

*Native People's*

# wellness

**Cancer Survivorship**

**Mary Lovato:  
Many Nations' Hero  
and Cancer Survivor**

**Native American  
Spirituality and  
Healing**

**Messages of Hope  
from AI/AN Survivors**



# Many Nations' Hero and Cancer Survivor

## Mary P. Lovato's Story

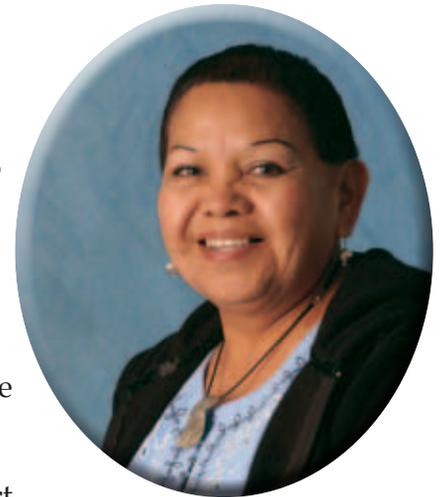
Mary P. Lovato was a member of the Santo Domingo Pueblo Tribe of New Mexico. She was diagnosed with bone cancer in 1987, then leukemia, and then kidney cancer. She survived 23 years before walking on in February 2008. She was a courageous daughter, mother, partner, and friend who always displayed good humor and was a heroine to everyone she knew.

Ms. Lovato created the first national American Indian cancer support and education program in the United States. Despite numerous challenges which were primarily cultural, Ms. Lovato not only

### Mary's words of wisdom:

- "The only way we can help other patients ... [is] not to go through the same thing silently like we did in the past. Talking about our stories helps them come out of their own shell with their diagnosis of cancer and it all opens up to see that there [are] options of life out there. It's not a death sentence... We have to take care of ourselves, and I'm learning a lot about healing now."
- "Think positive while on the treatment with chemo. I take the medicine bag from the chemo drug that they put me on and I talked to that drug telling that drug to work on my body and to let it not suffer as much as you know it could. And I also think positive as I get on the chair and I always make a lot of humors."
- "People sometimes still come to the house and ask me to come over during their supper time. And that's the best time to talk to the families while they're eating because they swallow it in what you tell them. And what advice you give them ... is ... swallowed [with their food]."

initiated a cancer survivors' support group in her home pueblo in New Mexico, but she also created a weeklong training to help others start Native support groups. When she created these programs there were no culturally relevant cancer education or support services available for her pueblo or elsewhere in Indian Country.



After seven years of tireless efforts, her tribal nation agreed to allow Ms. Lovato to begin cancer education and support within the community. She created a weeklong education program called "A Gathering of Cancer Support". Her trainings were developed based on her own experiences, curricula from the People Living Through Cancer, Inc. (PLTC) organization, and with input from staff from the Indian Health Service (IHS) Cancer Program. Beginning in 1995, IHS provided financial support that included resources to promote the training, educational materials, and travel support to defray the cost for participants. The training faculty included Ms. Lovato and staff from PLTC, as well as, speakers from organizations such as the IHS, the American Cancer Society, the New Mexico Cancer Center, Native American Cancer Research Corporation (NACR) and the Cancer Information Service. Trainings were held in Santo Domingo and Albuquerque New Mexico, usually twice a year. Ms. Lovato provided personal one-on-one support to the trainees and to patients as well.

Excerpts of her videos are available at [http://www.natamcancer.org/vignettes/vignettes.html#l\\_text](http://www.natamcancer.org/vignettes/vignettes.html#l_text)

# Native People's Wellness

Cancer Survivorship

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## Editorial Credits

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## Disclaimer

This publication should not substitute for professional advice from a healthcare provider. Readers should always consult a physician or other medical professional for medical screening, treatment and advice. Please note that the phrase "see your healthcare provider" includes oncologists, tribal clinic professionals, doctors, dentists, physician assistants, nurse practitioners, nurses and/or midwives.



## NACR

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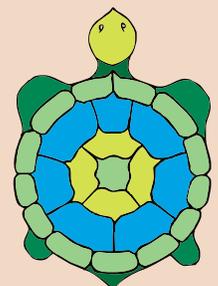
Native American Cancer Research Corporation (NACR) is a national non-profit organization dedicated to improving the lives of American Indians and Alaska Natives by helping them prevent cancer, detect cancer early and provide the highest quality care and life style for cancer survivors and their loved ones.

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## Back cover:

The turtle on the back cover was drawn by Mody B. Harjo, Seminole Nation of Oklahoma. The turtle is sacred to the Seminole People. Their shells are worn on the legs by the women during ceremonies and dances where they provide the rhythm for the singing and dancing.



# What is Cancer?

**Cancer (CAN-sir)** is a group of more than 100 diseases. While each is different, cancers have three things in common: 1) there is an abnormal growth of cells somewhere in the body; 2) the cells can invade (move) into other tissues and organs; and 3) the cells can spread to other parts of the body through the blood stream and lymph (LIMF) system. Cancers can cause serious illness when they invade healthy tissues. Treatment for cancer is most effective in the earlier stages; however treatments at all stages of cancer are more effective today than they were in the past. If untreated, it will lead to death.

Normally, cells grow in an orderly manner and divide until no longer needed. Then they stop growing and dividing (like when a cut heals). Cancer cells grow without control and divide even when no longer needed. They also do not die when they should.

Cancers usually are named by where they begin to grow in the body. A cancer that begins in the breast is breast cancer; a cancer that begins in the colon is colon cancer. This is the primary tumor (TOO-mer). In most cancers, the cells clump together to form a tumor. As a tumor grows, it can harm the normal cells around it and may spread to other parts of the body, harming healthy tissues.

Tumors can be benign (be-NINE) or malignant (mah-LIG-nant). A benign tumor does not spread to other parts of your body. It can grow very large, press on other body tissues and cause harm. Benign tumors rarely cause death. A malignant tumor may spread to other areas. This process of spreading is metastasis (ma-TASS-tuh-sis).

A tumor spreads when the cancer cells invade tissues next to where it is growing or enter the blood stream or lymph system. When cells enter the blood or lymph system, they travel to other places in the body. Once in a new place, the cells invade normal tissues and begin to grow without control in the new location. This new tumor is the same type as the primary tumor (so a breast cancer cell in the liver is metastatic breast cancer).

## Who gets cancer?

Cancer is more common in older people (over the age of 50) but can occur in children. Anyone at any age can be diagnosed with cancer.

## Why do people get cancer?

As shared earlier, cancer is a complex group of diseases and there are many possible causes. Known causes, include genetic factors and family history; lifestyle factors such as tobacco

use, poor diet, lack of physical activity; certain types of infections; and environmental exposures to different types of chemicals and radiation. Healthy people can get cancer and people with poor health habits can get cancer. Health habits such as smoking tobacco, drinking alcohol or getting HPV through sexual contact can increase one's risk for some cancers. Living a healthy life with a good diet, plenty of exercise, and minimal use of tobacco and alcohol may decrease a person's risk of cancer. Cancer is not contagious. This means you cannot get cancer if someone who has cancer breathes on or touches you.

## Can cancer get better or go away?

Remission (ree-MIH-shun) means that all signs of cancer are gone from the body. To get into remission, the cancer cells need to be killed or removed through some type of cancer treatment such as surgery, radiation or chemotherapy. Cancer can be life threatening. The key to effective treatment is early diagnosis. If cancer is diagnosed and treated early, there is a high chance that the cancer can go into remission and stay that way. Remission is the goal when anyone has cancer.

## What is cancer survivorship?

Cancer Survivorship begins the moment you are told you have cancer and lasts for the rest of your life. Survivorship is the experience of living with, through, or beyond cancer. It is a continual process that extends far beyond getting treatment. It continues through thrivership (having a zest for life) or until you die. Anyone who has been diagnosed with cancer can be proactive in taking part in screening and healthy behaviors for the rest of their lives.

Survivors may experience short and long term side effects of treatments, late effects from treatments, and have a higher risk for a new cancer diagnosis and cancer recurrence than do people who have never been diagnosed with cancer. Today, many American Indians and Alaska Natives who were diagnosed with cancer are living well-beyond 5 years without recurrence and report having good health and a high quality of life.

