# What It Takes to Be a Caregiver

## Who is a caregiver?

Life changes when a person is told “You have cancer.” But the patient is only one of the people affected by the cancer. Life also changes for those who care about and love the person with cancer. And life also changes for the person who will help the patient get through the cancer experience – the caregiver.

Here, the caregiver is defined as the person who most often helps the person with cancer and is not paid to do so. Professional care providers are paid to give care. They tend to have more limited roles, and they are not discussed in detail here.

Unpaid caregivers are sometimes called *informal caregivers* or *lay caregivers*. In most cases, the main (primary) caregiver is a spouse, partner, parent, or an adult child. When family is not around, close friends, co-workers, or neighbors may fill this role. The caregiver has a key role in the patient’s care. Good, reliable caregiver support is crucial to the physical and emotional well-being of people with cancer.

Here is some idea of what to expect if you become a caregiver for a person with cancer along with some tips on ways to take care of yourself during this time.

## Why is a caregiver needed?

*Today people spend far less time in the hospital than in the past. This means that sicker people are being cared for at home.*

There has also been a shift in cancer treatment, and a lot of it is now done in outpatient treatment centers. This means the family has to be part of the day-to-day care of the person with cancer.

Today, families provide about 80% of home-care services. Caregivers are now doing things that, until recently, were done by trained health professionals.

## What does a caregiver do?

Caregivers have many roles. These roles change as the patient’s needs change during and after cancer treatment. Caregivers serve as home health aides and companions. They may help feed, dress, and bathe the patient. Caregivers 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 with cancer, and still meet the needs of other family members.

As a caregiver, you have a huge influence – both positive and negative – on how the cancer patient deals with their illness. Your encouragement can help the patient stick with a demanding treatment plan and take other steps to get well, like eating healthy meals or getting enough rest.

## Caregivers solve problems

The person with cancer faces many new challenges. As the caregiver you can help the patient deal with these challenges and get through any problems that come up. The best way to prioritize and manage problems is to first try to understand the problem, as well as the desired result. Caregivers who are realistic, but positive; careful, but creative; and focused, but flexible are sources of strength and security for people with cancer.

For example, suppose the patient's white blood counts drop, they develop a fever, and as a result, need to be in the hospital. This can be very upsetting and may be seen as a setback by the family and the patient. The caregiver can:

- Help address their 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 doctor's prescriptions for non-cancer related medicines taken at home, such as thyroid or blood pressure medicine.
- Call all the doctors involved in the patient's care and tell them about the infection and that the patient is in the hospital.
- Check that arrangements have been made for the patient to stay on the antibiotics at home or as an outpatient after leaving the hospital. If daily visits to the outpatient clinic for IV (intravenous) antibiotics are needed, the caregiver can coordinate people to help the patient get there and back each day.

These kinds of tasks may be too much for the patient to tackle while fighting infection. This kind of help is valuable. It's a reassuring sign for the patient that this short-term problem can be managed and solved.

## Caregivers are part of the team

The caregiver is part of a health care team made up of the patient, other family and friends, and the medical staff. As a caregiver, you may find yourself working closely with the health care team, doing things like:

- Giving drugs
- Managing side effects
- Reporting problems
- Trying to keep other family members and friends informed of what's happening

- Helping to decide whether a treatment is working

As part of the team, you will help coordinate the patient's care. Caregivers often have to keep track of prescriptions, know which tests are to be done, and make sure all involved doctors know what's going on. They often find themselves preventing mix-ups and keeping track of paperwork.

A good caregiver is a vital health care resource. In many cases, the caregiver is the one person who knows everything that's going on with the patient. Don't be afraid to ask questions and take notes during doctor visits. Learn who the members of the health care team are and know how to contact them. Getting the right support and information can help both you and your loved one with cancer.

## Caregivers involve the patient

Good communication with the person you are caring for is the most important part of your role. It may be hard for the patient to take part in daily planning and decision-making because they're dealing with the physical, emotional, and social effects of cancer and treatment. Your job is to involve the patient as much as possible, so they know they're doing their part to get better. Here are some things you can try to do to keep the patient involved:

- Help them live as normal a life as possible. To do this you might 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 enjoyed the most.
- Encourage them to share feelings and support their efforts to share. For instance, if they begin talking to you about their feelings about cancer, don't change the subject. Listen and let them talk. You might want to share how you're feeling, too.
- Let the patient know you are available, but don't press issues. For example, if they are trying to do something, such as dress themselves -- they might be struggling, but it's important for them to be able to do this. You may want to do it for them, but don't. 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 to say what you're feeling, but a gesture such as holding hands might show how you feel.
- Take your 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 his need to remain quiet.
- Be realistic and flexible about what you hope to talk about and agree on. You 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. Sometimes, we all need time alone – even you.

