

A program of the  
Tohono O'odham  
Nursing Care Authority



# DESERT PATHWAYS

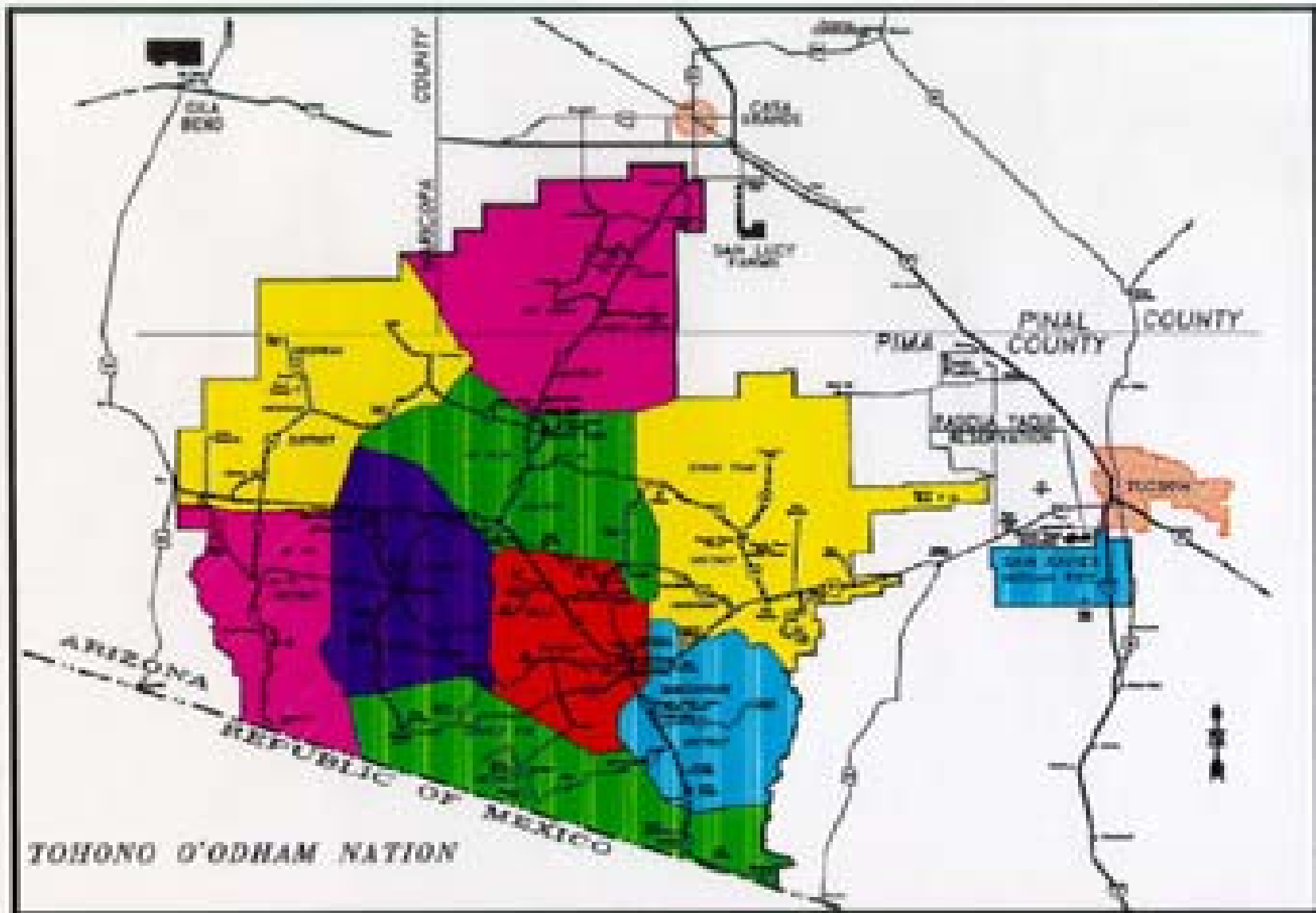
# Presenters

- ✘ Lee Olitzky, Administrator
  - ✘ Dorothy Low, RN, ANP-C, Program Manager
  - ✘ Mark Joaquin, Jr, MSW, Social Worker
  - ✘ Charlene Conde, CNA, Home Health Aide
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ENTERING  
Tohono O'Odham  
Reservation



