

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:

Caregiving

Revised October 2015

Chapter 4: Support for Caregivers



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Support for Caregivers

Group Discussion			
	True	False	Not Sure
1. There are not many support services for caregivers.			
2. It is important to allow others to help so the caregivers can take a break.			

Caregivers need a range of support services to remain healthy, be good caregivers, and stay in the caregiving role. They have been shown to have less distress and feel less burdened when they have social support. Human connections make a difference. Caregivers should let people know what is needed and ask for help. They cannot and should not try to be responsible for all the caregiving by themselves.

The support of friends and family is very important to both the person with cancer and the caregiver. Caregivers often feel tired, isolated, depressed, or anxious, and are less likely to reach out for help. Physical problems like heart disease, high blood pressure, sleep problems, increased risk of infections, depression, and fatigue have been linked with caregiving. A caregiver may not have thought much about it, but while they are helping their loved one, they must also take care of themselves.

Importance of Self-care

Overwhelming concern for a loved one who is sick may distract a caregiver from taking care of themselves. They may find there is conflict between the needs of the patient, their own needs, and the needs of their family. Many caregivers forget to eat, don't get enough sleep or exercise, and ignore their own physical health concerns.

Caregivers need to be sure to make and keep their own health care appointments, get enough sleep, exercise, eat healthy foods, and keep their

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normal routine as much as they can. It is important that they not to feel guilty or selfish when they ask for help or take time for themselves. In taking care of themselves, a caregiver is much more able to care for a loved one.

A caregiver can begin by being clear within themselves about what they can and cannot do. Caring for someone with cancer can be an overwhelming job.

To support themselves, caregivers may want to consider different types of activities that:

- Involve other people, such as having lunch with a friend.
- Give them a sense of accomplishment, like exercising or finishing a project.
- Make them feel good or relaxed, like watching a funny movie or taking a walk.

It can help to continue simple routines like watching the news or taking time to read the morning paper. Caregivers may want to set aside time during the day, like during a meal, when they do not talk about their loved one's illness. It can help to keep a sense of humor and to recognize those things that they did well, too. It also helps for a caregiver to keep in mind why they chose to take on this job, which can be quite difficult and stressful.

The many responsibilities of caring for someone with cancer does not leave much time for caregivers to take care of their own needs. If a caregiver needs some time away from work, they can speak with their boss or benefits office. If the workplace has an employee assistance program, they can look into what it offers. Some offer counseling services for money concerns, stress, and depression.

If a caregiver can't or doesn't want to stop working, they may be able to take unpaid time off under the Family and Medical Leave Act. Whether they will be able to do this depends on their job and how they are related to the person they care for. Please see Appendix C for more information about the Family and Medical Leave Act (FMLA).

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Support Groups

There are many kinds of support programs, including one-on-one or group counseling and support groups. A support group can be a powerful resource for caregivers. Talking with others who are facing the same challenges can help ease loneliness. A caregiver can also get useful ideas from others that might be helpful. Studies have found that people who take part in a support group have an improved quality of life, including better sleep and appetite.

Some groups are formal and focus on learning about cancer or dealing with feelings. Others are informal and social. Some groups are made up of only caregivers, while others include spouses, family members, or friends. Other groups focus on certain types of cancer or stages of disease. The length of time groups meet can range from a set number of weeks to an ongoing program. Some programs don't accept new members, and others are open to new, drop-in members.

Online support groups may be another option. The Cancer Survivors Network, an online support community of the American Cancer Society, is just one example. Visit csn.cancer.org to find out more about this community. There are many cancer organizations that have online communities for caregivers to connect to education and support resources. Through online or in person support groups, people can share their stories, offer advice, and support each other through shared experience.

Counting on Family and Friends

The caregiver needs to know whom they can talk to and count on for help. Families can become stronger in the face of cancer. If family members do not offer help, or if a caregiver needs more help than they can provide, they may be able to set up a circle of friends to help. Church members, neighbors, and others may be willing to help. Include them in family meetings. Share information with them on the patient's condition, needs, and care.

