

Native American Elders Diagnosed with Cancer:

Decisions, Coping & Communication

What are these issues?

- Most of us do not have accurate information about cancer.
- We have to make a lot of decisions in a short amount of time with limited information.
- We often do not know how to talk with the provider, our family and friends about cancer
- Many of our Native cultures encourage us to keep our health problems private and deal with them alone.



Arlene and Francis
Wahwasuck
Prairie Band Potowatomie
Dx 2002 breast cancer

What are the problems related to decisions, coping and communication?

- We usually feel that we should be able to go through this experience without "bothering" or "worrying" others
- The stereotype of being a *stoic* Indian makes it hard to let others help. You will need help from time to time. You need to *let* others help you. Your family or friends need to know what is going on so that they can be more helpful to you.
- We learn to talk and think about things differently than non-Natives. Non-Native providers frequently do not understand what we are trying to tell them. This makes it harder for them to help us.
- Each person reacts to the cancer experience differently. Emotional reactions to cancer may include denial, fear, frustration, and anger. Some will experience all of these while others may experience none or only a few. Providers might not realize that we may go through the cancer experience differently than people from other cultures.

What can you do?

- You can get help with a lot of your questions from Native American Cancer Research toll free number or their web site (see below)
 - They have examples of questions that other Native cancer patients have asked their doctor
 - They have culturally relevant information for many cancer topics
 - They can work with you to find resources or the help you or your family needs
 - They can help you meet and talk with other Native elder survivors to help you understand what is happening.
- Print out some of the questions that you want answers to from the "Native American Cancer Education for Survivors" Quality of Life Tree.
 - Practice saying the questions out loud to yourself or to another.
 - Learn how to do the "I-Messages" from the website's communication branch
 - Bring someone with you who can advocate for you.
 - Bring someone with you to your appointment who can help you remember what the provider tells you and can help make sure your questions get answered.
- Take someone with you or tape record what you and your provider talk about so that you and other family members can better understand what is happening or what s/he is saying



Denver Native American Cancer Advocates (303) 837-7163

National Native American Cancer Advocates 1-800-537-8295

"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

What did elder Native patients say about these issues?

- "There were some words there that I didn't know. My wife understood, but when they were giving her some options, and she turned and asked me what I think. I said I know it's your body, but I need you around here, but I would like to see you go for it." (4-4-06)
- There was a] "lack of providers who were able to translate at an easy to understand." (4-4-06)
- it is real important to share it with your family what's going on, so that your family can share it with you. (04-04-06)
- [It is important for providers] "to open up and use layman's terms... There should be someone there that can speak in a more simple language—in words that are understandable." (04-04-06)
- "We didn't have any cancer on either side. It was something really new for us So this really kind of a shock for our whole family, so it was several weeks before we really had an idea of what kind of cancer it was and talking about invasive or fast moving cancer and those kinds of things really make you think. You don't know what the outcome is going to be, but there isn't really something you wish you had known before because it really catches you off guard. So you needed everything!" (4-13-06)
- "When my biopsy [from new growth] came back, it was okay. You know you have that relief that" okay" is a huge word. It just empowers you that you are going to be okay." (04-04-06)
- "Communication was so important and we never had it in our family. We actually helped him, he didn't tell us he had cancer, but he wanted to go to a medicine man, so we took him and he got a treatment through this man. Then he took some herbs that grow in California and he allowed us to [give him the herbs in] the hospital." (04-04-06)
- Tou need to have a good doctor I think. It's hard to find a good doctor." (04-04-06)
- "The family rallied around me which I needed. You need a support group, somebody you can talk to about it. Just to relieve your own feelings. This group is making strides towards that and the more information you can get out there the better." (4-4-06)
- "Your Indian belief system has a lot to do with fighting off the disease. Your emotional stability has a lot to do with any kind of disease. That's how I look at it. We have the power to heal ourselves as we learn how to take care of our bodies and our whole quality of life." (4-13-06)

What did elder Native patients say about these issues?

- "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. And that's what I learned in the process. Don't go through it alone and as an Indian person, you don't have to go through it alone. You have your ceremonials and your ways to share. This is beautiful, something that is so fearful and taboo. Years ago people just didn't talk about these things. This is beautiful that we can sit here and share with our families and communities just what we learned." (4-4-06)
- "When I had lost about 25 pounds and when I had cancer and even after I had the operation, I gave up. You can't give up, you have to get a positive attitude. Now I am trying again to lose weight. I have an upbeat attitude. I don't let it get me down." (4-4-06)
- "You don't really think about it and again, it's the way you're brought up with traditions and beliefs and all those things come in to play. And you are just there... things will get better and stay positive and they do for most people." (4-13-06)

What are Unique Issues affecting Elder Native American Cancer Patients?

- Most of us are taught to not talk about our own diseases, illnesses, or fears. We do not have the words or ways to say things because we never learned to talk this way.
- None of our 217 Native languages has a word for cancer. So you have to use the English and your translation may not say what you really mean.
- It is really hard to talk to some of the people who provide resource services that are supposed to help you. They may:
 - Talk with you like they do not think you are telling the truth about your needs.
 - Say things like, "Well, all you Indians have those Casinos now, so why do you need our help?"
 - Insist that Indian Health Service has to provide you with all of your needs and that they cannot help you.

These are not appropriate ways for them to act with you or your family. It is because they do not understand the Indian Health Service, Tribal and Urban Indian Health programs.