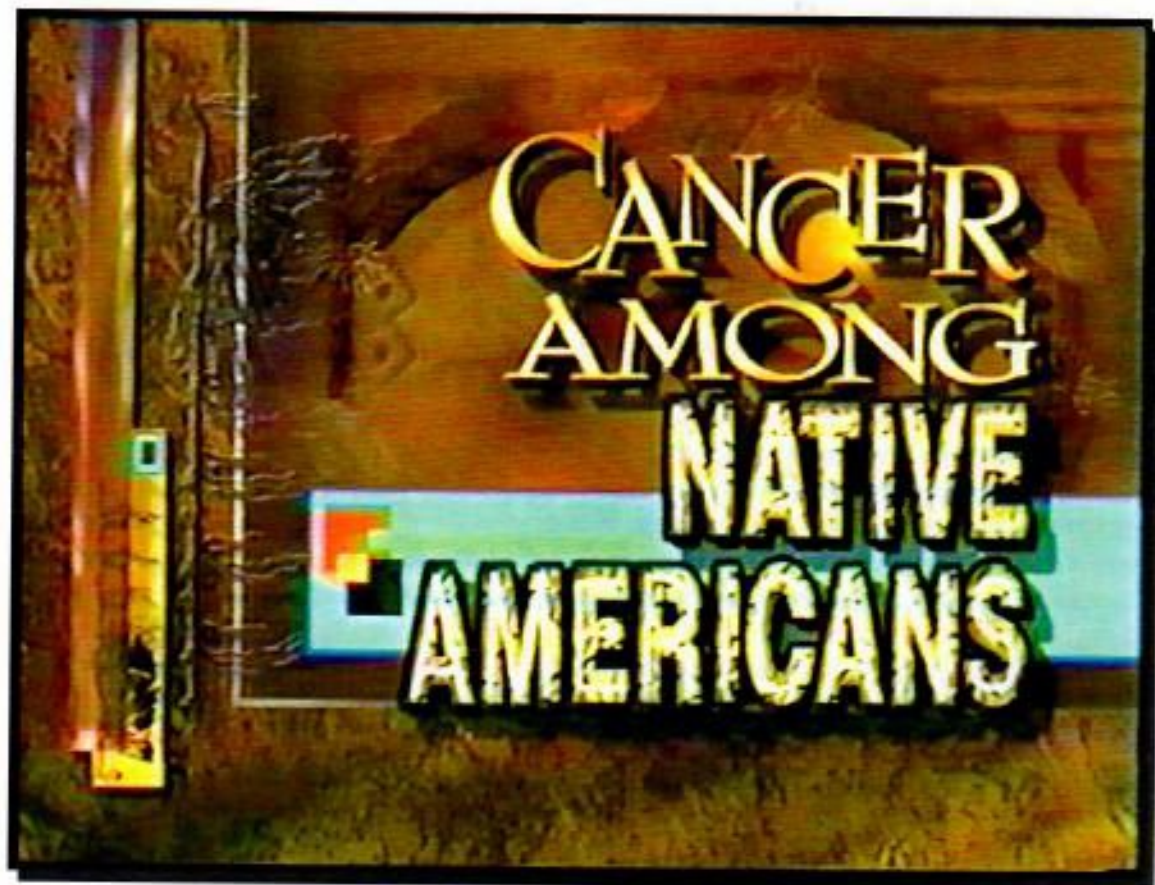


**Native American Breast Cancer
Survivors:**

***Stories of Our Breast Cancer
Treatments***



Native American Interviewers:

Mary Helen Deer Smith (*Kiowa*), Judith S. Kaur (*Choctaw/Cherokee*), Mary P. Lovato (*Santo Domingo Pueblo*), Angela Russell (*Crow*), Barbara J. Stillwater (*Yurok/Inuit*), Don Thornton (*Western Cherokee*)

Special thanks to our Native American "patients" for sharing their stories to help others through this experience.

Katherine Big Hail (*Crow*), Mary Lou Calabaza (*Santo Domingo Pueblo*), Mary Lou Davis (*Caddo/Cherokee*), Georgianna D. (*Fort Bend*), Ruth Demit (*Athabaskan-Tanacross*), Eloise D. (*Standing Rock Sioux*), Patricia Horse Johnson (*Kiowa*), Jennie Joe (*Navajo*), Frances Johnson (*Fish River Inupiaq/Yupik*), Candi Miller (*Haida*), Martha Red Willow (*Oglala Sioux*), Dominga Rosetta (*Santo Domingo Pueblo*), Angela Russell (*Crow*), Carolyn Shubert (*Fish River Inupiaq*), Carolyn Spotted Horse (*Crow*), Norma Staples (*Mandan/Sioux*), Gloria Suazo (*Taos Pueblo*), Cyndi Thornton (*Western Cherokee*), Evelyn Trujillo (*Yaqui*), Esther ("Bunny") Venes (*Inupiaq/Yupik*), Annie Williams (*Yupik*)

PURPOSE:

The purpose of this booklet is to share stories of strength from Native women who have been diagnosed with breast cancer. The intended audience for this booklet is others who are going through a similar experience, and for their loved ones. Although we have made videotapes of these stories, for many Native families, print materials are easier to use. We have prepared these materials to help prevent anyone from going through this experience alone. Many Native American cultures discourage discussing personal health problems. But with a disease like cancer that is surrounded with so much misinformation (such as a cancer diagnosis means a death sentence), we need to help one another through the experience. By sharing such information for this booklet, the Native women wanted others to learn from their stories so that they would seek diagnostic services and if cancer is present, that it be diagnosed and treated in early stage of growth (while it is still curable). These women shared their stories to help others through this experience.

Our program had many delays in developing these materials. We experienced severe budget cuts and without the help of our current supporters (see the back panel of this booklet), we would not have been able to produce these materials.

It has been an honor to learn from these women.

Dr. Haida Kuskokwimov

TABLE of CONTENTS

SURGERY.....	1
Pre-Surgery Planning	1
Mastectomy	5
Lumpectomy.....	11
Lymph Node Removal.....	13
CHEMOTHERAPY.....	16
RADIATION	22
HORMONAL THERAPY	27
RECOVERY FROM THE TREATMENT.....	27
Physical Reactions to Treatment: Pain.....	27
Physical Reactions to Treatment: Baldness	29
Other Physical Reactions to the Treatment	31
RECONSTRUCTIVE SURGERY	34
FOLLOW-UP CHECK-UPS	39

Pre-Surgery Planning

Questions to Ask Your Doctor Before Your Breast Operation

- How long will the operation take?
- How should I expect to feel after my operation?
- Will I need blood transfusions during the operation and should I bank my own blood before going to the hospital?
- What will the scar look like? Please show me where it will be.
- Will I be in pain? What will you do for my pain?
- How long will I be in the hospital?
- Will I need special care at home after the surgery?
- When can I get back to my regular routine? Will I have to take any special precautions?
- What kind of exercises should I do?
- If I decide to have breast reconstruction, can it be done as part of this operation?
- If I decide not to have reconstruction, what other choices will I have?

