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If You're About to Become a Cancer Caregiver

Caregiver is defined here as the person who most often helps the person with cancer and is not paid to do so. 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.

Today, most [cancer treatment](#)¹ is given in outpatient treatment centers – not in hospitals. This means someone is needed to be part of the day-to-day care of the person with cancer and that sicker people are being cared for at home. As a result, [caregivers have many roles](#)². 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.

On top of the normal day-to-day tasks, such as meals, cleaning, and driving or arranging transportation, as a caregiver, you'll also become an important part of the cancer care team. This busy schedule could leave you with no time to take care of your own needs. You also may feel the need to turn down job opportunities, work fewer hours, or even retire early to meet the demands of being a caregiver.

Here are some things to think about if you are about to become a caregiver for a person with cancer.

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're 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 you 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 cancer 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 with 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.

You'll need to take care of yourself, too

It's hard to plan for a major health problem like cancer. Suddenly you've been asked to care for the person with cancer, and you're also needed to help make decisions about medical care and treatment. None of this is easy. There will be times when you know you've done well, and times when you just want to give up. This is normal.

There are many causes of stress and distress in cancer caregivers. Dealing with the crisis of cancer in someone you love, the uncertain future, financial worries, difficult decisions, and unexpected and unwanted lifestyle changes are just a few of them. Fear, hopelessness, guilt, confusion, doubt, anger, and helplessness can take a toll on both the person with cancer and the caregiver. And while the focus tends to be on the patient, all of this will affect your physical and mental health, too.

Depression

Depression is common 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 if 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 won't make them go away. Early attention to [symptoms of depression](#)³ 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 remind you to enjoy life. They might help prevent a more serious depression that can develop 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, when you can enjoy friends socially
- Help from a trained mental health professional

But caregivers often focus on the person with cancer and don't take care of themselves. You may be a caregiver, but you still have your own needs that cannot and should not be put aside.

Plan things that you enjoy

There are 3 types of activities that you need to do 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 illness.

Getting professional help if you think you need it

It's normal to feel overwhelmed sometimes by caregiver responsibilities. But if it becomes a constant problem, you may need to see a mental health professional. Below is a list of serious signs of trouble. Get professional help if you:

- Feel depressed, physically sick, or hopeless
- Feel like hurting yourself or hurting or yelling at the people you care for
- Depend too heavily on alcohol or recreational drugs
- Fight with your spouse, children, stepchildren, or other family members and friends
- Are no longer taking care of yourself

Take a break or time for yourself

Most caregivers hesitate to take a break from their caregiving responsibilities, even 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.** Try to get out of the house and away from your loved one every day – even if it's only to take a short walk or shop for food. If you can't leave the patient alone and don't have friends or family to relieve you, you might want to look into getting help from respite caregivers.

Respite care

Respite care is the term used to describe short-term, temporary relief for those who are caring for family members who might otherwise need professional care. Respite is a short break from the exhausting challenges of being a caregiver. It's been shown to help keep family caregivers healthy and improve their sense of well-being.

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, church or 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 knows what to do if there's an emergency 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. This gives the caregiver a chance to take a vacation from caregiving and catch their breath, whether or not they leave town.

Depending on your state, Medicaid or Medicare may help cover respite costs. Also check with the patient's health insurance to see what kind of respite help might be offered.

Know what you can't do

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.

Some caregivers feel they have to do it all alone. They may believe that, as the partner, sibling, son, or daughter they're responsible for the sick loved one. It's painful for them to admit that they can't do it all and still keep their own health and sanity. They'll bend

over backward to meet their loved one's every need. Some feel guilty if they can't do it all and say they feel "selfish" if they ask for help.

Set realistic limits on what you can do. For instance, if you have a back injury, and/or if your loved one is too big for you to lift, you may be able to help them roll over in bed, but don't try to lift them alone or catch them when they fall. (You may end up seriously injured or sick and become unable to help anyone.) There are ways you can safely help a person sit up or walk but you have to learn to do it without hurting yourself. This is where expert help is needed – home care nurses or physical therapists can show you how to do it safely. They can also help you get special equipment, if needed.

