

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 7: Money Concerns and Legal Issues

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

Money Concerns and Legal Issues

Group Discussion			
	True	False	Not Sure
1. Caregiving is a full-time job.			
2. There are laws in place that can provide support for caregivers when they are not able to work.			

Researchers have just begun looking at the financial costs of being a caregiver. Many caregivers are already employed, but we know that caregiving can be a full-time job itself. This can lead to work-related issues like missed days, low productivity, and work interruptions. Some caregivers even need to take unpaid leave, turn down promotions, or lose work benefits. The stress of caring for someone on top of worrying about keeping a job can feel like too much. Dealing with these issues is important to both the employer and the employee.

There will be times when there will be more demands on the caregiver. Some of the more difficult times are when the patient is being diagnosed, getting cancer treatment, getting treatment for recurrence, or nearing the end of life. The person who is employed may end up taking time off from their paying job for caregiving. For people in certain types of jobs (temps, freelancers, consultants, entrepreneurs), this is very difficult. If they don't work, they don't get paid. For those with regular jobs in larger companies, there may be benefits to help them take time off and still keep their jobs.

Some people find that there is no one else to offer care to the cancer patient on a long-term basis, and cut back to working part time. This can mean loss of benefits for many caregivers. Some feel that they have to quit their jobs entirely. If a caregiver needs to keep their job but the interruptions and time off are creating problems, they may want to check into a different schedule during the times their loved one needs them most. Some companies allow people to take some paid leave if they are caring for a spouse or close relative. A caregiver may be able to work half-days or split shifts, or take one day a week off for health care provider

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

visits, for example. Or the caregiver can ask for help from others during these times when the patient's needs are greater than usual.

There is a federal law called the Family and Medical Leave Act that guarantees up to 12 weeks off per year to take care of a seriously ill family member (spouse, parent, or child). It only applies to larger companies, and not every employee qualifies for it. Even though some companies pay the employee for part of the time, using FMLA leave will enable a person to keep their health insurance benefits. But FMLA may not allow a caregiver to arrange enough time off to give all the care their loved one needs. And if the patient is not a parent, child, or spouse, the law does not apply.

Even if a caregiver does not qualify for legal job protection, they may still explain their situation and ask their employer if they can adjust their schedule to allow them to give care without leaving their job. Some employers are flexible in these situations. The caregiver will need to think ahead and be ready to spell out clearly what they can keep doing and how long they think they will need extra time off.

Money Concerns

For the person who has lost their income because they had to quit their job to be a full-time caregiver, financial problems can mount up very quickly. If a caregiver is still working, the patient may need extra help – someone else to check in while they are at work. Some caregivers may be able to check in by phone as long as their loved one can do some of their own basic care. Or they can start pulling their family together to find people who can be there or call while the caregiver is at work. If the person has the need for skilled nursing care, the patient may be able to get home health visits through their health insurance.

If a caregiver looks carefully and finds that they cannot afford to quit their job and lose their insurance, options such as FMLA or special arrangements with employers may allow them to keep working.

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

Options for Health Coverage if a Person Loses Insurance at Work

When caregivers quit their jobs, they usually lose their own health insurance coverage as well as their source of income. But if a person can pay for their own insurance, COBRA will allow them to be covered for some months after leaving a job. COBRA lets a person continue 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. 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.

Members of federally recognized tribes and ANCSA shareholders have the option to enroll in a State Marketplace plan 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 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 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. Visit healthcare.gov/american-indians-alaska-natives for special information on insurance for American Indians. 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 marketplace due to loss of income, they can apply for Medicaid for themselves and Child Health Insurance Program (CHIP) for their children at any time. 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).

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

Patients and Work

The patient with cancer often wants to keep working through their cancer treatment. In some cases, it is possible. In others, it doesn't work well. The patient with cancer may benefit from the Americans with Disabilities Act. This federal law requires larger employers to make "reasonable accommodations" for an employee with a long-term or permanent disability. Still, the person must be able to do the main job functions in order to qualify for this protection. And it doesn't apply to every employer. If the patient with cancer has to quit their job during or after treatment, and is ready to go back to work, there are some protections to prohibit job discrimination.

