension from end-of-life care for cancer patients to palliative care for the elderly is a major challenge that we are now facing.

**The strategy**

To help individuals and national palliative care organizations develop effective strategies to meet these needs, the EAPC in close collaboration with the International Association for Hospice and Palliative Care (IAHPC) and the Worldwide Alliance for Palliative Care (WPCA) decided to launch a two-year campaign for and with the national associations to develop strategies at the country level. This campaign will include commitments to accomplish goals within a proposed framework. All the regional associations (African Palliative Care Association (APCA), American Academy of Hospice and Palliative Medicine (AAHPM), Asia Pacific Hospice and Palliative Care Network (APHN), Eastern and Central Europe Palliative Task Force (ECEPT), Latin American Association of Palliative Care (ALCP)) as well as the National Hospice and Palliative Care Organization (NHPCO) from USA, Palliative Care Australia (PCA) and the International Observatory on End of Life Care (IOELC) have been invited to participate in the process and in the development of the framework.

**The framework**

This initiative is based on a strategy which includes using a framework that will help identify and establish development goals in five major areas: **Drug availability; Policy; Education; Quality and Research.**

Within this framework, national associations for palliative care will be invited to choose commitments from a list of proposals or draft their own among these five areas. The commitments should be based on measurable indicators.
The framework will proceed in three phases:

Empowerment
During the spring 2007, the initiators of the Budapest Commitments will contact the national associations and present the outline of the campaign. The associations will be invited to join the campaign and propose specific commitments tailored to meet their palliative care needs in the five main areas. This involvement ensures peer support for the framework from the national associations, propelling the Budapest Commitments forward by the bottom-up approach.

Commitment
During and after the 10th congress of the EAPC in Budapest (7th – 9th June 2007, www.eapcnet.org/budapest2007/welcome.html) the national associations will be asked to define commitments that they will aim to achieve in the next two years.

- Budapest, June 6th, 2007: An initial meeting took place prior to the 10th EAPC Congress, with representatives of the supporting organizations and national and regional palliative care associations. The five main areas within the framework (policy, drugs, quality, education and research) will be presented and discussions on commitments will follow. Several of the sessions throughout the congress will cover these aspects of development.
- Budapest, June 8th, 2007: Meeting of the EAPC Task force on National Associations, with representatives of the National Associations during which additional discussions were held.
- Budapest, June 9th, 2007: The summary of the project were presented in an open workshop as well as the commitments proposed by each association.

In order to focus activities towards the chosen commitments and thus increase the chances of success, each association should define their priorities and choose a limited number of commitments (not more than five, recommendation: three commitments). The commitments will be announced through the EAPC, IAHPC and Hospice Information Services bulletins and newsletters as well as websites. National associations not able to join the discussions in Budapest will be invited to participate in the campaign and submit comments and commitments via the websites after the Budapest conference.

Advocacy
The commitments will require the national associations’ efforts and participation in political and social activities. It is recognized that in order to be successful national associations will need to undertake a considerable and regular amount of advocacy over the next two years. The EAPC Task Force for National Associations will actively seek to provide support in this process.

A review of the commitments and the status of accomplished objectives will be carried out in time for the next Research Forum of the EAPC in Trondheim, 2008. Barriers and challenges will be identified in those cases in which the commitments were unmet and new strategies and solutions will be identified and proposed in order to accomplish the goals.

The results of the commitment and the advocacy work will be presented at the next EAPC congress in Vienna in 2009.

The commitment proposals
Examples for commitments in five areas are listed below. They may serve as models for specific commitments aligned to individual national associations’ priorities, thus making this list the core of a commitments list to be developed by the national associations.

Drug availability
- To ensure availability and access to all the palliative care essential medicines of the IAHPC list available in the country (or close substitute) (De Lima L (2007) International Association for Hospice and Palliative Care list of essential medicines for palliative care. Ann Oncol 18(2): 395-9).
- To have more than 2 potent opioids available with at least an immediate onset and a modified release application form and at least an oral and a parenteral (subcutaneous) application form.
- To increase the rational use of opioids as reported by the INCB consumption reports (http://www.incb.org/incb/en/annual_report.html, accessed on 14.04.2007) to provide percentage of increase that is targeted until 2009.)
Policy

- To produce a report on the state of development and necessary next steps to be presented to the national authorities.
  - provide information when and how the report shall be presented

- To produce a guideline for basic palliative care endorsed by the national association (alternatively: by the medical board, or by the ministry of health)
  - provide details on the scope of the guidelines

- To establish the right for compassionate care leave for family members wishing to care for their diseased relative

- To have palliative care included in the national cancer and HIV/AIDS programs

- To establish reimbursement policies for physicians and nurses

- To identify and eliminate barriers in the laws and regulations which interfere with the rational use of controlled medications, based on the WHO Achieving Balance Guidelines (http://www.medsch.wisc.edu/painpolicy/publicat/00whoabi/00whoabi.pdf, accessed on 14.04.2007)
  - provide information on laws and regulations that have to be addressed

Education

- To have palliative care inserted in the curriculum for medical/nursing students (and other professionals)
  - provide content/knowledge and number of lessons that are mandatory for students

- To implement specialist training with the medical board
  - To implement specialist training with the medical board
  - provide detailed designation of speciality /sub speciality

- To implement specialist training for nurses

- To implement academic training
  - provide detailed description of academic grade

- To establish a certification process to recognize palliative care competence
  - provide description of the authority supporting the certification process

Quality

- To define standards of care
  - provide details of standards and of standard development process

- To introduce a standard documentation system for palliative care services
  - provide information about the implementation process

- To establish a quality assurance project, using benchmarking or audit-cycles

- To get a definition of high quality palliative care
Research

- To incorporate the proposals presented in the Venice Declaration to support the development of research in palliative care
  - provide description of the proposals selected for incorporation

- To initiate a research forum or a working group on research as a platform for future projects and training of researchers
- To produce a national agenda on palliative care research
  - provide details of research topics

- To establish funding or an award to promote research activities in the country
- To increase the publishing of papers in peer reviewed journals on issues relevant to palliative care
  - provide percentage of increase that is targeted until 2009

The Budapest Commitments – a worldwide campaign

The Budapest Commitments will help develop a framework that will be applicable in all regions of the world and can be modified to meet the needs of countries, according to their socio economic, cultural, geographical and epidemiological conditions. Priorities and resources vary vastly between the different regions of the world, and this has to be taken into consideration for the formulation of the commitments in the individual countries.

Developing countries may have to choose smaller goals for their commitments, but they will be able to identify goals and commit themselves accordingly. Developing countries may even show the developed part of the world how to make best use of limited resources, and might set new standards for realistic and down-to-earth work plans.

It is worthwhile to spread the campaign around the world, in close cooperation with the pan-national associations.

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