

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities



American Cancer Society Circle Of LifeSM
Cancer Education and Wellness for American Indian and Alaska Native Communities

Wellness along the Cancer Journey:
Treatment

Revised October 2015

Chapter 3: What to Expect During Cancer Treatment



Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

What to Expect During Cancer Treatment

Group Discussion		True	False	Not Sure
1.	Chemotherapy is always part of cancer treatment.			
2.	Everyone has bothersome side effects with cancer treatment.			
3.	If someone pays attention to what they eat while getting cancer treatment they may feel better.			

Preparing for Cancer Treatment

Until someone begins treatment, they won't know exactly what side effects they may have, or if they might be bothered by them. They don't yet know how they may feel. One way for someone to prepare is to think of treatment as a time to focus on self-care and on getting well.

They can often feel less anxious about treatment side effects by learning as much as they can about cancer and its treatment. They can also talk with their health care provider about their concerns. Planning how they will cope with possible side effects can make them feel more in control. They have their cancer treatment team to help them manage side effects.

A person may feel sadness, anger, guilt, fear, and many other emotions. But it's important to remember that no one has to feel alone. And they can find others to support them with the feelings that come up.

Health Insurance Coverage

A person might wonder why they would need health insurance coverage if they get services from the Indian Health Service, a tribal program, or an urban Indian health program. But enrolling in health coverage through the Health Care Marketplace, Medicaid, or CHIP means that a person has better access to services

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

that the Indian Health Service, tribal programs, or urban Indian programs (known as I/T/Us) may not provide. This can be very important to a person with cancer.

A person who enrolls in a Health Care Marketplace health plan, Medicaid, or CHIP (see below) can keep getting services from their I/T/U the same way they do now. When they get services from an I/T/U, the I/T/U can bill the insurance program. This benefits the tribal community, allowing I/T/Us to provide more services to others.

Keeping job-based health insurance might be a challenge for some with cancer. People who have Medicare or Medicaid don't have to worry about this, but people who have their health plan at work can have problems if they lose or quit their jobs.

When a person with cancer quits their job, they usually lose their health insurance coverage as well as their source of income. This can cause problems for a person who is getting cancer treatment. If a person can pay for their own insurance, COBRA will allow them to be covered by the same insurance plan for some months after leaving a job. COBRA lets a person keep their job-based insurance for many months, as long as premiums are paid. But there are a couple of other options when a person loses health coverage.

One option can help people who are married to someone with a health plan at work. If a person's spouse is employed and has health insurance, a person usually has 30 days to be added to their spouse's policy. This usually will cost more, and there may be a few weeks delay for a person to be added to the policy, so it's good to find out about this before you quit your job if you can.

It's also important to know that American Indians and Alaska Natives may have new health coverage benefits and protections in the Health Care Marketplace. Some special benefits are available to members of federally recognized tribes or Alaska Native Claims Settlement Act (ANCSA) Corporation shareholders. Others are available to people of Indian descent or who are otherwise eligible for

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

services from the Indian Health Service, a tribal program, or an urban Indian health program.

Members of federally recognized tribes and ANCSA shareholders have the option to enroll in their State Health Care Marketplace coverage any time of year. There's no limited enrollment period for these individuals, and they can change plans up to once a month.

In fact, a person can enroll in a Health Care Marketplace plan even before they lose their insurance, to be sure that the new insurance starts before the old plan ends. Buying a health care plan on the Health Care Marketplace is often a less costly option than COBRA coverage. Visit HealthCare.gov or call 1-800-318-2596 (TTY 1-855-889-4325) for more information. For special information on insurance for American Indians, see the healthcare.gov/american-indians-alaska-natives web page. It details the special process for buying a health plan any time of the year.

If a person can't afford to buy insurance on the Health Care Marketplace due to loss of income, they can apply for Medicaid for themselves and Child Health Insurance Program (CHIP) for their children. Visit HealthCare.gov or call 1-800-318-2596 (TTY 1-855-889-4325) for more information or to apply for these programs. You can also apply for Medicaid by contacting your state Medicaid office and learn more about the CHIP program in your state by visiting insurekidsnow.gov or calling 1-877-KIDS-NOW (543-7669).

