

*Circle Of Life: Cancer Education and Wellness*

*for American Indian and Alaska Native Communities*



American Cancer Society Circle Of Life<sup>SM</sup>  
*Cancer Education and Wellness for American Indian and Alaska Native Communities*

## Wellness along the Cancer Journey:

### Caregiving

Revised October 2015

## Chapter 5: Understanding the Health Care System



*Circle Of Life: Cancer Education and Wellness*

*for American Indian and Alaska Native Communities*

**Understanding the Health Care System**

<b>Group Discussion</b>			
	True	False	Not Sure
1. Caregivers work with the health care team and patient during treatment.			
2. Caregivers should not talk with the patient about questions to ask at appointments.			

Going into a hospital, a health care providers’ office, or talking to a health insurance company can be stressful. The people may seem to speak a different language, everyone may seem rushed, and the caregiver and the patient may feel overwhelmed by everything that is going on. This is normal. It takes time to get to know how the health care system works. It also takes time to get to know a health care provider and feel comfortable with them.

Not all health professionals are skilled in talking with patients and families. Many forget that the terms, procedures, and machines that they use every day are new and possibly frightening to others. Don’t be afraid to ask questions, and don’t give up until the answer is clear.

When providing care to someone with cancer, chances are that there will be many different medical professionals involved with treatment. Many of them are specialists or specialize in certain areas of medicine or mental health. This means that they have had extra training that focuses on a certain type of treatment, body system, or health problem. See Appendix E for a list of health professionals associated with cancer care.

**Talking to the Medical Team**

In general, the medical team can share information with the caregiver anytime they are with the patient. But there are laws that protect private health information. These laws affect what medical information the health care team can share when the patient is not present.

## ***Circle Of Life: Cancer Education and Wellness***

### ***for American Indian and Alaska Native Communities***

The caregiver can talk to the health care provider about what steps need to be taken so that they can discuss a patient's care at any time. The simplest and most common way to make sure a caregiver can get needed information is for the patient to fill out a release form that allows the health care provider to speak freely with the caregiver.

Keep in mind that there are different forms that are signed for different purposes. Here we are talking about a release form that allows the health care provider to share medical information with a caregiver. This type of release does not give the caregiver permission to make decisions about the patient's care.

The caregiver should be sure that there is a current copy of the release form in the patient's records. It is also a good idea for the caregiver to keep a copy for their files. When calling the health care provider's office, the caregiver may need to remind them that they have the form.

Even without a release, a caregiver can give information to the health care provider. A caregiver can also try asking for general information about problems the patient has; for example, "Is vomiting one of the side effects of the chemotherapy that Joe got this week?" Or they can ask for hypothetical advice; for instance, "If Joe has been vomiting for two days, should we come in to see you?" Even though the health care provider may not give details of the patient's care, they may be able to help in deciding what to do next.

The caregiver may want to get information from many of the health care providers involved in the patient's care, but it's a good idea to pick one health care provider. Most people choose the health care provider they see most often. The caregiver may want to ask the provider:

- Will you be the one to coordinate care for the patient?
- Will you keep the other health care providers updated on what's going on?

### **Preparing for a Medical Appointment**

Going to the health care provider with the patient is a good way to learn more about their medical condition. This can be very helpful when caring for the patient later on. It can also help the patient who forgets to mention problems to the

## ***Circle Of Life: Cancer Education and Wellness***

### ***for American Indian and Alaska Native Communities***

health care provider and comes home without important information. If a patient needs a referral, maybe for a specialist, social worker, or medical supplier, the caregiver may be able to get the names of people who can help.

The average health care provider's appointment is about 10 or 15 minutes with the patient, so it helps to be ready for each visit. Before the visit, work with the patient to figure out the most important issues. Make a list of questions and concerns. What are the most important things to talk about? It may be helpful to write down what needs to be shared with the health care provider as well. What are the current symptoms? When did they start? Having a list will help the caregiver and patient remember anything important.

Do not leave the office until the health care provider addresses all concerns and the caregiver and patient understand what to do next. Nurses can be great sources of information, and it may be possible to spend more time with them than the health care provider. Take notes on what is said. When getting back test results, be sure to understand the results before leaving. If blood work or other tests were done, find out when and how the patient will get the results and who will explain what they mean.

A voice recorder can also be a useful tool. Most health care providers and nurses are comfortable with their patients using one, but ask first.

### **Medicines**

If the patient gets a prescription for a new medicine, be sure to know the name of the drug, what it is for, and why the patient is getting it. Some other things to know are:

- How and when should the medicine be taken?
- What is the dose?
- Should it be taken with food or water?
- Are there side effects? (Like sleepiness, nausea, or dry mouth?)
- How will you know if it is working? How long before you can expect it to work?

## ***Circle Of Life: Cancer Education and Wellness***

### ***for American Indian and Alaska Native Communities***

- Will it interfere with any other medicines or supplements the patient is taking?
- Are there foods, vitamins, or medicines that should be avoided while taking this drug?
- What should you do if a dose is forgotten? Take another? Skip it?
- How much does it cost? Will health insurance cover it? Is there a generic substitute?