## How Can Survivors Stay Healthy?

Cancer survivors can help themselves stay healthy by eating a nutritious diet, getting regular exercise in their daily activities, and maintaining their cancer screening schedules. Avoiding the use of commercial tobacco (cigarettes, spit/chew) is particularly important to prevent new cancer diagnoses or recurrences.

## How do you feel when you get the diagnosis?

Are you able to listen to what your provider says? Or does the world seem to stop and you mentally shut down? Do you cry, get angry, or deny the possibility? Do you worry if the provider made a mistake? Do you wonder how you will tell your family? Could you have misunderstood what was said? You may have heard that your biopsy was “positive.” Well “positive” is a good thing, right? Unfortunately, while for many things, “positive” means good, when it comes to a cancer diagnosis, it’s just the opposite.

For each person, the words “you have cancer” will cause different emotions. There is no right way to feel when you learn you have cancer. Emotions run high and will change over time. You may feel sheer terror – “what happens next? will I get through it?,” “will I die?” or “I cannot get chemo! How will I manage it? I’ve heard it’s awful!” Common emotions include anxiety, sadness, fear, loss, despair, denial, disbelief, guilt and shock. You also may feel numb, confused, lonely, hopeless, or helpless. All of these emotions are normal. You may have all of them, none of them or different ones, in a short period of time.

It helps to know other survivors, people who have been in your shoes and have thrived. You also probably will remember those who have not survived, and wonder if that will be you. As you learn more and move through the cancer journey, you and your family will learn how to cope with cancer. Gather strength, patience and peace to get through it or to handle things as they come.

- Take a breath.
- Let the Creator help you hear what is being said.
- Ask the provider to give you a moment to allow you to pray for guidance and strength.
- If someone is with you, hold their hand.
- Most AI/AN will get through this experience.

## How to tell loved ones

From the moment you hear the diagnosis, you begin to process. People react differently. Some feel fear, frustration, and anger. Some may deny or block out the diagnosis. Yet others receive the news with little or no discomfort.

Most Native people are taught to not talk about their own diseases, illnesses, or fears. We do not have the words or ways to say things because we never learned to talk this way. AI/ANs usually feel they should be able to go through an illness without “bothering” or “worrying” others. You are likely to be concerned for others and their reactions to your diagnosis. But, telling your family and friends may be helpful to both you and them. It may be hard to share your diagnosis. It is a personal choice about if, how and when you tell others.

Think about what you want to say and practice it ahead of time. Some Natives say it straight out (“I have cancer”) and others build up to the topic (“This is going to be hard, but I need to tell you something”). Tell them in the way that feels best for you. Think about your own feelings, reasons for telling others, and what you expect of them. Be ready for a wide range of reactions. You decide when and who you do and do not want to tell. When you share information about your diagnosis, your family and friends will have many different feelings, too. The following may be helpful to you:

- Reduce distractions. Make sure the room is quiet so you can have a private conversation.
- You may say, “You probably know that something is going on with me.” Ask what they think has been happening to you.
- Give small pieces of information at a time. Let them have some time to think about what you are saying and to ask questions.
- Wait through the pauses and silences. People need time to think. If the silence makes you feel uncomfortable, you may ask, “What are you thinking about?”
- Say what you know to be true. The truth may be painful for your loved ones. Tell them you will learn more at upcoming appointments. Offer to let them speak to your provider.
- If you are uncomfortable sharing your diagnosis with your family or friends, pick one person to tell. Ask him or her to help share the information with others.
- If you do not want your diagnosis shared with others, ask people not to share the information.
- If loved ones are ready to talk about the cancer before you are, thank them and tell them you’re not ready to talk about it yet.
- When telling children and teens, use words they understand. Be patient. Be hopeful. Encourage them to ask questions. They usually want to know more about what is going to happen. Tell them what you know and understand.

# What should a loved one do?

**The loved one** – There are many ways to help a survivor. The least helpful words are, “If you need anything, let me know.” Few survivors can name what they need or will call you and ask for help. You can make a list of what you are willing to do and share it with the survivor. Be specific. (On Tuesday and Thursdays, I can take you to the doctor).

**The survivor** – Make a list of all that you do on a daily basis or anything you might need specially done (taking the kids to school, cleaning the toilets, walking the dog, making

dinner, etc.). When someone offers something – take him or her up on it. If you do not feel up to responding, ask a friend or relative to be responsible for matching chores/tasks to offers.

It’s important to remember that your family and friends want to help, but may not know how. Similarly, it is often difficult for many survivors to ask for help. Helping allows others to show their affection and it is healing for both them and you. People are not doing this for you to feel the need to repay them. They are helping out of love.

## Native American Spirituality and Healing

Many AI/ ANs include traditional Indian and complementary medicines when diagnosed with cancer. Talk to your cancer provider about combining such therapies with modern western medicine. This is to make sure the treatments don’t interfere with one another and to prevent harm. Communication is key. The better cancer patients communicate with their cancer providers and their spiritual / traditional and religious leaders about their needs, the better they can work together to ensure the most benefit with the least risk for harm. Your traditional Indian healer will work with you so that you can participate in ceremony and still follow western medical instructions.

### Loved ones can:

- Participate in ceremonies in your honor.
- Hold prayer circles or pray for your healing individually.
- Invite religious healers or leaders to visit you.
- Share music, hymns, ceremonial or church music with you.

Cancer patients in the “Native American Cancer Education for Survivors” (NACES) program said that it was very helpful to them, the family and other loved ones to take part in a spiritual healing or cleansing ceremony prior to and following treatment. Some patients prefer traditional Indian ceremonies and others prefer Christian or other religious services. Both are helpful. When including traditional Indian and complementary medicines, talk with your provider before doing anything. Explain the traditional or complementary medicines and practices in general terms (more than just the name of the ceremony) so

that the provider can understand the ceremony or medicine and help you prepare.

The provider needs to know if you will be:

- Dancing without rest for long periods of time
- Going without sleep for one or more nights
- Fasting without water and/or food for long periods
- Exposed to extreme heat or cold
- Using any herbal or complementary medicine (share the names and dosages)

Don’t delay getting into treatment to participate in lengthy spiritual or religious events (Sun Dance, Stomp Dance). Most healers will pray and bless you using a different ceremony so that treatment is not delayed.

While taking part in ceremony:

- Eat while taking medication (e.g., chemotherapy)
- Drink fresh, bottled water

An alternative to taking part in ceremony while in treatment is to have a family member or loved one take part in your honor.

Avoid offering flesh during ceremonies. During and following treatments, survivors are prone to infections. Extra health and safety precautions need to be taken. Talk with the traditional healer before the ceremony to find alternatives that will avoid the risk of infection.

Reference: <http://cansurvivorblog.com/the-7-least-helpful-words-you-will-hear-when-you-have-cancer-and-what-to-do-with-them/>

# Messages of Hope from AI/AN Survivors

NACR has the largest AI/AN cancer survivors' supportive information and video program in the world. Almost 100 survivors have shared their stories. Most of these survivors are now over 60 years and half were diagnosed with cancer when they were younger than 50 years. Finding and sharing resources helped many live through their cancer diagnosis and on to recovery. The message from most survivors is that you will survive the cancer experience. There is hope for you to enjoy your family and friends, spiritual healing and zest for life for many more years. The following are example quotes from these survivors. More can be found at <http://www.natamcancer.org/vignettes/vignettes.html>.



**Dora Garcia**

"When I got to the support group, I saw about 15 to 20 people in the room. I looked around and said, 'They're all survivors? If they can do it, I can do it!' And from that time on, my life has changed. I thank Mary and her support group for that. My life has turned around."



**Bertha Underwood**

kids are grown, but now I had grandchildren. I wanted to live to see my grandchildren."

"If you get depressed ... you have to get yourself up. Say, 'This is not the way I want this.' I took a month off school ... a month of sick leave. I finished a single parka when I was on sick leave. You have to get yourself up, you can't just sit there and think about it. ... there's really other projects left to do in life. All my kids are grown, but now I had grandchildren. I wanted to live to see my grandchildren."



