In this section, European palliative care organisations are invited to explain their goals, express their hopes and voice their concerns

HPPA: the rise of Hungarian hospice and palliative care

From small beginnings 15 years ago, when just a few hospices got together to form a national association, the Hungarian Hospice Palliative Association (HHPA) has become a major player in hospice and palliative care, not only in its own country but also in eastern Europe

Katalin Hegedus, President, HHPA

The Hungarian Hospice Palliative Association (HHPA) was set up in 1995, when 19 hospices got together to form a national association. By 2009, it had grown to include 65 member associations. In 2006, the HHPA became a member of the Hungarian National Health Council. In 2007, it hosted the 10th Congress of the European Association for Palliative Care (EAPC) in Budapest. It is thanks to the HHPA that hospice care in Hungary is now financed by the national health insurance fund and that recommendations for hospice care have been included in the 2005 national programme for cancer control.

How it all began

The country's first hospice organisation, the Hungarian Hospice Foundation (HHF), was founded in 1991, after the political changes that saw the end of the communist state and the democratic elections of 1990. Hospice initiatives were supported by grants from the Open Society Institute and Soros Foundations Network.

Over the next few years, a debate took place in the country about the ethical and legal principles of hospice and palliative care, and the taboo around death and dying began to lift. A series of lectures on death, dying and palliative care was organised by the HHF in universities and medical organisations. Contacts were established with the Ministry of Health and Parliament, as well as with the publicly funded national health insurance.

Finally, in 1995, the 19 hospices then in existence in Hungary banded together to form a national palliative association, the HHPA. That same year, a national palliative care training programme accredited by the Ministry of Health, in the form of a basic course totalling 40 hours, was started. The HHPA members agreed that anyone wanting to work in hospice care first had to do this basic training course.

In 1997, hospice palliative care was included in a new Health Care Act. National hospice palliative care guidelines were drawn up in 2002. This work improved the relationship of the HHPA with policy-makers.

By 2002, the hospice movement in Hungary had already 11 years of experience; there were 28 hospice care providers; a legal framework for care existed; a good postgraduate training system was in place; and we had good international

Leaders of the European Association for Palliative Care (EAPC) and members of the Hungarian Hospice Palliative Association (HHPA), including Katalin Hegedus (second from right), at the 10th Congress of the EAPC in 2007 in Budapest

connections. But, despite all this, there was not enough money to finance palliative care.

Minimum standards of care

Concerns over this lack of funds for palliative care led to a media campaign, initiated by organisations involved in palliative care, human rights and patients' rights, to press for a parliamentary examination of the care of dying patients. As a result of this campaign, the Parliamentary Health Committee was forced to act.

The Ministry of Health invited specialists from the HHPA to produce minimum standards for hospice/palliative care. These standards were published in March 2004 and, in May of that year, the Hungarian national health service (NHS) started a financing programme for hospice/palliative care services.

According to these minimum standards, hospice/palliative care providers have to meet specific requirements. They have to plan resources and staff, provide adequate infrastructure, staffing levels and working conditions and put quality management in place. A system to monitor the provision of care is in place, the main elements of which are six-monthly reports and process control. The Hungarian NHS stipulates that the provision of care should be integrated, with inpatient and home-care services working in co-operation with each other.

Spreading the word

Since its inception, the HHPA has taken a significant role in co-ordinating and organising the Hungarian hospice movement; especially in establishing its legal framework, in setting up a national education and training system, in publishing textbooks, in issuing standards, and in keeping in touch with decision-makers. It published a series of booklets entitled *Hospice Patient Care*. In addition, 23 further teaching resources have been published with the help of the association.

We have translated many European documents into Hungarian, including the 2003 recommendation on palliative care from the Council of Europe;[1] the 2003 position paper of the EAPC on euthanasia and physician-assisted suicide;[2] the 2007 EAPC recommendations on paediatric palliative care;[3] and the 2007 indicators from the EAPC Task Force on the Development of Palliative Care in Europe.[4] The translations were published in our journal, *Kharon Thanatological Revue*, which appears four times a year.

