



Care for People Living with HIV/AIDS

The U.S. President's Emergency Plan for AIDS Relief is the largest commitment ever by any nation for an international health initiative dedicated to a single disease.

U.S. Department of State

U.S. Agency for International Development

U.S. Department of Defense

U.S. Department of Commerce

U.S. Department of Labor

U.S. Department of Health and Human Services

Peace Corps

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Palliative care under the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) is a comprehensive approach to providing services which support quality of life for HIV-positive adults and children. Although traditional palliative care has focused on pain and symptom relief at the end of life, PEPFAR programs take a broader view, incorporating clinical, psychological, spiritual, social and preventive care services.

Care complements and enhances antiretroviral treatment (ART), going beyond medical disease management to address symptoms and minimize suffering. It begins with the HIV-positive diagnosis and extends through the end of life, using a family-centered approach. Palliative care is provided with respect for patient autonomy and choice, support for care givers, and appreciation and respect for cultural values, beliefs and customs.

The Power of Partnerships:

- Through September 30, 2008, PEPFAR has supported care for more than **10.1 million people** affected by HIV/AIDS worldwide, including more than **4 million orphans and vulnerable children**.
- Through September 30, 2008, PEPFAR has supported training or retraining of **462,500 individuals** to care for people living with HIV/AIDS.

PEPFAR supports the following palliative care activities:

- **Clinical services** include preventive care with antibiotic prophylaxis for opportunistic infections (e.g. cotrimoxazole), insecticide-treated nets, and interventions to improve the quality of drinking water and hygienic practices; treatment and care services for opportunistic infections; pain alleviation and symptom management; nutritional counseling, assessment and rehabilitation for malnourishment; routine clinical monitoring, including evaluating the need for ART; support for ART adherence; and end-of-life care. PEPFAR support includes work with policy makers to develop appropriate policies related to antibiotic prophylaxis and pain control.
- **Social care** supports community mobilization, leadership development for people living with HIV/AIDS, legal services, linkages to food support and income-generating programs, and other activities to strengthen the health and well-being of affected households and communities.
- **Psychological services** provide mental health counseling, family care and support groups, memory books, cultural and age-specific approaches for psychological care, identification and treatment of HIV-related psychiatric illnesses, and bereavement preparedness.
- **Spiritual care** includes assessment, counseling, facilitating forgiveness, and life completion tasks.
- **Positive prevention efforts** should be incorporated across the spectrum of palliative care services to reduce the risk of transmitting HIV from HIV-positive persons to others. These services include counseling and HIV testing for the entire family, prevention counseling and services, and biomedical interventions that reduce transmission risk (e.g., treatment of sexually transmitted diseases).



PEPFAR at Work

The following are a few examples of how PEPFAR is working under national strategies and in partnership with host nations to support palliative care services:

- **In Uganda**, PEPFAR supported district-wide, community-based counseling and testing for families and a package of preventive care services. Preventive services included cotrimoxazole, a broad spectrum antibiotic that reduces the risk of opportunistic infections and mortality; insecticide treated nets to reduce the risk of malaria; commodities needed for point-of-use chlorination to improve water safety and reduce the risk of diarrhea; condoms; and prevention counseling for people living with HIV/AIDS. HIV-positive persons obtain replacement commodities from village health workers in their parish. By September 2006, the full package of care services had been delivered to more than 80,000 people, making substantial progress toward their goal of providing these services to all HIV-positive Ugandans.
- **In Kenya**, according to national guidelines, routine nutritional assessment (e.g., anthropometric, symptom and dietary), counseling and support are provided to HIV-positive persons receiving services at treatment centers. Clinically malnourished patients, pregnant and lactating women in prevention of mother-to-child HIV transmission programs, and orphans and vulnerable children six months to five years of age receive monthly rations of fortified blended flour products that are reconstituted as porridge. At some sites, patients and their families who are identified as being food insecure are linked to food production and income-generating activities to improve access to food. For example, a farm in Eldoret employs high productivity methods to produce eggs, milk, fruits, vegetables and grains that are rationed to food-insecure families to meet their food needs. The program also provides agricultural training opportunities for family members, which may improve their long-term prospects for improved food security.
- **In Zambia**, the government is developing appropriate policies and practices regarding pain management and opportunistic infection prevention. Cotrimoxazole is provided to pediatric patients enrolled in HIV care services at the University Teaching Hospital "Center of Excellence" in Lusaka. This experience demonstrates the importance of cotrimoxazole prophylaxis in reducing morbidity and mortality for HIV-positive children, pregnant women, and their newborn infants. Plans are under discussion to expand procurement and ensure routine cotrimoxazole prescription for people living with HIV/AIDS. PEPFAR supports the Palliative Care Association of Zambia, a national affiliate of the African Palliative Care Association, to take a leading role in developing standards, guidelines, and training materials, and advocating for a sustained national commitment to palliative care.
- **In Rwanda**, a Case Management Partnership model developed strong linkages between trained home-based care volunteers, patients, and nurse case managers at health facilities. The collaboration was formalized through a Memorandum of Understanding between health facilities and a PEPFAR-supported partner organization. Case managers conduct individual patient needs assessments; provide ongoing psychosocial support, and referral for facility-based care and treatment services; link patients to community-based care and support services in their catchment areas; and supervise community-based volunteers providing home-based care. By September 2006, 800 volunteers and 140 case managers had been trained or retrained in palliative care, and 9,000 patients had benefited from the program at 133 sites in the country.

Resources:

- The U.S. Government published guidance documents on evidence-based interventions as part of a preventive care package for adults and children, overall palliative care guidance, and food and nutrition guidance for U.S. Government staff and implementing partners, available at www.PEPFAR.gov/guidance/.
- The World Health Organization (WHO) issued guidelines covering several palliative care components, including: cotrimoxazole, nutrition, sexually transmitted infection management, and pain management, available at www.who.int/hiv/pub/guidelines/en/.
- Targeted at primary health centers, the WHO published the "Integrated Management of Adolescent and Adult Illness Modules," available at www.who.int/3by5/publications/documents/imai/en/. The document supports an integrated approach to the management of HIV and provides simplified guidelines on HIV care, including antiretroviral treatment (ART), acute care, palliative care, and chronic care. WHO provides relevant training on the use of these guidelines.