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I made sure that before I went into the hospital I had done all the things; . . . , I didn't... for instance want to come home and have to worry about vacuuming. So I cleaned my house, changed my sheets, put everything that I could . . . within easy reach. Dr. Blisher had explained

Caroline Shubert [Eskimo]



that I wouldn't be able to lift anything over 5 pounds . . . So I had deliberately put things I might need, so they would be handy.

I was able to contact some people that gave information to me and . . . , it helped me understand that I didn't have to make a decision right away, so . . . with reading the books . . . I was able to at least understand the type of cancer that I had . . . and the different stages of development or whatever.



Candi Miller
[Haida]



And then, . . . , they told me I'd have to come back to get or to do the radical or something. They were going to schedule it like in 2 weeks, but I was cleaning house, you know and here it start draining. So I told the doctor that it was draining and they took me in right away.

Norma Staples [Mandan]

. . . I think if I had been more insistent, saying well I really think I ought to have a second opinion on this, and I think that might be important... if they caught the cancer maybe a little bit earlier maybe I wouldn't have had the lymph glands removed, I don't know, but I do think that a second opinion would have helped at that time.



Mary Lou Davis
[Caddo/Cherokee]



Martha Red Willow
[Oglala Sioux]

Try and get second opinions. . . I really didn't have time to research it because I procrastinated so long and that's one of my major downfalls, that the minute you think you have something unusual a little lump or whatever and it may be minor or something, . . . get attention right away, because it does not go away.

I think at first there is always this urgency, because once you find out you have cancer it seems like within hours you're into something else; I mean the doctors don't wait, they don't say think about it for two weeks, I mean it's a matter of hours or days, I think that's one thing that I found unusual, I had to make these decisions fairly quick, sometimes without consulting my family . . . because they're not always readily available for these kinds of family discussions.



Jennie Joe
[Navajo]

TABLE 1. TYPES OF PROCEDURES TO DETERMINE IF A LUMP OR SUSPICIOUS CLUSTER IS CANCER

Type	Description
Fine needle aspiration	Uses fine-gauge needle to take fluid out of a cyst or to take cells out of lump. Usually done in doctor's office or outpatient area of hospital. No scar. May be followed by excisional or incisional biopsy.

**TABLE 1. TYPES OF PROCEDURES TO DETERMINE
IF A LUMP OR SUSPICIOUS CLUSTER IS CANCER**

(continued)

Core needle biopsy	Uses larger needle with special cutting edge to take a core of tissue out of breast. Use local anesthesia. Not used for very small lumps. Usually done in doctor's office or outpatient area of hospital. Usually no scar.
Needle localization; may also be called localization biopsy or mammographic localization with biopsy	Two-part procedure. Fine needle containing a wire is put into breast so that tip rests in area of change seen on mammogram. Second mammogram confirms needle is in right place. Surgeon takes out lump or cluster in area where wire is. Fine needle portion done in radiology department, with surgery in operating room with local anesthesia. Scar depends upon amount of tissue taken out.
Stereotactic biopsy or stereotactic localization biopsy	Patient may be sitting up or lying on table with hole in it to allow breast to hang down. Computer plans exact position for needle. Either fluid or cells can be taken from lump. Local anesthesia may be needed. No scar.
Incisional	Takes out part of the lump to be examined by a pathologist. Uses local or general anesthesia. Usually done in outpatient department of hospital. Operation lasts less than one hour, followed by an hour or two in the recovery room. Small scar. Since the advent of fine needle and core biopsy, rarely used for breast cancer.
Excisional	Takes out the entire lump or the suspicious area. Used for lumps that are small. Uses local or general anesthesia. Usually done in the outpatient department of a hospital or a surgical center. Operation lasts less than one hour, followed by an hour or two in the recovery room. May change the shape of your breast, depending on size of lump, where located and how much additional tissue is removed. Scar depends on type of surgery done.

Mastectomy

Table 2. TYPES OF OPERATIONS

Type	Description
Partial mastectomy; also called breast-conserving surgery, lumpectomy, or wide excision	<p>The lump in your breast is taken out, along with some of the normal breast tissue around it, to get clear margins. This is followed by radiation therapy to the part of the breast that remains. Survival rates are the same as with the modified radical mastectomy when cancer is treated in its early stages.</p> <p><i>Advantages:</i> If you are large-breasted, most of your breast is preserved. You have a better appearance than with a modified radical mastectomy. There is little possibility of loss of muscle strength.</p> <p><i>Disadvantages:</i> If you have small or medium-size breasts, you will have a noticeable change in your breast shape. You must undergo radiation treatments. If lymph nodes are not taken out, cancer may spread undetected.</p>
Lymph node dissection; also called axillary lymph node dissection	<p>Lymph nodes are taken out in the hollow of your armpit. Usually done at the same time as breast operation.</p> <p><i>Advantages:</i> Doctor can check to see if there is cancer in nodes.</p> <p><i>Disadvantages:</i> You have a risk of developing lymphedema.</p>
Total or simple mastectomy	<p>Entire breast is removed.</p> <p><i>Advantages:</i> Your chest muscles are not taken out and there is little loss of arm strength. Breast reconstruction is easier.</p> <p><i>Disadvantages:</i> The breast is removed. This operation is not a common one today.</p>
Modified radical mastectomy	<p>Entire breast, lining over chest muscles and lymph nodes under arm taken out. Usually only the smaller of the two chest muscles taken out. Survival rates are the same as with the partial mastectomy plus radiation therapy when cancer is treated in its early stages.</p> <p><i>Advantages:</i> Your chest muscles are not taken out. You can have breast reconstruction and you can plan it before your operation.</p> <p><i>Disadvantages:</i> Your breast is removed. You have a risk of developing lymphedema.</p>

So the doctor told me I could go in first thing in the morning, 6:00, and have what they call a modified radical mastectomy, which in laymen's terms means the removal of your breast, all your lymph nodes in your arm, which fights off infection, and also the first layer of your chest muscles. And that's [what's] involved in that.



