

# Keeping Our Spirit Strong



A video discussion guide for

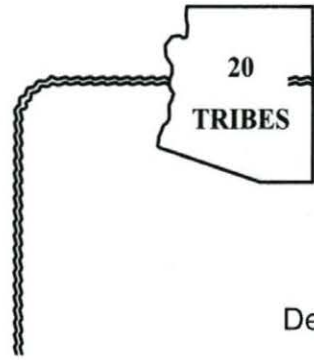
*“Cancer Has Crept among Us”*

and

*“American Indian Attitudes & Values: An Integral Part in Cancer Care”*



This project was supported by a grant awarded by the National Cancer Institute, Community Network Program (Grant Number 1U01 CA114696). The contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Cancer Institute – National Institutes of Health.



# INTER TRIBAL COUNCIL of ARIZONA, INC.

Dear Viewer,

In 2004, the Inter Tribal Council of Arizona, Inc. (ITCA) was awarded a five-year community network program grant (No. 1U01 CA11496) from the National Cancer Institute, Center to Reduce Cancer Health Disparities (NCI-CRCHD). To address the purpose of this grant – to eliminate cancer health disparities among American Indians in Arizona, Utah, and Nevada – the ITCA established a multi-disciplinary, multi-agency workgroup called the Southwest American Indian Collaborative Network (SAICN).

ITCA, Inc. along with its SAICN partners, the University of Arizona, Arizona Cancer Center and the Phoenix Indian Medical Center realized that cancer health disparities cannot be reduced without addressing the spiritual and cultural needs of American Indians affected by cancer. Currently, there are limited educational materials that specifically address these aspects of cancer care for American Indians.

To address these needs, two cancer educational videos, “Cancer Has Crept Among Us” and “American Indian Attitudes & Values: An Integral Part in Cancer Care” were produced in collaboration with Lizard Light Productions, an American Indian multimedia company in Goodyear, AZ. These videos provide a greater understanding and promotion of culturally responsive cancer care services appropriate for American Indian cancer survivors, family members, and health professionals serving American Indians. The interviews included in these videos demonstrate the uniqueness and need for providing more appropriate cancer care services for American Indians.

We are hopeful that people from all walks of life who have lived with and supported one another through cancer will benefit by viewing the videos. Talking about cancer and its’ impact can be difficult and we offer this discussion guide as a companion resource to guide conversations with others about the challenges and triumphs shared by American Indians, the families and communities as we face cancer together.

Sincerely,

M. Kathryn Coe, Ph.D.  
Principal Investigator

Sincerely,

John R. Lewis  
Executive Director

- MEMBER TRIBES**  
 AK-CHIN INDIAN COMMUNITY  
 COCOPAH TRIBE  
 COLORADO RIVER INDIAN TRIBES  
 FORT McDOWELL YAVAPAI NATION  
 FORT MOJAVE TRIBE  
 GILA RIVER INDIAN COMMUNITY  
 HAVASUPAI TRIBE  
 HOPI TRIBE  
 HUALAPAI TRIBE  
 KAIBAB-PAIUTE TRIBE  
 PASCUA YAQUI TRIBE  
 PUEBLO OF ZUNI  
 QUECHAN TRIBE  
 SALT RIVER PIMA-MARICOPA  
 INDIAN COMMUNITY  
 SAN CARLOS APACHE TRIBE  
 TOHONO O'ODHAM NATION  
 TONTO APACHE TRIBE  
 WHITE MOUNTAIN APACHE TRIBE  
 YAVAPAI APACHE NATION  
 YAVAPAI PRESCOTT INDIAN TRIBE



### Using this Video Discussion Guide

The purpose of the *Keeping Our Spirit Strong* Video Discussion Guide is to help facilitate group discussions after viewing the two videos:

- “*Cancer Has Crept among Us*” (10:54 minutes) and
- “*American Indian Attitudes & Values: An Integral Part in Cancer Care.*” (20 minutes)

### How you can use this Video Discussion Guide

Both videos have a set of questions that can be used to:

- Facilitate discussions with cancer support groups.
- Initiate discussions at educational events.
- Educate program staff and community members.
- Facilitate discussion with family and family members who are affected by cancer.

