Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

American Cancer Society Circle Of Life℠

Cancer Education and Wellness for American Indian and Alaska Native Communities

Wellness along the Cancer Journey:
Caregiving

Revised October 2015

WELLNESS ALONG THE CANCER JOURNEY: CAREGIVING

Goals: Those taking part will be able to describe some of the many roles of caregivers and to understand what to be aware of when caring for a person being treated for cancer.

Objectives: At the end of this section, those who take part will be able to answer these questions:

- What do caregivers do?
- What are common challenges caregivers may face?
- How can caregivers take care of themselves?

Photograph courtesy of Jason M. Edwards, J. Morgan Edwards Photography

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Chapter 1: Module Overview

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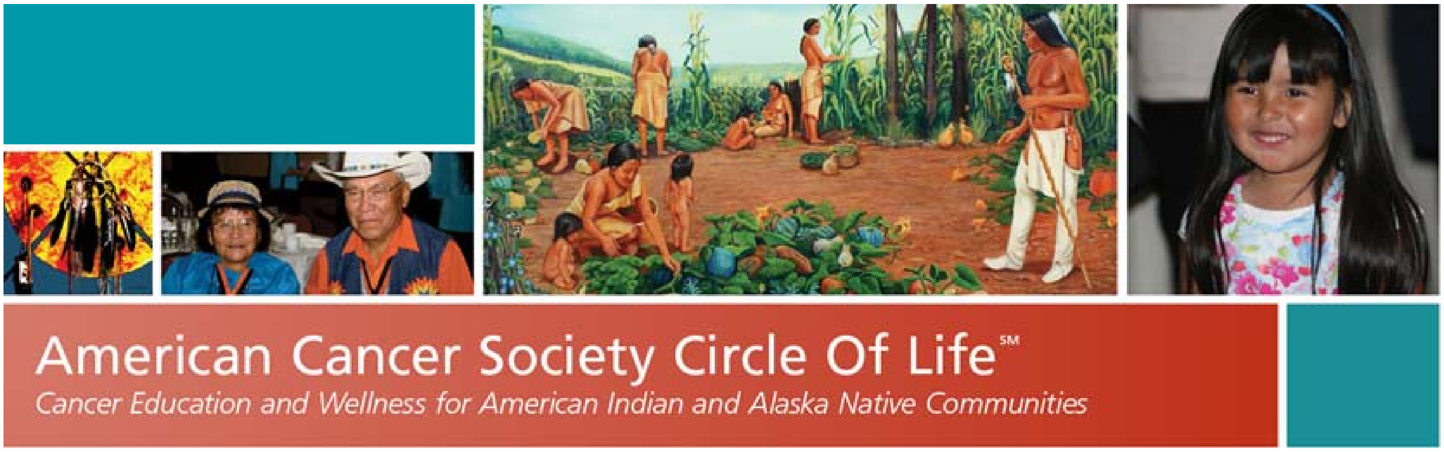
Module Overview

This module will look at what caregivers can expect when caring for someone with cancer and what they need to know when caring for a loved one at home.

Caregivers are often loved ones who give the person with cancer physical and emotional care. They may be spouses, partners, family members, or close friends. Most often, they are not trained for the caregiver job. Many times, they may be the lifeline of the person with cancer.

This guide offers general information about caring for a person with cancer at home. It includes the more common problems people with cancer experience, signs of problems to look for, and some ideas for what to do. It also lists some of the more common cancer treatments and possible side effects that go with them.

Caregiving can be an overwhelming job. Healthy eating, remaining physically active, and healthy ways to manage stress are also discussed in this guide. Additionally, support services for caregivers (such as respite care, that can give the main caregiver a break), tips on organization, and accepting help from others are also discussed.



Wellness along the Cancer Journey:
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Chapter 2: Caregiving Is Essential

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 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.

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 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.

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.

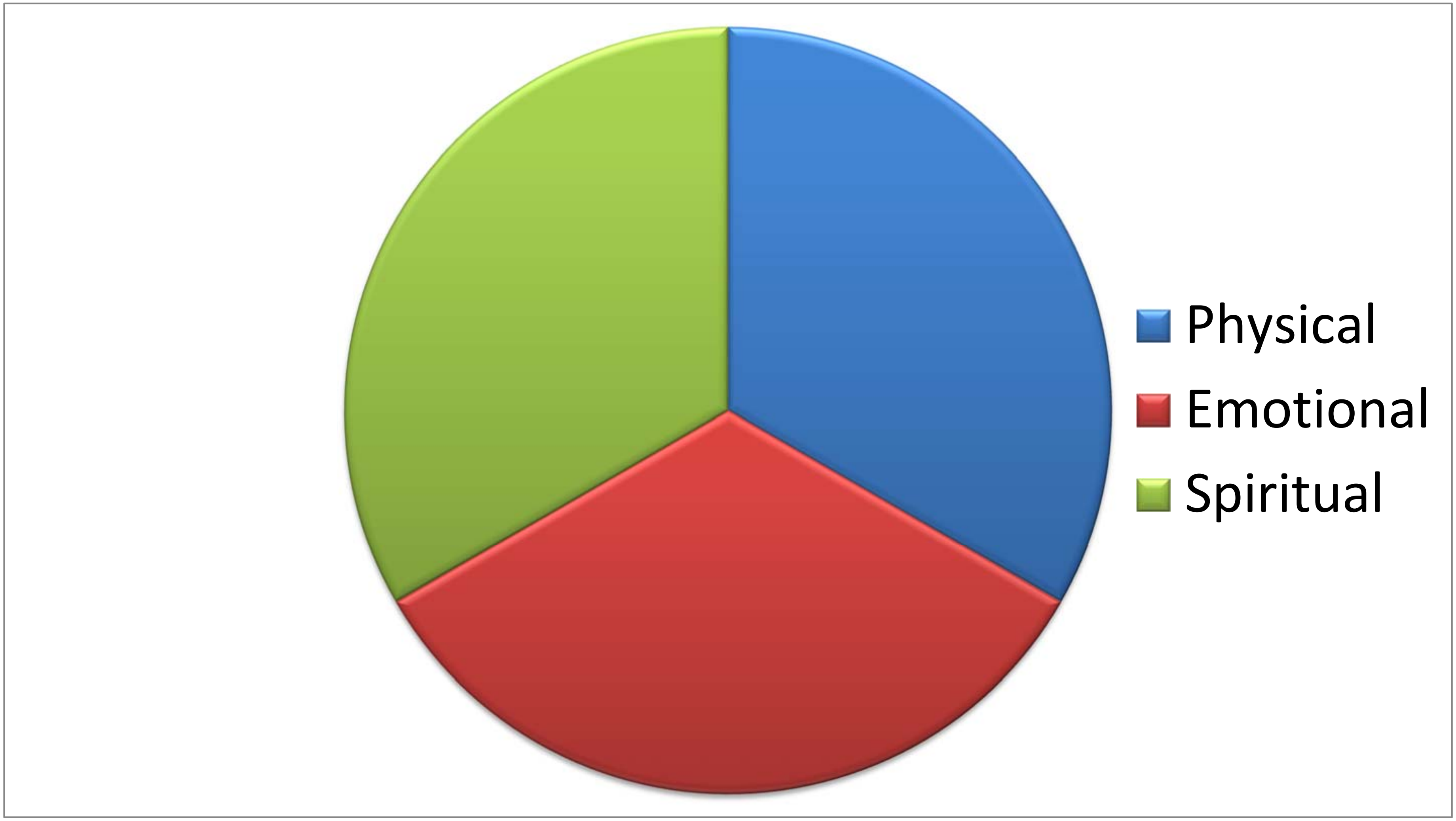
- Keep a list of all the medicines and treatments the patient is getting (include doses and schedules), and update it often.
- Make sure the person with cancer can reach people who help with care. This may mean buying a cell phone for the patient or setting up long distance service on their land-line 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.

Activity

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



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

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.

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Chapter 3: Caregivers Are Part of a Team

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Caregivers Are Part of a Team

Group Discussion			
	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."

- "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.

- 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 bus,y 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:

- 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 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® 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 the 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 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.

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.	• Identify who needs to be included. • Think about what needs to be said.	Allow family members and friends enough time to digest what is said.
Think about the roles that family members and friends can play.	• Make a list of all caregiving activities.	Examples of activities: • Home maintenance and living situation • Financial affairs • Transportation needs • Personal care • Health care • Communication
Find out about the diagnosis, what kind of care might be needed, and how to provide care.	• Visit cancer.org for cancer information. • Look up caregiving trainings. • Read *Caring for the patient with cancer at home* booklet.	Share what is found with family members and friends.
Think about a schedule and a plan for how caregiving activities can be carried out.	• Have family members and friends pick what they can do. • Have family members and friends give days and times they will be available.	Develop a schedule. Templates are available in Microsoft Word and Excel.

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.

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)

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

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

American Cancer Society Circle Of Life℠

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Chapter 4: Support for Caregivers

American Cancer Society®

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 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).

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 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:

- 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 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 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.

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.)

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.

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.

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Wellness along the Cancer Journey:

Caregiving

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Chapter 5: Understanding the Health Care System

Understanding the Health Care System

Group Discussion			
	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.

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 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?

- 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 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 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 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) 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.

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.

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.

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
☐	☐	☐
☐	☐	☐
☐	☐	☐
☐	☐	☐

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.

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.

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Wellness along the Cancer Journey:

Caregiving

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Chapter 6: The Treatment Timeline

American Cancer Society®

The Treatment Timeline

Group Discussion			
	True	False	Not Sure
1. Delays in cancer treatment are not possible.			
2. Once treatment stops the patient will still need help.			

One of the first steps after being told someone has cancer will be learning about the diagnosis. This will help the caregiver and other family members understand the disease process and get an idea of what lies ahead. Some of the first questions that should be asked are:

- What kind of cancer is it?
- Where is it? Has it spread beyond where it started?
- What are the treatment options? Which do you recommend?
- What is the goal of this treatment?
- How long will treatment last? What will it be like? Where will the treatment be given?
- What side effects should we expect?
- How will treatment affect everyday activities?
- What is the likely long-term outcome? What can we expect?

When a person has cancer, there are many ways it can go. While there is no way to know for sure, the health care team should be able to give an idea of how things are likely to go. This will become clearer over time and as they get to know the person with cancer better. Just a few possible scenarios are:

- Diagnosis, active treatment, finish treatment, then survivorship with a normal life

- Diagnosis, active treatment, finish treatment, then survivorship with possible long-term treatment effects
- Diagnosis, active treatment, finish treatment, cancer comes back (recurrence), active treatment, survivorship with ongoing treatment and ongoing treatment effects
- Diagnosis, active treatment, recurrence, survivorship with possible long-term treatment effects, another recurrence, end of life
- Diagnosis, active treatment, end of life
- Diagnosis of late-stage cancer, palliative (comfort) treatment only, end of life

Again, there are many ways that cancer can go. And things can change at any time, for better or for worse. While it would be great to know what to expect, there is no way to predict how someone will do.

Test Results

In most cases, the only way to know for sure whether a tumor or mass is cancer is for the health care provider to do a biopsy. This is when all or part of the lump is taken out with surgery and looked at under a microscope to see if there are cancer cells in it. A biopsy can also be done using a needle to take a small part of the lump. In the case of changes in blood counts, a bone marrow biopsy may be done. This is when a health care provider or nurse uses a needle to take out some of the liquid bone marrow that is inside the bones. It is checked for cancer cells. The type of biopsy depends on the size and location of the lump or the area that has changed.

Sometimes it can take awhile to get back test results. This can be a difficult time for the patient as well as for loved ones who know it might be cancer. Some notice that they think of worst-case scenarios and wonder if they will lose their loved one. Others may try to go through their days as normally as possible and not think about it. Most people have a mixture of dread and hope as they wait for the test results. It is important to know that it is normal to have these feelings. Some people find comfort in talking with other people about what's going on, while others wish to keep it very private. Try to respect the patient's wishes during this time.

Treatment Delays

Planning cancer treatment takes time. Most people want to start treatment right away. They worry that extra time taken to do tests or make decisions will take up precious time that could be spent fighting the cancer.

Cancer treatment should start very soon after diagnosis, but for most cancers there is no harm in waiting a few weeks to begin treatment. This gives the person with cancer time to talk about all their treatment options with the health care team, family, and friends, and then decide what's best for them.

The patient may also want to get a second opinion on what is the best treatment. This is often a good idea, especially if the patient can see a health care provider with a lot of experience in treating their type of cancer. A second opinion can give the person with cancer more information and help them feel more confident about choosing a treatment plan. Some insurance companies even require a second opinion before they will agree to pay for certain treatments. And almost all will pay for a second opinion. Still, it's a good idea to check the patient's health insurance coverage first.

