EAPC news and views

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An overview of the EAPC task forces

Task Force on Paediatric Palliative Care

The EAPC Paediatric Palliative Care Task Force was set up in September 2002. Its aims are threefold:

- To identify existing organisations providing and supporting palliative care in children in Europe
- To create a directory of such organisations to facilitate co-operation between them
- To formulate a strategy for supporting them.

The initial phase of the project has been spent canvassing the views of the EAPC task force as to the scope of the project and how it should best be approached. It has also provided an opportunity for input from the wider EAPC during electronic discussions regarding the academic programme for the forthcoming meeting in 2005.

Representatives from the working group recognise the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) to be the main organisation representing palliative care in children in Europe. The task force concurs that the specialty of paediatric palliative medicine has much to learn from its adult predecessor and that opportunities for exchange of knowledge between adult and paediatric palliative medicine physicians are currently limited and there is value in providing forums that allowed ‘cross-fertilisation’ of ideas. Working alongside ACT, the EAPC is well placed to facilitate this in Europe.

There is a minority view that paediatric palliative care should be practised by adult palliative medicine physicians rather than those trained in paediatrics. This was not endorsed by most members of the task force, but it is acknowledged that adult physicians will need to provide significant support to paediatricians for the foreseeable future, until there are enough paediatric specialists.

Research in Poland has already established a preliminary database of national organisations providing and co-ordinating palliative care for children in many countries of Europe. These data are soon to be published.

Paediatric palliative medicine in Europe has grown out of paediatrics rather than palliative medicine. The preliminary view of the task force is that this is appropriate, since expertise in the care of children is the first requisite of those working in paediatric palliative care. However, paediatric expertise alone is not enough to provide specialist palliative medicine to children. The paediatric specialty must look to adult palliative medicine for the specialist knowledge it can often offer. Currently, there is little opportunity for this to happen. The task force supports a vision which allows mutual exchange of expertise between the adult and paediatric specialties.

EAPC Task Force on Palliative Care Development in Europe

The task force was approved by the EAPC Board in June 2003 and will be completed by the next EAPC Congress in Aachen 2005. This task force is a collaboration between three institutions: EAPC Onlus, the International Observatory of End of Life Care and Help the Hospices. Financial support has been provided by Mundipharma Ltd and Help the Hospices. EAPC will pay towards the travelling expenses of the Head Office liaison.

The first meeting of the task force was held in the Strand Hotel, London, in September 2003 by Help the Hospices. Aims, objectives and a work plan were agreed as outlined below.

The aim is to achieve an overall vision of the care activity and development of palliative care teams in Europe.

The objectives are:

- To provide reliable information on the delivery of hospice and palliative care in Europe, in a manner relevant to the EAPC, as well as to intergovernmental organisations and national and regional governments
- To explain the current organisation of hospice and palliative care, taking into account political, social, healthcare policy and related factors
- To facilitate access and communication between relevant hospice and palliative care associations and societies that operate in European countries
- To identify key people who have studied the process of hospice and palliative care development in their own setting and who may provide country-specific data to assist policy makers, planners and professional associations.

The survey will include all countries with a national palliative care association, countries in the EU and those countries planning on becoming members of the EU.

This study includes:

- A review of the current situation: an effort will be made to compile and study all the information available on the development of palliative care in each country
- A study of palliative care within each country, by means of a survey directed at designated key people or experts.

The process will include:

- A systematic review of the current state of the problem, compilation and analysis of published material

- A review of services sponsored by national scientific societies
- Identification of key people and referees. The criteria to choose each one is well defined and all the societies will participate in the revision of their country's material
- A survey with each key person, using a pretested questionnaire.

The time frame is as follows:

- Jan–Sept 2004 – systematic literature review; list of papers ready; and articles selected and report ready
- February 2005 – distribute questionnaire
- June 2005 – collect questionnaire
- February 2006 – final report ready.

EAPC Task Force on Palliative Care Standards

Although major funding has not been available, the work has already started on a small scale. A review of available standards was presented as a poster at the EAPC congress in The Hague, carried out by the EAPC East group in Stockholm in collaboration with Dr Urska Lunder from Slovenia. A standards review article will be published in an international journal and the group have been invited to write an editorial on the subject for one of the palliative care journals.

During their work, the group has questioned the goal of creating one common European palliative care standard when the development of, and structures for, palliative care are different within different countries. The formulation of national or regional standards based on available information, knowledge and experiences is also important. The next step is to look into the factors that influence implementation and a sustained increased quality of care.

Plans for a workshop later this year are in progress. Authors of existing standards will be invited as well as task force members and a limited number of others. The aim of the meeting will be to share experiences from writing through to implementation and audit in order to consider what worked, as well as to find out whether a need for some form of a European standard exists. Another way forward is to create some sort of checklist that anyone wanting to write standards can follow. The need for a larger conference or forum on standards will also be assessed.

Task Force on Medical Education

The working party under the direction of Dr Marilène Filbet met in Aachen in December 2003 and a further meeting took place in March 2004 in Lyon. The group represents a broad spectrum of medical practitioners involved in the preparation and delivery of medical education throughout Europe. A meta-analysis of palliative medical education in Europe has been prepared by Dr Filbet and will be published on the EAPC website.

European Federation of Older Persons (EURAG)

Although this project is not strictly a task force, the collaboration between this group and the EAPC has been very positive. Indeed, the development of links with agencies that promote an ethos of care reflecting palliative principles is an example of the commitment of the EAPC to create links at the widest possible European level. In particular, the Task Forces on Standards and the Development have forged links with this group and a healthy working relationship is anticipated in the future. Carlos Centeno has agreed to act as liaison for the EAPC and has attended the EURAG conference on behalf of the EAPC earlier this year.

New task forces

Although the initial impetus for the choice of topics to be reported has largely come from within the Board of Directors, this does not preclude members from raising an issue which is relevant to the global development of palliative care in Europe and which enables us to strengthen the EAPC mission of 'One voice, one vision'.

Proposals for projects are welcome and details of how to apply are available through the website (www.eapcnet.org/projects/projects.asp). Here, updates of all projects will be given four times a year until completion.

The internal rules for the formulation of a task force are designed to give each working group the optimum guidance and support for their project. The group should be large enough so that no one person is left to undertake all the work and not so large as to make meetings and decision-making too complicated. The collaborative nature of the group at a European level is important to the process and prospective task forces are expected to seek sufficient funds to make their project viable. Hence, a financial plan is required before the task force can be ratified by the EAPC Board. Members are encouraged to make suggestions and contribute in any way to the function and development of task force work. They should contact the co-ordinator, Philip Larkin (philip.larkin@nuigalway.ie) for more information.

French conference at St Christopher's Hospice

St Christopher's Hospice offers the opportunity to people from French-speaking countries who are involved, or interested, in palliative care, to exchange experiences with other professionals in the UK. The conference will take place on 23–24 September 2004.

The first day will look at the principles of palliative care, total pain, taking care of families and working with bereaved children. The second day offers a more in-depth look at topical issues including management of palliative care units, management of change, working with volunteers and with the bereaved. These sessions will be led mainly by native French speakers, who are experienced palliative care practitioners working in the UK. For details on how to register, please contact Avril Jackson, email: info@hospiceinformation.info