As the patient's condition changes, ask about the need to continue medicines. For example, if the patient loses weight, some blood pressure medicines may not be needed. Or if treatment for cancer is stopped, there may be other drugs that can be stopped as well. Stopping medicines when they are no longer needed can lower expenses and reduce the chance of drug interactions and side effects. And it's one less medicine to keep up with.

### **Making Health Care Decisions**

The health care team will always discuss major health decisions with a patient if the patient can think clearly and share their thoughts. And the patient's decisions about their own health will be followed when their decisions do not create safety issues.

But sometimes, what the patient wants is not what others want. It may be something that others are not willing or able to do for them. When patients need help carrying out their wishes, it can be hard on those who want something different from what the patient wants.

It is good to know that the caregiver, family, and the patient don't always have to agree. Some of the decisions and problems that come with a cancer diagnosis can be very tough and very emotional. Remember to let the person with cancer make decisions about their care whenever possible. There are some things a caregiver can do to help them make the best choice:

- Have everyone explain their needs and wants clearly. As an example, the patient may want IV antibiotics at home, but will need someone's help. A

## ***Circle Of Life: Cancer Education and Wellness***

### ***for American Indian and Alaska Native Communities***

caregiver may need to say “This is too scary for me. I don’t think I can do this at home, but I can make sure you are at the clinic every day.”

- Offer choices or a time limit when decisions need to be made. A change in medicines is a good example. “Let’s try this sleeping pill for a few nights and see if it helps you get some rest. If not, we’ll talk to Dr. Smith about trying something else.”
- Focus energy and influence on the issues that are important. Let the patient make as many choices as possible. For example, arguing over what clothes to wear probably isn’t the best use of anyone's energy. But not taking medicines or not following activity restrictions may be issues that cannot be ignored. If reasoning with the patient doesn't work, explain that the caregiver will need to talk to the medical team and get their help – then do it.

Sometimes it is hard to know if something is “bad enough” to call the health care provider after hours or in the middle of the night. The best way to know when to call is to ask. Ask the health care provider or nurse what they want to know about right away, no matter what time it is. This may be things like fever, new pain, or some other symptom. A caregiver can also ask what can wait until the next day or the next appointment.

Also be sure to know whom to call after hours, on weekends, and on holidays. If a caregiver does not have 24-hour access to someone on the medical team, find out what to do if there are problems. Should they call the pharmacist if there are problems with the medicines? Should they go to the ER? It often seems like problems come up when the health care provider’s office is closed, so be sure to have an emergency plan in place.

### **When a Patient Will Not Be Involved in Their Own Care**

It can be a frustrating situation when a caregiver feels sure that the patient can do some self-care, but won’t. Sometimes there are medical or emotional causes for the problem, such as severe tiredness (fatigue) or clinical depression. Get the patient to the health care provider and state the problem clearly. The medical team can help the caregiver figure out what may be going on. Social workers and

## ***Circle Of Life: Cancer Education and Wellness***

### ***for American Indian and Alaska Native Communities***

occupational health professionals may be able to help with find out what a person can safely do on their own.

Keep in mind the following:

- Try to figure out what self-care tasks the patient can safely perform.
- Encourage the patient to do as much of their own care as possible.
- Encourage the patient to talk about things they enjoy so that the conversation is not always about cancer and illness.
- Let the patient make as many personal choices as they can. If they are overwhelmed with decisions, give them simpler choices by saying, “Would you prefer chicken or fish for dinner?” or “Would you rather wear your blue pants or the brown ones?”
- Get others involved if the patient is avoiding treatments or doing things that are harmful. Family members can be a strong source of influence. Rally them for support.
- Once a decision is made, accept it and move on. And if the caregiver disagrees with the decision that was made, remember that it is the patient’s decision to make. Congratulate them for being able to make a decision.

Remember that professional help is available for caregivers, too. It is normal to feel frustrated, upset, and stressed when caring for someone with cancer. Use the resources and services of the health care team when needed. They can help find support, such as mental health counselors, home care services, or financial assistance for the caregiver as well as the patient.

### **Moving or Relocating a Patient**

Open and honest discussion with the patient and other family members is the first step in deciding whether the patient needs to live somewhere else for a time. Cancer and its treatment can cause confusion and forgetfulness, and may worsen the symptoms of other conditions such as dementia. Patients can pose a danger

## ***Circle Of Life: Cancer Education and Wellness***

### ***for American Indian and Alaska Native Communities***

to themselves by forgetting medicines, not eating, leaving the house, or losing track while cooking. They can also pose a danger to themselves and others if they start to hit, bite, or throw things at caregivers and family members. The home setting is rarely set up to deal with these kinds of problems. In such cases, the cancer care team needs to know about these behaviors. The patient may need to be hospitalized, if whatever is causing the problem can be treated.

For problems that are less severe, such as mild forgetfulness, unsteady walking, and occasional minor confusion, there may be other options. Again, the cancer care team should be told about these problems to find out if there is a medical reason for them and if hospitalization is needed.

