Native American Cancer Treatment: Radiation

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Introduction

This section includes an overview of radiation with descriptions of things your family can do to help you before, during, and following your radiation treatments. Several Native American cancer patients share their experiences with radiation treatments.

Background: Radiation therapy has been in use for over 100 years. High doses of radiation kill cells or keep them from growing and dividing. Since cancer cells grow at a faster rate than do normal cells, radiation therapy can be very effective. Normal cells also are destroyed by radiation, which is why providers monitor the intensity carefully. About half of all people who have cancer take part in radiation treatment.

Side Effects. Most side effects from radiation therapy go away after a few weeks. Some side effects require immediate response from the provider, such as coughing, fever, or unusual pain. The provider takes multiple blood tests from the patient to monitor the white blood cell and platelet counts that drop during radiation treatment. When side effects become too severe, radiation is stopped and the patient must have some time to recover and heal before continuing the treatment. Side effects from radiation sometimes do not occur for several weeks. When they do occur, make certain that the provider knows about all of the side effects. DO NOT WORRY, but do talk with both the patient and the provider about the side effects. Talk with the provider before using any treatment, including lotions for the sunburned or dry skin. Lotions that normally respond to such conditions very well, such as aloe lotions, actually can irritate irradiation “burn” or dry skin.
Family members and radioactivity concerns
Family members are sometimes concerned that the patient is radioactive following radiation therapy. Talk with the provider about your feelings and your concerns. If very high dosages of radiation are used, the provider may recommend that the woman not hold infants or very small children for a short period of time. For most patients, the dosage is focused on a local area and such concerns do not exist.

How You Can Help the Cancer Patient Before the Radiation Therapy Begins
Radiation will interfere with the healing from the surgery. The cancer patient must wait until her surgery has healed before beginning the radiation therapy.

Work with a healer or story teller to help the patient prepare for how she will deal with uncomfortable feelings during the therapy. For example, the patient may be strapped down to help her stay in one position so that the radiation goes where it is supposed to go, and not affect other parts of the body. Then the machine may move to focus on different angle of the tumor (or place where the tumor was removed). The sound and the closeness of the equipment frightens some patients. Help the patient prepare for how she can deal with hearing the sounds, or the sudden movement of the equipment.

One healer prepared special prayers for the patient to say while she was going through the radiation therapy. She brought her token bag with her into the radiation treatment room so that she could hold the bag with the special “gifts” the healer prepared for her while she said her personalized prayers.

You can go with the patient when she is fitted for a cast or any other preparation to help her stay in one position. There are different techniques that are used to help her stay in a single position.

The radiation oncologist will mark the area on her skin where the radiation is to be directed. They will use India ink or another relatively permanent marker. She needs to avoid scrubbing off the mark. Once the mark is made, some women have had traditional healers do ceremonies over the marked area. Nothing should be placed directly on the marked area prior to or during treatment (such as a poultice).
How You can Help the Cancer Patient During the Radiation Therapy

- Radiation is given in different ways. If the patient has an implant, you may only need to help her get to and from her appointments and to help her deal with side effects, if any.

- If she is receiving radiation at the health care facility, you cannot be in the same room with the cancer patient while the treatment is being done (because the providers do not want you to be exposed to unnecessary radiation).

- Some radiation rooms have speakers or intercoms to outside waiting areas. If an intercom system or something similar exists, you can talk with the patient as long as talking does not result in her moving her body.

- Some patients have severe reactions to radiation which results in having to take additional medical prescriptive drugs, like cortisone (e.g., Prednisone). You can help by picking up the medications and making certain that any and all medications are taken as directed by the provider.

How You can Help the Cancer Patient After the Radiation Therapy

- Most patients do not feel too badly after the first few treatments and she may require little assistance initially (e.g., help walking to the car). However, she can suddenly begin to experience side effects. The most common are feeling very weak and tired, and experiencing red, tender dry skin on the area where the radiation is being focused. Be prepared to help her when she feels tired. See the Section on How to Help the Patient When she is Feeling Weak.

- For the skin problems, ask the provider for a lotion. They are likely to provide a sulfa cream.

- The patients who are going through radiation therapy are usually extra sensitive to sunlight and heat. They are likely to have no tolerance to heat.

- If the vehicle you use to transport the patient to and from the radiation therapy is not air conditioned, borrow a car or truck that is.