## Traditional Cultural Beliefs Effecting End of Life Care

- ✘ Importance of being “home” vs in the city
- ✘ Extended family and community involved by sitting with the patient and immediate family often providing spiritual support through rosary and songs
- ✘ Traditional healers and ceremonies difficult to fit into an “acute care” setting

# TOHONO O'ODHAM NURSING CARE AUTHORITY HISTORY

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- ✘ Chartered by the Nation in 1998 to develop a continuum of care for the elders
- ✘ First project a 60 bed SNF first accepting residents in 2002
- ✘ In 2007 identified the need of culturally appropriate end of life care

# TOHONO O'ODHAM HOSPICE

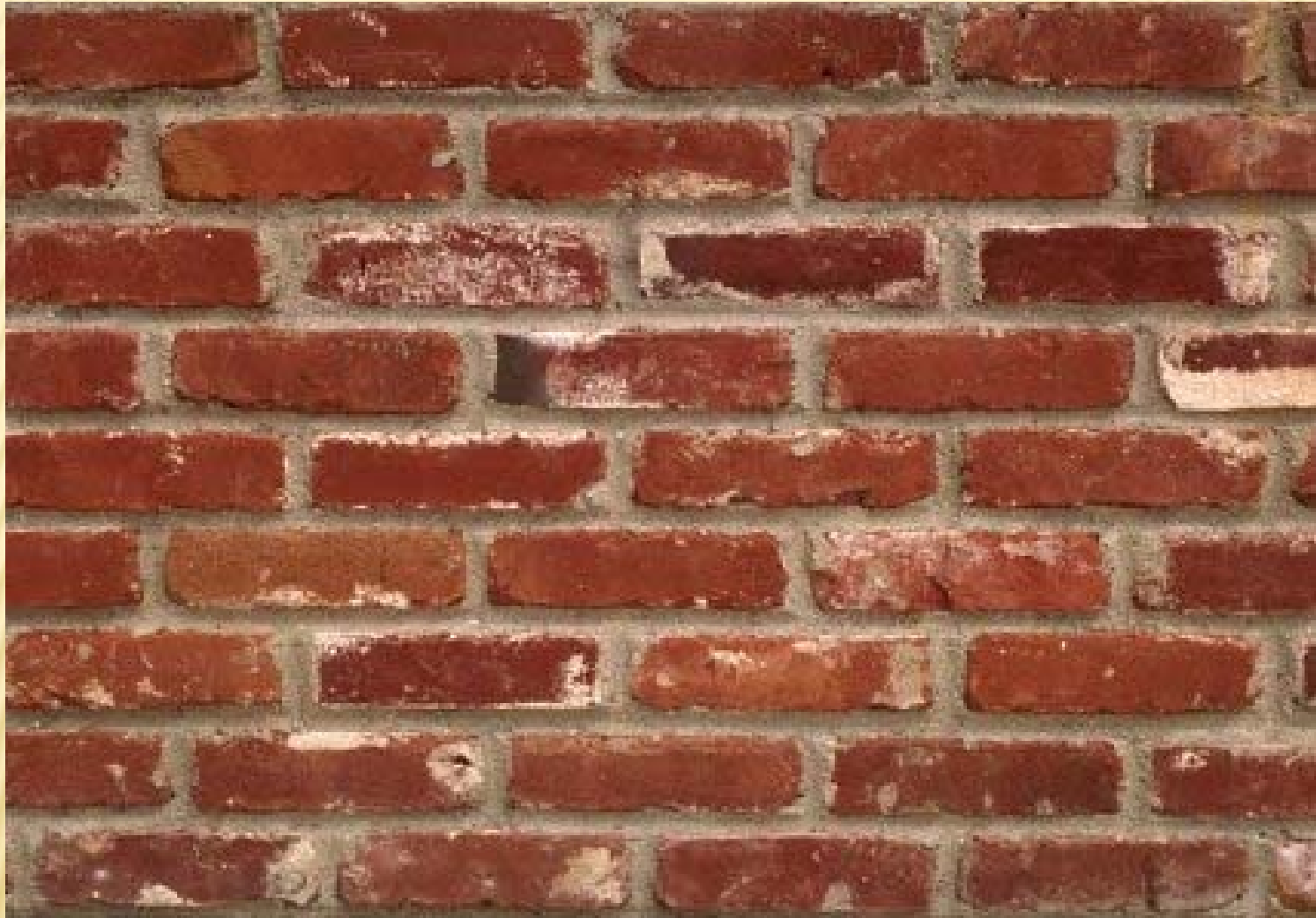
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- ✘ Involved TONCA employees who were tribal members in the development of literature and making presentations on available services to community groups
- ✘ Plan to provide hospice care anywhere in the 9 districts as well as providing hospice services to appropriate SNF residents
- ✘ Received CMS certification as a Medicare Certified hospice in March 2008





