



WORLD  
**HOSPICE &  
PALLIATIVE**  
CARE DAY



## **Key messages for World Hospice and Palliative Care Day with Voices for Hospices**

**October 10 2009**

### **Theme**

The theme for World Hospice and Palliative Care Day 2009 is “**Discovering your voice**”.

This Day brings an opportunity for people living with life-limiting illnesses, their families and carers to make their voices heard about what hospice and palliative care means to them. This is also an opportunity for the many people around the world who are unable to access the care they need to raise their voices.

This Day is about discovering the voices of policy makers at a global and national level on this issue. The time has come to find out what the commitments of policy makers are to provide quality hospice and palliative care for all those that need it.

Around the world events will be taking place in approximately 70 countries enabling the voices of people living with life-limiting illness, their families and carers to be heard. Events will include a global wave of Voices for Hospices concerts, education events and public awareness raising activities.

### **General international messages about World Hospice and Palliative Care Day**

- Hospice and palliative care, which is provided in a variety of settings including hospices, people’s homes, hospitals and the community, improves the quality of life of patients and their families. It aims to provide the best possible care for people living with and dying from a life-limiting illness and helps prevent and relieve suffering through pain and symptom relief as well through practical help, emotional and spiritual support
- Everyone living with a life-limiting illness has the right to high quality hospice and palliative care to enable them to live with dignity and without undue pain or distress

- Every year, millions of people around the world living with a life-limiting illness experience unnecessary pain and distress, either unaware of or unable to access the care they need
- It is most often in the areas of greatest need – i.e. developing countries with high levels of disease and high mortality rates - that hospice and palliative care services are least in evidence<sup>1</sup>. This must change
- Hospice and palliative care is not just for older people; people across all ages are affected by life-limiting illness – either their own illness or that of a loved one - and people of different ages have different needs
- Children and young people with life-limiting and chronic conditions have very specific palliative care needs that are often different to those of adults
- The estimated number of all people dying needing hospice and palliative care annually is just over 33 million. Death also affects family members and with one or two people shouldering the heavy daily routine of care. This gives a conservative figure of 100 million people who would benefit by the availability of basic hospice and palliative care at any given time<sup>2</sup>

## Discovering the voice policy makers

“Palliative care requires specialist training, and is one of the most neglected aspects of health care. A major stumbling block in many countries is created by unresolved political, legal and ethical issues surrounding the use of morphine and other strong painkillers.”<sup>1</sup>

**UNAIDS**

“Palliative care is an essential part of cancer control and can be provided relatively simply and inexpensively.”<sup>2</sup>

**WHO**

“The policy vacuum at global level on palliative care has allowed weak and sporadic implementation at country level, resulting in inadequate and poor quality care for many PLWHA.”<sup>3</sup>

**DFID Health Resource Centre**

“Palliative care for people living with AIDS includes symptom management, basic health care, social and emotional support, and end-of-life care. Workforce and institutional development remain key issues in the sustainability of such services.”<sup>4</sup>

---

<sup>1</sup> <http://www.unaids.org/en/PolicyAndPractice/CareAndSupport/PalliativeCare/default.asp> (Accessed Jan 09)

<sup>2</sup> <http://www.who.int/cancer/palliative/en/> (accessed Jan 09)

<sup>3</sup> Collin, K. al. Review of Global Policy Architecture and country level practice on HIV/AIDS and Palliative Care DFID Health Resource Centre

<sup>4</sup> [http://www.usaid.gov/our\\_work/global\\_health/aids/TechAreas/caresupport/caresupport.html](http://www.usaid.gov/our_work/global_health/aids/TechAreas/caresupport/caresupport.html) (accessed Jan09)

## Hospice and palliative care:

- Is 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
- Is much more than just providing specialist symptom and pain relief – although that is a very important part. It also addresses individuals' psychological, social, spiritual, and practical needs. It respects the individual's wishes and helps them in ways appropriate to them, both individually and culturally
- Is flexible and adaptable – it's a way of caring, not a building. In many situations, care can be provided at a person's home – for example with drop-in support from health workers and/or trained volunteers
- Doesn't 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.

## World Hospice and Palliative Care Day aims to:

- Share our vision to increase the availability of hospice and palliative care throughout the world
- Create opportunities to speak out about the issues which affect provision of hospice and palliative care around the world, to influence opinion formers including healthcare funders and policy makers
- Raise awareness and understanding of the needs – medical, social, practical and spiritual - of people living with a life-limiting 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
- Raise funds to support and develop hospice and palliative care services around the world

It is:

- A unified day of action to celebrate and support hospice and palliative care around the world
- For anyone and everyone who cares about or is involved in hospice and palliative care anywhere in the world, whether a person living with a life-limiting illness or someone who loves and cares for them, a health worker, a volunteer or a supporter – it is not 'owned' by any one organisation<sup>3</sup>

## **We are calling for:**

- People living with life-limiting illnesses, their families and carers to speak out about hospice and palliative care
- Individuals worldwide living with life-limiting illnesses to demand their human right to palliative care
- Policy makers, funders and service providers to listen to the voices of people living with life-limiting illnesses, their families and carers
- All countries to include palliative care in their national healthcare programmes and to make it available throughout existing healthcare infrastructures
- Greater and more secure funding to support hospice and palliative care services worldwide
- Essential low cost opioid analgesics for pain and symptom control to be made available, particularly in resource-limited countries
- Adequate care to be provided to people affected by a wide variety of life-limiting illnesses, including HIV and AIDS and cancer
- Increased availability of palliative care for people in developing 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 integration of hospice and palliative care into all health care professionals' education programmes, both undergraduate and postgraduate
- Palliative care to be provided not as a last resort but concurrently with disease treatment such as ARVs or cancer treatment

---

<sup>1</sup> *Mapping levels of palliative care development: a global view*, a report published by the International Observatory on End of Life Care in January 2007, found a strong correlation between palliative care provision and levels of human development, as measured by the United Nations Human Development Index

<sup>2</sup> *Palliative Medicine –global perspective* Sternsward and Clark in Oxford Textbook of Palliative Medicine 2004, Oxford University Press

<sup>3</sup> World Hospice and Palliative Care Day is co-sponsored by the World Health Organization and has been developed by the Worldwide Palliative Care Alliance (a network of national hospice and palliative care organizations) and other global partners. Details of members of the World Day organising group can be found at [www.worldday.org/partners.asp](http://www.worldday.org/partners.asp). The secretariat for World Hospice and Palliative Care Day is provided by Help the Hospices, the UK charity for the hospice movement.