You might find that the person you're caring for is acting different – angry, quiet and withdrawn, or just sad. If you get the feeling that they aren't talking to you because they want to spare your feelings, make sure they know that you are always open to listening, even about tough topics. If they keep acting very sad or withdrawn, you might want to talk to the cancer care team about what could be causing it and what can be done. (See our information, *Anxiety, Fear, and Depression* and *Distress in People With Cancer* on www.cancer.org, or call us for copies.)

# What does it feel like 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. You may see it as a meaningful role that allows you to show your love and respect for the person. It may also feel good to be helpful and know that you are needed by a loved one.

You might find that caregiving enriches your life. You might feel a deep sense of satisfaction, confidence, and accomplishment in caring for someone. You may also learn about inner strengths and abilities that you didn't even know you had, and find a greater sense of purpose for your own life.

The caregiving role can open up doors to new friends and relationships, too. Through a support group, you can get to know people who have faced the same kinds of problems. Caregiving can also draw families together and help people feel closer to the person who needs care.

Caregiving can also be frustrating and painful. People caring for very sick patients may notice their own feelings of severe sadness and emotional distress. They may feel sadness and grief over their loved one's illness and may also feel overwhelmed or frustrated as they try to manage many difficult problems. Caregivers can develop physical symptoms, like tiredness and trouble sleeping. This is more likely to be a problem for caregivers who aren't able to get the support they need, and who don't take care of themselves – especially those who try to press forward alone, even as their own quality of life suffers.

Caring for someone going through cancer treatment can be demanding, but being good at it can give you a sense of meaning and pride. These good feelings can help provide the strength and endurance to continue in the role for as long as needed.

# What if I don't want to be the caregiver?

It's quite normal to feel overwhelmed, burdened, and even trapped at times while caregiving. If your family has had troubled relationships in the past, you may wonder "why me?" You may feel that the caregiver role was dumped on you without your consent. You may feel unprepared or even unable to manage the responsibilities and feelings that go with it. You 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 you became a caregiver because of other people's wishes, you need to think about how you feel about being pressured into caregiving. Mixed feelings at the onset of this role can lead to a greater sense of frustration later on. You should decide on your limits and make them known as soon as you can – before the demands of caregiving become a problem. It's not easy to do this when others resist the change, and it can take a lot of courage to do it. If you know you're going to meet resistance, talk with the patient's team social worker first. Or you can ask their doctor about a referral so you can talk with someone about the caregiver problem.

Addressing the problems early can help you and the patient get the help you need, and if you have to, make other plans for care. In situations like this, it might be helpful to find someone to help you with caregiving so that you know from the start that the role will be shared. It also may be better to find someone else to act as the primary (main) caregiver.

# What about my needs and feelings?

It’s hard enough to deal with the fact that someone you love has cancer in the first place. Your loved one may be too sick to work or do their normal activities, and it’s painful to think that they now have an illness that might take them away from you. But being there and caring for that person as they go through cancer treatment can be even more stressful and exhausting. It takes emotional, spiritual, and physical strength. It also takes time: in one study, over 50% of caregivers spent more than 8 hours a day caring for patients who were getting chemotherapy. There’s often a financial burden to caregiving, too, if you lose time from work. And for some people, it may cost money to pay others to do things they usually do for themselves but no longer have time for.

On top of your normal day-to-day tasks, such as meals, cleaning, and driving or arranging transportation, you will become an important part of the cancer treatment team. This busy schedule often does not leave time for caregivers to take care of their own needs. You also may feel the need to turn down job opportunities, work fewer hours, or even retire early in order to meet the demands of being a caregiver.

If you need some time away from work, speak with your boss or benefits office. If your workplace has an Employee Assistance Program, look into what it offers. Some offer counseling services for money concerns, stress, and depression. If you can’t or don’t want to stop working, you might be able to take unpaid time off under the Family and Medical Leave Act. Whether you will be able to do this depends on your job and how you are related to the person you care for. (See our information on the *Family and Medical Leave Act (FMLA).* You can read it on our website at www.cancer.org, or you can call us and have a free copy sent to you.) You may also find that the people you work with treat you differently because of the time you must spend on caregiving tasks. This can affect you financially, as well as personally.

