

# Hospice and palliative care worldwide

## The facts

Estimates suggest that:

- around the world, over 50 million people die every year;
- 4.9 million people were infected with HIV in 2004;
- 3.1 million people died of AIDS in 2004;
- 39.4 million people have HIV / AIDS;
- there are over 10 million new cases of cancer every year;
- cancer causes 6 million deaths every year;
- there will be 15 million new cases of cancer every year by 2020.<sup>(1)</sup>

Many of these people will endure intense and unnecessary suffering and pain with little or no access to appropriate drugs. Thus, for many of them, palliative care is often the only humane option. Sub-Saharan Africa has only 1.5 per cent of global palliative care resources compared to 55 per cent in North America.

## The issue

In many developing countries there is limited access to affordable and appropriate treatment for cancer and HIV / AIDS. Palliative care is a humane way of relieving pain and distress. Moreover, since access to appropriate medication for pain relief and opportunistic infections is central to palliative care, commitment to its implementation will provide mechanisms for making all kinds of medications (including Anti-retroviral) available to communities.

## Who provides palliative care?

Palliative care is largely provided by non-governmental organisations, community groups and hospices. Increasingly, palliative care in developing countries is being delivered by community home-based teams of workers who have received basic training in physical care and communication skills and who work under the supervision of a trained nurse.

In resource-poor countries, where need is greatest, there are many obstacles to overcome. These include: lack of pain relieving drugs; problems of legislation enabling opiate use; lack of professional and public education; and lack of finance for research and development. Due to palliative care not being part of many governments' health or national strategic plans,

the majority of organisations providing palliative care have limited government support and are highly dependent on donor funding. This creates small islands of excellence which only a few people can access.

## What must be done?

Palliative care should be widely accessible and not a luxury for a lucky few. It should be integrated into the continuum of care and management of people with HIV / AIDS and cancer. To achieve this, palliative care needs to be included explicitly in national health policies.

There is little awareness of, and expertise in, palliative care at either the policy, health professional or community levels. If provision of palliative care is to be effective, training is needed for policy makers, health professionals, community health workers, patients and their families. Everyone concerned needs to understand the basic principles of palliative care and how it can be delivered.

## What is being done?

It is estimated that between 7,000 and 8,000 hospice and palliative care initiatives have been developed in over 100 countries around the world, in six continents, adapted to suit local needs and culture. There is continuing interaction between UK and overseas palliative care services, with much mutual learning and many initiatives to support training and development. **hospice information** publishes *Hospice and Palliative Care Worldwide*, listing hospice-type services (either established or planned) in six continents, and *Hospice Twinning - A guide to twinning partnerships in hospice and palliative care*, and can facilitate links and networks among palliative care practitioners.

## References

1. Source: World Health Organization ([www.who.int](http://www.who.int)) and UNAIDS ([www.unaids.org](http://www.unaids.org)) websites 2005.

## Useful resources

- [www.eolc-observatory.net](http://www.eolc-observatory.net)  
The International Observatory on End of Life Care presents research-based information about hospice and palliative care provision in the international context, including public health and policy data complemented by material drawn from the social and cultural analysis of end-of-life issues, including ethnographic, historical and ethical perspectives. Currently provides data on 28 countries in Eastern Europe and Central Asia; and on Argentina, Mexico, Swaziland and Zimbabwe.
  - Clark D, Wright M. *Transitions in End of Life Care: hospice and related developments in Eastern Europe and Central Asia*. Buckingham: Open University Press; 2003.
  - Saunders C and Kastenbaum R. Editors. *Hospice care on the international scene*. New York: Springer; 1997.
  - Rajagopal M.R, Mazza D, Lipman A.G. Editors. *Pain and Palliative Care in the Developing World and Marginalized Populations: a global challenge*. New York: Haworth Press Inc; 2003.
  - Many journals include articles on international aspects of palliative care development including: *The European Journal of Palliative Care*, *Palliative Medicine*.
  - Two publications from ***hospice information*** feature international palliative care:  
***'hospice information bulletin'*** quarterly magazine and *Worldwide Hospice and Palliative Care Online*, a free electronic newsletter produced every two months.
  - Lucas S. *Palliative care and HIV / AIDS: Worlds apart or a vision shared?* London: Help the Hospices; 2003.
  - *The UK forum for hospice and palliative care worldwide*, a part of Help the Hospices, aims to have a facilitative and enabling role that covers:
    - the development of a UK network of interested people and organisations
    - facilitating 'twinning' arrangements
    - funding, training, education activities and volunteer placements
    - information-giving, eg. about funding opportunities.
    - It also advocates with Government and other international organisations about the work of *UK forum* members and the role of hospice and palliative care.

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