The patient also may want or need time to prepare to put their normal activities "on hold" while getting treatment. For instance, arrangements for work or childcare may be needed, and taking care of these things ahead of time can help the patient better focus on dealing with treatment. Please see Appendix F for information called *Helping Children When a Family Member Has Cancer: Dealing With Diagnosis.*

Uncertainty

When a person has cancer, they go through different stages. There will be times when the caregiver and the patient do not know what will happen next. With an illness as serious as cancer, this can be scary. But there are no guarantees in cancer care. There is no way to know for sure whether the treatment will work. No one can predict the side effects or problems someone will have during treatment. And even after successful treatment, there is still the possibility that cancer will come back – there can even be a new, different cancer sometime in the future.

It can be hard for everyone to deal with a constant state of "not knowing." Here are some ideas that have helped others deal with uncertainty and fear and feel more hopeful:

- Try to let go of fears, but not deny them. It is normal for these thoughts to enter a person's mind, but it does not help to keep thinking about them over and over again. Letting them go can free a person from wasting time and energy on needless worry. Some people picture them floating away, or being vaporized. Others turn them over to a higher power to handle.
- Express feelings of fear or uncertainty with a trusted friend or counselor. Being open and dealing with emotions helps many people feel less worried. People have found that when they talk about strong feelings, like fear, they are more able to manage or let go of these feelings. Thinking and talking about feelings can be hard.
- Focus energy on wellness and what can be done now to stay as healthy as possible. Find ways to relax. Make time for regular exercise, and be as active as possible.

Control what can be controlled. Some people say that putting their lives back in order makes them feel less fearful. Being involved in the patient's health care, keeping life as normal as possible, and making lifestyle changes are just a few of the things that can be done. Even setting a daily schedule can give the caregiver more confidence and ease. And while no one can control every thought, some say they've resolved not to dwell on the fearful ones.

Adjusting to the Diagnosis

With time, the patient and loved ones will find out about and start to adjust to the cancer diagnosis. This is a time of change and action – everyone is getting used to the unexpected and scary situation that they now find themselves in. Even with all the activity, some people go through their days feeling numb and disengaged. Others may be sad, edgy, or angry. Emotions may change from minute to minute for everyone. Things may not feel settled for a long time, but there are appointments to keep, things to discuss, and plans to make.

It's important to get accurate, reliable information in writing so that the patient and caregiver are ready when questions must be asked or care coordinated:

- What is the exact name and location of the cancer?
- What is the stage of the cancer?
- What treatments are recommended? How are they done, and how long do they take?
- Will the patient need to be in the hospital? When and for how long?

Treatment for Cancer

Cancer treatment varies a lot depending on the kind and stage of cancer the patient has. The most common treatments for cancer involve surgery, chemotherapy, and/or radiation. So someone's treatment may involve time in the hospital or making many trips to a clinic for radiation or chemotherapy. The person with cancer may need more than one type of treatment, and each type comes with its own challenges.

A caregiver will want to be sure that they understand the treatment options chosen by the patient and health care provider, since they will likely be helping to plan how to make it happen. For some treatments, the patient may be able to go on their own. For others, someone may need to drive the patient or go along. In some cases, the person will get medicines that make them sleepy, or cause symptoms that will require help from others.

If the person gets chemotherapy, there may be nausea, extreme tiredness, easy bleeding, and infections to worry about. Depending on the treatment, there may be many other side effects, too. Treatment can be long or fairly short, but even short treatments tend to disrupt a person's life for several weeks. A caregiver may find that they need to take time off from work to help care for the patient. During treatment, they will want to learn about general cancer information, treatment effects, and how to manage side effects.

Some questions the caregiver may want to discuss with the cancer team ahead of time are:

- What symptoms do we need to tell you about right away? Which ones can wait?
- How do we reach you after office hours? On weekends? Holidays?
- What can we do to manage side effects?
- How will we know if treatment is working?

When Treatment Ends

After treatment the patient goes into a stage of healing and recovery. Less time is spent in the clinic and they will see the cancer care team less often. Patient distress may go down, but caregiver stress may not. Day-to-day care for and monitoring of the patient becomes the caregiver’s job, and not seeing the cancer care team as often may leave a caregiver feeling alone and without back-up or support.

A caregiver may want to ask the health care provider these kinds of questions, and write down the answers for later:

- What kind of follow-up visits are needed? How often and for how long?
- Are there any symptoms that we should let you know about? Who should we call for other problems?
- When will the patient be able to go back to a regular work schedule (if they have been off work or working fewer hours)?
- How will we know if the cancer has come back?

After treatment is over, be sure that the patient has copies of their cancer treatment information. They will need to keep these records for the rest of their lives:

- Summary of the person’s exact diagnosis and cancer stage
- Treatments used (including all medicines and doses)
- Summary of surgery (if one was done)
- Biopsy or pathology reports
- Radiation treatment and dose records
- Discharge reports from any stays in the hospital
- Records of any major problems or complications during treatment

The patient may need to go to different places to get these records. For instance, the hospital medical records department will usually have hospital discharge and surgical reports. If radiation or chemo was done on an outpatient basis, the health care provider who coordinated the treatment can explain how to get the reports. The patient may need to ask the surgeon where to get copies of pathology reports.

It is important that these records be collected soon after treatment. Clinics and hospitals destroy records after a few years, and the only copies may be the ones the patient has.

After all this information is collected, the caregiver may want to keep copies as well. These records are important in the event that questions come up later, the patient needs to see a different health care provider in the future, or if the cancer comes back.

Going Back to Work or Normal Activity

As curative treatment winds down and the healthcare provider checks the patient for any remaining signs of cancer, the patient may be given the “all clear” to go back to work. Or it may be that a loved one needs to slowly increase their work duties; this will depend on their physical condition and the type of job they have.

The caregiver may need to help get the notes from the health care provider that will be needed to clear the patient for full work duties when the time comes. But when a loved one starts working a more normal schedule, there may be days of fatigue in which the caregiver’s help will still be needed. It may take some time to get past this phase. So the caregiver may still need a circle of helpers so that they too, can start getting back to a more normal schedule.

If the fatigue continues, the patient may need to go back to the health care provider to see if there is a new problem or if there is anything more they can do to help. This may be a time where the Americans with Disabilities Act can be helpful to some patients. It can be used to negotiate for special equipment or a different work schedule. See Appendix G for more information about the Americans With Disabilities Act.

It is possible that life-saving treatments affect the patient in ways that will not go away. For some people, long-term effects mean permanent life changes, so that they cannot go back to the life they had before treatment. It is normal for the patient and sometimes loved ones to grieve the patient's loss of whatever they might have lost due to treatment. Accepting these losses can take time for both the patient and caregiver.

The caregiver may find themselves continuing to do the things they did when the patient was in treatment. But it is important that, over time, the caregiver let the patient go back to doing the things they can and should do on their own. This may take place over a period of months as the patient gets stronger. Check in every week or two to see what they are doing and can start doing, either alone with a little help. If there are things that the patient can’t quite do, the caregiver can talk with the health care provider about a referral to a physical therapist or occupational therapist. These professionals may be able to help the patient improve their abilities by helping build muscle strength and/or offering assistive devices.

When Cancer Returns

Sometimes there is no evidence of cancer when treatment is finished, but the cancer still comes back. In that case, it helps to find out whether there is hope for a cure, what kind of treatment the health care provider recommends, and what the goals of this treatment are.

It may be that the cancer is not curable, but that treatment may prolong life. If that is the case, the patient may want to know the pros and cons of getting more treatment and of not getting treatment. For instance, if treatment can stop the cancer and is likely to prolong survival for several years, it may be worthwhile even if there will be serious side effects every few weeks. On the other hand, if treatment is expected to prolong life for four to six months and cause troublesome side effects, the patient might choose palliative (comfort) care rather than active treatment. Talk over the expected effects and outcomes of getting treatment versus not getting treatment to be sure the situation is well understood. The caregiver needs to be sure about what is being asked of them if further treatment is given.

Ongoing Treatment

Sometimes treatment doesn't come to an end at the expected time. In some cases, cancer becomes a chronic illness – a disease that people can live with and manage on a day-to-day basis over a long time, much like diabetes or heart disease. The person with cancer may decide to continue treatment as long as it slows down or stops cancer growth, even if a cure is no longer possible.

Caring for someone getting ongoing treatment is more complex. More and more often treatments are managed as an outpatient or even given at home. This means more responsibilities for the caregiver. And as time goes on, the people who were there to help may need to limit the time they spend helping the patient. This can be a very demanding situation for a caregiver. The caregiver is helping the patient as they get treatment, so there are ongoing side effects and frequent appointments to deal with. The difference is that this time, it is not known how long this will last. Living with this uncertainty can be an extra challenge.

Some patients are able to go back to work during this period of ongoing treatment. They may need extra help only for a few hours or days after each treatment. They may also need help with home responsibilities, family, and bills. In other cases, less frequent chemo treatments and better management of side effects mean that the caregiver can work a more normal schedule during long-term treatment. In some cases, both the patient and caregiver go back to outside jobs. Still, chemo or other treatments usually mean that some schedule changes will be needed.

Even if everyone goes back to their jobs, someone will still need to keep up with the treatment plan, the medical records, and the bills. This can be demanding for the patient and caregiver. They may both need support with the amount of work that is needed on top of working and dealing with cancer. And emotional support may be needed to help the patient, caregiver, and other family members cope with knowing that the cancer cannot be cured.

When Treatment Stops

If treatment is no longer helping and the cancer is still growing, a patient may decide to stop treatment. They may choose to get care that only helps with symptoms. It helps if the patient can put into words and share what is most important to them with others who are close to the person. The patient will have to decide things like, "When do I stop trying to beat the cancer and enjoy the rest of my life?" or "Would I rather spend the next two months reading and playing with my grandchildren or dealing with side effects?"

Sometimes, caregivers can help patients clarify their highest priorities so that they can focus on them before the chance is lost. Other times, it may take someone on the treatment team or a mental health professional to help the patient clarify what is most important to them, and what can be expected from further treatment. This is a difficult time for everyone, and help from the medical team may be needed to fully understand the situation and figure out what is best for the patient.

Once the decision to stop curative treatment has been made, make sure that other family members and loved ones understand and can support the patient's decision. It is now time for another family meeting, where questions can be answered and concerns addressed. Be sure that other day-to-day caregivers are invited, if they are still involved in the patient's care.

It is also time to talk with the health care provider about palliative care. There are many things that can be done to manage the symptoms of cancer, such as pain, trouble breathing, and fatigue. When these symptoms are relieved, the patient may have more energy to spend time doing those things that they value most. The caregiver will want to be in close contact with the health care provider to be sure that any new symptoms are quickly addressed.

If the patient is expected to live only a few months, hospice may be a good option. Hospice is intended to relieve discomfort and make the patient better able to enjoy the time they have. In most cases, hospice is given at home and requires that the patient have a primary caregiver. Having hospice staff on call 24/7 can make it easier for the caregiver to know whom to call when the patient has a new problem or a symptom that is not relieved. Hospice also provides emotional and spiritual support for the family and caregiver during this transition. The caregiver may wish to talk with the hospice nurse or chaplain about coming to a family meeting to talk about the new goals of care and how they will work with them. Again, it is helpful if the patient is able to attend.

As the caregiver works with the patient and helps make the most of the rest of their life, it is normal to feel sad and even start to grieve. A caregiver will want to continue their circle of support. A support group or mental health professional may also help during this time.

Activity

Please use the simple table to begin thinking about financial matters that should be tracked. One tip is to keep a file of bills and EOBs to make notes on them.

	Monthly Expenses	Insurance Claims	Medical Visit Co-pays	Medication Co-pays
January				
February				
March				
April				
May				
June				
July				
August				
September				
November				
December				

Story of Hope

“No question is too small or too silly to ask. I never was afraid to call the doctor or staff with questions about anything even questions about our bills and insurance. I found that our doctor and his staff were willing to answer any question.”

– Judith, husband’s caregiver

Key Messages

- Cancer treatment should start very soon after diagnosis, but for most cancers, there is no harm in waiting a few weeks to begin treatment. Sometimes it is not possible to start treatment right away.
- Cancer treatment varies a lot depending on the kind and stage of cancer the patient has. Explore all of the options that are available and make sense.
- After treatment is over, be sure that the patient has a written summary of their diagnosis, treatments used, and other important medical information. This is very important for health care after treatment.
- When a loved one starts working a more normal schedule after treatment, there may be days of fatigue in which the caregiver’s help will still be needed. Please remember to take care of yourself.

