

*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 2: Caregiving Is Essential

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Caregiving is Essential

Group Discussion			
	True	False	Not Sure
1. Caregiving can be a rewarding experience.			
2. Caregivers are not a part of the cancer team.			

Good, reliable caregiver support is crucial to the physical and emotional well-being of people being treated for cancer. In most cases, the main caregiver is a spouse, partner, adult child, or other family member. When the main caregiver is not around, another family member, close friend, co-worker, or neighbor may fill this role.

People spend far less time being cared for in the hospital than in the past. This means that when people go home they often have greater health care needs. This shift in cancer treatment means that a lot of care is done in outpatient treatment centers. This has led to a need for people at home to be part of the day-to-day care of the person with cancer.

Today, families provide about 80 percent of home care services. Caregivers often find themselves doing things that, until recently, were done by trained health professionals (Source: <http://www.cancer.org/treatment/caregivers/copingasacaregiver/howtocareforalovedonewithcancer/being-a-caregiver-why-needed>).

Deciding to Be a Caregiver

Despite the sadness and shock of having a loved one with cancer, many people find personal satisfaction in caring for that person. A caregiver may see it as a meaningful role that allows them to show their love and respect. It may also feel good to the caregiver be helpful and know that they are needed by a loved one.

Caregiving can be an enriching experience. A caregiver may feel a deep sense of satisfaction, confidence, and accomplishment in caring for someone. They may

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also learn about inner strengths and abilities that they did not even know they had, and find a greater sense of purpose for their own life. These good feelings can give the caregiver the strength and endurance to continue in the role for as long as they're needed.

Caring for someone being treated for cancer can open up doors to new friends and relationships, too. Through a support group, a caregiver may get to know people who have faced the same kinds of problems. This experience can draw families together and help people feel closer to the person who needs care.

It is also quite normal to feel overwhelmed, burdened, and even trapped at times while being a caregiver. If a family has had troubled relationships in the past, someone may wonder "why me?" They may feel unprepared or even unable to manage all that is needed. A person may feel pressure from family members, friends, and members of the health care team to provide care, despite having little or no desire or ability to do so.

If someone chooses to become a caregiver because of other people's wishes, they may want to think about how they feel about being pressured into this role. Mixed feelings at the beginning of this journey can lead to a greater sense of frustration later on. A person should decide on their limits and make them known as soon as they can – before the demands of care become a problem. This way other plans for care can be made if needed.

If you're OK with doing part but not all of the care, it may help to find someone to provide assistance so that everyone knows from the start that the role will be shared.

What Caregivers Do

Caregivers have many roles. They serve as home health aides and companions. They may help feed, dress, and bathe the patient. Caregivers also arrange schedules, manage insurance issues, and provide transportation. They are legal assistants, financial managers, and housekeepers. They often have to take over the duties of the person being treated for cancer, and still fill their normal roles and try to keep to keep doing their usual tasks.

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The person caring for someone with cancer must also be a problem solver. The caregiver can help the patient get through many challenges and unexpected situations that may come up. To do this, they must do their best to understand the problem and be willing to ask for help or advice from members of the cancer care team when needed.

Here is an example of how a caregiver might manage a situation when a patient suddenly needs to be in the hospital for an infection:

- If the patient has any trouble communicating due to their infection, talk with the hospital team about what health problems they have been having and how they have been managed so far.
- Share with the hospital team a complete list of the medicines and doses the person with cancer takes to be sure that none have been forgotten.
- Help address concerns by pointing out that the patient will need to be in the hospital for only a short time until antibiotic treatment has the infection under control.
- Make sure that the patient has everything they need while in the hospital, including prescriptions for non-cancer-related medicines they may be taking at home, such as thyroid or blood pressure medicine.
- Call all the health care providers involved in the patient's care and tell them about the infection and that the patient is in the hospital.
- When the patient goes home, check that arrangements have been made for them to stay on the antibiotics at home or as an outpatient. If daily visits to the outpatient clinic for IV (intravenous) antibiotics are needed, the caregiver may need to coordinate people to help the patient get there and back each day.