**Doug Six-Killers-St. Clair**

## AI/AN Men do well too!

so it purified me ... so that I could help get myself into balance after being through the rigors of all of those massive amounts of poisons that they put into my body. It was the cultural perception of who we are as people that got me through it. Being well means that you're in harmony and balance."

"I contacted a couple of Native healers that I knew from back home... they would say some prayers, offer some tobacco. What they wanted me to do is to go through the chemotherapy, and then come back and go to a water ceremony..."



**Laurie Cropley**

it in my own hands and be a part of the recovery and not a victim of the disease. I didn't know I was doing that then. I realize it now."

"I think one of the things that helped me survive was that I just was a lot stronger mentally, than I thought I was. I really had an inner strength and a determination to really go with it, and really heal from it. I traveled to Canada to see a medicine man... I realized that I was very motivated to take the recovery process and to put



**Tobias Martinez**

Note: Tobias died in a fire in 2009.]

"The cure included kindness and caring for other people. The people that I felt closest to were the disabled because I felt disabled. ...I volunteer a lot of my time with old veterans... for young children ... at that point, I felt those spirit holes that the doctors had shot into me starting to heal." [Ed.



**Andrué Davis**

## Childhood Leukemia

"Now I have hair and I can play with my friends at recess!"

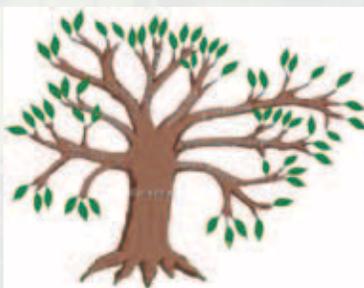
# Take care of yourself!

As a survivor, it is important to take care of yourself! You can simply survive or really thrive following your cancer diagnosis. It is vital to protect yourself, live a healthy lifestyle and know when to contact your provider. Here are some tips to help you live life more fully as a survivor:

1. Know your medications – know what you take, why you take them, when to take them and any potential side effects. Take your medications as prescribed and keep taking them as long as the doctor suggests, even if you start feeling better.
2. Keep your follow-up appointments – when you have an appointment, ask questions and repeat the answers to make sure you understand; ask if you can tape the conversation using your phone or a tape recorder. If possible, bring another person along to hear what the provider says. Ask when you should come back for the next appointment.
3. Eat a diet with plenty of fresh fruits and vegetables.
4. Don't use store-bought tobacco or tobacco products regularly.
5. Don't abuse alcohol or other substances.
6. Get exercise daily – try to walk 10,000 steps per day; begin slowly (maybe even as few as 100 steps) and gradually increase your steps.
7. Make sure to get plenty of sleep; at least 7 hours per day.
8. Keep out of the sun, particularly in the middle of the day, and wear sunscreen and a hat.
9. Try to foresee any health problems; call your provider right away if you think something is wrong, don't wait to see if the problem will go away.
10. Get your routine screening exams that are required for your age and sex (e.g., mammogram, Pap test, colon screening test).
11. Get out into nature, if not daily, then at least several times each week – take a walk, go for a drive.
12. Do things you enjoy and pamper yourself in healthy ways.
13. Be kind to yourself, know that emotions may run high and you may feel sad, happy, angry, or experience other feelings, all in a short period.

## AI/AN Cancer Education for Survivors

Native American Cancer Education for Survivors (NACES) is the largest AI/AN cancer survivor support education program in the US. An average of 1,000 people visit this webpage daily. It is a free resource available online at <http://www.NatAmCancer.org>. Its purpose is to improve quality of life for AI/AN cancer survivors by increasing knowledge and informed choice. Cancer survivors, family members, patient advocates and navigators,



or anyone interested in helping people survive cancer can use NACES. While originally for Native breast cancer survivors, most information fits both men and women with any type of cancer.

NACES is laid out as a tree. The roots include support of family and friends; personal beliefs, practices and knowledge; and traditional cultural beliefs and practices. The trunk includes a quality of life survey. The limbs contain information in eight broad areas: spirituality, communication, cancer treatments, clinical trials, side effects, health information, more health problems and help and support.

Each limb has branches with general topics. Each branch has leaves with content specific to that topic. Most branches include a leaf to introduce the overall branch and a leaf identifying which storytellers talk about the branch topics. The medicine wheel is the basis for most branches with leaves on the body, mind, emotions and spirit. The leaves include video vignettes of Native survivors talking about the topic. Some branches have activities to help you talk with your providers or practice a skill. A hummingbird shows where you are on the tree.

A sidebar is on every page. It includes site resources such as the video vignettes (more than 90 Natives discussing survivorship issues) and storytellers (sharing stories from survivors who do not wish to be identified). There also are sample questions that survivors might ask providers and definitions of common cancer terms.

The NACES website is a convenient resource providing AI/AN-specific information to help cancer patients improve their quality of life. More than 900 AI/AN cancer patients provided survey information. Most are long-term cancer survivors sharing the message that you, too, can survive and thrive.

# Side Effects

Survivors often have side effects because of cancer treatment. Generally, these side effects are divided into three groups. The first group is the short-term, also called acute, side effects. These usually occur during treatment and improve when treatment is over. Often your provider can manage these during treatment. The second group includes the long term or chronic side effects. These may start during or shortly after treatment, but they last a long time. They may or may not improve following treatment. The final group includes the late effects. These do not occur until months or even years after treatment ends and may become more of a problem for your health over time. Below are common side effects. Some acute side effects may become long-term problems. Most chronic side effects can be managed but do not completely go away. Your healthcare provider can tell you if you are likely to have any of these side effects. Your provider can also help you manage these side effects and let you know how long they might last.

Short-term Effects(Acute)	Long-term effects (Chronic)	Late Effects
Pain Nausea and vomiting Sleep problems Anxiety and/or depression Constipation or diarrhea Difficulty eating; no appetite Hair loss (Alopecia) Urinary frequency Increased infections Bleeding Tiredness Mouth sores (mucositis) Problems with intimacy Infertility (no periods, low sperm counts, not able to become pregnant) Skin changes such as acne or dryness Nail changes (ridges, splitting or peeling nails) Decreased vaginal lubrication	Fatigue (extreme tiredness) Numbness and tingling in fingers and toes (Peripheral neuropathy) Brain fog, "Chemo brain" or difficulty paying attention (cognitive dysfunction) Premature menopause Sterility Decreased interest in sex Erectile dysfunction (ED) Lymphedema Pain Loss of voice (hoarseness)	Heart problems Lung problems, COPD Lymphedema Bone fractures; osteoporosis Early menopause Infertility/sterility Higher risk of a new cancer Cataracts Lymphedema Problems with teeth and gums including increased number of cavities Hypothyroidism Problems with memory

## Recurrent, Secondary or New Cancers

Everyone who is diagnosed with cancer wonders if they will be cured and hopes that once the cancer is gone that it never comes back. This will be true for many survivors. For some, cancer may go away and then come back (recur) within months or years after treatment has ended. Some will be diagnosed with secondary cancer that is due to the radiation or chemotherapy used to treat the first cancer. For others, a new, different type of cancer may appear. This may happen a short time or even years after the first cancer was treated. Statistically, a person who has already had cancer is at higher risk for getting another cancer than a person who has never been diagnosed with cancer.

A recurrent cancer is the same cancer that you had originally. It may be in the same place or a different one. For example, if your original cancer was in your breast, and it spread to your liver, it is breast cancer in your liver. Some of the cancer cells were not killed during your treatments that traveled to your liver. Although many tests are done, there

is no way for sure to tell if every cancer cell was killed.

New cancers may occur in the same part of the body as the original cancer or they may show up in a different place. For example, a person may have breast cancer and then be diagnosed with a new type of breast cancer or be diagnosed with colon or lung cancer. You can decrease your risk of a new cancer by taking care of yourself as a survivor.