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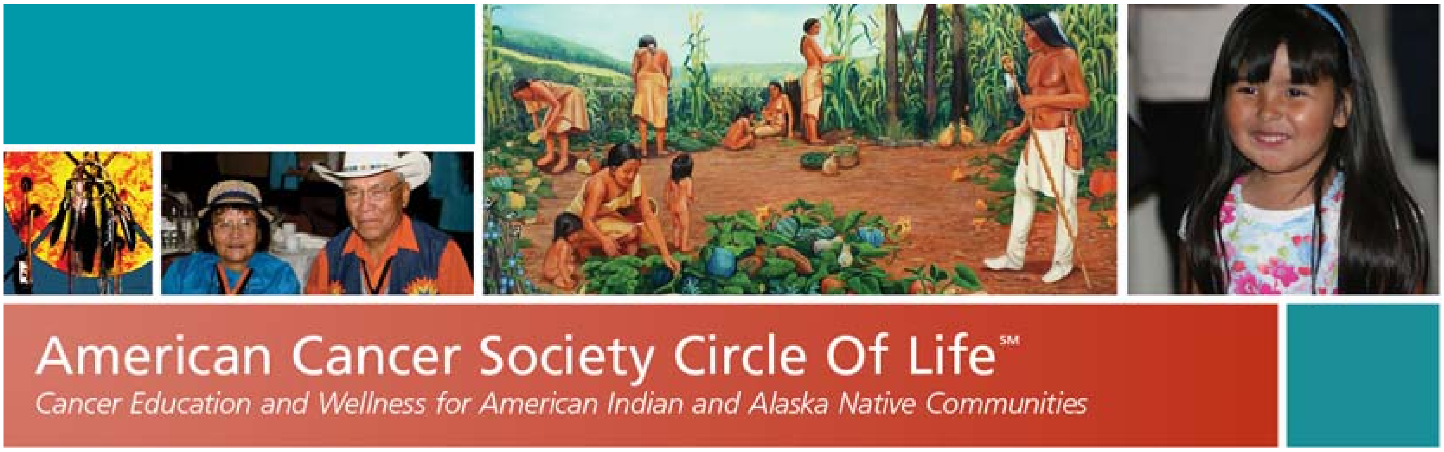

Wellness along the Cancer Journey:

Caregiving

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Chapter 7: Money Concerns and Legal Issues

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 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.

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).

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

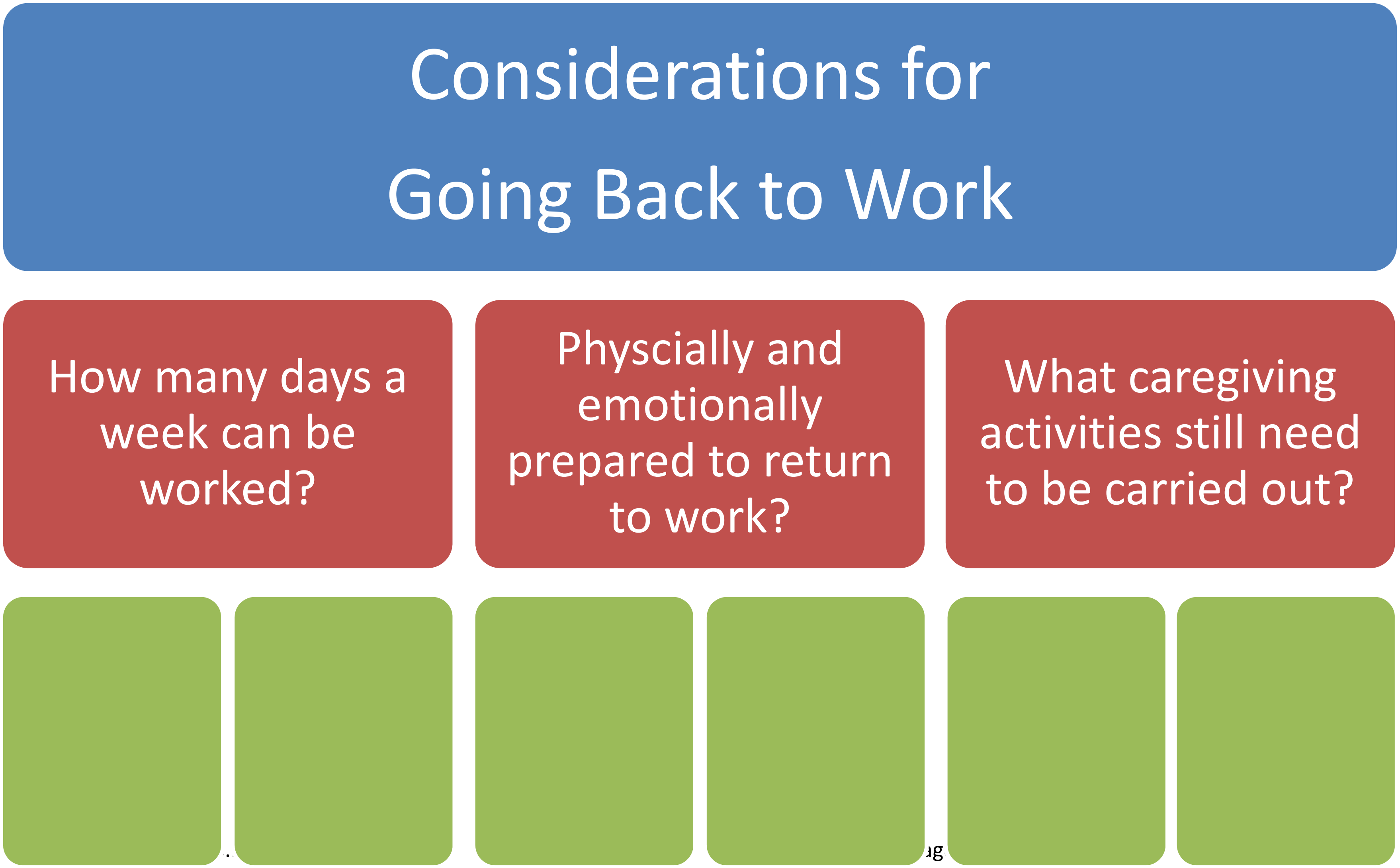
It may be hard to talk about, but legal issues can be a huge source of stress for caregivers, patients, and families. Common worries include who will manage the person's money and who will make important health care decisions if the patient is unable to do so. It is important to bring these up with the 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.

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 (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.

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?

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.

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

American Cancer Society Circle Of Life℠

Cancer Education and Wellness for American Indian and Alaska Native Communities

Wellness Along the Cancer Journey:

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Chapter 8: Knowledge Questions

Knowledge Questions

Please answer the following questions.	True	False	Not Sure
1. Caregiving can be a rewarding experience.			
2. Caregivers are not a part of the caregiving team.			
3. The patient does not need to be involved in their care.			
4. Having family meetings can help manage caregiving for the patient.			
5. There are not many support services for caregivers.			
6. It is important to allow others to help so the caregivers can take breaks.			
7. Caregivers work with the health care team and patient during treatment.			
8. Caregivers should not talk with the patient about questions to ask at appointments.			
9. Delays in cancer treatment are not possible.			
10. Being a caregiver can take away time from working a job.			
11. Caregiving is a full-time job.			
12. There are laws in place that can help caregivers when they are not able to work.			

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Cancer Education and Wellness for American Indian and Alaska Native Communities

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Chapter 9: Appendices

Appendices

Appendix A: National Organizations and Websites

Family Caregiver Alliance (FCA)/National Center on Caregiving
Toll-free number: 1-800-445-8106
Website: caregiver.org

> Provides information and resources on long-term caregiving

National Alliance for Caregiving (NAC)
Toll-free number: 1-800-896-3650
Website: caregiving.org

> A national coalition of organizations focused on caregiving issues; provides familycaregiving101.org, a resource for answers, new ideas, and helpful advice for caregivers

National Family Caregivers Association (NFCA)
Toll-free number: 1-800-896-3650
Website: thefamilycaregiver.org

> A national, nonprofit, membership association whose mission is to support, educate, and empower family caregivers to help them become their own advocate

Well Spouse Association (WSA)
Toll-free number: 1-800-838-0879
Website: wellspouse.org

> A national, nonprofit membership organization (dues are charged) that provides emotional support to spouses and partners of chronically ill and/or disabled people. Also offers Regional Respite Weekends for spousal caregivers.

National Respite Locator Service
Website: respitelocator.org

> Helps caregivers and professionals find respite services (a way for caregivers to get a break from caregiving) in their state and local area

Lotsa Helping Hands
Website: lotsahelpinghands.org

Helps coordinate services for friends, family, colleagues, and neighbors to assist loved ones in need. You can set up a free online program that allows volunteers to sign up to help with meals, rides, and other tasks on an easy-to-use, private group calendar.

American Association for Marriage and Family Therapy
Telephone: 703-838-9808
Website: aamft.org

Sponsors therapistlocator.net, which provides referrals to local marriage and family therapists. The site also contains educational materials on helping couples live with illness, as well as other issues related to families and health.

Cancer Legal Resource Center
Toll-free number: 1-866-843-2572 (1-866-THE-CLRC)
TDD: 1-213-736-8310
Website: cancerlegalresourcecenter.org

A nonprofit program offering free and confidential information and resources on cancer-related legal issues to cancer survivors, their families, friends, employers, health care professionals, and others coping with cancer

Cancer Hope Network
Toll-free number: 1-877-467-3638 (1-877-HOPENET)
Website: cancerhopenetwork.org

Volunteers provide free and confidential one-on-one telephone support for people with cancer and family members.

CancerCare
Toll-free number: 1-800-813-4673 (1-800-813-HOPE)
Website: cancercare.org

Offers free professional support services, including telephone counseling, online support groups, and educational materials, to people with cancer, their loved ones, and caregivers

Cancer Support Community
Toll-free number: 1-888-793-9355
Website: cancersupportcommunity.org

> A website that provides free support for people living with cancer – men, women, teens, and children – along with their families and friends. It provides networking and online support groups, workshops, education.

National Cancer Institute
Toll-free number: 1-800-422-6237 (1-800-4-CANCER)
Website: cancer.gov

> A good source of up-to-date information about cancer for patients and their families

The American Cancer Society is available 24 hours a day, seven days a week to provide – among other things – the latest cancer information, emotional support, or free lodging when patients need treatment away from home. Visit us at cancer.org or call us at 1-800-227-2345.

Appendix B: Medicine List

Name of drug*	Dose	Time(s) the drug is taken	What is the medicine for?	Who prescribed the medicine?	How long has this medicine been taken?	When should this medicine be stopped?

*Be sure to list everything you take. Include things like vitamins, herbs, or other supplements. Also list drugs you take “as needed,” or every now and then, and things like Tylenol or allergy medicines you get at the drug store.

Appendix C: Family and Medical Leave Act (FMLA)

The American Cancer Society does not offer legal advice. This information is intended to provide general background in this area of the law.

What is the FMLA?

The Family and Medical Leave Act (FMLA) of 1993 was designed to help employees balance their work and family responsibilities by allowing them to take reasonable unpaid leave for certain family and medical reasons. The FMLA gives certain employees the right to take up to 12 weeks of unpaid, job-protected leave per year. It also requires that the employee's group health benefits be maintained during the leave.

To whom does the FMLA apply?

FMLA applies to all public and private employers with 50 or more employees. These employers must provide an eligible employee with up to 12 weeks of unpaid leave each year for any of the following reasons:

- For the birth and care of the newborn child of an employee
- For placement with the employee of a child for adoption or foster care
- To care for an immediate family member (spouse, child, or parent, but not a parent-in-law) with a serious health condition
- When the employee is unable to work because of a serious health condition

Note that some states have family and medical leave laws with broader rights than FMLA. The US Department of Labor can help you get information about your state. (See the section "To learn more" for their contact information http://www.dol.gov/whd/fmla/employeeguide.pdf..)

Special FMLA rules

Military families

In 2008, the FMLA was expanded to include military family leave entitlements. FMLA can be used by military families for these purposes:

- The spouse, son, daughter, parent, or next of kin of a member of the Armed Forces can take up to 26 work weeks of leave to care for the service member with a serious injury or illness.
- There may be urgent family situations (called qualifying exigencies) that arise due to active military duty, which may qualify family members to take up to 12 weeks of FMLA (www.dol.gov/whd/fmla/fmlaAmended.htm).

Spouses that work for the same employer are limited to a combined total of 26 work weeks in a single 12-month period if the leave is to care for a covered service member. There are other differences and limitations in FMLA for military families. You can get more details from the Department of Labor (see "To learn more") or visit dol.gov/whd/regs/compliance/whdfs28.pdf to read their fact sheet online.

Airlines and school employees

Airlines have different rules about eligibility, and there are some limits on reduced schedules and taking FMLA leave near the end of a school term.