This circle of friends may not be able to be a part of the patient's care every day, but perhaps a friend can come once a week for three or four hours so that the caregiver can take time for themselves. Someone else may be able to be there for

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an hour or two twice a week so the caregiver can go to a support group, shopping, or church.

Spiritual Support

Religion can be a source of strength for some people. Some find new faith during a cancer experience. Others find that cancer strengthens their existing faith or their faith provides new-found strength. For those who are religious, a spiritual leader, minister, rabbi, other faith leader, or a trained pastoral counselor can help provide spiritual support. Some members of the clergy are specially trained to help people with cancer and their families.

People may also find spiritual support through meditation, journaling, and being outside in nature. For others, serving at a local homeless shelter or other types of volunteer work may renew their energy.

Stress and Depression

There are many causes of stress and distress in cancer caregivers. The crisis of cancer, the uncertain future that lies ahead, financial worries, difficult decisions that must be made, and unexpected and unwanted lifestyle changes are just a few of them. Fear, hopelessness, guilt, confusion, doubt, and anger can take a toll on both the person with cancer and the caregiver. While the focus tends to be on the patient, all of this affects the physical and mental health of the caregiver, too.

Depression is a common problem in caregivers, but caregiving does not always cause depression. And not all caregivers have the difficult emotions that go with depression. Everyone has emotional ups and downs, but when a person always feels down, has no energy, cries a lot, or is easily angered, it may be a warning sign of depression. Many people see the feelings of depression as a sign of weakness rather than a sign that something is out of balance, but ignoring or denying these feelings will not make them go away.

Early attention to symptoms of depression can make a big difference in how the caregiver feels about their role and how well they can do the things they need to do. There are ways to help reduce stress and be renewed. They may help prevent the development of a more serious depression over time:

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- Support from family and friends in caring for the patient
- Exercise
- A healthy diet
- Spiritual support, such as religious activity, prayer, journaling, or meditation
- Recreational time to enjoy friends socially
- Help from a trained mental health professional

It is normal to feel overwhelmed sometimes by the responsibilities of care. But if it becomes a continual problem, a caregiver may need to see a professional health care provider for support. Below is a list of serious signs of trouble. Get professional help for any of the following:

- Feeling depressed, physically sick, or hopeless, not enjoying life
- Feeling like hurting oneself or hurting or yelling at loved ones
- Depending a lot on alcohol or recreational drugs for stress relief
- Fighting with a spouse, children, stepchildren, or other family members and friends
- No longer taking care of oneself

Taking Time Off

Most caregivers are hesitant to take time off from their responsibilities for a short time. In fact, most would probably feel guilty if they did this. But no one can be a caregiver every day, 24 hours a day, for many months and even years. It is important to get out of the house every day – even if it's only to take a short walk or go out to do some shopping. If the person being cared for cannot be left alone and there are no friends or families to provide relief, respite care (see below) is an option to consider.

Respite care is the term used to describe short-term, temporary relief to those who are caring for family members who might otherwise need professional aid. Respite is a short break from the exhausting challenges of being a caregiver. It can

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range from a few hours to a few days. It has been shown to help keep family caregivers healthy and improve their sense of well-being. Some hospice and home care programs have respite programs built in. You may also be able to find out about respite care from the cancer team.

In most cases, the respite caregiver comes to the home and gets to know the patient, the family routine, and things like where medicines are stored. Sitter-companion services are one respite option. This is sometimes offered by local civic groups, religious groups, and other community organizations. A regular sitter-companion can provide friendly respite care for a few hours, once or twice a week. Be sure that the sitter-companion is trained to know what to do if an emergency comes up while the caregiver is gone.

Another type of respite uses a specialized, local facility where the patient may stay for a few days or even a few weeks. Depending on the state, Medicaid or Medicare may help cover the costs. Also check with the health insurance provider to see what kind of respite help might be offered. See Appendix D for groups that can help find respite care.