Your risk of having a recurrence or a new cancer depends on the kind of cancer you have and the stage or extent of your disease at the time you were diagnosed, and your treatment. Personal factors such as lifestyle, environment and genetics can also play a role. To decrease the risk for recurrence, it is important to get into treatment as early as possible and to complete the course of treatment that is prescribed. Research is underway to identify ways to reduce the risk or recurrence or new cancers. Living a healthy lifestyle can help cancer survivors thrive.

# Stories from AI/AN Cancer Survivors

## Anita Jackson: Living in Hospice



Anita Jackson

The doctors have said that I am “dying” for the last ten years... (Giggles) but I am still here!

My story began on a small island off Maine. I was born into the Penobscot Nation. The people of the Penobscot Indian Nation are traditionally known as the penawahpskewi.

Together with the Passamaquoddy, Maliseet, and Mik Maq Nations, the four Northeastern Woodland tribes make up the Wabanaki Confederacy.

The land was rich with rivers and plant life. We lived off the land; swam and fished the river. Having such rich resources lead to the development of logging camps and paper mills. Our environment changed with the dumping of chemicals and waste from the mills. To this day they are wondering if that might contribute to cancer of the Natives peoples of the island.

I came to the states, married, worked, and raised six children. For many years I was isolated from friends and relatives, and was solely dependent on my husband. When I finally decided to divorce, I had no idea how to live on my own and became more involved in the American Indian community.

I always practiced good health and had regular health screenings of mammograms and pap smears. Then in 1983, my breasts became irritated. I couldn't believe it when they seemed to bleed at the nipples. The doctors thought it was breast cancer, and decided on surgery to remove the tips of both my breasts. I thought that would end it, so I went along with the decision.

In 2003, I began spotting irregularly and the next thing I know I can't pee. “What now?” I thought to myself, and immediately went to the hospital. A series of tests followed to help identify the type of cancer, where it was located, and whether it has spread to other parts of the body? They said it was kidney cancer and that it was very aggressive and spreading at a fast rate.

It was scary knowing the cancer had spread so quickly to my lungs, chest, left side and my back. Radiation and chemotherapy treatments followed. I

tried to keep as much as I could from the kids, and took myself to treatments. Sutent Clinical Trial was offered to me in 2008. At first, I didn't know what to expect. I stayed with the program for two years. The medication that was given to me made me so ill. I stopped the program, I just couldn't do it.

## Make a Wish Foundation Honoree

In April of 2011, I was selected as a recipient for the Make a Wish Foundation. What a wonderful gift! I returned home to see my birth place one more time. My childhood memories flooded back, and my heart became filled with a sense of calmness and peace. It had kept its beauty.

In 2012, a new Voltrient Clinical Trial was being offered. I don't know why I decided to try it, but I am so glad I did. I have been on the new chemo for a year and half, and my body feels stronger than it has in some time. My hair is even coming back. I am going backwards now... (She laughs, with a big smile). My hair which was black before had gone completely white after chemo. Now it is growing back and changing to black! People tell me, “You sure look good!”

Today, I continue to struggle with cancer but consider myself very blessed. My cancer doctors have been so wonderful. I recently started a new clinical trial for Vitamin D Deficiency. The doctors have said that I am “dying” for the last ten years... giggles, but I am still here! I don't know why but God must have some purpose for me. I value time spent attending the Native American Cancer Survivor's group, and volunteer to coach others who have cancer.

I am content with my life and pending fate. Although my children seem to think I will live forever, I do not fear death. “The Great Spirit” has shown me through visions; that my relatives await my arrival in heaven and again we will fish in the river streams.

<http://www.penobscotnation.org>

## April Gibson

### Our Miracle Angel

April Gibson is “our miracle angel,” shared Dr. Wilson who heads the clinical trials department at University Hospital in Aurora, CO. “She continues to amaze us” proclaimed the doctor following surgery to replace a stent. The procedure needs to be done every three months due to her bladder cancer.

I am Sioux and Ojibwa. I never knew my father, and my mother passed when I was just two in a car accident. My grandmother took care of me until I

# Survivors Stories (cont'd)

was twelve. I give her all the credit in the world for my survival today. She taught me the core values which I have lived by.



**April Gibson**

“Give prays to our Creator; treat people the way you would like to be treated.”

When my grandmother passed, I was sent to live with distant family members, and was abused for many years. By the time I was 17, I had had enough, and stole monies to return to Minnesota. The

family tried to send me to boarding school, so I decided to come to Denver and live with my sister. I became pregnant and gave birth to my first child at 18 and through the years, I added two more.

I adjusted to life in the urban area, worked hard, exercised regularly, and watched what I ate. I went through a time where I doubted my spiritual beliefs and became involved with the wrong crowd. This lead to a time of recklessness and I neglected myself. This behavior is so common living in a big city.

I gave all that up, went back to my spiritual beliefs. Got up early every day, praised the lord and went for long walks. I felt great and my heart was at peace. I purchased a house, which I thought was impossible for me to achieve, just a perfect little two bedroom house. Life was good.

Then in November of 2011, things started to change. I felt ill, wasn't sure what it was... just knew something was not right. I began having pain in my lower abdomen. The pain went around to my back. Urinating was uncomfortable and I had a fever. I knew these where all signs of having a bladder infection.

I had medical insurance. The doctors, without having any testing done, determined that it was aurinary track infection and sent me home with antibiotics. When I told my doctor that I was continuing to have issues he never expressed any concerns. I knew in my heart that something was really wrong, I just knew it! Once I was diagnosed and began treatment, I felt glad that the doctors had finally found it and I had a chance to get better. Spirituality has played a big role in how I have dealt with this experience and life journey.

## **Florence July RN (retired) – Cancer Survivor Creek Nation “I am not a quitter”**



**Forence July**

Being a nurse, I thought I was taking good care of myself when in 2008 I found a huge lump in my left breast.

The biggest thing for me was that I could not convince anyone that the lump was there. I notified my doctor but he said, “oh, I am sure it is nothing

but keep an eye on it.” It's crazy but I actually had to take a co-workers hand; brush her hand over my breast to feel what I was feeling... this lump. I worked for a hospital, and it took a year to get an exam!

It was May of 2009 by the time I had a mammo-gram, and breast cancer was diagnosed at stage III. Things moved fast after that and surgery was scheduled for the next day. My children were so angry with the health system. But, me, I was not. I have great spirituality and faith. Part of my life is prayer and my prayer was to our lord, “Father, I have a problem, and am going to give it to you; and I will give you the glory every day.”

“If I am coming home,” she says with laughter and a twinkle in her eyes, “then make it a straight line and as little pain as possible. I am not a quitter. I lost my hair but stayed busy while I underwent chemotherapy and radiation treatments, and babysat for my grandchildren. It was very difficult but I didn't have time to think. A voice came to me. I heard it clear as day. It spoke firm and loudly to me, it said, ‘God's in control’ and I knew he would take care of me.”

One of the most important things to remember about having cancer is that; “You need to talk with your family about the important things, they may not want to hear it but...” and that “You are not alone, even though you may feel hopeless, find a support group and talk about your story, have faith.”

It is because of my faith and the prayers of my church members along with the grace of God that I am still here today. The doctors call me a walking miracle and I agree.

# Survivors Stories (cont'd)

**Ronnie Trentham, Stilwell, OK**  
**7th National Smokeless and Spit Tobacco**  
**Summit 2013 Awardee**



I'm a six-time cancer survivor! So I am a happy guy, and doing well.

Throat cancers can be cured in 90% of patients if detected early. Most cancers of the throat develop in adults older than 50. People who

**Ronnie Trentham** smoke or use tobacco are at risk of developing throat cancer. Excessive alcohol use also increases risk.

It all started back in October of 2003 with cancer diagnosis #1. I visited my doctor for a sinus infection and she noticed something unusual in my mouth, what I thought to be a cold sore. She didn't like the way it looked so we had it biopsied. When the test came back it was positive for squamous cell carcinoma (cancer that begins in flat cells lining the larynx, the paranasal sinus and the nasal cavity). I was a firefighter and used chew tobacco instead of smoking. I started chewing when I was 15 until the age of 28; when I developed extreme heartburn and quit. The cancer was removed and I had a little radiation. We were home healing up and when I say, "We," I mean the whole family because it affects us all. Eleven months later, in 2004, #2 was diagnosed. I woke up with a tooth ache on the same side as the previous cancer; two teeth along with soft tissue were removed and biopsied, again positive for squamous cell carcinoma.