**Hospice Logo Designed by O'odham Artist Gus Antone**



# THE BRICK WALL

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- ✘ Patient census stagnant to declining
- ✘ Hearing from providers that people were refusing hospice services
- ✘ Finding people in the community passing away without hospice services
- ✘ Hearing from people with unmet needs r/t serious illness
- ✘ Finding people lost to follow up r/t chronic disease

# BARRIERS TO HOSPICE

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- ✘ History of hospice as an off reservation place where you go to die
- ✘ Minimal experience with having medical needs met without a face-to-face encounter in the provider's office
  - + Case Example
- ✘ Family's lack of confidence as caregivers
- ✘ Not wanting to face impending death
  - + Cultural belief that talking about death makes it happen and that preparing for death means abandoning hope

# DISMANTLING THE WALL

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- ✘ How do O'odham talk about Serious Illness
- ✘ How does hospice become recognized as a philosophy of care instead of a place you go
- ✘ Other than distance, what are the objections to hospice
- ✘ Are people with serious illness appropriately supported in understanding their disease and having needs met and symptoms managed

# CREATING NEW PATHWAYS

“Pi ma:cidag wog ‘i-we:mta”

(walking uncertain roads)

Assisting patients and families to understand the disease process

Providing education that supports individual and family autonomy in health care decisions (disease process, effects of treatments, questions to ask, etc)

+case example

# LESSONS LEARNED IN PROGRAM

## DEAFGOLIAEM I

- × First Hand experience vital
  - + New programs require people to change their thinking
  - + People require new programs to change their thinking
  - + **CHANGE TAKES TIME**
  - + Overcoming lack of confidence as a caregiver requires a relationship with the “tech support” team of professionals that help the family
  - + Elder will often make it clear to the family that they want to be at home.
    - × Case Example
  - + Family needs to see hospice as a way to honor their loved one’s wishes while providing symptom management.

# CONT.

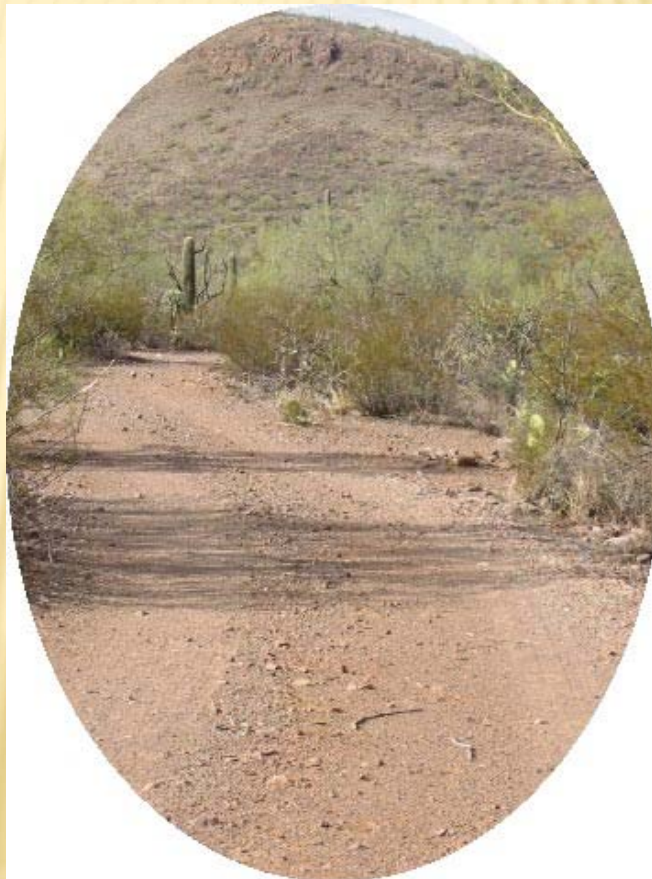
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- ✘ Patient who is going through chemo may have as many symptoms to manage as the person who has stopped chemo
- ✘ Traveling distances to the provider's office may be a physical stress on the patient causing increased symptom burden and decreased quality of life
- ✘ Need to be in the home to really understand what is needed/desired
- ✘ Elders often resist the clinic because they know there is little that can be offered

