The European Association for Palliative Care Initiative in Eastern Europe

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Introduction

The ideal development of palliative care would be the provision of high quality, easy accessible care at the end of life for all citizens who need it. Palliative care should be available at the patient's choice in any health care institution, special palliative care unit, hospice or in the patient's home.

European Association for Palliative Care (EAPC)

EAPC is an association with about 25,000 members, a majority in national organizations for palliative care, also to some extent in Central and Eastern Europe. The objectives of EAPC are to increase awareness and promote the development and dissemination of palliative care at scientific, clinical and social levels. Implementation of existing knowledge through education and publications, such as the European Journal of Palliative Care (EJPC), is promoted. Other important issues are advancing research activities, bringing professionals together, and building networks. The EAPC definition of palliative care was endorsed and published by the World Health Organization (WHO) in 1990.

EAPC works through task forces, at present in the areas of ethics, research and Eastern European development. The biannual congresses organized by EAPC are valuable meeting places for palliative care professionals. The next congress will take place in The Hague in The Netherlands, April 2003. The Research network has arranged research-oriented congresses in Berlin 2000 and in Lyon 2002, which have been unique gatherings for palliative care researchers. The EAPC web site is www.eapcnet.org.

The EAPC Initiative for Eastern Europe

Palliative care in Eastern Europe is in a developing phase, with big differences within and between countries. Similar to the development of palliative care elsewhere in the world, progress is dependent on pioneering initiatives and activities from physicians with different backgrounds, as well as nurses and social workers. Generally, palliative care and its advocates get little recognition by society and the health care system. A lot of the work is being done on a volunteer basis.

As a specific response by EAPC to the needs of palliative care professionals working in Eastern Europe, a coordination center was set up in 2001, in Stockholm, Sweden. This has been made possible through a generous grant from the Open Society Institute (OSI), in collaboration with the Stockholm Sjukhem Foundation and the Karolinska Institute, the medical and comprehensive health care university in Stockholm. Stockholm Sjukhem is a palliative care center with a home care service, inpatient unit, day care, and a consultation service. Palliative care research and education is given high pri-

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ority, with a chair in palliative medicine and academic positions for several other palliative care team representatives.

The overall objective for the *EAPC East* initiative is to support the development of palliative care in Eastern Europe. Emphasis is put on personal contacts, networking and practical support. Collaboration has been developed with other organizations and associations with similar objectives, including WHO, Council of Europe and ECEPT (Eastern and Central Europe Palliative Task Force), and also with the PaCe group of Prof. D. Clark in Sheffield, UK.

In a postal/email survey to professionals working in palliative care in Eastern Europe, 100 questionnaires were returned. These represented 18 of 20 countries addressed. A majority of the responders were physicians (80%). Results showed the following top priorities for support: legislation and availability of drugs, education and training, availability of books and journals, twinning and cooperation, policy and standards, economical resources.

These priorities will be reflected in the supportive activities.

Much of the work in the *EAPC East* initiative has so far been on an individual level, administrating grants and connecting people. Efforts in education and twinning have also started as well as joint applications for projects.

Documents on minimum and specialist standards for palliative care have been developed by e.g., professional palliative care organizations, individual researchers, government initiatives and the WHO. Such documents include e.g., definitions, need for staff and competence, education, organizational issues, research and national development within the different models for health care. However, even worldwide, few examples exist of a structured implementation of such standards. Based on existing documents, a consensus of minimum standards for clinical implementation will be produced. Hospices and home care teams will be invited to use the standards as an aid for development.

A variety of different palliative care courses exist, also in Eastern Europe, directed towards different professional groups. Such education may include pain and other symptoms, psychosocial issues, ethics and communication skills. The EAPC initiative includes training for teachers in courses specific to palliative care. Such courses also imply strengthening of identity and practice of teamwork. Courses will cover adult learning and the learning processes, teaching skills, evidenced-based knowledge and adaptation of course curricula relevant to different learning situations, as well as planning of future teaching.

The introduction of the skills and attitudes of continuous quality improvement in the development of a palliative care programme will be part of the program. The objective is to integrate patient focused quality improvement tools into the palliative care services. This will be supported by specific training and supervision.

The supportive effect of regular meetings and workshops throughout the project may well be as great as the practical parts of the program. A continuous exchange of ideas, experiences and questions during meetings and through the website, www.eapceast.org will be supported.

A specific package of information and tools will be developed for use by other services under development in all parts of Europe, and worldwide. The package will include the common minimum standards, experience and strategies for implementation and follow up. Further it will include curricula and practical guides for training of teachers in palliative care and a practical guide for using the patient oriented quality improvement tool.