The current role of the HHPA

Today, the HHPA monitors and co-ordinates 83 national hospice organisations, in which 1,200 people are involved and which comprise 12 hospice inpatient units, 64 hospice home-care teams, four hospice-type nursing homes and three hospital support teams. (Sixty-five of the 83 organisations are collective members of the HHPA.) Each year, the HHPA publishes statistics on care provision and sends them to its member organisations and policy-makers for presentation at national and international conferences. The association regularly informs its members about training, events, grants, new laws, and so on, via its website.[5]

In 2009, the HHPA started to work on the further development of professional guidelines and minimum standards for specialised hospice care, with emphasis on the specifications of service provision, staff competences and qualifications, and codes of practice.

The association has organised accredited basic and further training in palliative care with the Institute for Basic and Continuing Education of Health Workers. More than 4,000 people have now participated in training sessions.

The HHPA also organises biannual conferences on hospice and palliative care, which provide a forum for sharing practical experience and scientific knowledge.

Two movements gaining strength

The attitude of Hungarian society towards palliative care is changing and two movements are gaining strength in the country.

- One is centred around the World Hospice Day. Last year, on 10 October, 30 venues hosted special programmes (including concerts, exhibitions and masses) to highlight the needs of the dying patient. The HHPA had called for applications for studies on hospice care, death and bereavement. By 31 October 2009, 30 applications had arrived and the best study will be published in *Kharon Thanatological Revue*.
- The other is centred around the Fields of Hope programme[7] launched by the HHF in 2007 and inspired by a campaign from the British Marie Curie Cancer Centre. It has adopted the yellow narcissus flower as its symbol. Every autumn, narcissus bulbs are planted on the main squares of Hungarian towns and in schools and kindergartens. In the spring, when the flowers bloom, solidarity walks take place. The aim is to transform attitudes towards suffering at the end of life. It stresses that human dignity can and should be maintained until the very end.

The Eastern European newsletter

The HHPA became a member of the EAPC in 1999, and hosted the 10th EAPC Congress in Budapest in 2007. In 2005, it launched a monthly online palliative care newsletter, published in English and Russian, for central and eastern European countries.[6] The aims of the newsletter are:

- To cover palliative care activities in the region
- To increase the participation of the countries of Eastern Europe and the former Soviet Union in international associations, movements and actions
- To link those palliative care organisations that are members of the EAPC.

The newsletter, which is supported by the EAPC and the Open Society Institute and Soros Foundations Network, has been successful in achieving its purpose. Thanks to its information on grants, more than 330 East-European professionals were able to participate in the 10th EAPC Congress in Budapest. Between 2005 and 2009, the number of Eastern European palliative care organisations who had joined the EAPC as collective members increased from three to 11 ■

References

1. *Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care.* Council of Europe, 2003.
2. Materstvedt LJ, Clark D, Ellershaw J *et al;* EAPC Ethics Task Force. Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force. *Palliat Med* 2003; **17:** 97–101. *European Journal of Palliative Care* 2003; **10:** 63–66.
3. Craig F, Abu-Saad Huijer H, Benini F, Kuttner L, Wood C, Cornaglia Ferraris P, Zernikow B; Steering Committee of the EAPC Task Force on Palliative Care for Children and Adolescents. IMPaCCT: standards for paediatric palliative care in Europe. *European Journal of Palliative Care* 2007; **14:** 109–114.
4. Centeno C, Clark D, Lynch T *et al;* EAPC Task Force. Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC Task Force. *Palliat Med* 2007; **21:** 463–471.
5. www.hospice.hu (last accessed 16/02/2010)
6. www.eapcnet.org/CeeFsuNlt/index.html (last accessed 16/02/2010)
7. www.hospicehaz.hu/cikkek.php?grp=meltosagmezeje (last accessed 17/02/2010)

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