- If the patient must walk in the sunshine for daily activities (such as walking to the mail box to pick up mail, or to feed and water animals), have other members of the family help with these duties, or provide an umbrella or a wrap to help shield her from the heat of the sun.
Native American Cancer Survivors’ Stories about their experiences with radiation treatments

The following are excerpts of several Native patients talking about their radiation. The people are from many different tribal Nations. They also have different types of cancer. Radiation is a treatment for many types of cancer. Native Americans appear to have more side effects and problems with radiation than do people from other racial groups. A study is going on (2006 to present) to try to find out why our people have so many problems. The results of this study may change the way we are treated with radiation. For example, may we will need lower dosages of radiation. Or, we might need to have longer breaks in between the radiation treatments. For more information about this study, please contact Dr. Daniel Petereit at the Rapid City Regional Hospital in South Dakota.

<table>
<thead>
<tr>
<th>Patient</th>
<th>Diagnosis</th>
<th>Experience</th>
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<tbody>
<tr>
<td>Dilly Adsuna</td>
<td>Breast (2003)</td>
<td>I went through … eight weeks of radiation. I think for someone to go through …radiation… It would be very good if they had… have somebody there with them. Knowing someone is there waiting</td>
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<tr>
<td>Sarah S. Allman</td>
<td>Cervix (1970)</td>
<td>First I was in the hospital twice with radiation. Four days each time, and then after that five and a half weeks of x-ray treatments. … A few times I stayed in town because I was so sick to my stomach. It made me sick to my stomach</td>
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<tr>
<td>Name</td>
<td>Disease Date</td>
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<tr>
<td>Viola M. Beyer</td>
<td>1990</td>
<td>Uterine</td>
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<tr>
<td>Dorcas Bloom</td>
<td>1998</td>
<td>Breast</td>
</tr>
<tr>
<td>Maxine Brings Him Back Janis</td>
<td>1978 2002</td>
<td>Cervix Breast</td>
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<tr>
<td>Name</td>
<td>Tribe</td>
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<tr>
<td>Ruth E. Burch</td>
<td>Muskogee Creek / Seminole</td>
<td>DX 1988 Non-Hodgkins Lymphoma</td>
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<tr>
<td>Mary Lou Calabaza</td>
<td>[Santo Domingo Pueblo]</td>
<td>Dx 1994 Breast</td>
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<tr>
<td>Abe Conklin</td>
<td>[Ponca-Osage]</td>
<td>Dx 1987 Prostate</td>
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<tr>
<td>Mary Lou Davis</td>
<td>[Caddo / Cherokee]</td>
<td>Dx 1993 Breast</td>
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<tr>
<td>Name</td>
<td>Tribe</td>
<td>Diagnosis</td>
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<tr>
<td>Ruth A. Demit</td>
<td>Athabascan-Tanacross</td>
<td>Breast 1985</td>
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<tr>
<td>Esterlene Gee</td>
<td>Creek</td>
<td>Breast 2002</td>
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heat that they blow in your face to open your pours I still have trouble in going into the sauna and but I think the… heat… because of that radiation.

I … went back and he said we are to have to do radiation on you. So I went through the full 26 cycles of radiation.

I lost my teeth. I almost had to have my tongue removed but because of the radiation my jaw deteriorated so last September I went to the University of Washington in Seattle, and I had to have huh a bone removed out of my leg and replaced it my jaw to replace the jawbone.

it does affect a person a heck of a lot. Especially, if you have to live the rest of your life as I do with our own considerable amount of disfiguration because of possible surgeries…

During my treatment phase, I did a lot of native medicines along with scientific stuff that the doctors were doing.

Mainly you lose your saliva glands and huh, little of nerve damage will come back. Because of my surgery last September, it is not going to happen, I will not get nerve tissue back in my face because those were snipped it when they did the operation.

throat cancer is a hard one to handle. Especially when you have to live the rest of your life having a hard time eating solid foods because you can't swallow because your throat and your body doesn't develop the necessary means to swallow. This is something you have to live with or you have to have reconstruction to your face or your throat.
As a modern person we travel with our ancestral spirits, and we do that all the time and every ritual of encounter engages my ancestry. So even while we meet with other tribes. I'm meeting their ancestors. Those who have passed on and we acknowledged those in words, and we also acknowledge that they're behind us and then we also acknowledge the living those are that are with us today. So heritage is from who we were and who we are today so I knew that … every time I went in to radiation to hear from radiation, I had all these ancestors with me and I kind of imagine that they are all shuffling to get closer to me while I was having radiation. And I was lying there thinking, because you're quite isolated. You're on a bed in the middle of a room, and you're all lined up with the grid pacer and you've got the radiation going on, and they're all hiding in the other room because radiation is not really good for you so they're all hiding and I'm on the table with all that radiation going on.

