



**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 3: Caregivers Are Part of a Team



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

## Caregivers Are Part of a Team

<b>Group Discussion</b>			
	True	False	Not Sure
1. The patient does not need to be involved in their own care.			
2. Having family meetings can help manage giving care for the patient.			

A caregiver is part of a health care team made up of the patient, other family members, friends, and the medical staff. Caregivers work closely with health care providers. As part of the team, they will coordinate much of the patient's home care. In many cases, the caregiver is the one person who knows everything that is going on with the patient.

### **Communication**

Good communication with the person being cared for is a very important part of a caregiver's role. Caregivers must balance respect for their feelings, needs, and desires with those of the patient. It is good to set a goal of openness and sharing right from the start. Share fears and worries. Sometimes it may be hard and there will be disagreements and maybe even arguments, but openness will allow the option to work out the conflict. It will also help reduce distress and anxiety. Acceptance and sharing will help keep the relationship strong.

A caregiver might want to try something like:

- "This is a scary time for both of us, but I want to be here for you and will help you get through this. You are not alone."
- "I will do whatever I can to help you through this. I may do the wrong thing sometimes, or not know what to do, but I will do my best."

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- “We can do this together. Let’s try to be open with each other and work with each other no matter what happens.”

A person with cancer may act different than they usually do – angry, quiet and withdrawn, or just sad. If a caregiver gets the feeling that the person isn’t talking because they want to spare others’ feelings, make sure they know that there are people such as spiritual leaders and health care providers who might be helpful to them. If the person keeps acting very sad or withdrawn, a caregiver may want to talk to the cancer care team about what might be causing it and what can be done.

### **Involving the Patient in Their Own Care**

It may be hard for the patient to take part in daily planning and decision making because they are dealing with the physical, emotional, and social effects of cancer and treatment. It is important to try and involve the patient as much as possible.

Suggestions for keeping a patient involved in their care:

- Help the person live as normal a life as possible. To do this, start by helping them decide what activities are most important. They may need to put aside those that are less important in order to do the things they enjoy most.
- Encourage the person to share feelings and support efforts to share. For instance, if they begin talking about their feelings about cancer, listen and let them talk. A caregiver might want to share how they are feeling, too.
- Let the person know help is available, but don’t press issues. This might involve something that the patient is trying to do, such as dress themselves. They may be struggling, but it is important to them that they be able to do this. Let them decide when they need help.
- Remember that people communicate in different ways. Try sharing by writing or by using gestures, expressions, or touch. Sometimes, it may be really hard for a caregiver to say what they are feeling, but a gesture such as holding hands may be all that is needed.

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- Take cues from the person with cancer. Some people are very private while others will talk more about what they are going through. Respect the person's need to share or to remain quiet.
- Be realistic and flexible about what to talk about and agree on. The caregiver may need or want to talk, only to find that the patient does not want to do it at that time.
- Respect the need to be alone. Everyone needs to spend time alone sometimes, even caregivers.

Everyday choices are easier to make if the caregiver understands the patient's preferences, habits, and values. What is most important in the patient's life? Everyday choices include things like what to wear, when to bathe or eat, and what else to do after that. But even these simple choices can be overwhelming and hard to make when a person is dealing with cancer. Sometimes a small crisis can cause the patient to be unable to express what they want or need. As much as possible, honor the patient's wishes. But keep in mind there may be limits on what caregivers can do. Even a request that seems like a small thing may turn out to be too much for a caregiver who is already overwhelmed.

### **Family Meetings**

Today's families are very busy, and it can be hard to keep everyone up to date on what is happening with the patient. Family members may feel frustrated and left out. They may not understand the medical condition, especially if the patient is having problems. They also may not know that their help and ideas are needed, or how to best help.

One way to keep everyone informed is to have a family meeting with the health care team. When planning a family meeting, it is important to include everyone who is or will be part of the home caregiving team. This may include a family friend, neighbor, or paid caregiver – and don't forget the patient! If it is hard to get everyone together, a conference call or speaker phone might help solve the problem.