Helping the Patient Be More Independent

Assistive devices are tools that can help the person being treated for cancer be more independent. Health care providers may also use the terms adaptive equipment or independent living aids. These tools can be something as simple as a cane, or as complex as a high-tech lift used to move the patient. Some other examples are walkers, wheelchairs, shower chairs, bath mats, grab bars, portable commodes, or urinals. Monitored medical response systems, webcams, and intercom systems are other options that can help some patients feel safer and give the caregiver peace of mind. But even little things like a pill organizer or large wall calendar can make things easier for everyone.

Think about the tasks the person with cancer wants or needs to do and how one of these devices may make it easier or safer. Talk to the health care team. They may be able to help or to refer the patient to an occupational therapist about tools that might help at home. These professionals can share ideas for ways to

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help the patient. They can also help find out where to buy or rent the assistive devices. Some may be covered by health insurance, too.

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Activity

Coping Checklist for Caregivers

Caring for someone who is sick, taking on new responsibilities, and worrying about the future can be exhausting at the very least – and can quickly lead to “burnout.” When the caregiver is busy caring for the person with cancer, who is taking care of them?

So take a moment to look at the statements below, which describe some healthy situations and ways of coping. This list offers an idea of how well a caregiver is holding up, and may provide some thoughts about where they need to make a few changes to care for themselves. If a caregiver isn’t already using all of these 10 ideas, they can look at ways they can start adding those that appeal to them.

- I have a supportive family around me.
- I pursue a hobby or project for work, church, or my community, for example.
- I take part in a social or activity group more than once a month.
- I am within 10 pounds of my ideal body weight for my height and bone structure.
- I use relaxation methods such as meditation, yoga, or progressive muscle relaxation five times a week
- During an average week I exercise at least five times for 30 minutes or more.
- I eat a well-balanced, wholesome meal two or three times during an average day. A balanced meal has lean protein such as fish, poultry, and beans, is high in vegetables, fruits, and whole-grain foods, and is low in red meats and processed meats.
- I do something enjoyable “just for me” at least once during an average week.
- I have a place where I can go to relax or be by myself.
- I set priorities and manage my time every day (such as deciding what tasks are most important, how much I can and can’t do, and by getting help when needed.)

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Some coping methods aren't as healthy, though. If a caregiver is using any of the four strategies listed below to help them get by, they may find that over the long term they actually lower their ability to deal with important issues in their life. These habits may also make a person less healthy and lead to serious problems. Talk with a health care provider if help is needed to quit tobacco, alcohol, or other drugs.

1. I smoke cigarettes or use tobacco several times a week.
2. At least once or twice during an average week I use medicines, alcohol, or other substances to help me sleep.
3. At least once or twice during an average week I use alcohol, medicines, or other substances to reduce anxiety or help me calm down.
4. I bring work home at least once or twice during an average week.

This checklist was adapted from one created by Dr. George Everly Jr. of the University of Maryland. The original appears in the US Public Health Service pamphlet *What Do You Know About Stress* (DHHS Publication No. PHS79-50097) and is in the public domain. Please give appropriate credit if you copy it.

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Story of Hope

“You need to learn ways to take care of yourself. Because if you’re not taking care of yourself, you can’t take care of anyone else. Don’t be afraid to ask questions. Don’t be afraid to ask for help.” – Jane

National Cancer Institute. (2007). Caring for the caregiver. Retrieved on July 29, 2011, from cancer.gov/cancertopics/coping/caring-for-the-caregiver.pdf

Key Messages

- Caregivers need a range of support services to stay healthy, be good caregivers, and stay in the caregiving role. Don’t be afraid to ask for help.
- The support of friends and family is very important to both the person with cancer and the caregiver. Set up a calendar so that everyone is aware of what needs to be done and knows how they can help.
- Caregivers need to be sure to make and keep their own health care appointments, get enough sleep, exercise, eat healthy foods, and keep their normal routine as much as they can.
- There are many kinds of support programs, including one-on-one or group counseling and support groups. A support group can be a powerful tool for both people with cancer and their loved ones.