The rest of the information here is focused only on FMLA for serious health conditions such as cancer.

Who can take FMLA leave?

Employees are eligible for FMLA leave if **all** of the following apply:

- They've worked for their employer at least 12 months
- They've worked at least 1,250 hours over the past 12 months, or about 25 hours per week.
- They work at a location where the company employs 50 or more employees within 75 miles.

Military reservists returning from active duty are entitled to the rights and benefits they would have had if they had been continuously employed.

For example, George returned to his regular job on June 1 after a one-year tour of active duty. On July 6, he learned that his child has cancer and will need intensive treatment. He can request FMLA to care for his sick child right away, even though his hourly job requirement was not fulfilled. For more details, visit dol.gov/vets/media/fmlarights.pdf to see the memo from the Solicitor of Labor, or contact the Department of Labor (see the “To learn more” section).

What if I left my job and then returned to it? What counts toward the1,250 hours that I need to qualify for FMLA?

First, the 12 months of service do not have to be continuous or consecutive; all of the time you’ve worked for the employer is counted. But you still must have worked 1,250 hours in the past 12 months to qualify (unless you are a military reservist returning from active duty). The 1,250 hours include only those hours actually worked for the employer or spent in active military duty. Paid leave time, previous FMLA leave, and other absences from work don’t count toward the 1,250 hours.

Your individual record of hours worked is used to decide whether 1,250 hours had been worked in the 12 months before you start FMLA leave. The following may help you figure out whether the 1,250-hour requirement has been met:

- Roughly 25 hours worked in each of the 52 weeks of the past year, **or**
- More than 104 hours worked in each of the 12 months of the past year, **or**
- About 40 hours worked per week for more than 31 weeks (over 7 months) of the past year.

If you’re a military reservist returning to your job after active military duty, you’ll be treated as if you had been continuously employed during your active duty period. See the section called “Who can take FMLA leave?”

What counts as a serious health condition?

There’s more than one way to define a serious health condition. It can mean any illness, injury, impairment, or physical or mental condition that involves any period of illness or treatment connected with inpatient care. This means at least one overnight stay in a hospital, hospice, or residential health care facility, **and** any period of illness or treatment that involves incapacity afterward (the person cannot work, go to school, or perform regular activities).

But a serious health condition doesn’t always mean a hospital stay. It may also be a condition that has ongoing treatment, which includes any length of incapacity due to **any** of the following:

- A health condition (including treatment and recovery from it) that lasts more than three days in a row, and any treatment after that. It includes any length of incapacity related to that same condition, and must also involve:
    - Being treated two or more times by or under the supervision of a health care provider, or
    - Being treated once by a health care provider with an ongoing regimen of treatment.
- A permanent or long-term condition for which treatment may not be effective (for instance, a severe stroke, terminal cancer). Only supervision by a health care provider is required, not active treatment.
- Any absences for surgery or multiple treatments for a condition that would likely result in a period of incapacity if not treated (for example, chemotherapy or radiation treatments for cancer).

How far ahead of time must I request FMLA leave?

If possible, an employee must give an employer at least 30 days notice before FMLA leave is to start. This only applies to planned medical treatments and elective surgery. Knowing that far ahead is rarely possible when you have cancer or when you are taking care of a loved one with cancer. In the case of unexpected need due to serious illness, you must let your employer know as soon as possible, at least within one to two business days of when you first learn you'll need leave.

May I use FMLA to take off several short periods?

FMLA leave can be taken all at once or it can be taken in shorter blocks of time, such as 2 days a week, or 1 week a month, as long as it's taken for a single reason. FMLA can also be used to reduce the amount of time you work each day, for instance, so that you work a part-time schedule for a while. You'll need a doctor's note to verify that the medical condition is serious and you are unable to work for these times, or that your family member's serious illness requires you to take this time for their care. See the section "What is medical certification and must I give my give my employer my medical records?

Does time I took off for illness or pregnancy count against my FMLA time if I need to take off again for a new illness in the same 12 months?

Time taken off work because of any illness, pregnancy, or complications of pregnancy can be counted against the 12 weeks of family and medical leave in a 12-month period. The employer must let the employee know that the pregnancy leave was counted as FMLA.

Does workers' compensation leave count against my FMLA leave?

It can. FMLA leave and workers' compensation leave can run together. This means that time off for a serious work-related injury or illness can be counted as FMLA leave. The employer must notify the employee when the leave time starts that the workers' compensation leave will be counted as FMLA leave.

Who defines the 12-month period during which I can take off up to 12 weeks under the FMLA?

In selecting your 12-month period, the employer may choose to use:

- The calendar year, January through December
- Any fixed 12-month "leave year" such as their fiscal year, or a year required by state law
- A year that starts on the your anniversary date (counted from the date you were hired)
- The 12-month period counted forward from the date your first FMLA leave begins
- A "rolling" 12-month period measured backward from the date you last used FMLA leave

Can I use my sick or vacation time for FMLA so that I can be paid?

The FMLA only requires unpaid leave. But it lets an employee choose to use accrued paid leave, such as vacation or sick leave, for some or all of the FMLA leave period. The law also lets the employer require the employee use paid leave for FMLA.

The employer must decide if an employee’s use of paid leave counts as FMLA leave, based on information from the employee. When paid leave is used instead of unpaid FMLA leave, it may be counted against the 12 weeks of FMLA leave if the employee is notified that this is the case when the leave begins.

Who counts as immediate family?

For FMLA purposes, an employee’s spouse, son or daughter under the age of 18, and parents are immediate family members. The term “parent” does not include a parent in-law. The terms “son” or “daughter” do not include those age 18 or over unless they are unable to take care of themselves because of mental or physical disability that limits one or more of the major life activities as those terms are defined in regulations issued by the Equal Employment Opportunity Commission (EEOC) under the Americans With Disabilities Act (ADA). The term “parent” may include people who are acting as parents to the child, even though their legal relationship may not be formalized.

For military families in certain situations, the son, daughter, parent, or next of kin of an adult armed forces member can take FMLA to provide care for up to 26 work weeks. See the section called “Special rules for military families” under “What is the FMLA?”

If you are taking FMLA leave to take care of someone else, your employer may require that you prove your relationship with that person. You may also have to provide proof that they have a serious illness.

What is medical certification, and must I give my employer my medical records?

No, you do not have to provide medical records to use FMLA. But for any leave taken due to a serious health condition, the employer can request that you provide *medical certification*, which confirms that a serious health condition exists. This is usually a note or form signed and dated by a doctor that states all of the following:

- That you (or your family member) have a serious illness
- When the illness started
- Whether absences are expected to be continuous or in short blocks of time
- When you may be expected to return to work

- Whether further treatment will be needed after the absence

If your employer asks you for an update on your medical certification or for a second opinion, you might need to provide it to keep your FMLA rights (see below).

Can my employer ask questions about my leave while I'm absent?

Yes, your employer can ask questions about your leave while you are out, but they can only ask you. Your employer may ask you questions to be sure the leave you are taking qualifies for FMLA. The employer may also make you give them reports on your status and ask whether you intend to return to work after leave.

If the employer wants a second opinion about your condition, you may have to get another medical certification (a letter or form signed by a doctor that states that a serious illness is involved). The employer would have to pay for this second opinion.

The employer may also have a doctor representing them contact your doctor or health care provider, but they need your permission to do so. They can contact your doctor only to clarify what is said in your medical certification or to be sure that it was actually written by them. They may *not* try to get more information about your health condition or that of a family member.

Can my employer make me come back to work before I run out of FMLA time?

Under some conditions, your employer may deny your continuing on FMLA leave if you don't provide the required medical certification (written information signed by your doctor). But the employer may not make you return to work early by offering you a light duty assignment.

Will I lose my job if I take FMLA leave?

Most of the time, employees will not lose their jobs if they use FMLA leave. When you return to work, employers must give you the same job or an equivalent one. Employers are not allowed to interfere with, restrain, or deny any right provided under this law. Employers cannot use taking FMLA leave as a negative factor in employment decisions, such as hiring, promotions, or disciplinary actions. Also, FMLA leave cannot be counted under "no fault" attendance policies. (A "no-fault" policy might have a fixed maximum number of allowed absences and automatically discipline or fire a person who reaches that number, regardless of the reason for the absences.)

The employer doesn’t have to allow certain highly paid, salaried (“key”) employees to return to the same job after FMLA leave. But the employer still must allow the FMLA leave and maintain the employee’s benefits. The key employee can ask to be restored to their former job after the leave is over. It’s important to know that the employer may refuse to let the employee go back to their previous job if doing so causes “substantial and grievous” financial injury to the company.

Employers are also not required to continue FMLA benefits or give jobs back to employees who would have been laid off or otherwise would have lost their jobs if they had continued to work during the FMLA leave period as, for example, due to a general layoff.

Employees who state that they don’t intend to return to work lose their rights to FMLA leave and the job. Employees who are unable to return to work and have used up their 12 weeks of FMLA leave in the 12-month period (see section, “Who defines the 12-month period during which I can take off up to 12 weeks under FMLA?”) no longer have FMLA protections of leave or of getting their jobs back.

In some cases, if an employer has told an employee that they need a medical statement that they are fit for duty and can return to work, and the employee doesn’t get that statement, the employer may not allow the employee to come back to the job. Or the employer may delay the employee’s return until they get the statement.

Can my employer refuse to grant me FMLA leave?

If you are an eligible employee who has met FMLA’s notice and certification requirements (written information from your doctor), and you have not already used up your FMLA leave for the 12-month period, you may not be denied FMLA leave. But any employee who lies or uses fraud to get FMLA leave from an employer loses their FMLA rights to get back their job or keep their health benefits.

Do I have to pay for my health insurance while I'm on FMLA leave?

Your employer is required to keep your group health insurance coverage while you're on FMLA leave if health insurance was provided before the leave was taken. It must be kept on the same terms as if you had continued to work. If you paid all or part of the health care premiums, arrangements will need to be made for you to continue to pay your share while on leave.

In some cases, the employer may make you repay the premiums it paid to keep your health coverage if you do not return to work after FMLA leave. Your employer cannot do this if your reason for not going back to work was your or your family member's serious health condition. You may need to check with the Wage and Hour Division of the Department of Labor if your employer asks that you pay back the premiums. (See the "To learn more" section.)

Note that your employer is not required to continue your other benefits like Life insurance, accrual of seniority, etc. during FMLA. Employers must reinstate your benefits on return to work.

Are federal government employees covered by the FMLA?

Most employees of the United States government are covered by the FMLA or similar rules. Federal employee leave policies are administered by the US Office of Personnel Management (OPM). You might need to contact your agency's personnel or human resources office to find out exactly what applies to you.

I work for a company that employs fewer than 50 people. Is there any kind of leave my employer must offer?

Some states have their own laws or requirements for employers, and there may be other laws that apply to your situation. You can contact the Department of Labor (listed in the "To learn more" section) to find someone who knows more about your state.

Where can I find out more about the FMLA?

To learn more about FMLA provisions and rules, read the FMLA Fact Sheet posted on the US Department of Labor website at www.dol.gov/whd/regs/compliance/whdfs28.pdf, or call the Wage and Hour Division's referral and information line at the Department of Labor at 1-866-4-

USWAGE (1-866-487-9243). They can give you other helpful information and tell you how to reach the Department of Labor division office nearest you.

To learn more

More information from your American Cancer Society

Here is more information you might find helpful. You can find the following information on our website at cancer.org or order free copies from our toll-free number, 1-800-227-2345www.cancer.org.

Job protections for people with cancer or other disability

Americans With Disabilities Act: Information for People Facing Cancer (also in Spanish)

Caregiving

What It Takes to Be a Caregiver

Insurance and finances

Health Insurance and Financial Assistance for the Cancer Patient (also in Spanish)

How to Find a Financial Professional Sensitive to Cancer Issues: Financial Guidance for Cancer Survivors and Their Families

In Treatment: Financial Guidance for Cancer Survivors and Their Families (also in Spanish)

Advanced Illness: Financial Guidance for Cancer Survivors and Their Families

Children Diagnosed With Cancer: Financial and Insurance Issues

What Is COBRA? (also in Spanish)

What Is HIPAA? (also in Spanish)

National organizations and websites*

Along with the American Cancer Society, other sources of information include:

United States Department of Labor, Wage and Hour Division
Toll-free number: 1-866-487-9243 (1-866-4-USWAGE)
TTY: 1-877-889-5627
Website: dol.gov/whd/fmla/

> Visit dol.gov/dol/topic/benefits-leave/fmla.htm for a direct link for citizens/employees. For more detail, visit: www.dol.gov/whd/regs/compliance/whdfs28.htm. This site includes subsections with pages that explain more about FMLA, including how it impacts state law, employer policy variations, links to airline crew rules, specific changes for military families, and more.