### Suggestions for Viewing Videos and Using this Guide

Below are suggested viewing strategies:

- You may view and discuss one video during one session
  - Allow at least an hour for viewing and discussion;
  - You may discuss only the questions that are relevant to your group’s interests;
  - Or you may discuss all the questions.
- Plan to host four meetings to view and discuss multiple segments per meeting. Suggested segments include:
  - Meeting 1: *Cancer Has Crept among Us*: Questions 1-4
  - Meeting 2: *Cancer Has Crept among Us*: Questions 5-7
  - Meeting 3: *American Indian Attitudes and Values*: Questions 1-4
  - Meeting 4: *American Indian Attitudes and Values*: Questions 5-8

### Guidelines for Facilitating a Discussion

The videos bring challenging questions to the forefront and may evoke strong emotions from viewers.

Below are some suggestions to help you facilitate an open and engaging discussion.

#### 1. Prepare for the Discussion

- Review the video before the group discussion.
- Review and understand the questions prior to group discussion.
- Determine where the video will be viewed.
- Collect the materials, equipment and supplies: sign-in sheet, flyers, pens, paper for participants to take notes and television/DVD player. You may want to offer water or snacks, but it’s not necessary.
- Set-up the room ahead of time.

#### 2. Introductions

- Introduce yourself.
- Introduce the video and purpose for the discussion.
- Remind the group that a major goal of the discussion is to better understand and talk about the various issues that impact American Indians in regards to spirituality and cancer care services.

#### 3. Guiding the Discussion

- Keep the group size small (no more than 15 people).
  - You may have 1 large group discussion.
  - You may have them sit in a circle so they can see each other.
  - You can break the group into small groups to discuss one of the questions and report

back to the larger group.

- Manage the time for discussion; let them know how much time there is for discussion.
- For questions from the group, ask others to share their ideas before you answer.
- Keep in mind that talking about cancer is a difficult topic.
  - The group can be very open with intense emotions.
  - There should be no judging about what someone feels.

#### 4. Summarize

- Ask participants what they have learned from the experience.
- Ask participants how they might use what they learned.
- Clarify questions and concerns.
- Review key points.



# Cancer Has Crept among Us



(Video length 10:54 minutes)

## About the Video

The video, "Cancer Has Crept among Us," focuses on a family living in a rural reservation in northwestern Arizona. An American Indian cancer survivor, Linda shares her story of fighting cancer and the many ways that cancer touched her life and the lives of many of her family members.

Linda encourages viewers to draw upon their spiritual and cultural traditions as a source of hope for individuals, families and communities affected by cancer.

This video was developed after the cancer survivor, while attending the 2007 SAICN Spiritual Care Conference with her daughter, asked the question, "Why is cancer killing my family?"

## Discussion Questions

### Video time 0:42

1. In the beginning of the video, Linda states, "Cancer has crept among us, the Natives. I never realized that anyone in my family or community would be affected by this."
  - a. In what ways can you relate to Linda's description of her family's experience with cancer as "unexpected"?
  - b. How does *culture* (i.e., traditions, customs, local practices, language) affect cancer awareness?
  - c. How do *economic factors* play a role in cancer awareness, education, treatment and/or survivorship?
  - d. How do *physical location*/geographic isolation play a part in cancer awareness, education, treatment and/or survivorship?



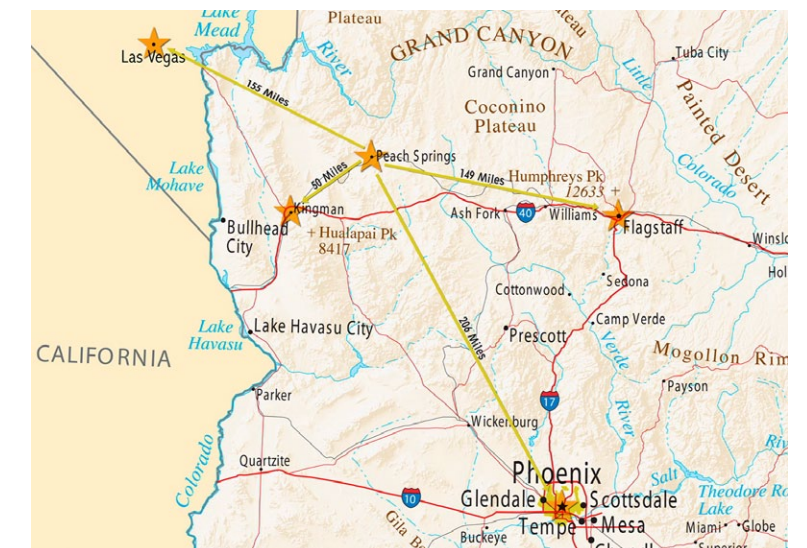
**Key point:** Many American Indians live in communities that are in many ways, culturally, economically, and physically distinct from mainstream society.