This kind of help from a caregiver is very valuable. It is a reassuring sign for the patient that a short-term problem can be managed and solved. Caregivers who are realistic and positive, careful and creative, and focused and flexible are sources of strength and security for the person with cancer.

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Caregivers shoulder much responsibility and have great influence on how the cancer patient deals with their illness. Encouragement from a caregiver can help a patient stick with a demanding treatment plan and take other steps to care for themselves.

Long-distance Caregiving

If the family lives far away, caregiving from a distance has its own special challenges. The cost of travel, phone calls, missed work, and out-of-pocket expenses are higher when a caregiver does not live close to the person needing care. Sometimes paid “on-site” caregivers are needed, and this can be another large expense.

There may be increased stress and greater feelings of guilt with long-distance caregiving. A caregiver may worry, “What if something happens and I can’t get there right away?” Or, “Who’s going to make sure the patient eats, takes their medicine, doesn’t fall, etc.?” And if other family lives close to the person with cancer, a distant caregiver may feel guilty that this burden falls on these family members.

There are things a caregiver can do to help their loved one and take an active role in their care – even when far away.

- When it is possible to visit, check the house for safety issues like cluttered walk ways, loose rugs, or bad lighting. Maybe grab bars in the bathroom or a shower seat would be helpful. Help to make improvements or arrange for someone else to do so.
- Is the house clean? Is the yard cared for? Is there food in the house? Arranging help for chores like these can be a big help to the person with cancer.
- Get in touch with people who are nearby. This may be other family members, friends, neighbors, or the health care team. Call them and give them your contact information. Invite them to call when needed.
- Plan for a crisis. Who can be counted on to check on the patient anytime, day or night? Keep that person’s contact information handy.

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- Keep a list of all the medicines and treatments the patient is getting (include doses and schedules), and update it often.
- Make sure the person with cancer can reach people who help with care. This may mean buying a cell phone for the patient or setting up long distance service on their land-line phone. The caregiver can also program important numbers into the phones. This can serve as a handy directory and help with speed dialing.
- Keep a phone book that covers the person with cancer's neighborhood. This way the caregiver will know what resources are nearby and can contact them if needed.
- Set up a web-based program; for example, lotsahelpinghands.org lets people sign up for different jobs or tasks. Then the caregiver can keep an eye on what is needed and what is being done.

Planning visits can be helpful. Having a plan can help the caregiver feel less overwhelmed and help keep them focused and less stressed. The caregiver can talk to their loved one ahead of time about what is needed and set clear goals for the visit. If other family members are doing most of the hands-on work, the caregiver can step in for them and offer them time off. It is important to remember to also spend time doing activities with the patient that are enjoyable.