The doctors gave me two options: one, I could get pain medication to be as comfortable as possible. Of course that meant to me, I would be waiting to die. Option two: have extensive surgery to remove the jaw bone with no guarantees, it might work or it might not. The doctors said I had an 85% chance of dying from the disease. But what I heard was, "You have a 15% chance of survival!" so I choose option two. Survival was the only option, and I never once gave up. A piece of bone and tissue was grafted from my leg to replace my jaw. I had great doctors and plastic surgeons that put me back together. The surgery was a success.

A few months later, I started feeling something funny inside my mouth. I called my wife, and she

took one look and just started laughing. I was upset with her, I told her this was a very serious matter, and I was so frustrated. "Just tell me how bad it is!" She just said, "Um honey, I hate to tell you this but you are growing leg hair in your mouth." OMG, really... I tried to shave it but I would just cut my tongue... (laughter)

Part of dealing with cancer is to have humor. I made jokes after that and said, I didn't need dental floss because I grew my own. Laughing helps. The most asked question from me now is: "do you still have hair growing in your mouth?" The answer is no, radiation treatments resolved that problem for me.

Diagnosis #3 was eight months later when I found a sore in my mouth. We knew this type of cancer was very aggressive, and had a good chance of returning.

Diagnoses #4 followed in six months. A biopsy was preformed the doctors felt the cancer could be in my genes. They decided to hold off chemotherapy or radiation.

Diagnosis #5 came five months later while shaving and felt a "speed bump," the cancer now had spread to my lymph nodes and I under went a lymph node dissection.

Finally, cancer diagnoses #6, was found during my follow-up appointment to see if I was to have chemo/radiation therapy treatments for diagnoses #5.

If I only had one message for my brothers it would be: "Get over yourself and being embarrassed. We as men need to talk about our health. You know when something is wrong. Be proactive and take care of your health now."

The bottom line is the earlier you catch it (cancer) the better off you will be!



# AI/AN Heroes

In many of our America Indian communities there are heroes who inspire our cancer survivors to live and be happy, to maintain their treatments, and to find meaning in life after cancer. Some of these heroes are men and some are women. Some are cancer survivors and others are family members and health workers. We honor them.

**Mary Tinsley**  
**Nurse Practitioner**  
**KAW Nation – KAW Women’s Health**  
**Breast & Cervical Program**



**Mary Tinsley** and Perkins in assisting tribal members with transportation or other services for cancer.

When we see survivors we know we are doing our job!

I have been with the KAW Women’s Health program going on 12 years. Our program works with the five different clinics including White Eagle, Kanza, Pawhuska, Pawnee

The program helps find the nearest clinic to them for services. Our motto at the clinic is, “We can call and ask and all they can do is say ‘No!’” We try to find places that accept and work with our grant guidelines to provide our client with the best care available.

Support goes beyond diagnoses. We here at KAW Women’s Health, support cancer survivors and have dinners to honor them and give them t-shirts and other goodies. Survivors are asked if they are willing to support other women who have a new diagnosis of cancer.

The women are supported from the beginning; before and after, at the early diagnostic stage. We see them prior to the diagnoses of cancer. We work with the women to make sure they continue get follow-up care. The program tries to make sure they (patients) get everything they need, and make sure they are not just getting lost out there between the doctors and clinics.

Patients are encouraged to take one step at a time and to bring family members with them to appointments. If we don’t have the answer, we find someone who does.

Each person and their cancer are different. We do one step at a time or worst case scenario for

those who want to know more. Spirituality is an individual choice; we can help with information on traditional healers if requested.

The most difficult part of my job is the women who choose not to seek treatment. We have a hard enough time getting them into screening. When they hear a positive cancer screening they decide not to go through anymore tests or treatments.

Some patients just don’t want to hear about their cancer diagnoses; but we tell them we want to give them as much information as possible so they can make an informed decision for themselves.

I tell them, “I am going to talk to you like you are my sister, my mother, my daughter or my best friend about what the consequences could be, and when we have spoken in this way, that is when I can accept your decision.” These women may take more time, but we understand that this is their decision and we have to respect it.

I have been asked how I keep my passion working with such difficult illness. I tell them, “it is just to see them (patients) survive and be there.” There are more survivors and that is just a miracle! It is so rewarding to see that, and it validates us when we see survivors because we know we are doing our job.

**Arlene Wahwasuck**  
**Prairie Potawatomi Tribal Member**  
**RN, MSN Capt., USPHS (retired)**  
**11 year – Breast Cancer Survivor**



For years, I have been encouraging women to get a mammography screening, but I didn’t listen to my own advice. I am a nurse, but I don’t nurse myself.

My career interest has been in public health, and the healing of our women.

When I first discovered a lump in my breast, it wasn’t easy for me to discuss my findings with co-workers. I think we all just didn’t want to believe that I, of all people, would have any type of problem, especially cancer.

A nurse practitioner looked at the lump, but she didn’t agree with me. I wasn’t told anything and I didn’t ask. So I decided to schedule a mammogram screening. Although, I am a nurse, I was still

# AI/AN Heroes (cont'd)

scared! The doctor spoke about a needle biopsy but decided against it.

They referred me to a surgeon in Topeka. I was told that she could not see me for six weeks. I was so worried that whole time.

I was scheduled for surgery, and when I got there they told me the surgery had been canceled! "What do you mean canceled?" I was very upset. Apparently, the doctor had an emergency and I was asked, "Do you think you are more important than the doctor's emergency?" Then they referred me to another surgeon. All my children were with me and they just cried. This was a very hard time for us all. First, I find out after much searching, that I indeed have breast cancer but now I feel as if my life is not worth anything. I am just being passed around. If it had not been for my diligence and mind-set, 'I want to live,' who knows how this could have affected my decisions.

Spiritually is important to us, prior to surgery my family hosted a dinner for me. That was very nice, we ate and laughed together and it was then I felt like I was really ready for surgery. When I did have surgery most of my family and friends were there. I had lumpectomy surgery. Following this, I decided to have a mastectomy.

My daughters took good care of me. The family was let in to my room. They told us no one had to leave. It was nice to have my family there. Today I am happy, feeling good and exercise regularly. If I only have one thing that I want people to know it is:

Seek care right away, if they tell you they are too busy – find someone else.

## **Eleanor McDaniel, Comanche War Hero – Cancer Survivor**



I was in treatment with six other tribal members. Today I am the only survivor.

I served 10 years in the US Army and am a combat veteran in the Gulf war during Operation Desert Shield and Desert Storm. I was assigned to an Explosive Ordinance

**Eleanor McDaniel** Cleanup Team, which was responsible for locating and destroying enemy caches of weapons and

ammunitions. I am a 100% disabled veteran as a direct result of my combat service.

I was diagnosed with breast cancer shortly after coming home from the war in 1994. I had found a small lump in my breast and had a mammogram done, but my report came back normal! I was having so much pain in my breast that I returned to the clinic. The doctor ordered an immediate biopsy. I was diagnosed with breast cancer, stage four.

I underwent surgery – a radical mastectomy – and received six months of chemotherapy. I was in treatment with six other tribal members, and today I am the only survivor. We are truly grateful for all our blessings.

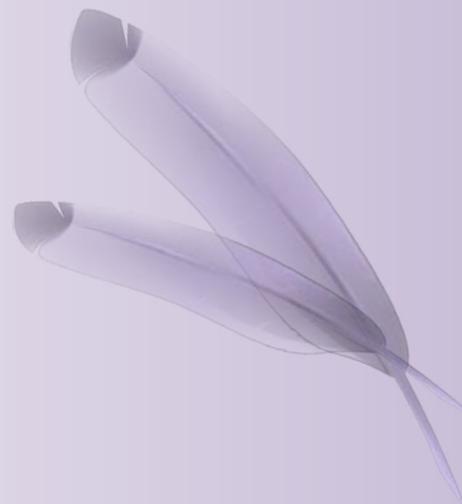
My grandmother was a Comanche Medicine Woman and it was her philosophy that helped me. She practiced her traditional medicine but also was one of the first converts to Christianity. I think the reason for her conversion was that Christianity paralleled her traditional philosophy.