**Key point:** Cancer awareness and access to cancer education is limited, particularly in rural and isolated American Indian reservation communities. For Linda and her family, cancer's devastating effects came upon them as a shock.

### Video time 6:35

2. Linda states that the points of medical referrals for Peach Springs are to Kingman (50 miles), Flagstaff (149 miles), Phoenix (206 miles), and/or Las Vegas (150 miles).
  - a. What have you or someone you know, experienced in seeking cancer care services in a location far from your home that relate to *transportation/travel issues*?
  - b. What have you or someone you know, experienced in seeking cancer care services in a location far from your home that relate to *spending time away from work and family*?
  - c. What have you or someone you know, experienced in seeking cancer care services in an *unfamiliar medical system/facility*?

**Key point:** Geographical distance is a barrier in seeking cancer care and treatment.





**Video time 4:45**

3. Linda states that cancer is unlike any other sickness, “Community members are shocked and wondering, ‘Is it the food we eat or the water? What is going on in our community?’”
- What are your thoughts when you hear Linda’s questions/concerns?
  - What resources/people would you seek out to answer these questions?

**Video time 5:13**

4. Linda mentions that fear can often prevent people from seeking medical care. She admits being afraid of seeking medical care but as a family - she and other community members will go to the doctor/clinic when they are not feeling well.
- What are some ways to minimize or move beyond fearful feelings of going to the doctor?
  - If you were seeking care that might include cancer care services, what concerns might you have?
  - What are some other (positive or negative) attitudes or emotions that may affect seeking medical care?

**Video time 7:15**

5. Linda mentions the importance of family and community support while seeking cancer care for herself and her family members. She states, “We need for them to help us. Take us to where we need to go...to the doctor or to the clinic to get help.”
- What are some practical concerns for elders and others when seeking cancer care?
  - Describe different ways of providing support for those with cancer and family members.
  - What types of support have you recognized that are important but are lacking in your community or family?

**Video time 7:30**

6. Linda mentions two gatherings that she and her family attended that have strengthened her spiritual and emotional well-being. One was a Spiritual Care Conference while the other was an annual tribal gathering known as the Gathering of the Pais. Linda states, “I have a lot of grandchildren and I know that I have to be strong so that they can see that we do have struggles and we do have hard times. But there is going to come a time when we have to be strong and let go.”
- What do you think Linda means when she stated, “...there is going to come a time when we have to be strong and let go”?
  - What are some ways of maintaining spiritual strength and healing from an experience with cancer?
  - What are some important lessons that can be learned from a cancer experience(s)?

**Video time 8:59**

7. At the end of the video, Linda states, “I hope that people will see this video and hear our experiences. Let them know that there is hope and that they are not alone. We are all in this together. We just need to be strong and be brave and do what we can to help ourselves.”
- Why does it take courage and strength to share your own or your family’s experience with cancer and cancer care?
  - In what ways might sharing your own experience with cancer benefit others?
  - There are many questions about cancer for which there are no answers. How does that make you feel?



**Key point:** The reliance upon spiritual and cultural well being has long been an integral and expected aspect of care for American Indians when seeking wellness and healing for illnesses.



# American Indian Attitudes & Values: An Integral Part in Cancer Care



(Video length 20 minutes)

## About the Video

The video, "American Indian Attitudes and Values: An Integral Part of Cancer Care," features interviews with American Indian cancer survivors, family members, community leaders and health care providers. The goal of this video is to emphasize the importance of providing spiritually appropriate cancer care services for American Indians.

