

## World Hospice and Palliative Care Day 2005

World Hospice and Palliative Care Day (WHPCD) is a new unified day of action to celebrate and support hospice and palliative care around the world. The first WHPCD takes place on 8 October 2005.

The day is for everyone who cares about or is involved in palliative care anywhere in the world, whether a person living with a terminal illness, a health worker, a volunteer or supporter. The idea has been developed in partnership with Voices for Hospices – the world's largest simultaneous singing event in aid of hospice care, which in 2003 involved over 500 performances worldwide taking place over 24 hours. Voices for Hospices has raised more than \$8 million (£4.5) for hospice and palliative care since it started in 1991. It is an integral part of the new WHPCD and provides a way anyone and everyone can get involved.

In addition to Voices for Hospices, the day is being developed by the following organisations: African Palliative Care Association; Asia Pacific PC Network; Australian Palliative Care Association; Canadian Palliative Care Association; Diana, Princess of Wales Memorial Fund; European Association for Palliative Care; Eastern and European Palliative Care Task Force; Help the Hospices, UK; Irish Hospice Foundation; Indian Association for Palliative Care; International Association for Hospice and Palliative Care; International Observatory on End of Life Care at Lancaster University, UK; Latin American Association for Palliative Care; National Hospice and Palliative Care Organisation, USA; and the Open Society Institute, USA

### *What are the aims of WHPCD?*

Every year millions of people around the world living with a terminal illness

experience unnecessary pain and distress, because they are either unaware of or unable to access the care they need. High-quality hospice and palliative care which aims to meet the needs of the whole person can and does provide an answer. This is an issue that affects literally everybody on the planet – we would all like our lives and the lives of those we love to end peacefully and comfortably.

The day has three key aims:

- To share our vision to increase the availability of hospice and palliative care throughout the world. To create opportunities to speak out about the issues which affect provision of hospice and palliative care around the world, to influence opinion makers, including healthcare providers and policy makers
- To raise awareness and understanding of the needs – medical, social, practical and spiritual – of people living with a terminal diagnosis and their families. To explain how hospice and palliative care can transform people's lives and to show how it can help to meet those needs
- To raise funds to support and develop hospice and palliative care services around the world – particularly through Voices for Hospices events.

### *Raising awareness*

First and foremost we hope the day can help to increase understanding of hospice and palliative care and how it supports those facing the end of life.

It's not about helping someone die but instead about helping someone to live as comfortably as possible with their illness. It's about seeing them as a living person, not a dying patient. It's supporting those closest to them and adding life to days, whether or not days can be added to lives.

This means much more than just specialist symptom and pain relief, although that is a very important part of it. It is a holistic approach that respects the individual's wishes and helps them in ways appropriate to them, both individually and culturally.

It is flexible and adaptable – it is a way of caring. In many situations, care can be provided at the person's home with drop-in support from a specialist health worker or trained volunteer.

It does not have to be expensive. There are low-cost drugs, treatments and ways of giving support which can make all the difference to the quality of people's lives. But this knowledge needs to be shared – and the work involved in setting up and running such programmes funded.

More specifically, there are many issues affecting hospice and palliative care today for which we hope to find a collective voice, for example:

- The need for all countries to include palliative care in their national healthcare programmes
- The urgent need for greater and more secure funding to support hospice and palliative care services worldwide
- The need for essential low-cost opioid analgesics for pain and symptom control to be made available, particularly in resource-poor countries
- The need to extend and develop the lessons learned in hospice and palliative care into wider disease groups, particularly in relation to the HIV/AIDS pandemic
- The need to try to improve availability of palliative care for people in resource-poor countries – particularly in rural areas. Also to reach marginalised groups throughout the world, such as prisoners, the homeless and those with special

- needs such as learning difficulties
- The need to integrate hospice and palliative care into *all* healthcare professionals' education programmes
  - That palliative care should not be a last resort but provided concurrently with disease treatment such as antiretrovirals or cancer treatment.

The World Health Organization and other international agencies believe that palliative care is an essential element of care and treatment. World Hospice and Palliative Care Day 2005 will include a global 'call to action'.

### ***How will the success of WHPCD be measured?***

As with any new initiative, it will take time for WHPCD to grow, and we should not expect a huge impact in the first year. However, this is an exciting time in the evolution of hospice and palliative care. In the USA, the President's Emergency Programme for HIV/Aids has pledged to give 15% of its resources to hospice and palliative care. The global focus on hospice and palliative care has never been greater, however, the unmet need has also never been so great.

One measure of its success will be if, in time, it takes on a life of its own. However, in this first year, we will measure its impact by the number of events which take place; the countries that get involved; the audiences reached, the effects on decision-makers and the funds raised to support hospice and palliative care organisations worldwide.

### ***What activities are planned?***

As activities develop they will be posted on the official World Hospice and Palliative Care Day website ([www.worldday.org](http://www.worldday.org)). Details of Voices for Hospices concerts may also be found online ([www.voicesforhospices.org](http://www.voicesforhospices.org)).

### ***How can I get involved?***

The best way to start is to visit the official website [www.worldday.org.uk](http://www.worldday.org.uk),

which will be updated regularly and will provide all kinds of information and tips on ways to get involved. Organisations and individuals may also email with enquiries or suggestions to [worldday@helpthehospices.org.uk](mailto:worldday@helpthehospices.org.uk) or call Help the Hospices on +44 (0)20 7520 8250.

This day is for everyone who cares and would like to make a difference, so please get in touch and see what you can do.

## **National Congress of Palliative Care**

The Portuguese National Congress of Palliative Care took place from 17–19 November 2004 in Lisbon. This congress was organised by a group of professionals from various healthcare sectors, who are also related to palliative care in different contexts.

Well-known Portuguese and foreign speakers were present, and the number of registrations was very high. For logistical reasons, it was not possible to have more than 500 delegates. Of those who were able to participate, more than 50% were doctors of various specialties, and the other 50% comprised mainly of nurses, psychologists, rehabilitation therapists and voluntary helpers.

The organising commission would like to point out several aspects that mostly contributed to the success of this event:

- The high number of participants from different professional groups
- The variety of themes that were presented, which shows how palliative care has become a specific sector in the world of medicine
- The high quality of, and participation in, free presentations and posters – nearly a hundred – involving participants from undergraduate education as well as specialised palliative care professionals. The majority were in the area of symptom control and

communications skills. A total of six prizes were awarded

- The public impact of this event, which was embodied by the interest of some politicians and the attendance of the Health Minister who presided at the opening of the congress, and by the media, who gave very good coverage of the congress, and drew attention to palliative care in Portugal.

This was the largest palliative care congress that has ever been organised in Portugal. It reinforced palliative care as a specific area in medicine and healthcare, its technical and scientific qualities, as well as its multidisciplinary aspects. We could also see that once again, questions concerning terminal illnesses and how to care for them reached our society as well.

On the other hand, the need for specific training to prepare professional and voluntary carers who want to work in palliative care was stressed, as was the need to put into practice the promises of the national program of palliative care that were approved in June 2004.

It was also possible to show that a group of people really dedicated to this cause and to giving it the visibility it deserves, were able to organise a congress of undeniable quality, thereby preparing the ground for a large international congress to take place in our country, in the near future.

We think that we can say that the interest in spreading and consolidating palliative care in Portugal was reinforced with this event and that both professionals and laymen are becoming more and more interested in this problematic subject. We hope that the authorities in question will support the commitments that have been made so far, and the seriousness that palliative care in itself deserves.

*The Organising Committee of the National Congress of Palliative Care*