My grandmother believed that a clean heart, clean mind, and clean body gave you strength in all things. She taught me that prayer was important, and that all things were possible if we put our trust in the great Creator.

It was a hardship for all the family. I am well now. We have survived and try to live every day to the fullest. I used a traditional philosophy, and modern medicine to fight the cancer. I am grateful for all that we have today.

Today, I continue in my beliefs and teach traditional arts, crafts and live life to its fullest!

**Love and Hope – find it, share it!**



# Native Survivorship Events

## Honoring American Indian and Alaska Native Cancer Survivors Across the Nation

Many American Indian communities and Tribal Nations sponsor annual cancer survivor events to share resources and services, provide time for survivors to share their stories, and to highlight available cancer screening and treatment opportunities. Each community initiates their own activities based on local interests and needs that grow out of grassroots cancer awareness activities.

## Tohono O'odham Cancer Program Host 3rd Annual Cancer Survivorship Summit in 2013

For the third year, the Tohono O'odham Cancer Program (TOCP) hosted its annual Cancer Survivorship Summit and found many members in attendance. Whether it was as a friend, family member, or cancer survivor, the general impression people spoke of was the healing they found at this event. Hosted by the TOCP and held at various sites throughout the nation, this annual event is a culmination of efforts between many resources on the nation, surrounding areas, and a plethora of resources outside the Nation. The word *himdag*, or traditions, was the central idea for this year's event and focused on how members of the Tohono O'odham Nation (TON) negotiate the journey one that follows a cancer diagnosis. This is a very personal journey that requires immense trust, which can be difficult at times. The highlights, as always were the individuals who comprised the survivor panel. Through their own words they communicate personal journeys offering hope and encouraging all people who have been diagnosed that healing comes in a variety of ways. Many leave this annual event humble yet far stronger than before they came.

## Providing Comfort Care for Our Loved Ones with Cancer

The Oglala Sioux Tribe promotes cancer awareness and survivor support through two annual events that focus on cancer survivors and their caregivers. One event brings in community resources including American Cancer Society, the Walking Forward Program from Rapid City Regional Hospital, and the Great Plains Tribal Chairman's Health Board. They honor the memory of cancer survivors with the reading of their names, the release of balloons and an Honor Song with a local drum group called the Hehaka Singers. They also invite a panel of American Indian cancer survivors to share their stories.

The Oglala Sioux Tribe project also provided an event related to cancer survivorship and caregivers to each of the nine districts on the Pine Ridge Indian Reservation "Providing Comfort Care for Our Loved

Ones with Cancer", a one-day training session held on Wednesday (November 28, 2012) 10:00am to 3:30pm at the Sacred Heart Parish Hall in Pine Ridge. There was an improvement in knowledge and skills of at least 20 Native Family Members responsible for caring for cancer patients in their homes during and after their treatment. The event was recorded and displayed on the local television station KOLC (Oglala Lakota College television station). The Program, "Providing Comfort Care for Our Loved Ones with Cancer" continues to get airtime. In addition to this event, the group participated in a 4 Directions Walk to congregate at the Parish Hall.

## Cherokee Nation Celebrates Survivorship



Each year during the early days of fall in the Cherokee Nation you will find a group of breast cancer survivors enjoying each other's company and celebrating their years of survivorship at the Cherokee Nation Breast Cancer Survivor Celebration. Last year, October 12, 2013 was no different as survivors meet for the "Fabulously Pink Picnic" on the grounds of the Cherokee Nation Heritage Center. "One of the greatest joys of the year is organizing and inviting 'our' breast cancer survivors to the celebration," says Barbara Neal, Cherokee Nation BCCEDP Health Educator. "We get to renew relationships with past survivors and encourage new survivors through their breast cancer journey."

Even though the theme changes each year from the Pink Luau to the Pink Hoe Down to the Pink Sock Hop, Cherokee Nation survivors are always ready to celebrate. The beauty of the celebration is there are breast cancer survivors who are celebrating 26 years of survivorship and there are newly diagnosed breast cancer survivors. It is a great realization for the new survivors to picture themselves in 26 years as a breast cancer survivor.

# Cancer Survivorship Care Plans

Cancer survivorship is defined by living on after you have been diagnosed with cancer, no matter what happens. You become a survivor the moment you learn you have cancer and remain one for the rest of your life. Being a survivor is a continual process. The goal for most cancer patients is not just to survive cancer, but to thrive and enjoy a life that includes all of the ups and downs and joys and sorrows that everyone has in life. Surviving means finding a “new normal” for your life that gives you the best chance to live a healthy and fulfilling life.

Over the last decade, there has been a push to give survivors a formal blueprint to help them move on after treatment and take steps to thrive in the years following diagnosis and treatment. These blueprints are called cancer survivorship care plans (SCPs). As described by the Institute of Medicine, SCPs serve as “road maps” to help survivors transition from cancer care to life as a cancer survivor. The goal of the SCP is to keep

Ideally, a SCP can be started before you even begin treatment, but this is not common. Most plans are made after you complete treatment. Regardless of who makes the plan or when it is made, all survivors should have one. The SCP should be easy to read and easy to follow. If created by your provider, you should have the chance to go through it with your doctor/nurse and provide input. You should have a copy and so should your primary care provider. You may want to bring it with you to all follow-up appointments and health screenings and update it regularly. Additionally, you may map your healthy lifestyle progress by keeping a diet, sleep and physical activity journal or take part in a social media blog, online chat, support group or other activity that promotes your healthy survivorship.

In 2012 the Commission on Cancer began requiring that all of its accredited cancer centers issue a SCP to every survivor who completes treatment (see

## Common Information in a Cancer Survivorship Care Plan

Diagnosis and Treatment Summary	Care Plan
1) cancer diagnosis 2) stage of disease 3) treatments 4) health problems during treatment 5) possible long-term side effects	1) follow-up appointments 2) routine cancer / other health screenings 3) symptoms of cancer recurrence 4) support resources 5) healthy lifestyle behaviors 6) legal, employment, financial and health protections

survivors informed about the treatments they have received, their long-term prognosis, and the recommendations made for them in terms of medical follow-up care, healthy lifestyle behaviors, and getting access to helpful resources. Usually, a SCP has two parts: a diagnosis and treatment summary and a care plan (a guide for a healthy future).

The plan also will give practical ideas about living a healthy lifestyle such as daily physical activity, getting enough sleep, eating well, maintaining a healthy weight and minimizing risky behaviors such as smoking, drinking and driving too fast. Some plans provide information on genetic counseling and testing, legal protections, health insurance, and managing employment and financial consequences. Most importantly, the plan will be tailored for each cancer survivor, to equip him or her with the specific information needed to optimize health and well-being after cancer.

resources below). While it may take awhile for this practice to become commonplace in every setting, this means that your healthcare provider (doctor, nurse or social worker) should create a SCP and deliver it to you. However, Cancer Journey (<http://journeyforward.org/patients/my-care-plan>) has also created a SCP called “My Care Plan” that you can fill out yourself. Once you complete it, you can take it to your provider to check you have accurate information and to fill in any gaps or make corrections.

Having and surviving cancer is hard work! Your SCP will help you stay on the right track, keep as healthy as possible, and reduce your risks for recurrence or a new cancer diagnosis.