## Discussion Questions

### Video time 0:50

1. In the beginning of the video, Linda Havatone, a member of the Hualapai tribe, shares her and her family's story about their experiences with cancer. Linda has lost her husband and son to cancer, while she and her daughter are cancer survivors. "Cancer has crept among us, the Natives. I never realized that any of my families or anyone in my community would be affected by this..."
  - a. Why do you think she used the word "crept" when she talked about cancer in her community? Why do you think that is a particularly good word to use to describe what happened?
  - b. Have you ever heard a story like Linda's before? Have you or someone you know been impacted by cancer in ways similar to Linda's story?
  - c. When you listened to Linda's story, what did she say that touched you or affected you the most?
  - d. In what ways can you relate to Linda's description of her family's experience with cancer as "unexpected"?



### Video time 3:50

2. In the video, John R. Lewis states, "...for American Indians, the concept of wholeness includes a balance of the physical, emotional, and spiritual. When working with American Indians, to not address the spiritual aspect of care "...is missing a very important part of their life and their outlook and their beliefs...this has to be a part of any healing process for the American Indian."
  - a. Could you please share with us your thoughts on his statement?
  - b. Based on your perspectives, in what ways can you relate concepts of "wholeness" and "balance" to wellness and illness?
  - c. What has been your experience with cancer care, or the care of any serious illness, when spiritual concerns were addressed or were not addressed by your healthcare provider?

**Key Point:** The role of spiritual care in cancer care treatment is basic and essential for American Indians...this is even more important because their lives revolve around many cultural aspects of their being.





**Video time 6:29**

3. In the video, Dr. John Molina states that he believes that the patient, them self, have to be the active participant in his/her treatment, "...the way [for a patient] to become an active participant is by them feeling comfortable that you are respecting their wishes and their way of thinking."
  - a. Why is it important that the doctor learns to understand the cancer patient's view of health and illness?
  - b. How would knowing the patient's view of health and illness influence the medical provider's approach to treatment of the cancer patient?
  - c. What is the benefit of actively participating in one's own cancer care?



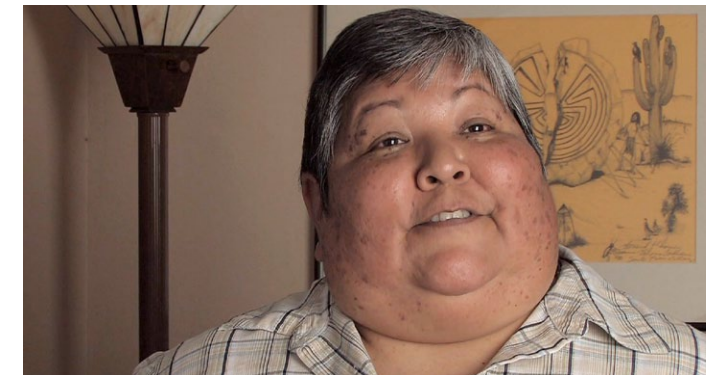
**Video time 8:48**

4. Dr. Donald Warne states that in the Lakota way there is a concept of "dying-healed" but in modern medicine, death is viewed as the ending and the enemy." Dr. John Molina shares that he has been at the bedside of many dying patients and although their body is failing, their spirit is strong and healthy and "...these people really inspire me."
  - a. In your cultural and spiritual understandings, how is death and dying viewed?
  - b. How might understandings about death and dying present both challenges and opportunities for new insights for patients, families, and/or healthcare providers?
  - c. Have you had an experience in which another has inspired you and/or given you hope even as they face death?



**Video time 12:53**

5. Martha Sadongei, a minister and cancer caregiver for her father, shared her experiences with her father facing his greatest fear—cancer. "My dad's greatest fear of going to the doctors was that one day the doctor was going to tell him that he had cancer; and that there was nothing that they could do for him."
  - a. In what ways do you relate to Martha's dad's fears? What are some ways to minimize or approach these fears as a loved one goes through a cancer care experience?
  - b. How can facing our greatest fears allow us to grow spiritually and emotionally in the midst of ongoing challenges with our health?
  - c. According to Martha, what are the emotions her father is experiencing as he goes through his cancer care? What are the emotions that Martha herself experienced as the daughter and caregiver?
  - d. Martha and her family expressed that they, like most families, have a hard time asking for help. However, going through a cancer experience requires support from others. Have you or your family felt similarly when facing challenges such as a cancer diagnosis?
  - e. Martha and her family found support in their congregation. Where have you found your support?
  - f. Sometimes in reaching out for support, we can be surprised by whom or what gives us strength and/or who or what does not provide strength/support. What has been your experience?