Martha Red Willow
[Oglala Sioux]



Cindy Thornton
[Western Cherokee]

The [Doctors] decided that I should under go a modified radical mastectomy and which I did. I waited 2 weeks until the surgery, which was the longest 2 weeks of my life. . . To this day, I don't know what happened the first three days. But on the sixth day that I was in the hospital. I just got up, I felt good. I stripped my bed, I start putting all my stuff and getting all my flowers together. And the nurse comes in and says, "What are you doing?" I said "I'm ready to go home now", they said "you can't go home, you've got one more day, you need to stay one more day". And I'm like, oh man, so make my bed again, put everything back out. Trying to take my time, and figure out. . . ., so I go "Can I have popcorn or anything like this?". Then people started coming to see me, my relatives and I call them, the "prayer chain". All my aunts and uncles came and prayed and I felt real strong and positive and I was ready to go home. On the seventh day they said, well you better wait for the doctor to come around.

Well I have the doctor's beeper. I beeped him at 7:00 a.m. and I said, Dr. Little you need to release me now, I'm tired of stripping my

bed and making it again. And he goes, "okay, we'll be by to see you and we'll let you go." They finally let me go home. My brother had put together a party with a picture of my son holding his head saying "Home Alone". There were balloons everywhere and I had my sister washing dishes, I have another one making beds. And I'm like, wow, this is cool, you know.



Eloise D.

[Standing Rock Sioux]

After my family went out of the room, I asked him, well I said, 'Well, what's going to happen to me now?' And he said I had two options to do, one was lumpectomy with 8 weeks of... treatment, and the other one was a mastectomy. So I chose a mastectomy and he said that I would have to talk to my husband. So, . . . I kind of got upset about it, cause I ask him, 'Why do I have to talk to him about it?' because this is my life on the line not his and

if he didn't like the way I was when I got through surgery, well one of us was just going to leave . . . I was laying there before the surgery thinking about this, I was wondering, you know, what was going to, what was going to happen to me? What was going to happen to my family because I thought cancer was death. And, how long did I have left to live, how long? Was it going to be painful? Was it going to... I just thought about all negative things...

[the doctor] explained to me that her recommendation was that I have a right mastectomy. So, I asked her, 'what is the likelihood that my left side is affected?' And she said, 'well, there's less than a 1% chance.' And I said, 'Yes, but there is a chance, right?' She



Caroline Shubert
[Eskimo]

said, 'Yes.' I said, 'would you consider doing my left side as well as my right side?' And . . . , she said, 'If you're certain that's what you want to do.' And so, I said I would like for you to set this procedure up as quickly as possible. . . And I said, 'Dr. . . at my age, because I'm 50, I said at my age my breasts are cosmetic it's not like they're functional. I mean it would be, my reaction I'm sure would be completely different if I was 20 or 25 or 30 years old. But I'm 50, and .

. . . , I'm not talking about a functioning part of my body, I'm talking about the cosmetic part of my body. And . . . , that's why I'm considering having, you know, bilateral.

the recommendation . . . , for my particular case was that I have surgery immediately or within three weeks and have a mastectomy and I went through that.

Angela Russell [Crow]



Francis Johnson
[Fish River Inupiaq]

they . . . want me to decide whether to take the breast out or leave it, make sure I didn't want cancer spread in my body, you know everybody want to live. So I said better to have surgery anyway.



I saw the surgeon that very same week. . . and they found it there and said that it . . . showed it was cancer. . . . And then I went ahead and had the other test with the surgeon and they sent me up to have the surgery.

Evelyn Trujillo [Yaqui]

oh, my doctor was really very thorough with explaining . . . the cancer. And his . . . suggestion [that] I have . . . [Modified radical mastectomy] . . . , that's what he suggested, but then he showed me also other options. Then, he thought that would be the best. So then . . . we went into his office and had a consultation, my whole family and I went, and he explained everything to us to the point where we could understand everything. And the following week I went into the hospital to get my mastectomy.



Gloria Suazo
[Taos Pueblo]



**Katherine
Big Hail** [Crow]

(Daughter translates) And then so that very next day, they sent her to Billings clinic here and that's when they scheduled her for the operation, the surgery.

Both doctors argued about what they were going to do. One wanted a complete and one wanted half, I got the complete . . . I guess I was fortunate . . . I got it in time.



Georgianna D. [Fort Bend]



the surgery went really beautiful, you know, they got it done and it wasn't very hard at all.

Evelyn Trujillo [Yaqui]

Table 3. STAGES OF BREAST CANCER

Stage	Description
In situ (TIS, N0, M0)	Very early cancer is found in only a few layers of cells. It has not spread to nearby tissues.
Stage I (T1, N0, M0)	Cancer is no bigger than about 1 inch across (2 centimeters) and has not spread outside the breast.
Stage II (T0-3, N0-1, M0)	Cancer is no bigger than about 1 inch across (2 centimeters) but has spread to lymph nodes under arm (axillary lymph nodes); or cancer is between 1 and 2 inches across (2 to 5 centimeters). It may or may not have spread to lymph nodes under the arm; or cancer is bigger than 2 inches across (5 centimeters) but has not spread to lymph nodes under arm.

Table 3. STAGES OF BREAST CANCER

Stage	Description
Stage IIIA (T0-3, N1-2, M0)	Cancer is less than 2 inches across (5 centimeters) and has spread to lymph nodes under the arm which have grown into each other or into other structures and are attached to them; or cancer is bigger than 2 inches across (5 centimeters) and has spread to lymph nodes under arm.
Stage IIIB (T4, any N, M0 or any T, N3, M0)	Cancer has spread to tissues near the breast (chest wall, including the ribs and the muscles in the chest); or cancer has spread to lymph nodes near collarbone.
Stage IV (any T, any N, M1)	Cancer has spread to other organs of body, most often the bones, lungs, liver or brain.
Inflammatory breast cancer	Rare breast cancer. Breast has red appearance and warmth. Skin may show signs of ridges and wheals or may have pitted appearance. Tends to spread quickly.
Recurrent	Means cancer has come back after it has been treated. May come back in breast, in muscles of chest (chest wall) or in another part of body.

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Lumpectomy

Questions to Ask About Radiation with Breast-Conserving Surgery

- When will the treatments begin? How long will each treatment take? When will all the treatments end?
- Who will be responsible for my radiation treatments? Who will be giving them? Where will they be done?
- What kind of short-term and long-term side effects will I have? What are the risks of this treatment?

- Will I have to spend any time in the hospital as part of these treatments? How long?
- Can I continue my normal lifestyle during treatments? Is there anything special I can do to take care of myself during these treatments? Should someone come with me to the treatments?
- Will my breast change in appearance after treatment? How?
- Will the costs of the treatment be covered by my health insurance?
- How often will I have to have checkups and tests after my treatment is finished?

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I was very fortunate in many ways because I had a good friend of mine who just had gone through the same process. In fact she was in chemotherapy at the time and who is a researcher and had made it her business when she found out she had breast cancer to read all the latest literature. And so she gave me information and when I started comparing what the research reports were saying about mastectomy versus lumpectomy, I decided my chances were as good with lumpectomy as it is with mastectomy so I went for, I asked to have the lumpectomy. So I think I made an informed decision.