# SCPs (cont'd)

Examples of Cancer Survivorship Care Plan Resources	
National Coalition for Cancer Survivors: Cancer Survivor Toolbox	<a href="http://www.canceradvocacy.org/resources/planning-your-care/">http://www.canceradvocacy.org/resources/planning-your-care/</a>
The Journey Forward: A guide for cancer survivors - includes My Care Plan	<a href="http://www.journeyforward.org">http://www.journeyforward.org</a>
Northwest Portland Area Indian Health Board (NPAIHB) Appointment Companion	<a href="http://www.npaihb.org/images/epicenter_docs/WTDP/2011/AppointmentCompanion2012.pdf">http://www.npaihb.org/images/epicenter_docs/WTDP/2011/AppointmentCompanion2012.pdf</a>
South Puget Intertribal Planning Agency (SPIPA), My Journal (Not a survivorship care plan, but a strong resource for documenting pain, distress and discomfort)	<a href="http://www.cancercorecompetency.org/uploads/Pain%20Docs/AIAN%20cancer%20D&amp;D%20journal_5.10.10_flattened2.pdf">http://www.cancercorecompetency.org/uploads/Pain%20Docs/AIAN%20cancer%20D&amp;D%20journal_5.10.10_flattened2.pdf</a>
Minnesota Cancer Alliance: Cancer Survivor Care Plan: What's Next? Life after Cancer Treatment	<a href="http://www.mncanceralliance.org/uploads/mn_cancercareplanbook_051910_l6_3.pdf">http://www.mncanceralliance.org/uploads/mn_cancercareplanbook_051910_l6_3.pdf</a>
American College of Surgeons (ACoS) Commission on Cancer®	<a href="http://www.facs.org">www.facs.org</a>
National Cancer Institute (NCI) Community Cancer Centers Program (example of a breast cancer survivor's care plan)	<a href="http://ncccp.cancer.gov/NCCCP-ASCO-Breast-Cancer-Surv-Care-Plan.pdf">http://ncccp.cancer.gov/NCCCP-ASCO-Breast-Cancer-Surv-Care-Plan.pdf</a>
LIVESTRONG Care Plan	<a href="http://www.oncolink.org/oncolife/print_pcpsummary.cfm?ID_KEY=5569921777&amp;review_plan=969&amp;toc_focus=7&amp;es=0&amp;Patient_Relationship=3">http://www.oncolink.org/oncolife/print_pcpsummary.cfm?ID_KEY=5569921777&amp;review_plan=969&amp;toc_focus=7&amp;es=0&amp;Patient_Relationship=3</a>
American Society of Clinical Oncology (ASCO) Survivorship Treatment Summaries	<a href="http://www.asco.org/institute-quality/chemotherapy-treatment-plan-and-summaries">http://www.asco.org/institute-quality/chemotherapy-treatment-plan-and-summaries</a> or <a href="http://cancer.net/survivorship">cancer.net/survivorship</a>
Susan G. Komen for the Cure® "Understanding Breast Cancer" (not a "care plan", but survivorship)	<a href="http://ww5.komen.org/BreastCancer/UnderstandingBreastCancer.html">http://ww5.komen.org/BreastCancer/UnderstandingBreastCancer.html</a>
Memorial Sloan Kettering Summary of Cancer Treatment and Follow-up	<a href="http://www.mskcc.org/cancer-care/survivorship/survivorship-care-plan">http://www.mskcc.org/cancer-care/survivorship/survivorship-care-plan</a>
The Prescription for Living Plan	<a href="http://www.nursingcenter.com/lnc/static?pageid=721732">http://www.nursingcenter.com/lnc/static?pageid=721732</a>

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# National Comprehensive Cancer Control Program Tribal Program Directors Contact List

This group of programs provide comprehensive cancer control services including tobacco cessation programs, community-wide cancer planning, screening programs, survivors programs, outreach and education, and other services to those diagnosed with cancer and the larger tribal community.

## **Alaska Native Tribal Health Consortium**

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## **Northwest Portland Area Indian Health Board**

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## **Tohono O'odham Nation**

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Program Supervisor  
Cancer Prevention & Awareness Program  
Tohono O'odham Department of Health and  
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(520) 383-6223  
[Janelle.jensen@tonation-nsn.gov](mailto:Janelle.jensen@tonation-nsn.gov)

## National American Indian Culturally Appropriate Resources

The following contact information includes educational materials, referrals to screening, survivor support circles, and cancer information.

### Native American Cancer Research Corporation (NACR)

3110 South Wadsworth Blvd., Suite 103  
Denver, CO 80227  
(303) 975-2449  
Fax: (303) 975-2463  
Survivor's Network 1 (800) 537-8295  
<http://www.NatAmCancer.org>

### Spirit of Eagles, Mayo Clinic (SOE)

Charlton 6  
200 First Street SW  
Rochester, MN 55905  
Telephone: 507-266-3064  
Fax: (507) 266-2478  
<http://www.nativeamericanprograms.net/spirit-of-eagles/>

### Walking Forward Program (WF)

Cancer Care Institute  
Rapid City Regional Hospital  
353 Fairmont Blvd.  
Rapid City, SD 57701  
Phone: (605) 719-2305

## Generic Cancer Support Organizations

### American Cancer Society (ACS)

1 (800) 227-2345  
[www.cancer.org](http://www.cancer.org)  
Call or go on the website to find information or your local ACS

### Oncology Nursing Society (ONS)

125 Enterprise Drive  
Pittsburgh, PA 15275  
(866) 257-4ONS (866-257-4667) (toll-free)  
+1 (412)859-6100  
Toll-free fax: (877) 369-5497  
Fax:: +1 (412) 859-6162  
[customer.service@ons.org](mailto:customer.service@ons.org)  
[www.ons.org](http://www.ons.org)

### Livestrong

2201 E. Sixth Street  
Austin, Texas 78702  
(877) 236-8820, or for cancer support call  
LIVESTRONG at 855-220-7777  
[www.Livestrong.org](http://www.Livestrong.org)

## Tribal Breast and Cervical Program Contacts 2014

The following programs provide breast and cervical health screenings for American Indian and Alaska Native women. They are funded by the Centers for Disease Control and Prevention (CDC).

### Arctic Slope Native Association Limited

Pilar Salamat  
Program Director  
SSMH Screening for Life Program  
Arctic Slope Native Association Ltd.  
PO Box 29  
Barrow, AK 99723  
(907) 852-9118  
Fax: (907) 852-5882  
[Pilar.Salamat@arcticslope.org](mailto:Pilar.Salamat@arcticslope.org)

### Cherokee Nation

Angela L. Leach, RN  
Program Manager  
Breast and Cervical Cancer Early Detection  
Cherokee Nation Cancer Programs  
1296 Skill Center Circle  
Tahlequah, OK 74464  
(918) 453-5756  
Fax: (918) 458-6267  
[angela-leach@cherokee.org](mailto:angela-leach@cherokee.org)

### Cheyenne River Sioux Tribe

Arlene Black Bird, RN, BSN  
Director / RN-Case Manager  
Cheyenne River Breast & Cervical Early Detection  
Program  
24276 166th St, Airport Rd, Box 3012  
Eagle Butte, SD 57625-0590  
(605) 964-0556  
Fax: (605) 964-1176  
[Arlene.BlackBird@ihs.gov](mailto:Arlene.BlackBird@ihs.gov)

## Tribal Breast and Cervical Program Contacts 2014 (cont'd)

### Hopi Tribe

Delores Ami  
Program Coordinator  
Hopi BCC & CRC Screening Programs  
PO Box 123  
Main Street  
Kykotsmovi, AZ 86039  
(928) 734-1151  
Fax: (928) 734-1158  
[DAmi@hopi.nsn.us](mailto:DAmi@hopi.nsn.us)

### Kaw Nation

Tamara Holden  
Project Director  
Kaw Women's Health  
3151 E. River Road  
Newkirk, OK 75647  
(580) 362-1039 x207  
[Tamara.Holden@ihs.gov](mailto:Tamara.Holden@ihs.gov)

### Native American Rehabilitation Association of the Northwest, Inc.

Amelia Mainord  
Clinic Manager  
NARA Wellness Center  
Co-Director, Women's Wellness  
12360 E. Burnside  
Portland, OR 97233  
(971) 279-4800, ext. 309  
Fax: (971) 279-2213  
[amainord@naranorthwest.org](mailto:amainord@naranorthwest.org)

### Navajo Nation

Angie Williams  
Program Director  
Breast and Cervical Cancer Prevention Program  
Navajo Nation Division of Health  
(Overnight Only)  
Window Rock Boulevard  
Administration Building 2  
Window Rock, AZ 86515  
(928) 871-6249  
Fax: (928) 871-6255  
[Angie.williams@nndoh.org](mailto:Angie.williams@nndoh.org)