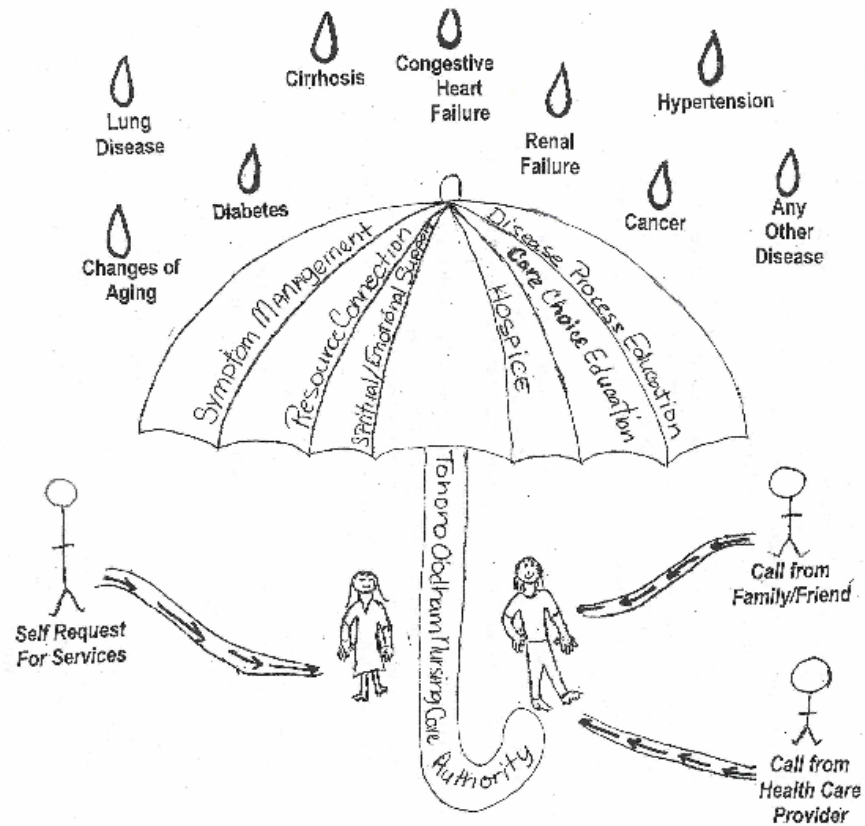


# BIRTH OF DESERT PATHWAYS

- ✘ “Help for Walking the Uncertain Roads of Serious Illness”



# AN UMBRELLA OF SERVICES



Desert Pathways Program (520) 383-1893 or 1-866-504-9697

# EDUCATION TO COMMUNITY

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- ✘ Presentations to Community groups
  - + Senior Meal sites
  - + District and Community meetings
  - + Church groups
  - + Tables at Health Fairs
- ✘ PSA's on tribal radio KOHN



# Desert



# Pathways

**Cancer**    Congestive Heart Failure    **Diabetes**    **COPD**  
**MAJOR SURGERY**    **Chemotherapy**    Cirrhosis    **Hypertension**  
*Radiation*    Asthma    **Renal Failure**

Are you and your family struggling with the information you are being given about your health?