For more about keeping a job during cancer treatment, see the section below called Working during and after Cancer Treatment.

Types of Cancer Treatments

Surgery, radiation, chemotherapy, and immunotherapy treatments may be used alone or together. The type of cancer, the stage and grade of the cancer, and other factors will be key in choosing the best type of cancer treatment.

Here are a few questions some people may want to ask about treatment options:

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

- Will treatments take place in the clinic (outpatient) or in the hospital (inpatient)?
- How long will each type of treatment last?
- What side effects are possible?
- What can be done to control side effects?
- Can this treatment affect sex or fertility?
- Will treatment affect the ability to do day-to-day activities?
- What would you (the health care provider) choose as a treatment for yourself or a loved one?
- Will you provide a treatment plan for the entire length of therapy?
- Can I work during treatment?

What about Clinical Trials?

Clinical trials are scientific studies that compare new cancer treatments with the best ones in use today. A clinical trial may be available for people with certain types of cancer. Clinical trial treatments can be given in a health care provider's office, clinic, cancer center, or hospital. A person will need to understand the possible benefits and risks of taking part in a clinical trial before they can start. And they must give their permission to be in it by signing a consent form. A person can also leave a clinical trial any time they wish.

Before taking part in a clinical trial, talk with a tribal health care provider. Some tribes may require permission from tribal leaders before taking part in a clinical trial. Some may not allow it.

Some reasons for Native people to think about taking part in clinical trials research include:

- The trial compares current treatments with new ones.
- The trial may help scientists study cancers in tribal communities and lead to better care.
- The person being treated most often gets very high-quality care.

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

- Some clinical trials help with getting back and forth to treatment.

(Native American Cancer Research, (2009). *Clinical Trials Education for Native Americans*.

Retrieved September 20, 2009, from

http://natamcancer.org/nnacc_downlds/SHEETS/16_AIAN_CT_FactSheet_03-10-2012.pdf)

Cancer Treatment Side Effects

There may be concerns about body changes and side effects of cancer treatment. Some people have side effects from cancer treatment while others report having none. This is because every person responds to treatment in different ways. Most side effects can be managed or treated.

Cancer treatment side effects vary by type of treatment and from person to person. It is important to talk to a health care provider about which side effects are most likely with each treatment. The health care provider may prescribe medicines to prevent some side effects before they start. Other side effects may need to be treated after they start.

Some side effects of surgery may include: scars, limited movement, swelling, fatigue, and being unable to do some activities. These can be long-term or short-term problems. Chemotherapy may cause nausea and vomiting, hair loss, bruising and bleeding, fatigue, infection, and forgetfulness. Radiation treatment may cause fatigue and dry, red, or irritated skin. Depending on the area being treated, it can also cause eating problems, digestive problems, nausea, vomiting, and weakness.

Health care providers understand the importance of listening with care to what a person being treated for cancer is going through. They want to take care of the whole person. Talk with the cancer care team about how long the problems are likely to last, and how to best manage them. Here are some ways someone being treated for cancer may be able to help their care team understand what they need:

- Write down what you notice after treatment, and take your notes to your health care provider. (Include things like when any problem started, how

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

long it lasted, whether anything helped or made it worse, and if it kept you from doing normal things.)

- Bring a family member or friend with you so they can help talk to the health care provider and help explain what is needed.
- Sometimes it takes more than one try to get a side effect or problem under control. Keep the cancer care team informed about what helps and what doesn't. There may be something else that works better for you.
- Be open with the health care provider about any traditional herbs or medicine being used.
- Discuss any important traditions and ask the health care provider how they can help with these needs.

Dealing with the Side Effects of Cancer Treatment

While cancer and its treatments may cause a different side effects, there are a few common issues people face. Someone being treated for cancer may notice the following:

Fatigue: Fatigue is the feeling of being tired physically, mentally, and emotionally. This is a kind of deep tiredness that does not get better with rest. Just as everyone's treatment is different, how tired someone feels will be different, too. And one person's fatigue may last longer than another person's. Managing fatigue is an important part of care.