Sometimes the employee with cancer who wants to keep their job needs to take time off during treatment. They may do this using either company benefits or the Family and Medical Leave Act (FMLA – see above). FMLA can be used by the person with a serious illness as well as by that person's caregiver (as long as they're a family member – spouse, parent, or child).

Taking leave under FMLA is usually much better for the person with cancer than quitting, because they get to keep their health insurance. Despite the complications of scheduling and working, this may turn out to be easier on the caregiver. Even though it is hard to keep up with health insurance and billing statements, it is even harder to get care with no health insurance at all. If the person with cancer later learns that they must leave their employment permanently, they should be able to use one of the options listed above to extend health insurance coverage or get a new health plan.

Legal Issues

It may be hard to talk about, but legal issues can be a huge source of stress for caregivers, patients, and families. Common worries include who will manage the person's money and who will make important health care decisions if the patient is unable to do so. It is important to bring these up with the patient while they are still able to make choices, so that the caregiver and the rest of the family can be clear about what the patient wants.

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

Money and financial decisions: There are certain legal tools that may help the caregiver and the patient with money, if the patient loses the ability to make their own decisions. One example is the durable power of attorney, which allows the patient to choose a person to make financial decisions on their behalf. (This is quite different from the *durable power of attorney for health care*, which only applies to health care decisions; see below.) It is useful for people who are having trouble handling their own finances due to illness or side effects such as fatigue. The patient can put limits on the power of attorney, such as that it can only be used for certain types of transactions, or that it only goes into effect if a doctor declares them unable to make their own decisions. The durable power of attorney does not affect health decisions. If you are the health caregiver, you may want to consider asking the patient to choose someone else to make the financial decisions.

Advance directives are for health care decisions: A durable power of attorney for health care (also called a health care power of attorney) has nothing to do with money or finances, only health care decisions. The health care power of attorney is a type of advance directive. It allows the patient to choose someone to make health care decisions. But it only goes into effect if the person becomes unable to make their own decisions. Most of the time, a patient will choose a close family member, partner, or spouse who is aware of the health condition and the patient's wishes. The caregiver is a logical choice in many cases, given their knowledge of the patient and their condition. But it becomes more difficult when the patient and the caregiver have different goals and values. For example, if the patient is nearing the end of life and wishes to stop treatment, and the caregiver is still looking for a cure, this may not work the way the patient wants. If this is the case, the patient may want to have a living will that spells out exactly what to do or not to do in certain health-related situations. The living will is another type of advance directive. The patient will need to be sure that the health care team and their family members have a copy of their living will and understand their wishes. It's important to do this before the patient loses the ability to speak for themselves.

Do you need a lawyer? In many cases, such as consent for the health care team to share information, legal issues can typically be handled without a lawyer

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

(attorney at law). There are times when a lawyer may be needed, though. In cases where there is disagreement about advance directives or durable powers of attorney among family members and loved ones, a lawyer can help. The lawyer can talk with the patient and draw up documents that specify who makes decisions for the patient if they become unable to do so.

Circle Of Life: Cancer Education and Wellness
for American Indian and Alaska Native Communities

Activity

Considerations for Going Back to Work

How many days a
week can be
worked?

Physcially and
emotionally
prepared to return
to work?

What caregiving
activities still need
to be carried out?

A row of six empty, rounded rectangular boxes in a light green color, intended for participants to write their responses to the questions above.

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

Story of Hope

“I think some families become stronger because of it. We’ve had our rough spots, but we have never again taken each other for granted.”

– Darryl

National Cancer Institute. (2010). *Life after cancer treatment: social and work relationships*. Retrieved on July 29, 2011, from cancer.gov/cancertopics/coping/life-after-treatment/page7.

Key Messages

- The Americans with Disabilities Act can help some people who want to keep their job during cancer treatment. It applies to larger employers, and the person must be able to perform the essential parts of their job.
- If a caregiver needs to keep their job but the interruptions and time off are creating problems, they may want to check into a different schedule during the times their loved one needs them most.
- A federal law called the Family and Medical Leave Act guarantees up to 12 weeks unpaid time off per year for eligible employees who are sick, or to family members who need to take care of a seriously ill spouse, parent, or child.
- It may be hard to talk about, but legal issues can be a huge source of stress for caregivers, patients, and families. There are many resources available for families facing cancer.