We can provide the information you need.

Desert Pathways staff are available to visit with you and your family at a time that is convenient for you so that you have the information that you need to make informed care choices. Call us

directly 24/7 at

**520-383-1893 Or 866-504-9697**

**(No Referral Needed)**

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**Desert Pathways Program**  
Living Well With Illness  
Not End of Life Care

If you or a family member are having trouble  
dealing with an illness,  
we can share information about the illness,  
or how you can better control your symptoms,  
thereby improving your quality of life.

Call us directly 24/7 at  
520-383-1893 or 866-504-9697  
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Desert Pathways is a program of the Tohono O'odham Nursing Care Authority

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# GUIDING PRINCIPLES

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- ✘ Earlier intervention in the illness process to be sure that educated decisions are made
- ✘ Develop relationships with providers and surrounding hospitals
- ✘ Improve home support services for elders who are choosing not to seek routine medical care at the clinic
  - + May not want to go because of the risk of not being at home at the end
- ✘ Develop a helping relationship prior to introducing hospice
  - + What needs will hospice better meet
  - + Family already aware of type of care that will be provided

# SUGGESTIONS FOR THOSE CONSIDERING

## MEM BERKOHAN?

- ✘ Needs assessment first
  - + What are the “felt” needs of the community
  - + What other programs are meeting part of those needs
  - + Are outside programs making sufficient effort to be culturally appropriate
  - + What are the logistical burdens involved in the current situation
- ✘ What are the community’s misconceptions about new programs targeted to meet identified needs

# CONT

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- ✘ End of Life Care may be appropriately delivered by formal hospice or by a collaboration of other programs
  - + Need to address 24/7 availability if possible to avoid off hours ER visits
  - + Program flexibility necessary to meet the needs of different family situations
  - + In remote locations, creative ways to have supplies available off hours is vital
  - + Need to have available inpatient care to be Medicare certified



# FUNDING FOR PROGRAMS

- ✘ Hospice is a Medicare/Medicaid reimbursed program
  - + Individual states and their relationship with tribes as it pertains to Medicaid support will vary.
  - + If a tribal member has coverage through a Medicare HMO, hospice is a carved out service.
  - + Current Medicare reimbursement of \$150/day needs to cover staff visits, meds, DME
  - + Medicare has specific staffing requirements including 24/7 RN coverage, MSW for social work, and volunteer involvement

# DESERT PATHWAYS FUNDING

- ✘ Funding for project development was through Tribal Support and a Robert Wood Johnson Foundation Grant
  - + *RWJ grant was in recognition of Frances Stout as a Community Health Leader*
- ✘ Long term Funding for Desert Pathways will come from efficient operation of the hospice program and tribal support

# FUTURE FUNDING OPTIONS

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- ✘ The future may find that IHS is funded for hospice services and thus through a 638 contract, be an additional funding source for tribal programs.
- ✘ Some of the services currently provided by Desert Pathways could be billed under skilled home care if available.

# O AND A

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## Contact Information:

Frances Stout [stt0820@cox.net](mailto:stt0820@cox.net)

Lee Olitzky [lee@wit2tucson.com](mailto:lee@wit2tucson.com)

Dorothy Low [dlow@toltc.org](mailto:dlow@toltc.org)

Mark Joaquin [mjoaquin@toltc.org](mailto:mjoaquin@toltc.org)

Charlene Conde [cconde@toltc.org](mailto:cconde@toltc.org)

Desert Pathways phone (520)383-1893

# THANK YOU

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Special recognition to the Tohono O'odham Nursing Care Authority Board for their Vision and Foresight in sponsoring and supporting the creation of The Tohono O'odham Hospice and Desert Pathways.

- ✘ Frances Stout, Chairperson
- ✘ Richard Ramirez, Vice Chairperson
- ✘ Janice Felix, Secretary/Treasurer
- ✘ Priscilla Domingo, Board Member
- ✘ Madeline Sakiestewa, Board Member
- ✘ Malinda Folson, Board Member

**With special thank you to the Tohono O'odham Nation**