Jennie Joe
[Navajo]



I had the lump removed at the same time, we had made a pre-arrangement, the doctor and I had, if it was malignant, they would go ahead and remove the tumor and tissue around it.

Mary Lou Davis [Caddo/Cherokee]



Norma Staples
[Mandan]

And here when I got to the doctor he said, "Norma," he said, "we don't have to do a radical, we can do which you called a ...'Lumpectomy.'" And I said what does that mean? He said they'll take the cancerous, you know, cut most of the cancerous part out and then I'd, . . . either take radiation or chemo. And so I said, well you know that's fine, you know, . . . I'd go for that . . . cause half a breast is better then none at all.

They gave us the choice to have either... And I thought well if they don't have to remove the breast, you know, it would be fine and then if they had to later, you know, they could. And but it went fine with the lumpectomy.

Evelyn Trujillo [Yaqui]



Lymph-Node Removal



and . . . during the surgery of course they check your lymph nodes and I had one cancer cell out of seventeen

Angela Russell [Crow]

... When I came out of surgery . . . I was in the recovery room with a lot of other people and they kept me in there an hour longer because my fingers were numb, and they were hurting. And he thought it would go away, but it took like a month for it to go away, because he said when he was taking the lymph nodes out . . . he might [have] . . . got a little rough so it hit a nerve.



Eloise D.
[Standing Rock Sioux]



. . . and then I went back five days later and they removed the fifteen lymph nodes and glands, and that was . . . the way it happened, and it all happened so fast, it was kind of a surprise.

Mary Lou Davis [Caddo/Cherokee]

Your arm is in shock [and] you have to go through therapy to get it to be semi-normal to use it [again]. There was one time I was going [to go] for my treatment [and I was] trying to put on a blouse, . . . [putting] it on one arm and [then] getting it over here. I had just gotten it on and my daughter came running in the room, "oh mom, let me help you", she took it off of me. You don't know what a struggle it was to get it back on there. . . I know before I had use of my arm again, I was using a curling iron, I was trying to curl my hair and the curling iron gets stuck in my hair and I was pulling it.



Martha Red Willow
[Oglala Sioux]



And they removed the lymph nodes under here and they were fine. And, . . . everything just went good . . . The surgery and even my incision doesn't show, you know, at all and under my arm it doesn't show.

Evelyn Trujillo [Yaqui]

After I had surgery, and had the lymph glands removed, and I had to wait a month until it kind of healed up a little bit, I guess it was longer than a month and then I started radiation treatment



Mary Lou Davis [Caddo/Cherokee]



Gloria Suazo
[Taos Pueblo]

[there are] 7 of my lymph nodes that were removed and I kept thinking had I not waited long maybe, . . . they wouldn't have done that. But it's, it's to late now to even think that. And I really get scared thinking what if I had waited much longer. It would have been passed the lymph nodes and some place else. It's really scary to even think that.

. . . he said that I have to have some more surgery procedure done to look at my lymph nodes to see if the cancer had spread there and

Jennie Joe [Navajo]



that was certainly something that he wanted to do . . . My particular cancer had spread through my lymph nodes—at least one of them was positive, so I didn't have a choice, I had to have the chemotherapy.

[the doctor took out 3] lymph nodes and . . . one of them was positive [had cancer cells]. So that meant I had to have, (they gave me a choice), either . . . the . . . breast removed and have chemotherapy or have radiation and chemotherapy.

Ruth Demit [Athabaskan]



CHEMOTHERAPY

Chemotherapy

Chemotherapy has been used for fifty years, but many changes have occurred in the types of drugs used, dosage, and frequency. Chemotherapy is sometimes recommended prior to surgery to shrink the tumor and make it more feasible for the surgeon to remove all of it. Chemotherapy affects the DNA of the cells by interfering with cell duplication. Chemotherapy affects both cancerous and healthy cell DNA. The healthy cells that are particularly susceptible to chemotherapeutic drugs are those which multiple quickly, like the skin (including hair), gastrointestinal tract, and bone marrow. Chemotherapy on healthy cell DNA results in side effects such as temporary hair loss (due to the effect on the DNA of the hair follicle), fever blisters or diarrhea (due to the effect on the DNA of the gastrointestinal tract). Although there are common effects of specific chemo regimens, every cancer patient responds differently and the chemotherapy is modified for the patient.



Angela Russell
[Crow]

Well chemo is not easy, because . . . , it really lowers your resistance to a considerable extent. Because they are trying to kill off the cancer cells, a lot of other good cells are killed in the process so your immune system is really assaulted . . . I think the thing that probably bothered me more than anything during chemo was a lowered resistance. One really needs to be careful during that stage, that you're not in contact with people that have contagious

diseases, that you're not around people who have a lot of colds and have the flu. You just got to be a lot more cautious, and once you catch something like even a minor cold, that could be major and . . . so you've really got to take care of yourself . . . [You] also have to keep that spirit up too. . . . but I always told myself while I was finishing up my chemo, "remember, you've got three months left, or two months left and when you're through with this you're going to go on a trip". And I think we need to take care of ourselves more than we do.

I finished the radiation, I did 6 months of chemo. I was 2 weeks on, 2 weeks off. And, . . . , then I had like a month between chemo and then I started radiation. I did that everyday for 8 weeks . . . it wasn't as bad as I thought. I [didn't] get as sick as I thought I was going to get. The chemo wasn't easy, but it wasn't hard . . . It wasn't fun, but it was worth it all. . . . , my husband went with me and when I did the chemo he would stand behind me, you know, with his hands on my shoulders. And it was really neat because I got sick and he got sick at the same time. . . . , when I started losing my hair, he lost his hair too. And everything I went through when I'd go in to get my chemo, I guess it was just like



Evelyn Trujillo
[Yaqui]

the smell of the, . . . alcohol that they [use to] clean before they start your chemo . . . I don't know what was the key, my husband, would get sick, my husband would get sick as soon as we went in. He would turn gray, his face would turn gray . . . , but he stayed there. And the doctor would say, "Mr. Trujillo you don't need to stand there behind her, you know." And he would say, "I know I don't have to, I want to." So I had a lot of support, and . . . it was good to know that so many people loved me and that were behind me and that were pulling for me.