Your body is a great instrument and it will really heal. If I had no brain, and I was lying there my body would heal … so I knew the biggest part of healing had to be in my head… And that takes time, because you can't just get instant healing.

I went through … the radiation treatment painting… painting. I'm an artist, so things I could relate to are visual. So I translated it into a visual form, my journey through the cancer experience.

So things happened in the way that it should. Your body responds and it gets well and I am sure that every bit of radiation is out of my system, and I'm just cranky on my own and I feel great and I'm well and I'm just happy to be here.
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<tr>
<th>Name</th>
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<th>Diagnosis 1</th>
<th>Diagnosis 2</th>
<th>Experience</th>
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<tbody>
<tr>
<td>Raelaine M. Hinton</td>
<td>Passamaquoddy</td>
<td>Dx 2001 Breast</td>
<td></td>
<td>I had the surgery, I had the chemotherapy and I had the radiation,</td>
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<tr>
<td>Frances Johnson</td>
<td>Fish River Inupiaq / Yupik</td>
<td>Dx 1986 Breast</td>
<td></td>
<td>I was scared to get radiation. I was glad when I get count the weeks only few more weeks I got better but I got weaker and weaker, very weak the last two weeks when I used to go to Providence Hospital.</td>
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<td>Mary P. Lovato</td>
<td>Santo Domingo Pueblo</td>
<td>Dx 1987 / 2004 Bone (AML leukemia)</td>
<td>Dx 2006 Kidney</td>
<td>I was in denial. I was denying my illness for a long time. And then going through my treatment was very hard I had a high dose of radiation and chemotherapy was something else I was going up constantly. I cried and cried because I thought my growing up was never going to stop and I thought I was never going to get well, because I would come down with something grow quickly. My immune system was real low, and I was in and out in an out of the hospitals. But um for myself, I've have gone into menopause every since I went through a high dosage of chemo and high dosage of radiation. And what I always stress to people is what I went through this my whole body system changed my whole body is so dry and my mouth is so dry. So I tell them I've already gone through menopause, which I didn't notice right away until way later and it started to occur to me that I'm no longer having my eggs ovulating and things like that. By noon time, I'm not myself. It's it the chemo and the radiation that got me; is still giving me tired.</td>
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| Christine Mangiati  
[Italian (non-Native)]  
Dx 2003  
Inflammatory Breast Cancer |
|---|
| Then I went into 8 weeks of daily radiation. They gave me 3 degree burns on my chest wall which severally weakened my heart and lung through the chemo and radiation and those won’t regenerate. My next step is for the rest of my life is to drop 50 lbs. because I need to take care of my heart. Breast, brain and bones is where they said my cancer goes. Then the next risk is a heart attack. You have to balance what you do.  
The fatigue was horrible. |

| Tobias Martinez  
[Mescalero Apache]  
Dx 1990 oral |
|---|
| The way it was explained to me, the radiation therapy was necessary with this type [ed. of cancer], and without it, the operation would be a success but the patient may die anyway  
I actually had fifty-nine shots five times a day at five times a week, except for the last one I took two double doses. So I guess it was about . . . three months total. The radiation therapy, at first it was easy to deal with. Radiation is a very strong thing, it doesn’t have any real way of being explained to the other person, except it’s painful, you never see it coming. I mean you sit there in front of this machine after the operation, which was difficult enough. I was lucky, mine was just straight radiation, that doesn’t mean that the cure was easy, I mean I went from 195 pounds or so down to 125 in five weeks.  
At this point, the sores had healed pretty much in my mouth, the teeth were gone because they were going to be shot out by radiation poisoning anyway, so at that moment during the operation they came back to me and said they wanted to take them all, and I said, “Well, you might as well.” So, over the next couple of months along with the radiation therapy they removed the rest of my teeth, it was necessary and I felt better afterwards because I actually ended up with a better set of teeth I mean I never had as good of . . . they’re a lot easier to take care of too. |
The hardest part of the radiation though was the side effects. It didn’t prepare me for the in the slightest way for what happened in my body, let alone what my mind was going through. It was a difficult moment to see all of my face being slowly but surely being blackened from the mouth down and all the way up in to my chest. I mean it was difficult enough to get to and from these sessions because at the time they explained to me that I was going to be dizzy and light headed and it was going to affect a lot of my motor functions in my neck and shoulder, but none the less I still persisted and went forward. There were moments where I just decided that I didn’t want to go.

