

Illustrative Palliative Care Activities	
Physical	<ul style="list-style-type: none"> • pain and symptom management • prevention and treatment of opportunistic and sexually transmitted infections • adherence support and medication review • nutritional counseling and support • reproductive health and family planning services
Social	<ul style="list-style-type: none"> • destigmatization activities • community and family activities and support groups • social welfare and income-generation support • occupational therapy and vocational counseling • estate counseling and planning • water, sanitation, and housing services
Emotional	<ul style="list-style-type: none"> • treatment for depression • peer and other support groups • disclosure, coping, and bereavement support
Spiritual	<ul style="list-style-type: none"> • spiritual counseling • life-review counseling • funeral and other life-completion task planning



Relieving Suffering & Improving Life Quality

FHI's Palliative Care Activities



HOW DOES FHI PROVIDE TECHNICAL LEADERSHIP IN PALLIATIVE CARE?

Many other FHI country offices are supporting palliative care work. In addition, FHI has a roster of technical staff available to help design, monitor and evaluate, and provide ongoing support for palliative care initiatives at all levels of the healthcare system. FHI has also invested heavily in developing palliative care technical guidelines and training materials:

- *FHI's Palliative Care Strategic Framework*
- *Palliative Care Standard Operating Procedures for Adults and Adolescents in Out-patient Settings*
- *Palliative Care in Vietnam: Results from a Five-Province Rapid Situational Assessment*
- *Vietnam: National Palliative Care Guidelines*
- *Community- and Home-Based Care (CHBC) Assessment, Lesotho*
- *Palliative Care Assessment in Côte d'Ivoire*
- *HIV/AIDS Care and Treatment: A Clinical Course for People Caring for Persons Living with HIV/AIDS (available in English, French, and Spanish)*
- *Establishing Referral Networks for Comprehensive HIV Care in Low-Resource Settings*

To view or request copies of these publications, visit www.fhi.org.

HOW CAN I LEARN MORE?

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Photos Community members work together to support palliative care (Jim Daniels, above); social worker provides palliative care services (Anita Khemka, front); home-based palliative care teams provide counseling and care, including ART adherence support (FHI/Vietnam, inside left); palliative care team members offer information that builds hope (Anita Khemka, inside right).



Design Jimmy Bishara
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WHAT IS PALLIATIVE CARE?

Each year, millions of people with serious illness endure pain or other distressing psychosocial and spiritual symptoms. Millions more struggle to care for sick loved ones or grieve their loss. Palliative care treats the symptoms, side effects, and psychological, social, and spiritual problems related to disease or its treatment. According to the World Health Organization, palliative care “improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.” The benefits of such care are many: reduced suffering, improved quality of life, better adherence to treatment, and reduced cost to families and the healthcare system.

WHO NEEDS PALLIATIVE CARE?

Adults, children, and families who suffer from problems associated with life-limiting illness may benefit from palliative care. Some of the suffering may be the result of

- **physical problems** such as pain, reactions to medication and treatment, or discomfort from the course of the disease
- **emotional problems** such as depression, anxiety, sadness, or fear
- **social problems** such as isolation, poverty, unemployment, inadequate housing, or stigma
- **spiritual problems** such as doubt in faith and life purpose, anger, guilt, or disorientation

Those who can benefit from palliative care include the estimated 40 million people currently living with HIV and the 24 million with cancer—two-thirds of whom reside in countries with only limited resources to provide it. These numbers will surely increase: in the next 20 years, more people worldwide will die from chronic illness than acute problems, and in the next 50 years cancer rates in Africa are expected to grow fourfold.



HOW ARE PALLIATIVE CARE SERVICES PROVIDED?

Palliative care is provided in a variety of settings, including homes, hospitals, clinics, hospices, and nursing homes. Furthermore, palliative care is holistic, which means it requires a team approach involving personnel from the healthcare and other sectors, including social work, mental health, nutrition, spiritual counseling, and community leadership. A nurse or doctor is part of the palliative care multidisciplinary team, and they work with others to provide the physical, social, emotional, and spiritual support needed to relieve suffering. The patient himself and his family are also part of the care team.

WHAT ARE THE PRINCIPLES OF PALLIATIVE CARE?

- **Available throughout the continuum of care:** Palliative care is provided from diagnosis of life-threatening or chronic illness to end-of-life care and bereavement support. It includes providing care in all settings: outpatient or specialized clinics, hospital, community-care services and, most importantly, home.
- **Empowering:** Palliative care involves those with life-limiting disease and their families in leading and providing care, and building their capacity to care for themselves.
- **Family-centered:** The family is the primary source of care and support for a chronically ill family member. Family-centered care provides care, treatment, counseling, follow-up, and psychosocial support to address the needs of the whole family.
- **Strong referral network:** Palliative care, because it works to address needs holistically, requires a strong referral network of service providers. This assures a seamless continuum of care and addresses the large variety of patient and family needs. A referral directory and organized network of providers provide confidentiality, appropriate follow-up, and feedback.

HOW DOES FHI SUPPORT PALLIATIVE CARE PROGRAMS?

Integrated Community Palliative Care in South Africa

In South Africa, the Integrated Community Care Program (ICPC) provides palliative care as part of the primary health system in four sites. The primary health clinic practitioners are trained in palliative care. They support community home-based care groups who have also been trained in palliative care. Multidisciplinary teams consisting of a nurse, home-based care supervisor, pastor, physiotherapist, and social worker assess, plan, and deliver services to patients referred through clinics (including ART and TB) or the community (self-referral, home-based care, or support groups). Together, the team of community resource people, clinic staff, and community home-based care providers bring pain relief, emotional, spiritual, and social support to patients and their families.

The benefits of palliative care include reduced suffering, improved quality of life, better adherence to treatment, and reduced cost to families and the healthcare system.



National Palliative Care Policy Development in Vietnam

FHI and partners, with support from PEPFAR, responded to a request from the Ministry of Health's Therapy Department to develop national palliative care guidelines. These guidelines are standards that will form the basis of a national palliative care program for the estimated 265,000 people living with HIV/AIDS and 150,000 people diagnosed with cancer each year. The FHI team is taking a stepwise process, first conducting a situation analysis to assess the palliative care service coverage and needs in Vietnam, using results to develop guidelines, and then preparing a national training plan to ensure improved care capacity of providers. This helps ensure that fledgling palliative care services are provided with much needed guidance and support.

National CHBC Training Certification in Nepal

In difficult political and geographic conditions, Nepal's National Center for AIDS and STDs Control, with support from FHI, USAID, and others, has developed comprehensive HIV care, treatment, and support programs that include community and home-based palliative care services in several locations of need in Nepal. A team representing the National Center, FHI, USAID, the Nepal Network of People Living with HIV, and the National Nurses Association convened to assess community and home-based care needs and develop a national certification training package to best meet the care needs of those living with HIV and their families. Such care is now being offered in Nepal as part of a continuum of care, extending palliative care to thousands who otherwise not have received it.