Sometimes these kinds of problems can be managed at home if there is someone who can stay with the patient at all times. But these problems deserve special discussion by the family. Otherwise, it may be easier for other family members to assume that the caregiver will be the one to stay home and provide 24-hour care for the patient. This can be an unpleasant surprise to the caregiver, who still has other duties and things to do.

Family meetings with the patient, spouse, children, siblings, and other key people can allow everyone to share their thoughts and can help decide what needs to be done. Sometimes these talks can be very difficult and emotional, but certain topics will need to be covered:

- What amount or type of care is needed?
- Does the patient need 24-hour supervision?
- What can they safely do without help?
- What other living arrangements are available?
- Can the patient move in with another family member?
- Can they move to an apartment closer to the main caregiver?
- Is an independent retirement community a good option?

This discussion can be tricky if the patient has times when they get confused or fearful. It helps to have the health care provider's or occupational therapist's (OT)



***Circle Of Life: Cancer Education and Wellness***

***for American Indian and Alaska Native Communities***

assessment of the patient's needs. For example, if their professional opinion is that the patient cannot be alone at all, and the only caregiver has to work full time to make the house payment, something else must be done. An occupational therapist's assessment can also find out if the patient can be kept safely in the home with certain modifications. Ask a health care provider about a referral to an OT. If the patient is in a hospital or extended-care facility, ask their health care provider or nurse about getting an OT evaluation before the patient's discharge day.

## *Circle Of Life: Cancer Education and Wellness*

### *for American Indian and Alaska Native Communities*

#### **A Nursing Home or Extended Care**

There may be a time when a person being treated for cancer needs extended care or nursing home care. Even though a caregiver is no longer with the person all day, they will still find they have many responsibilities. Caring for the patient may look different since the caregiver is no longer providing all of the hands-on care. But they will still be talking with the staff at the facility, visiting the patient, and staying in touch with those who are caring for the patient. The caregiver will also be the first one called if there is a problem.

Sometimes the person with cancer may decide they do not want to live elsewhere. They may resist leaving home. Patients may feel that they will no longer be able to set the rules or control their own lives, or they may be afraid of losing their independence. Maybe they don't want to feel as if they are a burden on others. And if they have lived in same place for a long time, they likely have strong ties to the community, family, friends, and health care providers, as well as social lives and daily routines.

The caregiver may want to start gently – keeping in mind that the patient is probably already distressed. Sit down with the patient. Ask if there is something that the patient would like to say. If the answer is no, ask if there is something the patient **doesn't** want to share. Give them a moment to consider it. Point out to the patient the signs of a new problem or worsening symptoms. Remind them that this could be a serious problem, or just a new symptom that may be easy for the health care provider to address. Mention how the problem is affecting the patient. If the caregiver is having trouble handling it, it can help if they say so; and share any concerns about needing help with it. If the problem is affecting others as well, say so. It is normal to want to protect loved ones. But sometimes this can become a problem. For instance, if the person with cancer is having certain symptoms or worsening symptoms that they do not tell the caregiver or the health care provider about.

In some cases the caregiver may have to be firm, especially if the situation is unhealthy or unsafe. If the caregiver has to act against the wishes of the person with cancer, it can help to be direct and explain what is going to happen.

***Circle Of Life: Cancer Education and Wellness***

***for American Indian and Alaska Native Communities***

In other cases, there is room for negotiation. Family and loved ones will need to talk about each person's concerns and discuss all the options. For instance, things like patient safety, convenience, finances, and the care needed should be discussed. Clear plans must be outlined. It helps to check out the physical setting and set up a timeline of patient needs.

If this still isn't working, a social worker may be helpful in exploring options and setting plans in motion. It may also help to have a family meeting with at least some members of the health care team to get their input and support.

*Circle Of Life: Cancer Education and Wellness*

*for American Indian and Alaska Native Communities*

Activity

Use this table to think about questions that can be shared with the health care providers as well as any alternative and complementary health providers.

Health Concerns	Emotional Concerns	Spiritual Concerns
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## ***Circle Of Life: Cancer Education and Wellness***

### ***for American Indian and Alaska Native Communities***

#### **Story of Hope**

“If there’s one thing that’s come out of taking care of someone, it’s that I’ve learned what’s important really fast. And that’s a lesson that I’ll carry with me forever.”

– Jenny

National Cancer Institute. (2007). *Caring for the Caregiver*. Retrieved on July 29, 2011, from [cancer.gov/cancertopics/coping/caring-for-the-caregiver](http://cancer.gov/cancertopics/coping/caring-for-the-caregiver).

#### **Key Messages**

- It takes time to get to know how the health care system works. Be patient.
- Not all health professionals are skilled in talking with patients and families. It may take a couple of visits to set up a communication system that will work.
- Before the visit, work with the patient to figure out the most important issues. Make sure to write them down and bring them to the appointment.
- The caregiver can talk to the health care provider about what steps need to be taken so that they can freely discuss a patient’s care. Make sure to ask about anything you don’t understand.
- It is good to know that caregivers, family, and the patient don’t always have to agree. Try to focus on what the patient wants as much as possible.