Martha Red Willow
[Oglala Sioux]

After that surgery then you go through six cycles of chemotherapy, if that doesn't get it all then you go onto radiation. Well I went through the chemotherapy with the six ... So I went in and had my surgery that morning, ... went through my chemotherapy, . . . , by then I was working two part-time jobs and around my surgery was February 8th of 1989 and I went to work in May, I [was] working two jobs, it's just something that you have to do, you don't have time to worry about my arm hurts, you know all of this, we just do it.

so my doctor then recommended that I go through a six month course of chemotherapy and he really said it was up to me . . . it was kind of like added insurance and I have a cousin who's a medical doctor and he called and he said you've really got to do it, it's really important, it's added insurance and it's not going to be all that difficult to get through six months of chemo, so I decided well maybe I



Angela Russell
[Crow]

should do it. So I went in immediately and did the whole six months of chemotherapy as an outpatient here in Billings. . . I changed my diet, I didn't eat red meat, . . . , I cut out all kinds of fats, didn't use chocolate or eat fruits that weren't grown in this climate, a very strict regiment, no coffee, . . . , so I tried to stick with that for the full year, half of that year of course I was on chemo, I think that made a difference to my body.



In my situation, my cancer was found so early and, . . . , I did not require . . . any chemotherapy or radiation.

Caroline Shubert [Eskimo]

I did go through chemo. I just wanted to sleep all the time or just stay home and they were trying to get me to be my old self again. They were really supportive.



Carolyn Spotted Horse [Crow]



8 [cycles of chemo] ... it really was [more intense] because my cancer was very [progressed] . . . that went for . . . 8 treatments. And, . . . I . . . use to hear a lot of scary stuff about chemo, you know how it makes you sick and you lose your

Gloria Suazo [Taos Pueblo]

hair and all this stuff. And I was scared of that more than anything else. But, when I started the treatment and went through it, it was just like, it was just like it was so easy.



Jennie Joe
[Navajo]

I had the chemotherapy and I had the radiation . . . the chemotherapy consisted of probably three different types of drugs. . . . , my treatment took almost a year . . . , because with chemotherapy, they always give you time for your body to re-build your blood cells, . . . , so I think you know the treatment isn't something that you can go in and have it done within two or three days. , the first time I went in for chemotherapy, four of my friends came in to sit with me so all of this was very helpful.

I chose radiation and chemo [rather than surgery]. And . . . I had seven weeks of radiation at Providence Hospital . . . after I was done with that I had to wait awhile cause I was kind of . . . burned . . . chemotherapy time was coming up and then Claudette and my doctor told me they said if your blood is not in good condition to take the chemotherapy we're not going to be able to give the chemotherapy. So I thought at the time

I would fix that, I drank all night and I, I went to work and I mean I went to the hospital and I was half shot and I was watching down the road and my landlord . . . said "you're not going anywhere Ruth", she says "I know what you're thinking" and I [said], "no I'm not thinking nothing". She says "I see you want to take off" and I knew if I had taken off



Ruth Demit
[Athabaskan]

from that hospital I wouldn't of come back . . . So, she hooked me up you know and needles didn't really bother me that much anyway . . . so . . . then we sat there and nothing really happened except I got cold as this waters cold you know it looks like plain water and stuff. So, I was reading in that book too you know drink warm, a lot of liquids, this is highly concentrated medication so that's what I did I drank hot water to warm myself up you know while they did it. The first time my landlord came with me, and then my oldest daughter, Linda, she came with me and we sat there and played cards and whatever, finally we got the knack of it and I came up there to the hospital by myself and I was writing my own letters while I was, you know [receiving chemotherapy]. I became real good friends with Claudette, the nurse you know. . . Claudette has helped me too . . . , I mean has asked me to come down to speak to some people. Like this one little lady, elderly lady and, I guess Claudette had trouble explaining to her, you know why they were giving her chemotherapy and she thought surely they were trying to kill her, you know. So I went down there and I spoke to her and I said you're sitting in the same chair where I used to be and she looked at me and she said you were here? And I says ya and they had me hooked up just like that. And I says, do you know why they're doing this? And she said ya, they're trying to make me sick, you know. And I says no, I says, this is the medication to keep you from getting sick and this kind of sickness can kill you. What this nurse and these doctors are trying to do is trying to make you well. And . . . , so later on when she, I went down to Claudette I said well how is this lady doing? And she said oh just fine she just marches right in and sits down. . . And my brother you know, oh my brother was something else, my brother he says, well sis how you doing on your with your chemotherapy and I says . . . , I says I'm doing fine some days I'll come home and I'll go to sleep for about three days and there are other times I'll come home and I'll clean my house and I'll go shopping. It just depended you know.

[Daughter translation] they didn't have the chemo right away, and . . . , lets see, from this was in May and she never had the chemo or anything until, . . . February, . . . February of . . . 94", . . . this last chemo she had, they, she was gaining weight and the doctor said I think she's like a 17 year old again. (Laughter) So you know I said no wonder I can't catch up with her. (Editor's Note: she was 74 years old) at the time of the interview



**Katherine
Big Hail [Crow]**

Radiation

Radiation Therapy

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 are also destroyed by radiation which is why providers monitor the intensity carefully.

"Radiation Therapy" goes by different names:

- radiotherapy
- x-ray therapy
- cobalt therapy
- electron beam therapy
- irradiation

As with other types of treatment, the goal of radiation therapy is to provide the patient with the best chance of a cure with the least amount of toxicity and simultaneously provide the highest quality of life during treatment and after treatment. About half of all people who are diagnosed with cancer undergo radiation. For many patients, radiation is the only type of treatment needed, in others it is used in combination with chemotherapy and hormonal therapy. Radiation may also be used at different times during ones' treatment, such as after having a mastectomy.



Francis Johnson
[Fish River Inupiaq]

[Daughter's translation] she was very afraid of the radiation, . . . and she was quite reluctant to undergo the radiation treatment because that's what was recommended in her situation. . . . , and it took a while before . . . my brother Johnny . . . finally came down from Nome. It took a while before we were able to convince her that it was in her own best interest to do something other than, you know, risk having a recurrence of the cancer. . . . , after she under went the radiation treatments, . . . , it took awhile of course because of her age [ed. she was 76 years of age at the time of diagnosis], . . . for her to recuperate].

When I got operated on, I had radiation. That's all I had was radiation, and the staff in Santa Fe... they really encouraged me too. I got scared when the big machine came down on me cause I never experienced nothing like that in my life, so I got scared so I started praying in my own prayers. I asked the machine, whatever you are, believe and get me well. That's what I said to the machine, get me well.



Mary Lou Calabaza
[Santo Domingo Pueblo]



After I had surgery, and had the lymph glands removed, I had to wait a month until it kind of healed up a little bit. I guess it was longer than a month and then I started radiation treatment . . .