I gave into the thought that it would be over in a matter of weeks, and it continued and persisted, the weight loss, the lack of appetite, the soreness, the redness of the mouth, the dizziness, they were almost worthwhile in the thought that I had to do it. I had to get through this to survive.

It was like the worst sunburn I’ve ever had. There’s five weeks, six weeks even afterwards that it took to heal the skin discolorations, the burns, the mouth problems. Even then I was still convinced that my doctors were trying to kill me, my oncologists was my worst enemy. It was not an easy thing to keep going back to these people, as pleasant as they were, and they were very good people. I hated them, and I told them more than once and at the end there I hated my doctors for saving me and I hated my drivers for picking me up, and at this point they were all in cahoots, I mean the wife, the doctor, the drivers, in my mind they were all plotting to kill me, so I started hiding. I mean I’d hide in the house, I didn’t hide very good, but when you’re mentally un-stabilized due to the powerful affects of radiation or chemotherapy, most of the time they’d like to sedate you but they couldn’t do that for me.

I was literally a lost soul. Radiation puts you there. It makes you worship nothing more than the fact that you
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<tr>
<td>Linda Meanus</td>
<td>[Yakama]</td>
<td>2004 Colorectal</td>
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<tr>
<td>Jeannie Harris Morris</td>
<td>[Mohawk]</td>
<td>1994 Lung</td>
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**Don’t want to be blasted anymore.**

But I had no life, there was nothing left. I mean I was weak and sick and tired and I had to go through physical therapy now, to learn how to talk, to learn how to use my left hand, to even turn my neck was more than I could bear. At mean at this point I was literally wanting to give up physically, I mean my body had had enough.

**So when I started doing my treatments. I had to do… three months of radiation every day for a half-hour.**

The radiation, to be very honest, I had no effects until after they stopped the radiation. When they stopped it, then I had heart burn, severe heart burn. To swallow hurt. I couldn’t eat food. Gee, I would say a good month. I would choke on my food as it was going down my throat. It would be raw and sometimes it would start to bleed, so I was scared to eat food, I barely ate in months.
Mary Nance
[Kickapoo / Hispanic]
Dx 2000 Breast

… not nice subject constipation. I avoided that by using … a lot of the **picilian** that really saved my life as that was my worst enemy during the course of the treatment. If you did not do something about the bowels, and I always … keep …my stomach clean and empty. So I wouldn't have all those poisons those toxins stored in it. So I kept flushing. If I forgot, I paid the price physically to the point of where I wish I was dead sometimes from the pain and the embarrassment… I could go the bathroom and have one of those attacks, and my girlfriend stood there and would hold my hand and she would be singing … well she's Christian… and we used a lot of singing in tongues in the spirit and stuff.

She would be there all day holding my hands while I was having this attack, and well blood ran down my legs from this big earthmoving experience and say that they hear it comes. You know and there was the time I couldn't laugh about it or joke about it. And now I can look back. That was a real friend that stood by me. She could help me undress cleanup and not complain. Not embarrass me or make me feel that she was a servant and you're doing a job or anything, you know that was good.

