EAPC news and views

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New on the web: the EAPC discussion forum

Palliative care is developing throughout Europe and has reached high standards of care in many European countries. However, with ongoing growth of palliative care services and distribution of palliative care into other areas of medicine such as oncology or geriatrics, an increasing scope of attitudes and opinions is seen. This is most evident in the controversial discussion of topics with ethical implications, such as palliative sedation. Palliative care standards for these topics will continuously be challenged unless they are based on a broad consensus developed by European palliative care specialists.

The EAPC has initiated a discussion forum on its website (www.eapcnet.org/forum) to provide a platform for discussion of those topics in palliative care where consensus has not yet been reached. The EAPC will allow access to manuscript drafts in the forum and invites you to comment on these papers. Comments may be submitted for the whole paper or on specific sections.

Comments will only be accepted if the name and email address of the submitter are provided. Comments will be regularly reviewed and the EAPC reserves the right to delete comments or even bar submitters if comments do not adhere to common rules of internet etiquette (that is, if they are abusive or racist).

The papers have been drafted by members of an international expert group on palliative sedation, the Sedation Consensus Group. Summaries of these papers were presented at the 9th EAPC Congress in Aachen in April 2005. Discussions among the group confirmed that there are still questions regarding this subject and therefore it was decided to present the papers on the EAPC forum to allow further discussion. Papers will be revised based on the submitted comments to provide the consensus.

Papers on other topics will follow. The EAPC forum will be a place to discuss controversies, identify the scope of attitudes and opinions in Europe and provide the basis for minimal consensus standards.

You are cordially invited to participate in the discussion. It is available at: www.eapcnet.org/forum

I look forward to receiving your comments in the forum ■

Lukas Radbruch, EAPC Vice-President, Department of Palliative Medicine, Aachen University, Germany

Establishing a national cancer control programme in Hungary

In September 2005, the Hungarian government announced the launch of the National Cancer Control Programme (NCCP) as part of its National Development Plan. Quality of life improvement and social and professional collaboration for fighting cancer were indicated as its main aims. A further aim is to 'accomplish a complex oncological approach and to form and operate an effective care system providing balanced patient care'. With this purpose, it follows the guidelines and recommendations of the WHO National Cancer Control Programme.

To develop the programme which was prepared by the Ministry of Health, the Hungarian Hospice-Palliative Association (HHPA) has offered to prepare the chapter on hospice and palliative care and recommendations and aims since these were not present in the first plan of the NCCP. Useful relationships were formed between the Association and the Ministry's Department of Health Policy while preparing the Palliative Professional Guidelines in 2002 and the Palliative Minimum Conditions in 2004, and while organising joint conferences in 2001 and 2005.

The first version was submitted for debate in November 2005. The HHPA represented itself at debates within the professional colleges and collected further additions and proposals via its member organisations.

The final NCCP (76 pages) was presented on 3 February 2006 at the National Institute of Oncology, with the Prime Minister in attendance, as well as Cecilia Sepulveda representing the WHO.

Unfortunately, palliative care is not covered as fully in the final NCCP as it was in the original version. It is covered as follows:

- Hospice (palliative) care: the concept of hospice care, its settings and data (Chapter 5)
- In 'Personal requirements: education of those participating in cancer care' (Chapter 9): the one year's hospice nurse and co-ordinator training that started in 2002 appears as one of the vocational trainings of accentuated support.

Palliative care also features as part of the action plan for development of the NCCP:

- To create a countrywide hospice network to improve the quality of life of cancer patients. To do this, the following tasks must be undertaken:

1. To establish, by the year 2010, at least one hospice inpatient centre in each region, operating as part of the health insurance system. Deadline: ongoing from 30 June 2006 to 2010
2. To achieve countrywide coverage of hospice care delivered within home

care services, in three stages (in counties, towns and their surroundings and in the whole country). Deadlines: 31 December 2007 (Stage one); 31 December 2008 (Stage two); and 31 December 2011 (Stage three)
3. To provide professional representation at education and training opportunities for hospice and palliative care, and to integrate it into education and continuing education. Deadline: 31 December 2007.

