

# Best Practices in Culturally Sensitive End-of-Life Care

## Program Profile: Tohono O'odham Hospice

### Tohono O'odham Nursing Care Authority – Tohono O'odham Hospice

#### Life, death, and dignity are uniquely defined by one's own culture.

- The Tohono O'odham Nation assembled an independent board tasked to develop a program for elders. The initial program opened in 2002 as a skilled nursing facility. Five years later, in 2007, a hospice program was developed.
- The Tohono O'odham Nation based the need for hospice care on the lack of end-of-life care in the immediate community and the non-tribal hospice's clear lack of understanding of cultural values.
- The development of the Tohono O'odham Hospice program was a community effort, with community and tribal council support.

#### Successes and Innovations

- The Tohono O'odham engage in regular and ongoing education and outreach to increase hospice awareness and provide insight into how hospice services benefit the community.
- Most hospice referrals come from community member recommendations and are based on their personal experiences.
- The program, tribal leadership, and wider community share in the commitment to provide a continuum of care for elders.
- Surveys, follow-up calls, and feedback from program referral sources are used to measure program success and progress.

**Operated by:** Tohono O'odham Nursing Care Authority

**Established:** 2007

**Location:** Sells, Arizona

**Area served:** Nine Districts of the Tohono O'odham Tribe

**Contact Information:** Dorothy Low, LPN, Administrator, (520) 383-1893

**Website:** <http://www.toltc.org/hospice.html>

**Mission Statement:** To take a leadership role in providing a continuum of care and services designed to enhance the physical and intellectual qualities of life for aging O'odham and other members of the Nation in need of skilled nursing care.



# Best Practices in Culturally Sensitive End-of-Life Care

## Program Profile: Tohono O'odham Hospice

### Incorporating Culture

- Use alternative terms to discuss the end of life, or describe it from another person's perspective.
- Avoid definitive language, terms, or timelines.
- Recognize and accommodate the decision-making process for families seeking hospice care.
- Incorporate patient and family beliefs and values, such as the use of traditional healers and religion.

---

"Culturally sensitive care is a learning curve that you are always on."

-Dorothy Low, LPN,  
Tohono O'odham Hospice

---

### Administration, Staffing & Facility

Tohono O'odham's palliative care and hospice staff includes one registered nurse, one CNA, one part-time social worker, and occasional volunteers. Currently serving about two patients, the program strongly believes in the importance of always having Tohono O'odham language speakers on staff.

### Funding

- The hospice program is Medicare certified.
- Program funding is supported by seed money invested by the nursing home from a tribal subsidy, which helps support tribal members who are unable to pay for hospice services and are ineligible for Medicare.
- Housed under the nursing home umbrella of service, funding to the hospice program is allocated through the nursing home budget.
- The nursing home is eligible to receive a tribal subsidy to help provide services.
- Symptom management in late-stage disease processes can be reimbursed under home care and can provide opportunities for discussion around care goals.

### Lessons Learned

- Sometimes, a lag exists between program start-up and establishing a steady funding stream.
- Be prepared to change funding streams. Stay flexible while finding funding to support programming. Tribal funds may be necessary for success.

### Future Directions

Tohono O'odham's next steps for improving the quality of end-of-life care include:

- Providing responsive care by having conversations with patients and families before hospice is imminently needed,
- Providing consultation to off-reservation entities about traditional healing and cultural traditions, and
- Pursuing the possible creation of a home health care service.