Lorencita Quintana
[Cochiti Pueblo]
Dx 1989 colon

I went for my radiation treatments in Albuquerque. The first thing was that I was still teaching, and I thought after the surgery, because one other doctors came in and told me “We suggest, that you have radiation treatments.” And I thought I could put that off, because I was thinking, my kids at school, what’s going to happen? My doctor said: The first person you have to think of is yourself. You need to get well and we can’t put the radiation treatments off. Because I was thinking I could have it done during the Summer when we’re off. He said: No, you need to take off from work.
<table>
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<th>Photo</th>
<th>Testimony</th>
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| Alice W. Scott  
[Fish River Inupiaq]  
Dx 1984 Colon |
> Within three days I was out of Nome and they brought me down here and the doctors took care of it. I went and had radiation over at Providence, for how long, it must have been about three months. I was okay. When they found out that I had a lump in my head. We were up at camp when we found that one out. I fought all the way down, but Scott dragged me back, and good thing too. Because as soon as I came down, they put me through radiation over at Providence. So I went through six and a half weeks of radiation at Providence. Which is good, because I’m glad I didn’t get sick with . . . oh you get weak, you get very weak, but you get over that after awhile, you get back on your feet. |

| Gloria Suazo  
[Taos Pueblo]  
Dx 1994 Breast  
Dx 2004 Stomach |
> I had radiation 25, 25 times I had to go. |

| Evelyn Trujillo  
[Yaqui]  
Dx 1992 Breast |
> The radiation was a piece of cake. |
I went [through] … a tried and true program of chemotherapy and radiation treatments … The problem … is that the doctors … never ever treated anybody at my age with this.

I was 36 … most of the people that go through this treatment are in their 60s and 70s

They weren't aware of what the long-term effects of the treatment …. so 10 years to 20 years later. I have experienced a lot of adverse reactions to it especially radiation.

the radiation was terrible and they burn me extremely bad

[I was supposed to have] 25 radiation treatments. it … burned my groin and all my testicles.

then after the first burning then I got an infection and got really, really, really, sick from that infection

After I got better from that and they ordered, resumed the radiation treatments and they started burning me again.

A young doctor that evaluated my burns …

I'm not getting burnt like that again.

I had two five day sessions of chemotherapy and end at 25 radiation treatments …over about six months.

The PET scans showed when they came out only one tumor. So he put radiation, and I went to about five weeks of radiation … In the middle of it I got very sick. I got to where I couldn't eat um ... I couldn't take my pain medicine …

[The doctor] said … “Dennis. I got you cured, you’re cured.” He said I do want to run one more M.R.I. though. So he runs one more M.R.I. And I got copies of it and I compared it to the first M.R.I. that was done from the back doctor, and it was the same thing and it showed my whole right pelvis covered with about five large tumors …The three-inch tumor had almost completely eaten through my right pelvis and my left pelvis had two large tumors and there was one tumor.
I got copies of it and took it to my doctors … [I] had the Inscription House in Northern Arizona and the I asked them to explain that to me and they said, this is multiple Myeloma

So when I saw him, he said no you're cured. This is just a single Plasmacytoma. I said well, how come this MRI shows that I have tumors everywhere.

I said I got one question for you, did you … put radiation on … the three-inch tumor or did you radiate my entire right pelvis, and he told me “I didn't know.”

And that was it for me, I just hate this. I you just can't imagine; I did everything I could to keep from blowing up right there on that spot. And I said, “number one you're fired. Nnumber two, I want a second opinion”…

Well, he referred me to the nearest oncologist from there because there's not too many in northern Arizona.

I want to encourage other people, other Native American Indians, not to take for granted what doctors tell you. Get copies of your paperwork [and] ask questions. And if you don't understand your paperwork, take your [paperwork] to your clinic …[to] talk to them; ask questions. Find out what that paperwork says.

I did my radiation I was … in Portland, Oregon. I learned more from the radiation … from a man [patient] that I met there. He was a Vietnam Veteran

CeCe Whitewolf
[Confederated Tribes of Umatilla]
Dx 1998 Breast
I was diagnosed with cervical cancer … went through the surgery, went through the radiation, day after day having to go to the cancer clinic having radiation. My radiation was at twelve noon every day. Now, this little boy is about three years old coming with me, just running around and talking and talking.

I would go in for my treatments and when I first went to the cancer clinic, they were all people basically in their fifties, maybe older. I was only in my early thirties so I didn't look like the part. They didn't talk with me, they didn't converse with me.

When I would come out of my radiation treatments, he would come up, mama, mama, have you got the power now? He would say, you went in there and I know you got the power now. This little boy couldn't talk very much, but he knew that I was getting touched by something powerful. He made life worth living.

I truly believe the Creator doesn't give you anything that you can't deal with. I have been lucky,