Mary Lou Davis [Caddo/Cherokee]

and I went everyday during the week for two months, from before Thanksgiving until the 17th of January and so. The last thirteen treatments were what they called . . . , electrons and they pinpointed right into where the tumor had been with . . . , rather than doing a field, the others is what they called a field x-rays and did thirteen treatments and that was really zapping. . . Well, I tell you what. You have to have a lot of . . . , positive thoughts to get through radiation because it just drags you down, gradually, just zaps your strength . . . Fortunately, I had my pottery and so, I would go down to the hospital and get my radiation treatment and then go over to the pottery and work for a couple of hours you know every day and it just took my mind off everything, and then I would get tired and come home and go to sleep. But that's the way it worked. . . We [have a traditional healer in our family] and he was here during the time I was doing radiation. And he . . . , did some prayers and we . . . worked on that and he said, if this doesn't all work we can go on and do Indian herbs and things, he said there's some other things that we can [do],

When, you ... say "cancer," you naturally think your going to [die], that's it, but now they have radiation and everything you know.

Norma Staples [Mandan]



I was scared a little bit. I was scared to get radiation. . . . My son John Johnson come down from Nome and [kept] [encouraging] me. [He kept] on telling me just take pictures everyday . .

Francis Johnson [Fish River Inupiaq]

. you'll be okay, I was undecided to get this radiation, six weeks they said they going to do that. I was, I thought maybe I might not really live . . . I feel weak anyway. But Johnny . . . [kept] on telling me to have the radiation. I was glad when I [could] count the weeks only few more weeks I [would get] better but I got weaker and weaker, [during] the last two weeks when I used to go to Providence Hospital.



Evelyn Trujillo
[Yaqui]

the radiation was a piece of cake. . . . I finished the radiation, I did 6 months of chemo. I was 2 weeks on, 2 weeks off. And, . . . , then I had like a month between chemo and then I started radiation. I did that everyday for 8 weeks . . . today, this year I'm seeing my radiation doctor every 4 months and then I'll see the oncologist 2 times this year. And then I'll be, everything will be fine, I hope.

After the chemo I had radiation. I had radiation 25, 25 times I had to go. And I just completed that, as a matter of fact, just a couple weeks ago.

Gloria Suazo [Taos Pueblo]



I had the chemotherapy and I had the radiation .
..

Jennie Joe [Navajo]



Ruth Demit
[Athabaskan]

I chose radiation and chemo. And . . . I had seven weeks of radiation at Providence Hospital and then . . . after I was done with that I had to wait awhile cause I was kind of, kind of of burned . . . [Radiation] wasn't painful for me, it wasn't painful. . . [But] I didn't like the radiation treatment. It's was, it's like walking into a different world. You know, it's just different language you know a lot of medical terms and

all that stuff and . . . , and then they put me on a table and strapped me down stuff like that and . . . , I . . . , I would not, I wouldn't talk about it, and I thought well I'd be tough you know and I would just, I would not say anything and the only thing that really got me mad was . . . , I was tied up on the table there and one of the technicians has seen a tear come down my face and I was so mad because I didn't like to be tied down. And . . . , so they called in a social worker you know, and I thought you guys don't know what you're doing, you know just leave me alone . . . So . . . , finally, when I finally got used to it, it was almost towards the end, I finally accepted it. . . I met a lot of new friends . . . when I was going through radiation. . . I mean radiation, I had to have cab drivers who volunteered their time to . . . cancer patients to pick me up from [my] home and take [me] to Providence and the majority of them were Christian. . the literature they had given me I had set it aside, it was collecting dust because I didn't want to have nothing to do with it, you know, just leave me alone, period! And . . . , and there was nothing on t.v. so I reached out and picked up this book and started reading on it. And it was just like something opened my mind up, you know, and I was ready to accept it and so I cooperated. And that was shortly before the end of radiation. . . But . . . , there was a lot of problems during my treatment because of my alcoholism. One time I refused to go to radiation you know, and

that doctors really nice, he . . . , he called me up and really talked to me, he said you're too young to die and I thought, wow, I'm not going to die you know . . . And he says you know, he says you are one of the very few women in that date and age that has survived cancer. So I believe that you know, God helped me out throughout that because I really mis-behaved bad you know.

HORMONAL THERAPY

[Linda B's Editor's Comment: Hormonal therapy, such as using tamoxifen, helps prevent cancer from growing in the remaining chest and breast tissue. Not one out of the 21 Native American breast cancer survivors interviewed mentioned anything about being tested for hormonal receptivity, nor about taking any type of hormonal therapy!]

RECOVERY FROM THE TREATMENT

Physical Reactions to Treatment: Pain

Two ... nurses came in and they told me I have to walk and go to the bathroom. And to myself, 'they're not taking me [to] the bathroom, I'm going myself.' So, I had no pain, you know, in

Eloise D. [Standing Rock Sioux]



my breast, the surgery itself I had no pain. And I sat up, they helped me sit up, and when I slid off the bed and my feet touched the floor, the pain was there. And I, I just hung on to one of them and a table and stood for awhile and then the pain went away, but I felt this numbness come over my arm and my back and then I felt top heavy. So they had to hang on to me and so I walked and I made it to the bathroom and I did what I was supposed to do. Then, when I came out of there, well, they said I had to take a walk down the hallway. So I did and they were following me and kept asking are you sure you're alright? Do you have any pain? I had no pain. And I walked the length of the hallway and I came back and got back in bed . . . Then I had supper and after supper, well, the doctor came to check on me and I was out walking and so he was coming down the hallway and I thought he recognized me, but he didn't and went on into my room. Then all the sudden he was walking, he came out backwards and he looked at me and said 'Eloise?' and I said 'Yea.' And he was so happy to see me walking and he asked me if I was having any pain? And I said no, I wasn't having any pain. So I got back in bed and he examined me and said everything was fine. And he wrote out a order if I had pain in the night to give me . . . , a hypo. But I didn't have any pain, I didn't need any medication for that.

I feel after the surgery, I woke up, nothing pain,
. . . but it's really touchy there but nothing hurt,
nothing wrong, no pain

Annie Williams [Yupik]



Physical Reactions to Treatments: Baldness



**Carolyn Spotted
Horse**
[Crow]

By going back to work . . . , in fact I went back [the] first part of March and I still had two more [chemo] treatments, and I was still, well I wasn't bald but I still had to wear that wig and the people that I work with were really nice and were understanding and that helped a lot. . . [my family was] . . . really supportive, [they] wanted me to just go to the Cancer Place, The American Cancer Society, to pick out some wigs and they had the ugliest stuff over there (laughter), I mean they did, I mean it was free,

but it was ugly. My (native tongue) I went and ordered one myself and it was a hundred and something and I didn't have to pay anything because my brothers and my sisters, they all pitched in and bought it for me.