You can read more about this programme on the web: www.hospice.hu/english/nccp.htm ■

Katalin Hegedus, President of the Hungarian Hospice-Palliative Association, Budapest, Hungary

Outpatient palliative care activities in Latvia

Six years' experience in outpatient palliative care work has given us a good understanding of the need for this sort of activity. It was first started in Riga, as a part of the palliative care team's work at the Latvian Oncology Centre (LOC). In order to select patients with advanced disease, oncological as well as non-oncological, for admission to the palliative care unit, specialists participated in outpatient clinics at the LOC.

Analysis of the data suggested the necessity and importance of multidisciplinary teamwork according to the WHO standards. Precise selection of patients using the outpatient consultancy service is possible to arrange inpatient admission at the specialist palliative care unit. Care plans are designed for each individual patient. The essence of the outpatient consultancy is to improve quality of life for patients and their relatives. All the patients who were seen in the outpatient setting are registered and the data is to be analysed in further studies. Special emphasis has been put on effective pain control, symptom identification and treatment, as well as social, psychological and spiritual issues. Each case is analysed individually to cope with the existing problems either at home or at the palliative care unit.

There were 757 patients with advanced cancer seen in the outpatient department in 2005, of whom 386 were female and 371 male. Home care plans were designed for 135 patients (17.8% of cases), but 622 patients (82.2%) required hospitalisation. In 2005, hospitalisation was indicated in 59% of cases. Major social problems (low income, unemployment, homelessness and drug addiction) were identified for 14 patients (1.8%) in comparison with 20% in 2004. Moderate-to-severe pain (nociceptive and/or neuropathic) was identified in 494 cases (65.2%) in comparison with 80% in 2004. Other symptoms included fatigue (405 patients), pleural effusion in 62, ascites in 62, dyspnoea in 26, ileus 13 and bleeding in 11 patients. Other medical conditions were identified, such as cachexia, oedema, anaemia, fits, cramps, pathological bone fractures, psychological problems, urinary retention, strictures (oesophageal, rectal, gastrostomal), paralysis and decubitus ulceration.

In 2006, there are currently 80 inpatient palliative care beds in Latvia and an additional 45 will be established by 2010. Therefore, to improve symptom control and resolve psychosocial and spiritual problems, palliative care is to be organised on an outpatient level provided by multidisciplinary team members in those hospitals where palliative care units already exist. Both inpatient and outpatient care can cover the large number of palliative care patients in Latvia as well as resolve any serious issues. Both settings are regarded as powerful tools to develop the palliative care system further in Latvia. Palliative care programmes and pain control should be implemented on a much wider basis by educating family doctors, different specialists, nurses, carers, social workers, volunteers and society in general ■

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UK's All Party Parliamentary Group on 'Dying Well' launched

The UK's All Party Parliamentary Group on 'Dying Well' was launched at Westminster on 10 January 2006. The group is opposed to the legalisation of assisted suicide and euthanasia. They are calling for better and more widely available end-of-life care and for people to have the right to choose whether they die at home, in a hospice or in a hospital.

Ilora Finlay, Professor of Palliative Medicine, University of Wales College of Medicine, is the Vice Chair. The group's website contains much useful information including downloadable papers, links to other organisations and reports and a frequently asked questions section. You can access the site at: www.dyingwell.org.uk

World Hospice and Palliative Care Day – 7 October 2006

Thousands of people around the world will be staging events to raise awareness and funds for hospice and palliative care services locally, nationally and internationally to mark this annual global event. The theme this year is Access to Care for All, highlighting that millions of people who desperately need care at the end of life are not getting it.

The first ever World Hospice and Palliative Care Day took place in October 2005 with more than 1,100 events taking place in 74 countries. It was launched by Her Royal Highness Princess Anne in London, and supported by Archbishop Desmond Tutu, who described it as 'an important global event'.

To find out more and get involved in World Hospice and Palliative Care Day 2006, visit www.worldday.org or email: worldday@helpthehospices.org.uk