Cancer and Careers
Telephone: 646-929-8032
Websitecancerandcareers.org

> A resource for working people with cancer and their employers, including articles, news, charts, check lists, tips, and a community of experts, patients, and survivors

Cancer Legal Resource Center (CLRC)
Toll-free number: 1-866-843-2572 (1-866-THE-CLRC)
TTY: 213-736-8310
Website:cancerlegalresourcecenter.org

> A non-profit program that gives free and confidential information and resources on cancer-related legal issues to cancer survivors, their families, friends, employers, health care professionals, and others coping with cancer

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

The American Cancer Society is available 24 hours a day, seven days a week to provide – among other things – the latest cancer information, emotional support, or free lodging when patients need treatment away from home.Visit cancer.org, or call us at **1-800-227-2345**.

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United States Office of Personnel Management. Family-Friendly Leave Policies for Federal Employees. Accessed at www.opm.gov/oca/leave/html/levbro.htm on November 14, 2014.

This document from www.cancer.org at http://www.cancer.org/treatment/findingandpayingfortreatment/understandingfinancialandlegalmatters/family-and-medical-leave-act. Accessed on May 1, 2015.

Appendix D: List of Respite Care Resources

Well Spouse Association (WSA)

Toll-free number: 1-800-838-0879
Website: wellspouse.org

A national, nonprofit membership organization (dues are charged) that provides emotional support to spouses and partners of chronically ill and/or disabled people. Also offers Regional Respite Weekends for spousal caregivers.

National Respite Locator Service

Website: respitelocator.org

Appendix E: Health Professionals Who Provide Cancer Care

List of Health Professionals

Word	Pronunciation	Definition
Anesthesiologist	(**an**-es-**thee**-zee-**AHL**-uh-jist)	a doctor who specializes in giving drugs or other agents (like gasses) that cause a total loss of feeling or relieve pain, especially during surgery. These drugs may put the patient into a deep sleep so that they are not aware of procedures or surgery
Case manager		a member of the cancer care team who coordinates the patient's care throughout diagnosis, treatment, and recovery; often a nurse or cancer nurse specialist. The goal of case managing is that one person is directing or overseeing a patient's care. For example, a case manager may help the patient get through the complexities of the health care system by working with the health insurance company, getting quicker responses to important questions, managing crises, and connecting the patient and family to needed resources.
Chaplain		a member of the clergy who attends to the spiritual needs of the patient and family. Often a chaplain is trained to minister to patients of many denominations, faiths, and beliefs.
Dermatologist	(**der**-muh-**TAHL**-uh-jist)	a doctor who specializes in the diagnosis and treatment of skin diseases. A dermatological oncologist has specialized training in diagnosing and treating skin cancers.

List of Health Professionals

Word	Pronunciation	Definition
Dietitian	(**die**-uh-**TISH**-un)	an expert in the area of nutrition and food who has at least a bachelor's degree and has passed a national board exam. Many RDs specialize in areas like weight management, exercise science, cancer care, or cardiac rehabilitation. See also nutritionist.
discharge coordinator:		often a nurse or social worker who helps make sure that patients leaving the hospital have what they need to continue their recovery at home, or may help a patient find other places to go after leaving the hospital, such as a nursing home or rehab, where they can continue to get the care they need.
Doctor of osteopathic medicine (DO)	(**os**-tee-uh-**PATH**-ick)	a doctor with a licensing and educational background much like that of a medical health care provider (MD). They tend to be primary care physicians and are specially trained to use a "whole person" approach to medicine rather than just treating specific symptoms. See also primary care physician.
Dosimetrist	(doe-**sim**-uh-trist)	a person who calculates and plans the correct radiation dose (the amount, rate, and how the dose is spread out) for cancer treatment or other diseases that require radiation treatment. Some of the factors that determine radiation dose include body size, sex, and age.
Endocrinologist	(**en**-duh-kruh-**NAHL**-uh-jist)	a doctor who specializes in diseases related to the glands of the endocrine system, such as the thyroid, pituitary, pancreas, pineal, and adrenal glands

Enterostomal therapist	(**en**-ter-o-**STO**-mal **ther**-uh-pist)	a registered nurse who is qualified by education in an accredited program in enterostomal therapy to teach people how to care for ostomies (surgically created openings such as a colostomy or urostomy) and other wounds. Also called an ostomy nurse or a wound care nurse.

List of Health Professionals

Word	Pronunciation	Definition
Gastroenterologist	(**gas**-tro-**en**-ter-**AHL**-uh-jist)	a doctor who specializes in diseases of the digestive (gastrointestinal or GI) tract including the esophagus (swallowing tube), stomach, small intestine, colon, rectum, gallbladder, and bile duct
Genetic counselor	(juh-**net**-ick)	a specially trained health professional who: • Helps people decide whether to have genetic testing done • Helps people understand the risk of occurrence of a genetic disorder within a family • Provides information about the options available depending on the results of genetic testing • Helps the patient consider the screening and preventive measures that are best based on the test results
Gynecologic oncologist	(**guy**-nuh-kuh-**LA**-jik on-**kahl**-uh-jist)	a doctor who specializes in cancers of women’s reproductive organs

Gynecologist	(guy-nuh-KAHL-uh-jist):	a doctor who specializes in women's health, including their sexual and reproductive function and the diseases of their reproductive organs, except diseases of the breast that require surgery
Hematologist	(**he**-muh-**TAHL**-uh-jist):	a doctor who specializes in diseases of the blood and blood-forming tissues

List of Health Professionals

Word	Pronunciation	Definition
Home health nurse		a nurse who provides care in the patient's home, including giving medicines and certain treatments; teaches patients and families about their care; and checks on the patient to see if further medical attention is needed
Licensed practical nurse (LPN) or licensed vocational nurse (LVN)		a nurse who has completed a year or so of technical health training, and passed a licensing test. This nurse may give medicines, help patients with physical hygiene and care, and perform many other health care-related tasks
Medical oncologist	(on-**kahl**-uh-jist)	a doctor who specializes in diagnosing and treating cancer with chemotherapy and other drugs. A medical oncologist is different from a surgical oncologist, who mostly treats cancer with surgery.
Neonatologist	(**nee**-o-nay-**TAHL**-uh-jist)	a doctor who specializes in the care of newborn babies (until about 6 weeks of age, longer for babies who are born prematurely)
Nephrologist	(neh-**frahl**-uh-jist)	a doctor who specializes in kidney diseases
Neurosurgeon	(**nur**-o-**SUR**-jun)	a doctor who specializes in operations to treat problems involving the brain, spinal cord, or nerves

List of Health Professional

Word	Pronunciation	Definition
Nurse practitioner	(nurs prak-**tih**-shun-er)	a registered nurse with a master's or health care provider degree who has advanced training and clinical experience in a certain area of medical and nursing practice. Licensed and certified nurse practitioners diagnose and manage illness and disease, usually working closely with a health care provider. In most states, they also prescribe medicines.
Nutritionist	(noo-**trih**-shun-ist)	a term used sometimes interchangeably with dietitian, but educational requirements for nutritionists vary by state. Programs to certify nutritionists now exist, but again, requirements vary. See also dietitian, .
Occupational therapist (OT)	(ok-you-PAY-shun-uhl)	a licensed and specially trained health professional who works with people who have disabilities to help them relearn how to perform daily activities so that they can be as independent as possible. They also work to prevent disability and maintain health. The practice of occupational therapy includes evaluation, treatment, and consultation.
Oncologist	(on-**kahl**-uh-jist)	a doctor who specializes in diagnosing and treating cancer
Oncology clinical nurse specialist (CNS)	(on-**kahl**-uh-jee **klin**-ih-kull nurs **spesh**-uh-list)	a registered nurse with a master's degree and advanced clinical practice in oncology nursing who specializes in the care of cancer patients. Oncology CNSs have many different roles depending on the setting. They may give direct patient or family care; supervise staff caring for patients and families; do nursing research related to cancer patients; or teach patients, families, and staff about cancer, treatment, and side effects.

List of Health Professionals

Word	Pronunciation	Definition
Oncology social worker	(on-**kahl**-uh-jee)	usually a person with a master's degree in medical social work who is an expert in coordinating and providing help with the social and emotional needs of the cancer patient and family. The oncology social worker may do counseling, help patients and families manage financial problems, work on housing or child care issues (when treatments must be taken at a facility away from home), and help people cope with different types of emotional distress.
Ophthalmologist	(**off**-thuhl-**MA**-luh-jist):	a medical doctor who specializes in diagnosing and treating eye diseases
Oral and maxillofacial surgeon	(**max**-ill-o-**FAY**-shul)	a surgeon who specializes in surgery of the mouth, jaw, and face
Orthopedic surgeon:	(or-thuh-**pee**-dik)	a surgeon who specializes in diseases and injuries of the muscles and bones, also called the musculoskeletal system
Otolaryngologist	(**o**-toe-**lair**-in-**GOL**-uh-jist)	a doctor who specializes in diseases and injuries of the ear, nose, and throat. Also called an ENT (which stand for ears, nose, and throat) or a head and neck surgeon.
pain specialists		oncologists, neurologists, anesthesiologists, neurosurgeons, or other health care providers, nurses, or pharmacists who are experts in pain management. In many places there is a team of

		health professionals who are available to address issues of pain control.
palliative care specialists	(PAL-ee-uh-tiv)	doctors, nurses, and/or pharmacists who help keep a person comfortable by managing bothersome symptoms, such as pain, nausea, or fatigue. They are not trying to cure the disease, but help the person have the best possible quality of life. They can help at any stage of cancer, from diagnosis to the end of life.
palliative care team	(PAL-ee-uh-tiv)	typically includes a palliative care doctor who leads the team and works with a nurse, social worker, patient navigator, and maybe a person with a spiritual role such as a chaplain or a priest, to treat symptoms but not necessarily the cause of the symptoms.

List of Health Professionals

Word	Pronunciation	Definition
Pathologist	(path-**all**-uh-jist):	a doctor who specializes in diagnosing and classifying diseases by lab tests, such as looking at tissue and cells under a microscope. The pathologist determines whether a tumor contains cancer, and, if it is cancer, the exact cell type and grade.
Patient navigator		the person who guides patients and their families through complex medical systems and helps them work with the rest of the cancer care team to overcome barriers to care that may come up so they can successfully complete their treatment. Navigators can be lay people with special training and experience or health care professionals, like nurses or social workers.
Pediatric oncologist	(**pee**-dee-**AT**-trick on-**kahl**-uh-jist):	a doctor who specializes in caring for children with cancer
Pediatrician	(**pee**-dee-uh-**TRISH**-un):	a doctor who specializes in caring for children, including the prevention of illness, primary health care, and the treatment of diseases
Physical therapist (PT)	(**fiz**-ick-uhl)	a licensed health professional, who has at least a bachelor's degree in physical therapy, who helps examine, test, and treat physically disabled people by using exercises, heat, cold, and other methods to restore or maintain the body's strength, mobility, and function

Physician assistant (PA)		a certified and licensed medical professional with a master's or doctoral level degree. Physician assistants practice medicine on teams with doctors and other health care professionals, providing a wide range of services. They may specialize in certain diseases or fields of medicine depending on their training and experience.
Plastic and reconstructive surgeon	(**re**-kon-**STRUCK**-tiv)	a surgeon who specializes in altering or restoring appearance or in rebuilding removed or injured body parts. In reconstruction, the surgeon may use tissue from the patient or some special material with the right consistency to hold a shape or form over time.

List of Health Professionals

Word	Pronunciation	Definition
Primary care physician		the doctor a person would normally see first when a medical symptom or problem comes up. A primary care physician could be a general practitioner, a family practice health care provider, a gynecologist, a pediatrician, or an internal medicine health care provider (an internist).
Psychiatric clinical nurse specialist (CNS)	(**sy**-key-**AT**-rick **klin**-ih-kull nurs **spesh**-uh-list)	a registered nurse with a master's degree in psychiatric/mental health nursing who specializes in the mental health of patients. The psychiatric CNS may assess, counsel, or teach patients and/or families. They may also have a role in supervising mental health care or doing research in psychiatric nursing.
Psychiatrist	(sy-**ky**-uh-trist)	a medical doctor specializing in the causes, treatment, and prevention of mental, emotional, and behavioral disorders. Psychiatrists provide counseling therapy and can also prescribe medicines or other treatments.
Psychologist	(sy-**kahl**-uh-gist)	a health professional who specializes in the study of the structure and function of the mind and related mental processes in humans and animals. A clinical psychologist has a graduate degree in psychology and training in clinical psychology. They may provide testing and counseling services to patients who may have an emotional or mental health problem.