**Video time 15:49**

6. Dr. Lois Steele, a cancer survivor, states, "...you have to figure out who you are at that time...what makes you happy, what makes you fulfilled, and then concentrate on the 'being happy.'" Studies have shown that the people that are happy actually survive longer." Please share your thoughts regarding Dr. Steele's statements.
7. Dr. Steele gives the following advice in order to keep the spirit strong: 1) Nurture your sense of humor; 2) Laugh at yourself and not at others; 3) Learn to see humor in the tough situations; 4) Live life to the fullest and take risks involved in change and 5) Understand and adapt to the changes that are inevitably going to happen in life. Give an example from your own life or that of someone you know to which you can relate to this advice.
8. Dr. Steele as well as other speakers in the video highlights the importance of family and friends in the healing experience. Dr. Steele shares her experiences of healing for herself and others which occurs at the annual gathering of the Sun Dance. Where and with whom do you gather to receive support when facing profound challenges in life?





**Video time 18:33**

10. Dr. Warne states that the seven core values in the Lakota Way are fortitude, wisdom, generosity, courage, honor, respect and humility. What values are important in your own life and that of your family? What role do they play in your understanding of healing?
11. Dr. Warne quotes from the Lakota healer, Black Hawk, the importance of humility, "...in the traditional belief system when you lose your humility, you lose your ability to heal." Do you agree that doctors who are humble are better able to heal?
12. Dr. Warne stresses the importance of working with a provider who is open to and understands the beliefs of a patient. How might talking with your provider about your spiritual needs help that doctor better assist you in your healing process?

**Video time 10:45**

9. Catherine Witte, a chaplain, describes the spiritual care programs at an Indian Health Service hospital. Both traditional Indian practitioners and chaplains work together to meet the spiritual needs of their American Indian patients and families.
  - a. Why would addressing the cultural and spiritual needs of a patient be important in receiving cancer care?
  - b. Does a spiritual care program exist where you receive health care? If so, please describe. If not, how might you help to develop one?





**Credits**

The *Keeping Our Spirit Strong* discussion guide was produced by the Inter Tribal Council of Arizona, Inc. Southwest American Indian Collaborative Network (SAICN). The content was written and developed by Naomi A Lane, MPH, Inter Tribal Council of Arizona, Inc. and Catherine Witte, MDiv, Indian Health Service Phoenix Indian Medical Center. Appreciation is due to all of the people featured in the videos for their generous participation in this project.

*Cancer Has Crept among Us* and *American Indian Attitudes & Values: An Integral Part in Cancer Care* were produced by the Lizard Light Productions ([www.lizardlight.com](http://www.lizardlight.com), [info@lizardlight.com](mailto:info@lizardlight.com)) for the Inter Tribal Council of Arizona, Inc. (ITCA) Southwest American Indian Collaborative Network (SAICN). Lizard Light Productions also provided the layout for this discussion guide.

This project was supported by a grant awarded by the National Cancer Institute, Community Network Program (Grant Number 1U01 CA114696). The contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Cancer Institute – National Institutes of Health, Indian Health Service, or the agencies affiliated with the authors and those interviewed in the videos.

No part of the *Keeping Our Spirit Strong* discussion guide may be reproduced, used as a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without prior written permission of Inter Tribal Council of Arizona, Inc., 2214 North Central Avenue, Suite 100, Phoenix, AZ 85004. Please send permission requests to the attention of Kenton Laffoon, MSW, SAICN Program Director.

*This discussion guide and the videos are also available online at*  
[www.itcaonline.com/saicn/Resources.html](http://www.itcaonline.com/saicn/Resources.html)  
[www.ihs.gov](http://www.ihs.gov)