

Caring for those nearing end-of-life:

Providing compassion and dignity for our elders



“The elder became very tearful and said, ‘You know, I want to go home. Take me home.’ But there was no place to go.”

Program administrator,
Tohono O’odham Nation

The Need in Indian Country

High rates of chronic disease¹



A lack of care options in tribal communities



Desire to receive care at home



Types of End-of-Life Care

Palliative care

Designed to relieve symptoms from serious and life-limiting illnesses

May be offered at the same time as treatment to cure illness

- Nursing care
- Home health services
- Pain management
- Advance care planning
- Medical social services
- Family and caregiver support
- Traditional medicine

Hospice care

For terminally ill patients no longer seeking a cure

Last 6 months of life

Focuses on physical and emotional comfort

In addition to palliative care, it often includes care for the dying and bereavement support



Where is end-of-life care provided?



- Homes
- Assisted living facilities
- Hospice facilities
- Hospitals

Who provides care?

End-of-life care typically involves a team of people, including:

- Family
- Doctors
- Traditional healers
- Nurses
- Social workers
- Other health workers
- Volunteers



Providing culturally sensitive end-of-life care to elders

Beliefs about death are sacred and personal, involving different customs, traditions, and religions. Programs designed by tribes can:



Address pain and death in ways that are mentally and spiritually healing

Balance Medicare’s hospice requirement of a prognosis of less than six months of life with cultural views discouraging planning for death



Help non-tribal medical professionals navigate language barriers, cultural beliefs about discussing death, appropriate behaviors regarding touch and eye contact



Tribal communities can successfully plan for end-of-life care

Successful strategies include:

- Seeking guidance from elders and tribal leaders
- Combining traditional end-of-life practices with Western medicine
- Involving the community
- Developing and using culturally specific materials
- Educating family members
- Educating non-tribal care providers



Create a hospice program in your community

Find resources on the LTSS Technical Assistance Center

<http://go.cms.gov/aianltss>

- A step-by-step Roadmap for Planning to establish Programs
<http://go.cms.gov/aianltssroadmap>
- Research and examples of tribal hospice and palliative care programs
<http://go.cms.gov/aianhpcare>

Sources

1 Finke et al. 2004, Hampton 2005, Indian Health Service 2006, Kitzes 2003, Arenella et al. 2010