Some of the things that may be covered in a family meeting are:

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- Discuss the latest report from the health care provider.
- Find out/discuss how things are going and what is expected next.
- Share feelings and concerns.
- Discuss what the person with cancer wants and needs.
- Determine how much time each family member has to help out or visit.
- Discuss who else might be available to help and how much care will cost.
- Discuss other financial help that is available.
- Find out the sort of support the main caregiver needs.
- Discuss the need for a break from caregiving from time to time.
- Help with meals, shopping, cleaning, laundry, yard work, child care, etc.
- Discuss motional support by phone or email.
- Help with medical care, like taking the patient for treatment or to health care provider's appointments.
- Help with sharing news and updates on the patient's condition so that the main caregiver doesn't have to spend time repeating the news each day.

Every family has a history with each other. This history affects each person's role within the family, how members relate to each other, how they feel toward the person with cancer, and how they deal with illness. There are often unspoken rules about what can be expressed and what emotions are OK. It may be hard to hold family meetings if the patient's condition requires the group to discuss these taboo topics.

If the caregiver thinks there are family issues that will get in the way of the patient's needs, they may want to think of ways to defuse the situation beforehand. Consider writing up a list of questions that everyone can look at and add to on their own. That way there is a specific agenda for the family meeting. Sometimes a wise family member can help. Or the caregiver may want to talk

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with a social worker or other professional about how to bring up delicate subjects.

#### **When Others Want to Help**

Almost always there is just too much for one person to do when caring for a person with cancer. Asking for help or letting others help can take some of the pressure off and allow the primary caregiver time to take care of themselves. Often family and friends want to help but may not know how or what is needed.

Here are some tips for working with family and friends:

- Look for areas where help is needed. Make a list or note them on a calendar.
- Hold regular family conferences to keep everyone involved. Use these meetings as updates and care-planning sessions. Include the patient.
- Ask family and friends when they can help and what jobs they think they can do. Contact people with specific requests. Be very clear about what is needed.
- As the caregiver hears back from each person, they can note it on their list to make sure the patient's needs are covered.

#### **Staying Organized**

A caregiver will be getting a lot of information – new information that can be hard to understand – and it helps to keep it all in one place. A notebook or a small file box might work well. Some people rely on their electronic devices, which is good as long as it is secure and there are backup copies. Whatever a caregiver uses, they should bring it to every office visit and every treatment.

There are also many online resources to help caregivers manage their responsibilities, such as the American Cancer Society Cancer Survivors Network<sup>®</sup> and Gilda's Club. Please see Appendix A for a list of national organizations and websites. These offer support to people with a loved one who has cancer. Some sites also offer other features, such as areas to create personal websites that loved ones can access for updates on how the patient is doing. One example is

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the [caringbridge.org](http://caringbridge.org) website. As mentioned before, there are other websites that let you set up jobs or tasks so that others can sign up for them.

**Medicines:** Keep a list of all medicines the patient is taking, including prescription and over-the-counter medicines, and any vitamins, herbs, or other supplements. This list should include the following:

- Name of the drug
- Dose (number of milligrams [mg] per pill; this is usually on the medicine bottle)
- Schedule (which days of the week and what times of the day it is taken)
- Reason for taking it
- Health care provider who prescribed it (if the patient sees more than one health care provider, one may not know what the other has prescribed)
- Remember to list medicines the patient takes every now and then or “as needed” – for instance, drugs for pain, fever, itching, or sleep.

Ask the health care provider’s office to make a copy of this list and be sure to update it each time a medicine gets added, taken away, or if a dose changes. Share the new schedule with each health care provider on the next visit. Some caregivers make lists or spreadsheets on their computers and print out copies to post on the refrigerator. That way a list is handy when someone comes in to help. A second copy in a purse or wallet may be useful, too. Please see Appendix B for an example of a medicine list.