Pulmonologist	(**pull**-muh-**NAHL**-uh-jist)	a doctor who has specialized experience and knowledge in the diagnosis and treatment of lung (pulmonary) conditions and diseases

List of Health Professionals

Word	Pronunciation	Definition
Radiation oncologist	(**ray**-dee-**A**-shun on-**kahl**-uh-jist)	a doctor who specializes in the use of radiation to treat cancer
Radiation therapist	(**ray**-dee-**A**-shun **ther-**uh-pist)	a person with special training to work the equipment that delivers radiation therapy. This expert often helps the patient get into the right position for treatment and then actually gives the treatment.
Radiation therapy nurse		a registered nurse who is an expert in the radiation therapy care of patients. This nurse may teach the patient about treatment before it starts and help manage any treatment side effects.
Radiologic technologist	(**ray**-dee-uh-**LAH**-jick teck-**nah**-luh-jist)	a health professional (not a health care provider) trained to position patients for x-rays, take the images, and then develop and check the images for quality. The films taken by the technologist are then sent to a radiologist to be read.
Radiologist	(**ray**-dee-**AH**-luh-jist)	a doctor with special training in diagnosing diseases by interpreting (reading) x-rays and other types of

		imaging studies that make pictures of the inside of the body

List of Health Professionals

Word	Pronunciation	Definition
Registered nurse (RN)		a professional nurse who has completed a college program and passed a national examination. RNs may assess, educate, and treat patients, families, or even communities. They may work in almost any health specialty, and can obtain further education to qualify for advanced practice such as oncology nurse specialist, nurse practitioner, and others.
respiratory therapist	(RES-per-uh-TOR-ee THAIR-uh-pist)	a professional who works with people who have breathing problems. This can include breathing treatments and managing patients on ventilators (breathing machines). A CRTT or certified respiratory therapy technician may also examine the patient, collect information about lung function, and set up and maintain equipment, such as ventilators.
Sex therapist		a mental health professional with special training in diagnosing and treating sexual disorders and problems with sexual functioning. These problems may include erectile dysfunction (ED, often called impotence), orgasm problems, premature ejaculation, and lack of sexual desire. Sex therapy may include education, special exercises, and work on improved communication between partners.
Social worker		a health professional with special training in dealing with social, emotional, and environmental problems that may come with illness or disability. A social

	worker may help people find community resources, and provide counseling and guidance to help with issues such as insurance coverage, nursing home placement, and emotional distress.
Speech therapist	a person specially trained to work with people who have problems with their speech, such as a loss of the ability to speak or problems speaking clearly. Speech therapists treat patients with exercises and other techniques to restore speech or other communication skills. They also make sure that patients can eat and drink safely if they have swallowing problems.

List of Healthcare Professionals

Word	Pronunciation	Definition
Surgeon		a doctor who performs operations
Surgical oncologist	(on-**kahl**-uh-jist)	a doctor who specializes in using surgery to treat cancer
Thoracic surgeon	(thuh-**ras**-ick)	a surgeon who operates on organs in the chest, including the lungs, ribs, the sternum (breast bone), the diaphragm (the muscle that helps breathing), and other associated muscles
Urologist	(yur-**ahl**-uh-jist)	a doctor who specializes in treating problems of the urinary tract in men and women, and of the genital organs in men

Appendix F: Helping Children When A Family Member Has Cancer: Dealing With Diagnosis

It is normal for families facing a new diagnosis of cancer to be upset and worried about this crisis. Families with young children or teens also may be concerned about how children will react to a diagnosis of cancer in a family member. Here we discuss how to help children understand and deal with a parent or close family member's cancer diagnosis.

How will children react to a parent's cancer diagnosis?

Children take cues about cancer from parents and other adults. How a child reacts to a cancer diagnosis often depends on how their parents or other close adults handle the crisis. Kids learn through their parents' behavior. Although parents know this, they are under a great deal of stress and have their own intense feelings of fear and uncertainty. Sometimes, with the right kind of help, parents and their children *can* and *do* learn to cope well with cancer and its treatments.

Why do we need to tell children that a parent has cancer?

Some parents are afraid their children will worry more if they are told the facts about what is happening. It is important to keep in mind that parents and children have very different life experiences. This makes it is unlikely that a child will react to a problem the same way an adult would.

Cancer is an impossible secret to keep. It is likely that you've already noticed that children tend to overhear adults talking about subjects not meant for them. This happens even when the child looks busy with other things and doesn't seem to be listening. Some kids even look for ways to listen without being noticed if they think something is being kept from them. When children hear these conversations, they often detect the anxiety and worry of their parents. And even if they don't overhear anything, they can see that others are acting differently and usually sense that something is wrong. Kids tend to be afraid and believe the worst if they haven't been given complete information. The effort it takes to keep such secrets may rob the parent of precious energy, too.

If children hear about their parent's cancer from someone else, like a curious neighbor or a classmate, it can destroy the trust that parents have worked to build. If children think their parents are being vague on purpose or are trying to hide something from them, they find it hard to believe they are being told the truth. It is better that parents learn how to share this information truthfully, and in a way that allows the child to understand and take part in the discussion.

Another problem in keeping cancer a secret is that the child may assume that whatever is happening is too terrible to talk about. This may cause the child to feel isolated or shut out from the family, because no one will talk about their biggest concern. This means that the natural desire parents have to protect their kids sometimes only makes things harder for the child. Parents know that it is impossible to shield children from all of the stressful parts of life, and that part of their job is to teach their children how to manage these challenges.

Finally, once treatment starts, the child may see side effects like tiredness, weight changes, hair loss, or vomiting. They see that the parent is sick, and may assume that the parent is going to die. They may think that others in the family will get the same illness. They may think that life as they know it will end. Not knowing what is going on or how to cope with it can be terrifying to a child. To avoid this, children need to be told about the illness. They should know in advance the kinds of side effects that are likely to happen during cancer treatment.

How should children be told that a parent has cancer?

Age is an important factor in deciding what and how much you should tell a child about a cancer diagnosis. The guiding principle should be to tell the truth in a way that children are able to understand and prepare themselves for the changes that will happen in the family. Kids thrive on routine – it helps them feel safe. When life becomes unpredictable, they will need help adjusting to the changes.

Young children (up to 8 years old) will not need a lot of detailed information, while older children (8 to 12 years old) and teens will need to know more. Teens, who are testing their independence and limits, will have very different concerns from a 5-year-old who needs parents for basic caregiving.

All children need the following basic information:

- The name of the cancer, such as breast cancer or lymphoma
- The part of the body where the cancer is
- How it will be treated
- How their own lives will be affected

First, set up a quiet time when you won't be disturbed. You may wish to talk to each child alone, depending on their ages, so that information can be tailored to what the child can understand. This can also help the parent pay closer attention to how each child responds. The child may also be more willing to ask questions when away from the other children and potential distractions. Be sure you have time to answer questions and a plan to manage possible interruptions before you start. If you stop to answer the phone, turn off the stove, or let the dog out when your child is opening up to you, the child may find it more painful to try again.

It helps to plan how you will talk with each child. Think about what you want to say and how to answer questions on a level each child can understand, but in a serious and thoughtful way. You are trying to lay the groundwork for an open line of communication with the child – a way for the child to come to you with their concerns, needs, and fears. If you can start this and keep it going by regularly checking in with each child during and after the cancer treatment, it can be a great comfort to them.

Young children (up to age 8) can be told that the body is made up of lots of different parts. When someone has cancer, it means that something has gone wrong with one of these parts and it's stopped doing what it's supposed to do. Part of the body is no longer normal. Over time, a tumor or lump has developed, or a bunch of bad cells started to grow (in the case of leukemia and lymphomas).

The tumor (or the bad cells) should not be there. Cancer can keep growing in other parts of a person's body, so the person needs treatment to either take out the tumor or stop it from spreading to other places. Some kids may not have any questions at first, but invite them to ask you later if they think of any. Older children (in general, ages 8 and up) may be able to understand a more complex discussion. They may want to see pictures of cancer cells or read about cancer treatment. Again, encourage them to ask questions that they may think of later.

Besides the illness itself, children have other worries about the cancer. The most common of these is that something they did or didn't do may have caused the parent's illness. We know this isn't true, but most children believe this at some point during the cancer experience. Parents know that children engage in "magical thinking." They believe they are the center of the world and that they can make all kinds of things happen. Children can also believe that bad things happen because they have been angry with their mom or dad. So when a parent gets sick, children often feel guilty and think they are to blame for the cancer. Kids usually won't tell you this, so it's a good idea to reassure them about it. Parents can say something like, "The health care providers have told us that no one can cause someone else to get cancer – it's nothing that any of us made happen." It's better not to wait to see if children bring this up because they may be feeling guilty without saying so.

Children may also worry that cancer is contagious and they can catch it, or that everyone dies from it, or that the other parent will get it, too. It's a good idea to correct these ideas before the child has a chance to worry. Kids can become confused about how people get sick. A common worry is that cancer can be passed from one person to another, like a cold.

Parents can explain that cancer is a different kind of illness and the child doesn't have to worry that someone passed it on to their mom or dad or that they will get it. Parents should also say that it would be very unusual for the other parent to get sick. They may want to tell their children something like this: "Years ago, people often died from cancer because health care providers didn't know much about how to treat it. Health care providers have learned a lot more about it since then, and there are treatments that can cure many cancers. Now, people can live with cancer instead of dying from it."

So along with the basics about the parent's cancer as noted above, be sure to stress these facts:

- No one caused the parent to get cancer. (It's not the child's fault.)
- You can't catch cancer like a cold or the flu – it's OK to hug or kiss the person with cancer.
- The family will work together to cope with cancer and its treatment.

- Even though the sick parent may not have as much time with them, the children are loved and will be taken care of while the parent is sick.

You may need to make these points more than once. More important, the parent and other adults in the child's life can serve as examples and remind the child of these things, too. Children pick up on small cues in how you and others act around them, so if they notice adults don't hug the sick parent like they used to, a child may worry. Or if adults are in a hurry and don't speak as kindly to the children as they once did, the children may think the adults are mad at them or blame them in some way for their parent's illness.

Should I expect my child to be upset?

Some children may become very upset when learning about a new cancer diagnosis, while others may act as if nothing is wrong. The goal is to give the child a balanced point of view. The child should realize that cancer is a serious – but not hopeless – illness.

A child's emotional reaction to this news will depend on many things, including how the information is given to them and the child's experience with illness. It is important for parents to choose a time when they are feeling fairly calm to talk to their children. In a 2-parent household, it's a good idea for parents to talk to their children together. For single parents, it may help to ask an adult relative or friend who is a stable, consistent influence in the child's life to be with them if they're feeling a bit shaky about the talk.

If people are feeling upset or unsure about what to say, it might be better to wait until their emotions are a bit more under control. That is not to say that parents need to pretend that there is nothing to worry about. It is OK if their kids see them crying sometimes. Parents can admit that this is an upsetting time, that cancer is a scary disease, and that it's OK to have strong feelings about it. But that doesn't mean that the family won't be able to handle it.

Sometimes parents worry about showing pain or negative emotions in front of their children. They may worry this will scare the children. Or they may fear that negative feelings will somehow affect their child's ability to cope with the illness. In the media and from others, you often get advice to keep a "positive attitude."

For the most part, feeling positive is a good way to approach life. But when people try to deny the very real feelings of fear and sadness, which are a part of any cancer diagnosis, the effort often just doesn't work. The energy it takes to hold in "bad" feelings can make coping much harder.

For many people, a grieving process starts with a cancer diagnosis. It is normal to be sad and upset after being told you have cancer. It often feels as if nothing will ever be the same. Patients grieve for the loss of safety and predictability in their lives, and for the future that may not turn out as planned. When they face these feelings, it is much easier for them to work on having a positive mindset the rest of the time about the challenges ahead.

No one wants to alarm their children by being hysterical. But there is nothing wrong with shedding a few tears when the family has a crisis. Parents can tell their kids that there will be times when they will need to cry, because that can help them feel better. Parents can assure them that at some point they will no longer need to cry about the situation, but it's OK to express all of their feelings. Everyone deals with problems in a different way, and it's fine to feel angry or sad as long as you don't use these feelings to hurt others. It is important for parents to give themselves permission and time to figure out what is best for them and each family member.

If other family members have died from cancer in the past, children may assume that will happen again. It may help for parents to explain that there are more than 100 different kinds of cancer, and that there are many kinds of treatments. The kids need to know that all patients respond differently to treatment and have different outcomes for the future. Make sure they understand that each person is different, and just because the grandpa died five years ago doesn't mean the same thing will happen now. Cancer treatment changes from year to year and better treatments are being tested all the time. Even though no one can predict the future, many people are approaching cancer treatment today with new hope.