Only the person being treated for cancer knows if they have fatigue and how bad it is. No lab tests or x-rays can measure the level of fatigue. The best measure of fatigue comes from someone's own report to their health care provider. The person can describe their level of fatigue as none, mild, moderate, or severe. Or they can use a scale of zero to 10, where a zero means no fatigue, and a 10 is the worst fatigue they could imagine.

The cause of cancer-related fatigue is not always clear. But the person should talk to their health care provider so they can help them decide what to do. For some people, fatigue is worsened by problems that can be treated. Getting help with the cancer team to treat known problems, adding physical activity, and good

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

nutrition may help with fatigue. Education and counseling can also help some people learn how to save energy, reduce stress, and focus on things other than the fatigue.

Seven tips for someone being treated for cancer to manage cancer-related fatigue:

- Rest, but not too much. Take short naps or breaks, rather than one long rest. If a person has trouble sleeping, they should talk to their health care provider.
- Stay active. Regular moderate exercise – especially walking – is a good way to help fatigue.
- Save energy. Spread activities throughout the day. Store items within easy reach of where they are used.
- Get help. Ask family or friends for help with errands, meals, child care, and housework.
- Get support. Think about joining a support group, talking to a counselor or a spiritual leader. Sharing their feelings can help.
- Drink plenty of water and juices. Eat well.
- Call their health care provider if they feel too tired to get out of bed for 24 hours. They should also call if they get confused, dizzy, lose their balance, if they are unable to eat or drink for a day or two, or if they have any problem breathing.

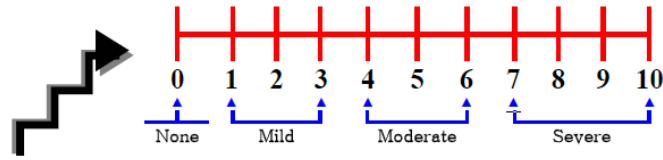
Cancer Pain: Not all people being treated for cancer will have pain during treatment. But sometimes people have pain, and need help from their health care provider to manage it. It's important that a person getting cancer treatment talk with their health care provider about any pain and find the best way to manage it.

It is important to give a health care provider enough information to assess pain levels. Many providers ask a person to rate their pain on a scale from zero to 10. Zero means that someone has no pain, and 10 means that they are in the highest level of pain they can imagine.

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

0 – 10 Numeric Rating Scale (page 1 of 1)



Health care providers may also use this faces pain scale to ask a person about their level of pain:



As with other problems, it sometimes takes more than one try to get pain under control. Keep the cancer care team informed about what helps and what doesn't. Let them know if there are any side effects with your pain medicines, too. There may be something else that works better for you.

More about palliative care: While not all of a person's symptoms or pain can be completely erased during cancer treatment, most of them can be brought down to a level that allows a person to function day to day. There are many medicines and other measures the cancer team can offer that can help a person feel better. This type of care is called palliative care, and it's most often given along with cancer treatment.

The *Symptom Self-management Worksheet* in Appendix A can help a person make a plan for handling side effects.

Relationships and Intimacy: Some people feel closer than ever to their loved ones while going through their cancer journey and may want to be physically close. Others may not want this closeness because of the physical changes and emotional stresses of having cancer and getting treatments. A person being treated for cancer may worry that changes in how they look after treatment or

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

surgery may make their loved one less attracted to them. Loved ones may fear being close because they are afraid they will hurt the person during cancer treatment.

The stress level felt by one person may affect the stress level of another. Loved ones may also fear they can catch cancer. But cancer is not contagious – no one can catch it from someone else.

“It’s important to remember that everyone who’s been through cancer has a story, and the changes to your body are just a part of that tale.”

(Silver, J.K. (Ed.), (2009). *What Helped Me Get Through: Cancer Survivors Share Wisdom and Hope*. Atlanta: American Cancer Society.

A person being treated for cancer should try to share their feelings and needs. If it’s hard to share feelings with family or friends, a person may want to speak to an elder, a counselor, or spiritual leader. They may need someone with whom they can speak more openly.