**Health Insurance:** Even if the patient has health insurance, it surprises many people to learn how much they have to pay out of pocket for cancer care. And the person is likely to need help keeping track of it all, figuring out what’s covered and what isn’t, and paying deductibles and co-pays.

The caregiver or another loved one will probably need to help set up a system for tracking costs, comparing insurance statements, and keeping careful records. Or the patient may ask another trusted family member to be the one to track the

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bills and insurance payments. Getting someone else to do this can free up time for other things, which can help the main caregiver. Still, the main caregiver may need to take part in tracking the actual health care provider visit dates, treatments, and prescription refills.

The patient will need to stay in touch with their insurance plan in case there are reimbursement problems. The patient may need to give permission to the insurance company to talk with the person chosen to help with insurance problems and disputes.

It is a good idea to keep all medical bills, insurance EOBs (Explanation of Benefits), prescription drug receipts, and so on all in one place.



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#### Activity

Caregiving can be an overwhelming job. The table below lists things to think about when planning to provide care to a loved one. Choose one from the list and start working from there.

Prepare to talk with family members and friends.	<ul style="list-style-type: none"><li>• Identify who needs to be included.</li><li>• Think about what needs to be said.</li></ul>	Allow family members and friends enough time to digest what is said.
Think about the roles that family members and friends can play.	<ul style="list-style-type: none"><li>• Make a list of all caregiving activities.</li></ul>	Examples of activities: <ul style="list-style-type: none"><li>• Home maintenance and living situation</li><li>• Financial affairs</li><li>• Transportation needs</li><li>• Personal care</li><li>• Health care</li><li>• Communication</li></ul>
Find out about the diagnosis, what kind of care might be needed, and how to provide care.	<ul style="list-style-type: none"><li>• Visit <a href="http://cancer.org">cancer.org</a> for cancer information.</li><li>• Look up caregiving trainings.</li><li>• <a href="#"><u>Read <i>Caring for the patient with cancer at home</i> booklet.</u></a></li></ul>	Share what is found with family members and friends.
Think about a schedule and a plan for how caregiving activities can be carried out.	<ul style="list-style-type: none"><li>• Have family members and friends pick what they can do.</li><li>• Have family members and friends give days and times they will be available.</li></ul>	Develop a schedule. Templates are available in Microsoft Word and Excel.

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Put the schedule and plan into action.

- Give everyone a copy of the schedule.

Make sure to remain flexible as things may change and come up.

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#### **Story of Hope**



“I think for someone to go through chemo treatment and radiation it would be very good if they had, have somebody there with them. Knowing someone is there waiting or by their side. That’s the best thing is to have some kind of family support, and I didn’t have that so I want to share that with everyone else to have somebody there for chemo, radiation. Make sure you bring someone with you, cause it’s hard, very, very hard. My family lived in Nome, and I had to travel to Anchorage for my chemo and I didn’t have too much family in Anchorage at the time, so that’s why I went about it alone. So it’s best if you have somebody there holding your hand and supporting you, saying you’ll be OK that I did not have. And it was the hardest, hardest thing for me to go through my treatment, all alone.”

(Clark, R., (Producer) & Bloom, D. (Artist), (2007). *Survivor Video Vignettes: Family Support*. [Web]. Retrieved from [natamcancer.org/vignettes/marylouc\\_FamSupport.html](http://natamcancer.org/vignettes/marylouc_FamSupport.html))

#### **Key Messages**

- A caregiver is part of a health care team that includes the patient, other family members and friends, and the medical staff. A caregiver will help coordinate the patient’s care.
- Good communication with the person being cared for is the most important part of a caregiver’s role. It is good to set a goal of openness and sharing right from the start.
- A caregiver will be getting a lot of information – new information that can be hard to understand – and it helps to keep it all in one place.
- One way to keep everyone informed is to have a family meeting with the health care team if possible. Another way to keep everyone informed is to

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have family meetings planned near appointments, or to have someone set up a website to share updates with family and friends.