All these changes in your living situation can lead to anxiety, hostility, anger, resentment, frustration, and depression. These are normal feelings that must be recognized and managed. Ask the health care team about resources that are available to you and use them. Informed and supported caregivers can better manage the harder parts of the role. They are better able to see the good parts of the role, too. They are also better able to see the value of their care.

The support of friends and family is key 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. In one study, California caregivers of patients with brain tumors thought it would be very helpful to be able to talk to someone who had been through a similar experience, but more than half had not been able to satisfy this need. They also mentioned the need for support to deal with their anxiety or stress, with more than half reporting that they did not have enough support. Physical problems like heart disease, high blood pressure, sleep problems, increased risk of infections, depression, and fatigue have been linked with caregiving. You may not have thought much about it, but while you are helping your loved one, you must also take care of yourself.

Overwhelming concern for a sick loved one may distract you from taking care of yourself. You may find there’s conflict between the needs of the patient, your own needs, and the needs of your family. Many caregivers forget to eat, don’t get enough sleep or exercise, and ignore their own physical health concerns. Be sure to make and keep your own doctor appointments, get enough sleep, exercise, eat healthy foods, and keep your normal routine as much as you can. It’s important not to feel guilty or selfish when you ask for help or take time for yourself. By taking care of yourself, you will be better able to take care of your loved one.

You can start by setting limits on what you expect from yourself. Know that caring for someone with cancer can be an overwhelming job. It pays to ask for help before stress builds up. Here are some ways to take care of your own needs and feelings:

### Plan things that you enjoy

There are 3 types of activities that you need for yourself:

- Those that involve other people, such as having lunch with a friend.
- Those that give you a sense of accomplishment, like exercising or finishing a project.
- Those that make you feel good or relaxed, like watching a funny movie or taking a walk.

Make an effort to notice and talk about things you do as they happen during the day. Watch the news or take time to read the morning paper. Set aside time during the day, like during a meal, when you do not talk about your loved one's illness.

### Think about joining a support group for caregivers or using counseling services

Talk with a nurse or social worker or contact your local American Cancer Society for services in your area. Talking with other caregivers can help you feel less alone. If you can't visit a group in person, the American Cancer Society also has the Cancer Survivors Network (CSN), an online community of people whose lives have been touched by cancer. Other organizations have internet-based groups and even online counseling, too. Through online or in person support groups, people can share their stories, offer practical advice, and support each other through shared experiences.

### Most importantly, don't try to do it all yourself

Caregiving alone for any period of time is not realistic. Reach out to others. Involve them in your life and in the things you must do for your loved one.

## When others want to help

Although caring for someone with cancer can be fulfilling, it can also be demanding and stressful. Good communication can help you work through tough times, but almost always there is just too much for one person to do. Asking for help and/or allowing others to help can take some of the pressure off and give you time to take care of yourself. Often family and friends want to help but may not know how or what you need. Here are some tips for including family and friends:

- Look for areas where you need help. 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. You may also contact a person with a certain request. Be very clear about what you need.

- As you hear back from each person, note it on your list to make sure they have taken care of what you needed.

There are many online resources that can help you manage your job as caregiver, such as the American Cancer Society's Cancer Survivors Network, the Cancer Support Community, and others listed in the "National organizations and websites" section of "To learn more about caregiving and coping." These offer support for people caring for a loved one who has cancer. Some sites also offer other features, such as group calendars to organize helpers and areas to create personal websites that concerned people can access for updates. Examples of these are caringbridge.org, lotsahelpinghands.com, and thepatientpartnerproject.org. Some of these also allow others to sign up for specific tasks when help is needed. Taking full advantage of the resources available to you is another way you can take care of yourself.

# What if I make mistakes?

No matter what you do, you will very likely come to a point where you feel that you have failed in some way. It seems obvious that as a caregiver, you do the best you can. You try to include the patient, other concerned family members, and close friends in important discussions. You always try to make decisions that are in the patient's best interest – decisions that you and the patient can live with. But sometimes you will feel that you could have handled a situation better or done something a better way.

At these times, it's important not to blame yourself. Find a way to forgive yourself and move on. It helps to keep in mind that you will keep making mistakes, just like everyone else. Try to keep a sense of humor about it. And try to recognize those things that you do well, too. These things are often easy to overlook. It also helps to keep in mind why you chose to take on this often difficult and stressful job.

