



Native American Elders Diagnosed with Cancer: What is this all about?



Mary P. Lovato
Santo Domingo Pueblo
Dx 1987 bone cancer;
Dx 2004 leukemia;
Dx 2006 kidney cancer

What is this issue?

- When elders were young, any Native elder who had cancer died. Today, with early treatment, elders can survive cancer and have long lives with good quality of life.
- Many people think that having cancer is a death sentence. This is not true.
- Many of our tribal beliefs do not allow us to talk about death or cancer; so most of us know very little about the cancer experience.
- This may make it hard to talk with our families and friends about cancer



What are the problems or issues related to elders being diagnosed with cancer?

- We do not know what questions we should be asking the providers.
- We do not understand the words the provider uses when s/he talks to us.
- We have no idea of what to expect from the treatment or what will happen after treatment is done.
- We do not know how to get the resources or help we need.
- We do not know the type of help we are likely to need from our friends and family.
- We do not know if we will recover from the disease and treatments and ever feel good again.

What can you do?

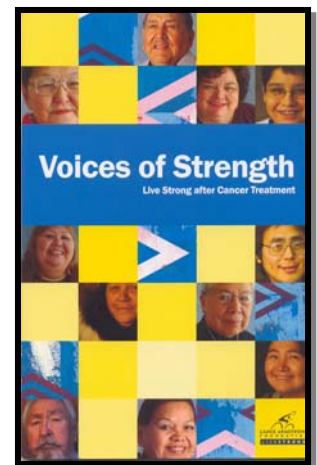
- Learn all that you can about your type of cancer so that you can make informed choices based on accurate information.
- Learn how to ask questions and how to help the provider talk with you using words and ideas you understand.
- Talk with your family about the disease and help them learn all that they can about the disease.
- Native organizations like Mayo Clinic's Native American Programs, Native People Circle of Hope and National Indian Women's Health Resource Center may also be able to provide you with basic and complex information about cancer.
- Non-Native Organizations like the National Cancer Institute Cancer Information Service, Lance Armstrong Foundation, Avon Foundation, and Susan G. Komen can give you accurate scientific answers and information



National Native American Cancer Advocates
1-800-537-8295 or 303-838-9359
“Native American Cancer Education for Survivors”
<http://NatAmCancer.org>

Native American Cancer Research
3022 South Nova Road, Pine, CO 80470-7830
303-838-9359; fax: 303-838-7629

The issues identified in this Fact Sheet are from intertribal focus groups held in 2006.
Thank you to those who participated



Co-Investigators :L Burhansstipanov; and LU Krebs; Developed through support from Colorado Program in Aging and Cancer; Project #9:2-5-26213 [PI: Byers NCI P20 CA103680] Spirit of Eagles Community Network Programs [NCI U01 CA 114609]; IHS [DHHS -6-0052 No. HHS1236200;: 6076042400; 064-CPC];

What did elder Native patients say about this issue?

- 👤 *"You know when we were kids, ... we would hear that somebody died of cancer and that was all there was to it. They were dead. We didn't know how, what they went through or anything else. We were just shocked that it happened." (4-13-06)*
- 👤 *"They need to know that process and that there is a way to walk through it. To walk through it alone with all this fear. I think that fear and that negative energy eats away at you just like that cancer does." (4-4-06)*
- 👤 *He knew he was sick and ... he wouldn't tell us until he literally collapsed and he lasted maybe three weeks. We thought he was sick, but he was very reclusive and he just made up his mind without telling any of us. It has been really hard." (4-21-06)*
- 👤 *[You] "hush about it because in our religion you are not supposed to be talking about death." (4-21-06)*
- 👤 *"I think as Indian people we tend to hide our aches our pains, we're not brought up to say oh my head, oh I'm so tired, oh it hurts. We're brought up to say it's a little thing, it will go away, keep on going...unless it is a major thing like profuse bleeding... We believe that once we show our sickness, our weakness, there are people out there that will take that weakness and use it in a bad way towards us, towards our families." (4-4-06)*
- 👤 *"I didn't even know my sister had cancer until the day she died. We talked probably twice a week." (04-13-06)*
- 👤 *"We had no tools and nobody was telling us anything and it was very frustrating and at that point we didn't have enough information...we had no information, nothing to know about the disease. That is what I would have like to know." (4-21-06)*

What are common myths?

- 👤 MYTH: There are no cures for cancer
 - ⊕ When cancer is treated early, people are more likely to survive and live normal lives.
- 👤 MYTH: Indians do not receive real cancer medicines
 - ⊕ Elder Natives can also get real medicines. There are good medicines to control nausea, pain, fatigue and other side effects from cancer and its treatment. But you are likely to need help getting these medications because IHS / tribal / and urban Indian clinics rarely have them in stock. They are expensive drugs and our Native programs don't have enough money to have them available for you.



What are the messages other Elder Native American Cancer Patients want to share?

- 📖 *Cancer is Not a Death Sentence (04-04-06)*
- 📖 *[Cancer] is survivable (04-04-06)*
- 📖 *“A lot of the cancer's curable technologies have come a long way. There are a lot of positive things that they don't know about.” (4-13-06)*
- 📖 *“All you gonna have is a new normal. You are going to live with this disease for the rest of your life and it will change you a little bit, or a lot, but it can all be positive.” (4-21-06)*
- 📖 *We need public information about survivors. I think any kind of success story out there, (04-04-06)*
- 📖 *We need elders who have survived this to deliver the messages! (04-13-06)*



- 📖 *should have acknowledgements, celebrations like for the Native Americans that survive. Let the community know and celebrate their lives Cancer is Not a Death Sentence (04-04-06)*
- 📖 *Our elders do this for somebody; they stood up to a risk for something. That's a huge risk to want to survive your cancer and come through it-- to be able to talk about . And when they honor them and these people will stand up and talk about it, and that's how we will reach the community. And a way to make this connection in a positive way.” (4-4-06)*
- 📖 *Our Native people that survive [cancer] and that are still in our communities, that they are able to give back what was given to them. (04-04-06)*



Yellow shawls and ribbon shirts given to and worn by Native Survivors at the “Quality of Life through Roots of Strength” conference, Sept 21-24, 2006, Denver, CO

Pink and Yellow Shawl Photos taken by **Maisie MacKinnon**, Cultural Communications, www.maisiemac.com