When you lose your hair, I'm mean I'm sure a lot of people have this thing with self esteem anyway. But because a lot of us are hiding behind our little gifts that we've been given-- hair, and eyebrows, and eyelashes and such-- that when they're gone, when they're stripped, you really lose a lot. Your femininity has been questioned, you know, because you identify certain things with being feminine. Your fingernail polish, your hair, or these little attributes that everybody has. And when that's gone, you don't feel feminine. . . . , it's something, not to have your hair, but it's



Alisa Rodulfo-Gilbert
[Tewa Pueblo]

something else not to have your breasts. It just doesn't matter if, you can put a wig on and you can put the fake prosthesis on, but they're not real. And the female figure is so sensual anyway an it's so, beautiful. The beauty that comes from a woman is incredible. And the breasts, when they're not there, you lose that. So I'm sure that every woman that goes through this process, goes through an entire identity crisis because I felt when they removed my breasts, that I was walking in a man's world because I couldn't identify. So I felt like my paths were split there.

My hair probably was half this length and I said I would never cut my hair again, because there's always a 5, 10, 15 percent chance of getting it again. You can't just totally put it out of your mind and say I don't have it and it's gone. It's something that will be with you forever and it's just learning to deal with it. I did lose a lot of hair and when I'd take a shower I felt like Wolf Man, just pulling my hair there was gobs of hair just in my hands. Luckily I have thick hair and I will never ever complain about having thick hair, thank you, God.



Martha Red Willow
[Oglala Sioux]



The only thing I did was lose my hair and that was also very drastic, you know. The very first treatment and my hair started falling out.

Gloria Suazo [Taos Pueblo]



Ruth Demit
[Athabaskan]

I . . . went in there and they told me the possibility of me losing my hair, I could handle that you know, I thought well I can handle that, but the actual part of removing the breast no, I said I cannot and I also prayed about that . . . And [my brother] says, well . . . , are you bald yet? And I says, no, and he says oh shucks, I always wanted a bald sister. And I says no, the wig is still up in the closet, you know.

Other Physical Reactions to the Treatments

A friend had called in the afternoon and I'm talking late in the afternoon and I was just getting out of bed. And see that was normal for me to start sleeping until 3'o'clock. Is this your normal, is this what your normal routine is now? Well, how long does it take you to make your bed? Let me ask that." And I said "Well I don't know, maybe an hour. You know, put one blanket down, sit down, do another, sit down." And that wasn't normal. But I, I couldn't, I wouldn't have known that. I wouldn't have known any different because I just thought, that's what happened to you when you're going through this treatment. I know I can only do one important thing today. Whether it's take my dog for a walk, or got get something to eat, do my laundry". That would be it for the day. And the rest of the day I was down. That is not living, that's not living, at all . . .



Alisa Rodulfo-Gilbert
[Tewa Pueblo]

I woke up so hungry. I called the nurse and told her I'm so starved if you [can] bring me some coffee and so she got me . . . two cups. And before she walked out and I told her I'm really hungry when they have breakfast I want to eat real breakfast, she said . . . she's [going to] call the kitchen. I was glad before those [day] nurses come back . . . She's the night nurse, [and] at 8:00 she [brings] my breakfast, boy I was hungry . . . While I was eating, my nurse came and she look



Annie Williams
[Yupik]

at me "Annnnie!!" . . . , I thought that when she look at me I thought there's something wrong with me (laughed) and she said you're not supposed to eat nothing, you're supposed to have liquids after you have a surgery, are you ok? I said I'm ok, I'm fine there's nothing wrong with me that's why I'm hungry. "And don't eat all of em, are you okay? Do you feel like puking?" I said, "No, I don't feel like puking. I m hungry" and she said "don't eat all of it, you're sick, you just had surgery you're not supposed to eat." As soon as she walk out, I eat as fast as I could go before the other ones come. (Lots of laughter) Just as I finished my food my doctor came in "Annie, you're not supposed to eat, you're supposed to eat liquids for the whole week" and he asked me "how do you feel?" I said "I'm fine, that's why I'm starving" . . . "how [does] your stomach feel?" , "my stomach's good, there nothing wrong." He keep asking me if you feel like puking? and I said no. The doctor said lots of em when they have the breast surgery they can't eat and every time they eat something they puking and really sick. I wasn't, I was hungry and the doctor said "Annie, you're tough ." . . . [Infection] After they take my breast off, I got really sick two weeks later for my stomach. I used to have a stomach ache all the time over seven years I got worse and every time I got stomach ache. I got . . . really bad diarrhea that time after two weeks later I got surgery on my breasts

and I don't remember some of it I got so bad stomach ache. I went down the hospital on Saturday they didn't take me they just give me the pills to help my stomach ache, it doesn't help. And that night I didn't sleep. I was so suffer and Sunday morning around 7:00 o'clock I went down the hospital and I don't remember some of it I was so suffer I think, I only remember I [walked] into the hospital and I don't remember some of it. Just like I woke up on the stretcher and boy my stomachs really bad pain. They put me in the hospital and they check . . . my guts and Dr. Stain was my doctor they take my breast out and he find out my guts got really bad infection that's what make me [have a] really bad stomach ache.



**Carolyn Spotted
Horse - [Crow]**

Oliver, my youngest brother, well, the youngest of our family, he took me skiing and he was trying to get me out, but I was forever tired, well you went through that, we're always tired. But they were supportive and were trying to get me back to doing things again. Because I like to do stuff like that before . . . the pills that they gave me knocked me out for about six hours at a time, and I lost a lot of weight, couldn't eat, I was depressed...[I got over it] By going out and doing things, I mean there wasn't anything that I could do; it had already happened. That had to sink in first and when it did is when I accepted it, I dealt with life again. It was embarrassing at first to go out because it seems like people were just staring at you, I mean they probably didn't even know, but it seemed like they did know.



and your muscles are all achy, so my mother told me she'd give me a back rub and she brought this tube in and she opened it and she started to put it on my back, it was toothpaste. There's a lot of funny stuff that you do,

Martha Red Willow [Oglala Sioux]

The tea we pick from the country in Council, "Alaska tea" we call em, we add to our tea and that tastes good too, we drink tea. That's about all I think, we eat the stuff we always eat like dried fish and boiled fish every summer, dry some fish.

Francis Johnson [Fish River Inupiaq]



RECONSTRUCTIVE SURGERY

Questions to Ask Your Plastic Surgeon Before You Have Breast Reconstruction

- What are the different choices of reconstruction surgery? What type do you think is best for me? Why?
- Should I have the reconstruction at the time of my mastectomy or should I wait until later? How much later can I have it done? If I need to have chemotherapy, should I wait until I have finished that treatment?
- What are the advantages and disadvantages of having reconstruction at the time of my mastectomy? Of waiting to have it until later?
- What are the side effects and risks that I should consider?