### South Puget Intertribal Planning Agency

Rita Andrews  
Program Director  
Native Women's Wellness Program  
South Puget Intertribal Planning Agency  
3104 Old Olympic Highway, SE  
Shelton, WA 98584  
(360) 462-3226  
Fax: (360) 427-1625  
[randrews@spipa.org](mailto:randrews@spipa.org)

### Southcentral Foundation

Kate Landis  
Program Director  
Breast and Cervical Health  
Southcentral Foundation  
4320 Diplomacy Drive, Suite 2630  
Anchorage, AK 99508  
(907) 729-8891  
Fax: (907) 729-3265  
[kslandis@scf.cc](mailto:kslandis@scf.cc)

### Southeast Alaska Regional Health Consortium=

Litia Garrison  
Interim Director  
Women's Health Program  
Southeast Alaska Regional Health Consortium (SEARHC)  
222 Tongass Drive  
Sitka, AK 99835  
(907) 966-8746  
Fax: (907) 966-8785  
[litiag@searhc.org](mailto:litiag@searhc.org)

### Yukon-Kuskokwim Health Corporation

Roxanna Anderson  
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Yukon-Kuskokwim Health Corporation  
PO Box 528  
Bethel, AK 99559  
(907) 543-6398  
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# Cover Girl Follow-up:

## Sharon Eli, Long-term Breast Cancer Survivor



Sharon Eli Cherokee:  
A Story of Survival

Tribes Celebrate  
Breast Cancer  
Awareness Month

Donna Wahnee  
Comanche: My  
Mammogram Was  
My Best friend

When the 2013 Native People's Wellness Breast Cancer Prevention, Detection and Care Booklets were delivered to the Mankiller clinic, Barbara Neal, the Cherokee Nation Health Educator, quickly opened the box of Native People's Wellness and presented the first copy to Sharon Eli, the clinic appointment clerk, who was featured on the front of the issue.

Sharon is a breast and colon cancer survivor and has had a long journey to survivorship. Immediately Sharon covered her mouth and giggled like a school girl for about 30 seconds. She had been interviewed months earlier when the booklet was being developed, and was so elated and to be on the cover. It was nice to see her so excited.

A few weeks later, the women's health case manager, Youlanda Cain had a magazine signing for Sharon. The whole clinic was on board and employees came to the signing. They were surprised to see Sharon on the cover as the booklets were kept a secret until the day of the signing. The clinic employees celebrated with pink lemonade and popcorn and Sharon signed booklets for everyone. It was a pleasure to see someone willing to open her life to others so they can understand her cancer journey.

*Article submitted by Barbara Neal, Cherokee Nation Health Educator.*

# Cancer Terms

## Definitions of words you may hear from your healthcare provider

- **Caregiver (KAYR-gih-ver)** – A person who cares for others. In cancer care this may be a family member, friend or loved one as well as a healthcare professional, member of the clergy or social worker.
- **Chemo Brain (Brain Fog)** – thinking and memory problems that can occur after chemotherapy. You may forget simple things or have trouble reading or paying attention.
- **Complementary therapies (KOM-pleh-MEN-tuh-ree ther-A-pees)** – treatments used in addition to standard western medical treatments. May include herbs or potions, special teas, vitamins, meditation and massage to name a few.
- **Fatigue (fuh-TEEG)** – extreme tiredness and lack of energy. It becomes worse as treatment goes on and goes away over time (months to years) after treatment ends.
- **Malignant (muh-LIG-nunt)** – Another name for cancerous cells. The cells can invade into nearby organs and tissues and cause harm or spread to other parts of the body.
- **Peripheral Neuropathy (peh-RIH-feh-rul noor-AH-puh-thee)** - Pain, numbness, or tingling usually in the fingers and feet caused by damage to nerves from diseases such as cancer or diabetes or drugs such as chemotherapy. Usually gets worse over time.
- **Physical activity** – Any kind of movement or exercise such as dancing, walking, housework, gardening, or weight training. Does not require a gym or fitness equipment.
- **Positive test result** – A test result that shows that a disease or condition is present.
- **Primary tumor (PRY-mayr-ee TOO-mer)** – A term to describe the original, or first, tumor.
- **Quality of life** – How well you are able to do everything you want to do: physically, mentally, emotionally, and spiritually
- **Recurrence (ree-KER-ents)** – Cancer that has come back. It may come back in the same place or in a new area of the body.
- **Remission (reh-MIH-shun)** – A decrease in or disappearance of signs and symptoms of cancer.
- **Secondary cancer (SEH-kun-dayr-ee Can-sir)** – A cancer that occurs because of the treatments given to treat your primary cancer. May occur years after the primary cancer and be the similar or a different type of cancer.
- **Side effect** – A problem that occurs when treatment harms healthy tissues. Common side effects of cancer treatment include fatigue, pain, nausea, vomiting, and hair loss.
  - **Short term (acute)** – occur during your cancer treatment
  - **Long-term (chronic)** – occur during or after treatment and continue to be a problem over time
  - **Late effects (after effects)** – side effects of treatment that occur months to years after treatment ends
- **Survivorship: (ser-VY-ver-ship)** – the time from when a person is diagnosed with cancer until the end of life.

### References:

- Livestrong (2013). Retrieved from: <http://www.livestrong.org/we-can-help/healthy-living-after-treatment/late-effects-of-cancer-treatment/>
- Mayo Clinic. (2013). Diseases and conditions. Retrieved from: <http://www.mayoclinic.com/health-information>
- National Cancer Institute. (2013). Dictionary of cancer terms. Retrieved from: <http://www.cancer.gov/dictionary>
- Ohio State University (2013). Cancer term glossary. Retrieved from: <http://cancer.osu.edu/patientsandvisitors/cancerinfo/pages/cancertermglossary.aspx?letter=#>

# Casey Lozar's Flathead Buffalo Stew

From "Cooking with the Fund: The American Indian College Fund's Guide to Healthy Cooking"

**Servings:** Makes 10 servings

**Directions:**

- 2 1/2 pounds buffalo, cut into small pieces (like stew meat)
- 2 Tablespoons whole wheat flour
- 2 cups vegetable broth
- 3 sweet potatoes, with skin
- 2 cups of baby carrots
- 2 medium onions
- 8 ounces of mushrooms
- 3 diced tomatoes
- 3 stalks of celery
- 4 bay leaves
- Oregano
- Fresh ground pepper

- Dredge buffalo in whole wheat flour, set aside.
- Slice sweet potatoes, place in bottom of slow cooker.
- Cut onions into large pieces and lay over sweet potatoes.
- Clean mushrooms thoroughly, cut in half, and layer over onions.
- Layer baby carrots over mushrooms.
- Layer floured buffalo over carrots.
- Pour diced tomatoes and celery over buffalo.
- Season with bay leaf, oregano and pepper.
- Pour vegetable broth over all.
- Cook on low for 6-8 hours, stirring towards end.

Calories	Protein	Carbohydrates	Fat
124	17	8	2

## Ways to Decrease Total Fat, Cholesterol and Calories

If Your Recipe Calls for:	Try Substituting:
Pasta, crackers, cookies, cereals	Whole grain versions
Butter, margarine, shortening or oil in baked goods	Applesauce, mashed banana, canned pumpkin, or prune puree for half of the amount. Do not substitute oil for butter or diet margarine for regular.
Dairy products: cheese, cream cheese, milk buttermilk, sour cream	Reduced fat or fat-free dairy products.
Eggs	Two egg whites or ¼ cup egg substitute for each whole egg. When baking, substitute half of the whole eggs with egg whites.
Ground beef	Extra-lean ground beef, lean ground turkey, chicken, venison or buffalo. Ground beef may be rinsed to reduce oil.
Oil-based marinades	Wine, balsamic vinegar, fruit juice or fat-free broth.
Nuts	Reduce the amount used and toast to reduce calories.

The turtle is sacred to the Seminole People. Their shells are worn on the legs by the women during ceremonies and dances where they provide the rhythm for the singing and dancing.

Illustration by Mody B. Harjo,  
Seminole Nation of Oklahoma.