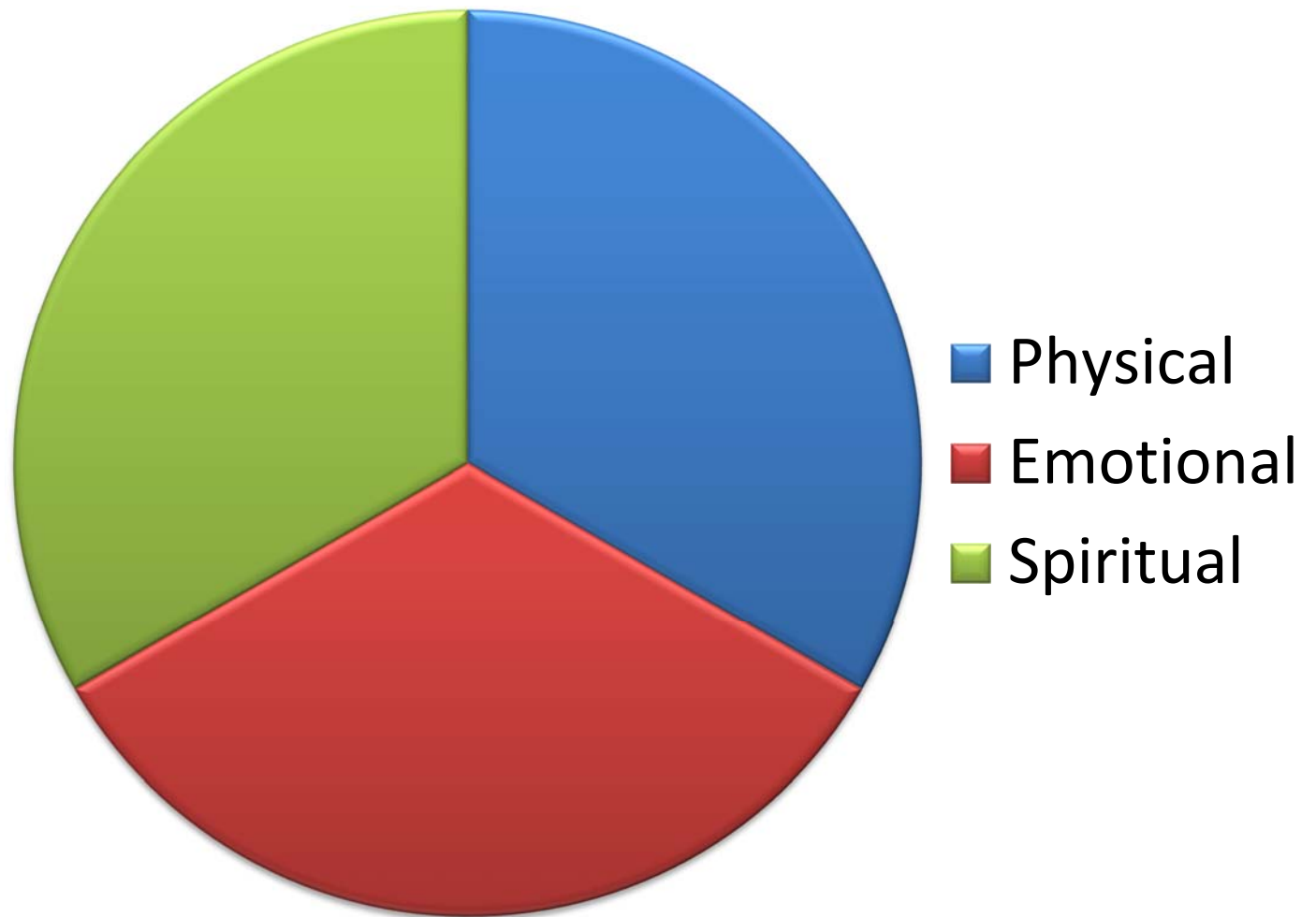
From a distance, it may be hard for a caregiver to feel that what they are doing is enough or important. But sometimes the distant caregiver is the one who ties things together and keeps everything organized. They may be the one called when something is needed or a problem comes up because they know what to do or where to go for help.

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Activity

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Name some ways to keep the physical, emotional, and spiritual balance.



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Story of Hope

“I think that all the words of encouragement that were offered, not only to me but to my husband, were the most precious to our family. I had to deal with cancer, but my husband had to deal with me and the cancer. I am truly thankful for all the kindness he received.”

– *Dorothy, breast cancer diagnosis*

Key Messages

- Caregivers play a key role in the patient’s care. They may have to coordinate care, give medicines, and offer emotional support.
- Shifts in cancer treatment to more outpatient procedures have led to more home care. Caregivers are needed now more than ever.
- Caregiving can be an enriching experience, and provide emotional and spiritual satisfaction.
- A caregiver who does not live close to the patient can still provide valuable support. That support can be given through creating calendars and schedules or setting up a web-based program so that family members and friends can sign up for tasks.