Are there certain responses that I should expect?

Every child is different, and each child responds in their own way to the news of a parent's cancer diagnosis. The child's age, personality, relationship to the parent, and the way information is presented are just a few factors that can influence how a child will react. Parents usually know their kids better than anyone else and can expect their children to react in ways that are typical of their personalities. For instance, a child who is very dependent may become even more so during that crisis of a new cancer diagnosis. A child who always imagines the worst may do so now. A child who plays rough with his toys when upset may get even rougher.

Children can't always tell you, but may show you how they feel.
Children are often unable to express how they are feeling in words. Most parents get an idea about what is going on with their kids by watching how they act. So, a parent who sees their kids fighting with each other more now can probably assume that this is their way of showing they're upset. Parents can put this into words by saying something like, "I know everybody is more worried right now, but let's talk about this instead of fighting."

A child may act less mature when upset.
In general, parents can expect that the stage of a child's development dictates how well they understand what is going on. Children tend to regress (act younger) when they are under stress. Adults often do the same. A child who has just become toilet trained may start having accidents. A child who has gone off to kindergarten quite happily may become upset when they have to be away from the parent. Kids who have problems paying attention in school may have even more trouble than before.

Children blame themselves.
Children often blame themselves when something goes wrong. This is because children normally see themselves as the center of the universe. This often happens in kids of divorcing parents – kids think they must have done something to cause the break-up. The same thing happens with illness. Children wonder if they are to blame. It is best to address this before the child asks about it, because children usually don't ask. Self-blame can be harmful to the child.

The child's level of trust will show up in their behavior.
In most cases, children who are truthfully told what's happening from the very start will be less anxious than children whose parents try to avoid answering questions. Being honest with your children during this time can help build trust.

This doesn't mean you should tell them everything all at once. Especially for younger children, it's best to give out the information in small doses, ask them if they have questions, and then answer their questions. If you don't know the answer to a question, tell them you will have to find out, and then get back to them. You can keep them up to date as events progress.

How can I reassure my child that everything will be fine?

Parents probably cannot offer the kind of overall reassurance they would like to when they first learn they have cancer. This is because no one really knows at that point how they will respond to treatment and that everything really will be OK. And you don't want to say this if it isn't true, because you can lose the child's trust. But there are things that parents can do to help their kids cope.

Parents can reassure children that no matter what, they will always be cared for. If the parent is feeling sick, they will arrange for someone else to fill in. The most important issue for children of any age is their own sense of security and safety. Children depend on their parents for their basic physical and emotional needs. A parent's cancer can make families feel that their lives are totally out of control.

During this time it is important to realize that the entire family is likely to feel anxious and unsettled. The person with cancer will make trips to the clinic or hospital, their partner may take time off from work, daily household life will change, and family members will feel – and show – all kinds of emotions. In spite of all this, parents should try to keep as much of their children's lives the same as possible. This may sound like a tall order, but it is usually possible to reorganize family routines at least for a short time.

When you talk about your diagnosis and treatment, it is a good idea to prepare children for the fact that certain changes will need to be made in the family routine. Parents will need to call on others to fill in for them during periods of active treatment. Maybe a relative will be moving in for a while to help out if a parent needs to be in the hospital. Maybe the sick parent has friends who have offered to take turns preparing meals for the family. A relative or friend may volunteer to pick a child up from school or take the child to sports practice or music lessons. Take people up on their offers to help out and try to find the support you and your kids will need at this time. Loved ones, friends, neighbors, and even the parents of your children's friends can be a great help in keeping daily life as normal as it can be.

When these changes in family routines are explained to children, they offer a powerful message that their mom or dad is still in charge and the child’s needs have not been forgotten. Life will go on as normally as possible given the crisis the family is facing. The children will not be left on their own. Parents should confirm that no one is happy that life seems turned upside down right now, but it will not last forever. In the meantime, tell children over and over again you love them and that you are working to be sure they are cared for.

Sometimes kids react strongly to changes in routine. Parents may feel frustrated and even angry as they try to meet everyone’s needs. Keep in mind that it is no one’s fault when a parent gets cancer, and nothing can be done change this. But people have choices about how to handle the situation. Find something in the situation that the child has a choice about, for example whom they would like to meet at the school bus, or what they would like to take with them when they go to a neighbor's after school.

Don’t spend endless time discussing issues – sometimes that’s just the way things have to be for now. Children are not expected to like it when their routines are disrupted – adults don’t like it either. Parents can admit this to their children, along with the fact that they have a right to feel angry and upset right now. Although parents can’t fix the situation, they should be concerned about how their kids are feeling.

Children’s needs vary depending on the age of the child and how available others are to help. Young children have basic survival needs and are more dependent on parents to feel secure and safe. Teens present special challenges because they tend to test their need for independence. But it makes sense to ask them to be there to fill in more for an absent or ill parent. Sometimes there may be a fine line between asking for help from a teenager and giving them too much responsibility. Parents may need to recognize their teenager’s normal desire for independence. It can help to assure them that you know they need their own time and space in spite of the fact that a parent is ill. It may also help to set up family meetings in which parents and children can review how things are going in the family and decide what should be different or stay the same.

Some families may find it hard to ask for help. The family may not be living together, or they may have had tension or conflicts. We know from experience that people who try to manage cancer alone will have a harder time. Try to remember that usually people really do want to help, and if you let them, they feel useful and needed. But you will need to tell them exactly what you and your family need from them. If no one is available to help, patients or their loved ones should ask to talk with the hospital social worker or the nurse in the health care provider's office about any community agencies that can help.

How will I know if my child needs extra help?

Deciding if your child needs help can be confusing as parents try to sort out what is a "normal" response to a new cancer diagnosis and what is not. This is new to all of you, and it will take some time to figure out what works best for you and your family. But while you are learning for the first time how your children react to cancer, you already have experience with how they deal with other stressful events. Most parents can tell exactly how each of their kids acts when they are upset. Because children, especially young ones, are often unable to talk about how they feel, they show us by their behavior. Some children will become withdrawn, while others may fight, whine, and complain. The most important thing to look for is how extreme the change is and how long it lasts.

Depression in children can look different than depression in adults. For instance, a common sign of depression in a child is a change in behavior, like suddenly getting poor grades in school or losing friends. Most children whose parents have cancer seem able to cope, but there may be times when it gets to be too much. If a child seems to be having trouble, it may mean a more serious problem than a normal, sad response to cancer.

Extra help is needed if a child:

- Is unable to handle the feelings of sadness
- Feels sad all the time
- Cannot be comforted
- Admits to thinking of suicide or of hurting themselves

- Feels extra irritable
- Becomes very angry very quickly
- Has changing grades
- Withdraws or isolates themselves
- Acts very different than usual
- Has appetite changes
- Has low energy
- Shows less interest in activities
- Has trouble concentrating
- Cries a lot
- Has trouble sleeping

When a child shows one or two of these symptoms, it may help to offer more support. But if the usual methods of handling these problems are not working, or if the problem goes on for more than one or two weeks, the child may need extra help. (For more serious problems, such as if the child is planning to hurt themselves, urgent help is needed.) It may be useful to talk with the child's pediatrician, school counselor, or with the social worker or counseling staff at the hospital where the parent is being treated. Since these experts know how other children have reacted to illness in the family, they may be able to offer a useful way of looking at the problem. They can evaluate the child and make sure that any needed help is given. They can also suggest books, videos, and children's support groups that may help. Rarely, a child may need to see a psychiatrist for medicine or counseling.

Finally, if one of the child's parents or main caregivers becomes depressed, the child is more likely to have problems. Sometimes the child's problem may not look very severe; the child or teen may say very little and hold everything inside. If you or your partner starts to feel overwhelmed or distressed, see a mental health professional to get an idea what kind of help you and your family may need. You can talk with your cancer team to find out where to start. Ask your health care provider or nurse, "Who can we talk to if one of us feels overwhelmed or depressed? I am worried about how this will affect the children."

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

From cancer.org; accessed on May 1, 2015. This is one of six documents covering topics to help young children and teens when someone in the family has cancer. The others cover information on: treatment, recurrence or progressive illness, terminal illness, losing a parent, and psychosocial support services. For more information on these and other topics, go to cancer.org/treatment/childrenandcancer/helpingchildrenwhenafamilymemberhascancer or call 1-800-227-2345 to have copies mailed to you.

Appendix G: Americans With Disabilities Act: Information for People Facing Cancer

The American Cancer Society does not offer legal advice. This information is given only to provide general background in this area of the law.

What is the Americans With Disabilities Act?

The Americans With Disabilities Act of 1990 (ADA)) is a law that helps protect the civil rights of people with disabilities. It can help people with disabilities have equal opportunities in:

- Employment
- Public accommodations
- Transportation
- State and local government services
- Telecommunications

How can the ADA help people with cancer?

People with cancer can have long-term disabilities that make it hard to work or get around. The ADA is intended to make it possible for people who can do the essential parts of their job to go back to work or keep working during and after cancer treatment. Even when a person with cancer doesn't have a disability, they may be thought of as being disabled. This alone can set the stage for discrimination at work, and the ADA addresses this as well.

The ADA can help people who might have trouble getting into buildings and using public accommodations (such as commercial and other buildings, stores, libraries, offices, transportation etc., that are intended to be used by the public) due to a disability. The ADA can also help people with hearing and speech problems use phone and electronic communications.

To find out if the ADA might help you, you'll want to know if it applies to your condition, your employer, and public accommodations, as discussed here.

What is a disability under ADA?

The Americans With Disabilities Act may apply to you if:

- You have a physical or mental problem that substantially limits one or more of your "major life activities."
- There is a record of having had such a problem in the past.
- Other people think you have such a problem, even if you do not actually have it.

Some of the "major life activities" covered by ADA include but are not limited to:

- Caring for yourself
- Doing manual tasks
- Seeing
- Hearing
- Eating,
- Sleeping
- Walking
- Standing
- Lifting
- Bending
- Speaking
- Breathing
- Learning
- Reading
- Concentrating
- Thinking
- Communicating
- Working

On January 1, 2009, the ADA Amendments Act of 2008 went into effect. It changed the way the definition of disability has been interpreted under the ADA. The Amendments Act covers disabilities in the body and mind, like the functions of the immune system, normal cell growth, digestive, bowel, bladder, central nervous system, brain, respiratory, circulatory, endocrine, and reproductive systems. These changes can help many people with cancer to clearly meet the definition of disability.

The next section deals only with employment or job discrimination, a potential problem for people who have or have had cancer. The part of the ADA that applies to jobs is called Title I. After the discussion of jobs, there's information about the ADA in settings and situations other than the workplace. The sections of the ADA that apply to these different settings and situations are Titles II through IV. (See the section called "How the ADA can help in settings other than work" for more on this.)

Does the ADA apply to my employer?

The law applies to employers with 15 or more employees. Job discrimination against people with disabilities by these employers is not legal if practiced by:

- Private employers
- State and local governments
- Employment agencies
- Labor organizations
- Labor management committees

Employees of the US government are not covered under the ADA. But they have the same protections under a different law, which is enforced by the Office of Federal Operations of the Equal Opportunities Commission (EEOC). To file a complaint, a federal employee must first contact an equal employment opportunity counselor at the agency in which they believe the discrimination took place. Visit eeoc.gov/federal/fed_employees/index.cfm to ready more about these protections.

Who is covered under the ADA?

In order to be protected by the ADA at work, the ADA must apply to your employer as noted above. You must also be qualified and able to perform the "essential functions" of the job. See the section called "What are the essential functions of a job under ADA?"

Although the ADA defines the term *disability*, it does not include a list of conditions that are always considered disabilities. Instead, each case must be looked at on its own merits.

According to the United States Equal Employment Opportunities Commission (EEOC), cancer is not always considered a disability. The ADA can help protect you when cancer prevents or makes it very hard for you to do everyday tasks, such as household chores, bathing, and brushing your teeth. But this kind of disability must be permanent or long term.

The ADA also protects you if you had cancer in the past, but are doing well now. An employer may not discriminate against you because you used to be sick. The ADA also prevents an employer from discriminating against you if they think you are sick, even if you aren't.

Which employment practices does the ADA cover?
If you have a disability and are qualified for a job, the ADA does not allow the employers noted above (see the section "Does the ADA apply to my employer?") to discriminate in employment practices, such as:

- Recruiting and advertising for job openings
- Job application and hiring
- Training
- Job assignments
- Tenure
- Promotions
- Pay
- Benefits
- Leave
- Firing
- Lay off
- All other employment-related activities, terms, conditions, and privileges

An employer cannot take action against you because you ask for your rights under the ADA. The act also protects you if you are discriminated against because of your family, business, social, or other type of relationship or association with a person who has a disability. For instance, this means an employer cannot discriminate against you because your spouse or child has cancer.