As a caregiver, you have an important and unique role in helping your loved one through their cancer experience. The American Cancer Society can offer you information, resources, and support. Call us at 1-800-227-2345 any day and any time you need help for yourself or your loved one.

# To learn more about caregiving and coping

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

## About caregiving

What You Need to Know as a Cancer Caregiver

Caring for the Patient With Cancer at Home (also in Spanish)

Distress Checklist for Caregivers

Coping Checklist for Caregivers

### Coping with cancer and treatment

After Diagnosis: A Guide for Patients and Families (also in Spanish)

Distress in People With Cancer

Anxiety, Fear, and Depression (also in Spanish)

Choosing a Doctor and a Hospital (also in Spanish)

Talking With Your Doctor (also in Spanish)

A Guide to Chemotherapy (also in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also in Spanish)

A Guide to Cancer Surgery (also in Spanish)

Nutrition for the Person With Cancer During Treatment (also in Spanish)

Sexuality for the Man With Cancer (also in Spanish)

Sexuality for the Woman With Cancer (also in Spanish)

Advanced Cancer (also in Spanish)

### Children and family members

Helping Children When a Family Member Has Cancer: Dealing With Diagnosis (also in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Treatment (also in Spanish)

### Job, insurance, money, and legal issues

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

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

Family and Medical Leave Act (FMLA) (also in Spanish)

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

What is COBRA? (also in Spanish)

Advance Directives

### Books

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at www.cancer.org/bookstoreto find out about costs or to place an order.

## National organizations and websites*

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

## Just for caregivers: information, support, and respite

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

> Offers a free caregiver welcome kit that covers things like how to hold family meetings, practical skills, online support, and www.lotsahelpinghands.com – a volunteer coordination service for friends, family, colleagues, and neighbors to help loved ones in need. The program lets a chosen "coordinator" and helpers sign up on an easy-to-use, private group calendar to help with meals, rides, and other tasks needed for life to run smoothly during a crisis.

**National Alliance for Caregiving (NAC)**
Website: www.caregiving.org

Provides information and other resources focused on caregiving issues, as well as www.familycaregiving101.org, a source of answers, new ideas, and helpful advice for caregivers.**Well Spouse Association (WSA)**
Toll-free number: 1-800-838-0879
Website: www.wellspouse.org

> A national, non-profit membership organization (dues are charged) which provides emotional support for spouses and partners of chronically ill and/or disabled people.

**Caregiver Action Network**
Telephone: 202-772-5050
Website: www.caregiveraction.org

> Supports and educates family caregivers, helps them connect with other caregivers; and helps them become their own advocates. Membership is free to caregivers.

**Medicare: Caregiving**
Website: www.medicare.gov/campaigns/caregiver/caregiver.html

> Fact sheets and information for caregivers. Choose "What caregiver support is available in my area?" for information on the Medicaid Cash and Counseling program that can pay some caregivers for their time.

**National Respite Locator Service**
Website: www.respitelocator.org

> Helps caregivers and professionals find respite services in their state and local areas so that they can take short-term breaks from caregiving

Legal and mental health help**American Association for Marriage and Family Therapy**
Telephone: 703-838-9808
Website: www.aamft.org

> Sponsors www.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)
TTY: 213-736-8310
Website: www.cancerlegalresourcecenter.org

> A non-profit program of the Disability Rights Legal Center offering free and confidential information and resources on cancer-related legal issues such as insurance, disability, discrimination, child custody, residency, and more to cancer survivors, their families, friends, employers, health care professionals, and others coping with cancer.

## Information and support for people with cancer and their families

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

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

**Cancer Support Community (was Gilda's Club)**
Toll-free number: 1-888-793-9355
Website: www.cancersupportcommunity.org

> Provides support for those living with cancer and their loved ones. Offers information, stress management, and online support groups led by professionals, including some in Spanish; has a special sub-site (http://grouploop.org/) for teens and their parents.

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

> Free professional support, such as phone counseling, online support groups, and educational materials, for people with cancer, their loved ones, and caregivers. Also offers CancerCare for Kids at www.cancercareforkids.org or CancerCare's main number, above. This program is for kids with a parent, sibling, or other family member who has cancer. It offers practical support, education, and counseling to parents and children. Spanish also available.

**National Cancer Institute**
Toll-free number: 1-800-422-6237 (1-800-4-CANCER)
TTY: 1-800-332-8615
Website: www.cancer.gov

> An excellent source of up-to-date information about cancer for patients, families, and caregivers.

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

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

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