World Hospice and Palliative Care Day

11 October 2008

Key international messages

2008 theme

The theme for World Hospice and Palliative Care Day 2008 is ‘Hospice and palliative care: a human right’ highlighting the fact that without access to the care they need, people affected by life-limiting illnesses suffer unacceptable levels of distress that amount to a violation of their human rights.

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 as through practical help, and 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, ie developing countries with high levels of disease and high mortality rates, that hospice and palliative care services are least in evidence[1]. 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, with one or two people shouldering the heavy daily routine of care. This gives a conservative figure of 100 million people who would benefit from the availability of basic hospice and palliative care at any given time[2].

Access to hospice and palliative care is a human right that is frequently contravened

Human rights, as defined by numerous national laws, international conventions and consensus statements, align closely with the central tenets of palliative care, which seeks to alleviate all forms of unnecessary pain and distress.

The Commission on Human Rights Resolution 004/26 Item 7c calls on states "to promote effective access to…preventive, curative or palliative pharmaceutical products or medical technologies".

General Comment 14 by the Committee on Economic, Social and Cultural Rights on the right to the highest attainable standard of health (interpreting the International Covenant on Economic, Social, and Cultural Rights) affirmed the importance of "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity" (para. 25). It also indicated that access to essential drugs, as defined by the World Health Organization (WHO) Action Programme on Essential Drugs, is part of the minimum core content of the right to health (para.12). Fourteen palliative care medications are currently on the WHO Essential Drug List yet it is estimated that 80% of cancer patients around the world have no access to the essential pain relieving drugs listed.

Widespread lack of investment in hospice and palliative care facilities, as well as in the training of healthcare professionals in hospice and palliative care practices, results in the contravention of the right to experience the highest standards of physical and mental health.

National laws restricting access to pain relieving drugs cause unnecessary and unacceptably high levels of pain. This breaches the right not to experience cruel, inhuman and degrading treatment and contravenes most patients' charters. The European Charter of Patients' Rights, for instance, states: "Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative care treatment and simplifying patients' access to them." The Declaration on the Promotion of Patients' Rights in Europe, promulgated by a WHO European Consultation, similarly asserts: "Patients have the right to relief of their suffering according to the current state of knowledge…Patients have the right to humane terminal care and to die in dignity."

Lack of access to pain and symptom relief can prevent AIDS patients, who may be experiencing painful and unpleasant side-effects from antiretroviral treatments (ARVs), from adhering to ARVs, with the result that their life expectancy is curtailed. This breaches the right to life.

Paul Hunt, UN Special Rapporteur on the Right to the Highest Attainable Standard of Health, stated in March 2008: "Every year, millions suffer horrific, avoidable pain. Very few have access to pain relieving drugs…In short, palliative care needs greater attention. Many HIV/AIDS strategies, for example, neglect this critical issue. 11 October 2008 is World Hospice and Palliative Care Day…I urge you to give this issue – and this Day – the attention it richly deserves."

UNAIDS has identified palliative care as a neglected issue in national and international AIDS policies. In its publication *Taking action against HIV – A handbook for parliamentarians*, it urges governments to: "Ensure that care and support include psychosocial support, and access to palliative care for pain control. Universal access also includes access to cheap, simple pain-relieving and other palliative drugs and interventions, as well as psychosocial support."

People are unable to obtain information about their diagnosis and prognosis and about palliative care treatments and services that can help them. This breaches the right to freedom of information and contravenes most patients' charters.

Certain groups in society are denied access to healthcare, including hospice and palliative care. Examples include drug users, refugees, people in remote rural areas and the elderly. This breaches the right not to experience discrimination.

Hospice and palliative care

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 is about seeing them as a living person, not a dying patient. It is 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 is 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
- 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.

World Hospice and Palliative Care Day

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 illness 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.

World Hospice and Palliative Care Day 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[3].

We are calling for:

- Individuals worldwide to participate in World Day to demand their human right to palliative care

- 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 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 healthcare 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.

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[1] *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

[2] Stjernswärd J and Clark D. Palliative medicine – a global perspective. In Doyle D, Hanks G, Cherny N and Calman K (eds). *Oxford textbook of palliative medicine* (3rd ed). Oxford: Oxford University Press; 2004.

[3] 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 organisations) and other global partners. Details of members of the World Hospice and Palliative Care Day organising group can be found at: 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.