Still, the ADA does not completely protect your job just because you have a disability and are qualified for the job. The employer can still fire or lay off (terminate) an employee with a disability for legitimate business reasons. For instance, a disabled worker would not be protected during downsizing.

What does the ADA consider reasonable accommodation?
Reasonable accommodation is how an employer makes adjustments to a job that allow an employee with a disability to perform the essential functions of that job. But reasonable accommodation can start even before hiring. For example, it may be a change in procedure that allows a qualified disabled person to apply for a job.

For those already working, reasonable accommodation can be a change that allows disabled people to have the same benefits and privileges of employment the same as those enjoyed by employees without disabilities. Examples of reasonable accommodations may include:

- Providing equipment or devices, or adapting them so the person with a disability can use them
- Restructuring a job
- Changing work schedules
- Reassigning the employee to a vacant position
- Adjusting or modifying tests, training materials, or policies
- Providing electronic readers and/or interpreters
- Making the workplace easy to get into and use by people with disabilities

An employer must accommodate a qualified applicant or employee with a disability unless the employer can show that making the accommodation would not be reasonable. That means that the accommodation would be very difficult or expensive (an “undue hardship” or unreasonable). These factors include the type and cost of the accommodation in relation to the size, resources, nature, and structure of the employer's operation. In general, a larger employer would be expected to make accommodations requiring greater effort or expense than would be required of a smaller employer.

The facts of your case will help determine whether an accommodation will make it possible for you to do the job and, if so, what kind of accommodation is needed.

Employers do not have to know about every kind of disability to know whether or how to make a reasonable accommodation. They are required to accommodate only those disabilities they know about and that do not cause too much hardship for the employer. The requirement is usually triggered by a request from a person with a disability, who often can suggest a workable accommodation.

Accommodations must be made on a case-by-case basis because the type and extent of a disability and the requirements of the job will vary in each case. If you do not ask for an accommodation, the employer is not required to provide one. If you ask for an accommodation, but cannot suggest one that will work for you, you and the employer should work together to identify one. There are also many public and private resources that can provide help without cost.

What are employers allowed to ask job applicants with disabilities under ADA?
When you apply for a job, employers can't ask you if you are disabled. They also can't ask about the type or how severe a disability you have. Employers may not ask you if you have or have ever had cancer. But they can ask you about your ability to perform certain job tasks. An employer can ask you to describe or show them how, with or without reasonable accommodation, you will perform the duties of the job.

If all new employees in similar jobs are required to have a medical exam, you may be offered a job conditionally, pending the results of a medical exam. The medical exams must be related to the job and in line with the employer's business needs. But an employer cannot reject you because of information the medical exam reveals about your disability unless the reasons for rejection are related to the job and necessary to conduct the employer's business. The results of all medical exams must be kept confidential. Medical files must be kept separate from work or personnel files.

Should I tell my employer I have a disability?
If you think you will need accommodation in order to be able to apply for a job or to perform essential job functions, you should tell the employer that you have a disability. Employers are only required to provide reasonable accommodation if they know about the disability. Generally, the employee is the person who must tell the employer that an accommodation is needed. But you are not required to

offer information about having cancer or another disability when you apply for a job.

Does my employer have to provide any accommodation I request?
No. There is some flexibility built into the reasonable accommodation requirement under the ADA. For example:

- Employers can choose among effective accommodation options and do not always have to provide the accommodation that the employee requests.
- Employers do not have to provide accommodations that pose an undue hardship for them.
- Employers do not have to provide personal-use items that are needed for daily activities both on and off the job.
- Employers do not have to make an accommodation for a person who is not otherwise qualified for the job.
- Employers do not have to remove essential functions, create new jobs, or lower production standards to accommodate a disabled employee.

Under ADA, does the employer have to hire a qualified applicant with a disability over other qualified applicants?
No. The ADA does not require an employer to hire a person with a disability over other applicants because the person has a disability. The ADA only prohibits discrimination on the basis of disability. It makes it unlawful to refuse to hire a qualified applicant with a disability just because they are disabled. It's also unlawful to refuse to hire the qualified person because a reasonable accommodation is required to make it possible for this person to perform essential job functions.

Do I have to pay for it if I need reasonable accommodation under ADA?
Generally, no. The ADA requires the employer to provide the accommodation unless doing so would cause an undue hardship on the employer's business. If the cost of providing the needed accommodation would be too much, you must be given the choice of:

- Providing the accommodation yourself, or
- Paying for the portion of the accommodation that causes the undue hardship

An employer cannot make up the cost of providing a reasonable accommodation by lowering your salary or paying you less than other employees in similar jobs. Typically, employers don't pay a lot to accommodate employees with disabilities. When asked, employers noted that most accommodations cost nothing; the rest typically cost only about $500.

If the health insurance offered by my employer does not cover all medical expenses related to my disability, does the company have to get extra coverage for me under ADA?

No. The ADA only requires an employer to provide employees with disabilities equal access to whatever health insurance coverage is offered to other employees. The same is true for employees with cancer or for employees who have family members with cancer or a history of cancer.

Under ADA, does an employer have to make non-work areas used by employees, such as cafeterias, lounges, or employer-provided transportation, accessible to people with disabilities?

Yes, unless making these changes would pose an undue hardship on the employer. Employers must accommodate the disabled person for all services, programs, and non-work facilities they provide, if the changes are reasonable. If making an existing facility accessible would be an undue hardship, the employer can provide a comparable facility that will let a person with a disability enjoy the same benefits and privileges of employment as those enjoyed by other employees, unless doing so also would be an undue hardship.

What agency enforces ADA job protections?

The Equal Employment Opportunities Commission (EEOC), along with state and local civil rights enforcement agencies, enforces the part of the ADA that covers employment protection.

What should I do if I think I'm being discriminated against in a work situation because of my disability?

You have a limited time to act, although the time limit varies by employer and the state in which you work (see EEOC page "Time Limits for Filing a Charge" at eeoc.gov/employees/timeliness.cfm for more information). If you think you have been discriminated against at work because of a disability, you can file a complaint with an EEOC- field office located in certain cities throughout the United States (visit eeoc.gov/laws/types/disability.cfm to see the Disability Discrimination page. If you work for a state or local government, the process is the same as for a private employer. A discrimination charge generally must be filed with the EEOC within 180 days of the action that you think is discriminatory. You can contact the the EEOC at 1-800-669-4000.

If you work for the US government, you have only 45 days to contact your agency's EEOC officer, and the process is somewhat different from that for private employers. See the section "Questions and answers about employment discrimination (https://eeoc.custhelp.com/app/answers/list)."

If your state or local laws cover discrimination on the basis of disability, the charge must be filed with the proper state or local fair employment practice agency within 300 days of the discriminatory action. EEOC field offices can refer you to the agencies that enforce those laws (see the "To learn more" section). But to protect your rights, it's best to contact the EEOC right away if you suspect discrimination at 1-800-669-4000.

If the EEOC decides that you have been discriminated against, you are entitled to a remedy that will place you in the position you would have been in if the discrimination had never occurred. You may be entitled to hiring, promotion, reinstatement, back pay, or reasonable accommodation, including reassignment. You also may be entitled to have your legal fees paid. Keep in mind that these decisions may take quite a long time depending on the nature of the claim and how it's resolved.

If the EEOC does not find proof that discrimination has occurred, or when attempts to resolve the problem have failed and the EEOC decides not to sue on your behalf, you can request a "right to sue" letter from the EEOC 180 days after filing your complaint. After you get this notice of right to sue, you have 90 days to file the suit. If you sue, you might want to hire a private attorney to represent you.

How the ADA can help in settings other than work?

This section deals only with discrimination in settings other than work.

What are "public accommodations" as defined by ADA?

Places of public accommodation are those generally open to everyone, such as restaurants, hotels, theaters, doctors' offices, drug stores, retail stores, museums, libraries, parks, private schools, and day care centers.

Private clubs and religious organizations are <u>not</u> considered places of public accommodation. They don't have to meet the ADA requirements.

The ADA requires the property administrators of these kinds of public places to remove barriers when it's "readily achievable" to do so. This means that it must be fairly easy to do without much trouble or expense. Examples of removing barriers would include making a simple ramp over a few steps or other modest adjustments to parts of a public place's physical structure that may impose barriers for people with disabilities.

What are the different sections of the ADA?

The US Department of Justice enforces the ADA requirements in three areas:

- Title I: Employment practices by units of state and local government (remember that the EEOC enforces most work-related practices)
- Title II: Programs, services, and activities of state and local government, including public transportation
- Title III: Public accommodations and commercial facilities (private businesses and nonprofit service providers). This can include privately owned or privately run transportation, movie theaters, restaurants, stores, doctors' offices, fitness centers, zoos, convention centers, private schools, day care centers, homeless shelters, funeral homes, and more.
- Title IV of the ADA covers people with hearing and speech problems, and is enforced by the Federal Communications Commission (the FCC). Visit fcc.gov/encyclopedia/title-iv-ada or see the "To learn more" section for more on the rules.

Where can I find information about discrimination in areas other than employment?

The US Department of Justice has a toll-free ADA Information Line (1-800-514-0301). ADA specialists are available Monday through Friday from 9:30 a.m. until 5:30 p.m. (Eastern Time) except on Thursdays, when the hours are 12:30 p.m. until 5:30 p.m. A Spanish language service is also available. This toll-free number permits businesses, state and local government officials, or others to call and ask questions about general or specific ADA requirements, including questions about the ADA Standards for Accessible Design.

To learn more

National organizations and websites*

Along with the American Cancer Society, other sources of information and support are listed here. Some have more specific information about ADA requirements affecting employment.

Job and work-related disability problems

Job Accommodation Network
Toll-free number: 1-800-526-7234
TTY: 1-877-781-9403
Website: askjan.org

> This is a free consulting service of the US Department of Labor that gives information on the ADA, your rights, how to talk to an employer, and how to ask for accommodations. Visit askjan.org/pubsandres/list.htm for a list of available publications.

US Equal Employment Opportunity Commission (EEOC)
Toll-free number: 1-800-669-4000
TTY: 1-800-669-6820
Website: eeoc.gov

> Tells you how to find EEOC offices in your area and how to file charges of workplace discrimination; has information on federal equal employment opportunity regulations, practices, and policies; offers publications such as *Questions and Answers About Cancer in the Workplace and the Americans*

with Disabilities Act (ADA), which has special information for people with cancer. Visit eeoc.gov/laws/types/cancer.cfm for more information.

Americans with Disabilities Act Technical Assistance – US Department of Justice
Toll-free number: 1-800-514-0301
TTY: 1-800-514-0383
Website: ada.gov

Specialists answer questions about the ADA and the programs, services, and activities of employers, as well as state and local governments. The website has a list of free booklets and publications you can order or read online, many of which are available in other languages.

Social Security Administration (SSA)
Toll-free number: 1-800-772-1213
TTY: 1-800-325-0778
Website: socialsecurity.gov

Has general information, qualification criteria, and information about how to apply for program benefits (such as Social Security Disability Income and Supplemental Security Income) if you cannot work. Makes referrals to local SSA and Medicare/Medicaid offices.

Other problems caused by disability
Easter Seals Project ACTION
Toll-free number: 1-800-659-6428
TTY: 202-347-7385
Website: projectaction.org

For more specific information about accessibility and transportation services for people with disabilities

Federal Communications Commission
Toll-free number: 1-888-225-5322
TTY: 1-888-835-5322
Website: fcc.gov/cgb/dro/trs.html

For TRS (Telecommunications Relay Services, which allow people with hearing or speech disabilities to place and receive phone calls) questions and fact sheets; also offers technical assistance on ADA telephone service requirements

American Speech-Language-Hearing Association (ASHA)
Toll-free number: 1-800-638-8255
TTY: 301-296-5650
Website: asha.org

Provides information and support so that all people with speech, language, and hearing disorders have access to quality services to help them communicate

Federal Transit Administration
Toll-free number: 1-888-446-4511 (FTA ADA Assistance Line, voice/relay)
TTY: 1-800-877-8339
Website: fta.dot.gov/civilrights/civil_rights_2360.html

For problems with public transportation only; to get information or file a complaint

United States Access Board
Toll-free number: 1-800-872-2253
TTY: 1-800-993-2822
Website: access-board.gov

Has specific information on accessibility requirements for people with disabilities. The board develops and maintains design criteria for the built environment, transit vehicles, telecommunications equipment, and for electronic and information technology

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

The American Cancer Society is available 24 hours a day, seven days a week to provide – among other things – the latest cancer information, emotional support, or free lodging when patients need treatment away from home. Visit us at cancer.org or call us at 1-800-227-2345.

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