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

Nutrition and Physical Activity during Cancer Treatment

While someone is coping with a cancer diagnosis and cancer treatment, what to eat may be the furthest thing from their mind. But, eating well is more important than ever. Eating healthy foods during and after treatment can help a person:

- Feel better.
- Keep up their strength and energy.
- Keep up their weight and their body's store of nutrients.
- Tolerate treatment-related side effects.
- Lower their risk of infection.
- Heal and recover faster.

Each person's body, cancer, and reactions to treatment are different. Someone being treated for cancer can ask their care team to help them make an eating plan. This plan should take into account their cancer, treatment, side effects, levels of immunity, and energy. It is also important for a person to listen to their body and pay attention to what it's telling them. This can help them shape their eating plan.

During treatment, you may not be able to eat everything you normally do. But try to include 2½ cups of different vegetables and fruits each day. Choose whole grains over refined starches and limit sweetened treats. Choose poultry, fish, and beans rather than beef, pork, or lamb. Limit intake of red meats – especially processed meats such as hot dogs, sausage, and lunch meats.

The cancer care team can help identify foods that the person likes and that are packed with the nutrients they need most. The cancer care team can also help plan the best kind of physical activity to help maintain a healthy weight, boost energy levels, improve mood, and increase appetite.

(Adapted from Bloch, A., Cassileth, B.R., Holmes, M.D., Thomson, C.A. (Eds.), (2004). *Eating Well, Staying Well During and After Cancer*. Atlanta: American Cancer Society)

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

Working during and after Cancer Treatment

Whether a person can keep working during cancer treatment depends on:

- The type of treatment the person is getting
- The stage of the cancer
- Overall health
- The kind of work the person does

What a person can do will depend on how they feel during treatment and how well their symptoms are controlled. Some people with cancer can still go to work and do their usual everyday tasks while they get treatment. Others find that they need more rest or just feel too sick to do much. The cancer team may also want a person to limit some activities during treatment.

Still, many people are able to keep working while they're getting cancer treatment. Some people work their usual full-time schedules. Some work the same schedules with special conditions, like being closer to the office bathroom so it's easier to deal with side effects. Others need a less demanding schedule, like taking extra days off or even working part time for a while.

The willingness and ability of a workplace to accommodate any special needs a person might have will affect their success at working during treatment. A person should talk with their employer about what might be needed at this time. Under federal and state laws, some employers may be required to let a person work a flexible schedule to meet their treatment needs. See our information on the [*Americans With Disabilities Act*](#) and the [*Family and Medical Leave Act*](#) to learn more. A person can get copies by reading them online at www.cancer.org or by calling us at 1-800-227-2345.

There are many benefits to continuing to work during cancer treatment. For example, people with health insurance at their job can keep it. Cancer treatment can be very costly even for people with insurance, and some health care providers

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

want proof insurance before they treat a person. This is why health insurance is important to cancer treatment.

Visit cancer.org for more details about working during cancer treatment or returning to work after cancer treatment. A person can also call us anytime at 1-800-227-2345 to have this information mailed at no cost to them.

Activity

“I heard over and over again from friends that their doctors won’t call them back. They have had an MRI or some big test, and they are sitting at home waiting for the doctor to call them back. The ones who seemed to do the best said, ‘You know, I’m really a part of this team, and I do have a voice here.’”

Susan C

What would you do if you wanted information from your health care provider?

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

Story of Hope

“I loved it when friends took walks with me. I was not very disabled by my treatment, so I did not need much in the way of doing. Mostly, I needed [and got] the ‘being with me.’ ”

Cathi, breast cancer diagnosis

(The Lance Armstrong Livestrong Guidebook: Planner and Journal.)

Key Messages

- Write down all the questions to ask a health care provider about cancer treatment and take it the appointment.
- The type of cancer treatments someone receives – surgery, radiation, chemotherapy, and other treatments – depends on the type and stage of the cancer.
- Side effects of cancer treatments will vary from person to person and depends on the types of treatments.
- Talk over any side effects with the health care provider. It may take a few tries to find the best approach to manage some side effects.
- Eating healthy foods during and after cancer treatment can help a person feel better.