Questions to Ask Your Plastic Surgeon Before You Have Breast Reconstruction (continued)

- Will you be using tissue expanders? A saline-filled implant? Can you use my own tissue?
- Will you explain how the surgery will be done? What kind of anesthesia will you use?
- What will I look like after the surgery? What kind of scars will I have and where will they be?
- What will my new breasts look like? Will it match my other breast? Will it change over time? Will I have to have anything done to my other breast?
- Can I have my nipple reconstructed? How will it be done?
- What is your experience with this operation?
- Do you have any before-and-after pictures you can show me?
- May I talk with someone who has had the operation?
- How many operations will I have to have? Will I need to be in the hospital each time? For how long? How long will I need for recovery?
- Will I be in much pain?
- Will I need to wear a special bra after my operation?
- How much will it cost? Will my insurance cover any part of it?
- What can be done if the surgery is not successful?

Printed with permission, Morra and Potts, *Choices*, Avon Books, 1994, p. 339.

So the breast was removed and I had the immediate reconstruction following that, it was a very long surgery... It was eight hours under anesthesia, it was difficult. . . . , a lot of plastic surgeons that do the breast reconstruction . . . aren't able to do an immediate reconstruction

Candi Miller [Haida]



with women that smoke. . . . , I'm a non-smoker now, I was a smoker then and that kind of made the difference in determining where I would have this done. ... it's called the free tram flap . . . , where they, they make an incision in your lower abdomen and then they take the muscle on the opposite breast and kind of weave it through and re-build, and I wasn't able to have that done because of the previous gall bladder surgery, because I smoked, so this doctor did the same tram-flap but what's called free tram-flap where portions of the muscle and tissue is actually removed from the body and placed and reconstructed. . . . It's very delicate work and I feel that he did a really wonderful job. I'm not disappointed.

Table 4. OPERATION CHOICES FOR BREAST RECONSTRUCTION

Description	Comments
<p>Expander Can be of several types. Empty silicone sack or double envelope with silicone layer and empty sack implanted under skin and muscle, gradually filled with saline (saltwater) solution through a valve over a period of weeks, stretching skin. Local or general anesthesia. Inpatient or outpatient. Surgery takes 1 to 2 hours.</p>	<p>Most common type of reconstruction. Provides greatest flexibility in breast size. Requires additional office visits (15 to 30 minutes) to add saltwater solution to stretch skin. May be uncomfortable for some women. Can have problems with valve. Another operation often needed to convert expander to permanent implant.</p>

Table 4. OPERATION CHOICES FOR BREAST RECONSTRUCTION

<p>Implant, also called fixed-volume implant Sack, filled with silicone gel or saline fluid, implanted under the skin and chest muscle. General or local anesthesia used. Can be outpatient or inpatient. Surgery takes 1 to 2 hours. Short recovery time. Low rate of complications.</p>	<p>Implants filled with silicone gel can be used only if a woman is enrolled in a clinical trial. Saline filled have silicone layer or envelope that contains filling.</p>
<p>Latissimus flap, also called back flap. Muscle called latissimus dorsi, and eye-shaped wedge of skin moved from back to chest wall and sewn in place, leaving tissue attached to original blood supply. Inpatient with general anesthesia. Surgery takes 2 to 4 hours.</p>	<p>May need blood transfusion. Major surgery that can be painful. Need to stay in hospital 3 to 6 days. Scar left on back or side. May have drain in for several weeks. May have fluid buildup in back area. May have slight bulge under arm that will shrink in time.</p>
<p>TRAM flap (transverse rectus abdominous myocutaneous), also called tummy tuck. Fat, skin and muscle taken from stomach area and moved up to form breast. Tissue usually</p>	<p>May need blood transfusion. Major surgery that can be painful. Hospital stay of several days. Recovery period may take several weeks, including inability of patient to stand straight for days or even weeks. Healing problems may occur, including thick tissue on flap. Scar in abdominal area.</p>

Table 4. OPERATION CHOICES FOR BREAST RECONSTRUCTION

<p>remains connected to abdominal blood supply, although in some cases microsurgery used. Inpatient, with general anesthesia. Surgery takes 3 to 5 hours., with general anesthesia. Surgery takes 3 to 8 hours.</p>	
<p>Microsurgery, also called free flap. Muscle and fat from other parts of body, such as buttock or thigh, are cut free from blood supply, moved to breast and reattached to breast blood supply by microsurgery. Inpatient with general anesthesia. Surgery takes 3 to 8 hours.</p>	<p>May need blood transfusion. Major surgery that can be painful. Hospital stay of several days. Recovery period may take several weeks, including inability of patient to stand straight for days or even weeks. Healing problems may occur, including thick tissue on flap. Scar in abdominal area.</p>
<p>Nipple Can be made from existing skin, pinched and tacked to make nipple, or created from tissue from other nipple or groin and attache to breast mound.</p>	<p>Areola reconstruction may also be done. May need tattoo to match color of other breast. If created from other nipple or groin, that area will feel tender for about 2 weeks.</p>

FOLLOW-UP CHECK-UPS



Eloise D.

[Standing Rock Sioux]

Since I had the surgery . . . , I was checked for a tumor in my head which wasn't, they thought it was a tumor, but it wasn't. And then just 2 weeks ago I was checked for lung cancer and . . . , [there] was nothing to that. So it's a fear, you know, that we're going to live with the rest of our lives.

Every year I still have to under go series of tests around the anniversary date of my surgery and I have one more year to complete the test before they say, what they say cancer free. . . My last test was my four year mark and it was pure hell, excuse the expression, but it was pure hell. Because they had to order a couple of extra tests because of some complaints I had in my rib cage since I had my breast removed. . . in 6 months I need to go back and get it rechecked to see if I have to get it removed or not. But every year its like, you know I have to psych myself up for a week long of tests.



Cindy Thornton

[Western Cherokee]

I try to go in on a regular basis for check-ups, . . . the chemical testing I guess is one thing that's always a little disconcerting because early on my alkaline phosphatase level for instance was not normal, but my . . . oncologist explained to me that if there are variances in it where if it fluctuates considerably, then that's



Angela Russell [Crow]

probably an indicator, but as long as it's staying at one level and staying there I think we're okay So it's really important to . . . make sure that you're eating right, that you're getting some exercise and that . . . spiritually and mentally that you're okay

Today, this year I'm seeing my radiation doctor every 4 months and then I'll see the oncologist 2 times this year. And then . . . , everything will be fine, I hope.

Evelyn Trujillo [Yaqui]



Annie Williams
[Yupik]

Now, I [have] nothing wrong with me. I don't have no more sickness no cancer or nothing. But I have to go check this every . . . three months. . . They say I am . . . doing really good, now my, . . . blood's good now too and they say from now on four months. Boy, I was really glad when they say four months, I'll go down to see him in January.

{Family and Friends} Then they make sure I come for my check-ups, somebody's always hollering at me, telling me make sure you go for your check-ups.

Georgianna D. [Fort Bend]



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In Honor & Memory of ***Katherine Big Hail*** [Crow]