Your own health and safety must come first if you want to keep helping your loved one.

When you need help, reach out to others, including professionals. Talk with the cancer care team about what you're doing and where you need help. Involve them in your life and your loved one's care.

Finding support for yourself

The support of friends and family is key to both the person with cancer and the caregiver. 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 those who care about them. Talking with others who are in situations like yours can help ease loneliness. You can also get useful ideas from others that might help you.

Talk with a nurse or social worker or contact your local American Cancer Society to learn about 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 has the [Cancer Survivors Network](#)⁴ (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.

Religion can be a source of strength for some people. Some members of the clergy are specially trained to help people with cancer and their families. People who are not religious may find spiritual support in other ways. Meditation, journaling, and being outside in nature are examples of different ways a person may feel they're part of something greater than themselves.

Ask others to help

Caregivers need a range of support services to stay healthy, be good caregivers, and stay in the caregiving role. But they often don't know where to go for help or how to accept help.

Caregivers have been shown to have less distress and feel less burdened when they have social support. Human connections can help you stay strong. Let people know what you need and ask for help. You cannot and should not try to be responsible for all the caregiving by yourself.

You need to know who you can talk to and count on for help. Families facing cancer can become stronger. If family members don't offer help, or if you need more help than they can give you, you may be able to set up a circle of friends to help you. 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.

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 situations where you need help. Make a list or note them on a calendar.
- Hold regular family meetings 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. Some sites offer support for people caring for a loved one who has cancer. Other sites have features like group calendars to organize helpers and areas to create personal websites that concerned people can access for updates. . 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.

Caring for your children during this time

If you have young children, you'll need to figure out how to take care of them and their needs while you're caring for the person with cancer. Juggling children's schedules and trying to keep their lives as normal as possible often requires a great deal more help

from friends and family members. As you're setting up care for the person with cancer, you might also need to tap into other parents and trusted friends and neighbors for help with your children.

Children can sense stress in their family members and notice that there's less time for them. They may start to have trouble in school or act like they did when they were younger. Even though your time is limited, you'll need to take time to check in with them to learn about their fears and concerns.

For more information, see [Helping Children With Cancer in the Family: Dealing with Diagnosis](#)⁵ and [Helping Children With Cancer in the Family: Dealing With Treatment](#).⁶

Being a caregiver and keeping your job

Caregiving itself can be a full-time job, but many caregivers already have paying jobs. 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 your job can be overwhelming. 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, for instance, when the patient is diagnosed, getting cancer treatment, getting treatment for recurrence, or nearing the end of life. The employed caregiver may end up having to take 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 traditional jobs in larger companies, there may be benefits to help you take time off and still keep your job.

Some people find that there's no one else to care for the cancer patient on a long-term basis, and cut back to working part time. Some feel that they have to quit their jobs entirely. If you need to keep your job but the interruptions and time off are creating problems, you might want to look into a different schedule to fit the times your loved one needs you most. Some companies allow you to take some paid leave if you are caring for a spouse or close relative. You might be able to work half-days or split shifts, or take one day a week off for doctor visits, for example.

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.

The [Family and Medical Leave Act \(FMLA\)](#)⁷ 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. If you can't or don't want to stop working, you might be able to take unpaid time off under the FMLA.

You may find that the people you work with treat you differently because of the time you must spend on caregiving tasks. This can affect you personally, as well as financially.

Keeping your health insurance if you have to quit your job

When caregivers quit their jobs, they usually lose their employer's [health insurance coverage](#)⁸ as well as their source of income. It's very important for you still to have some type of health care coverage. If you're able to pay for your own insurance, [COBRA](#)⁹ will allow you to be covered for some months after you leave your job. Another option might be insurance from the [Health Insurance Marketplace](#)¹⁰.

If you make mistakes

No matter what you do, you will very likely come to a point where you feel that you've 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'll 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.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects.html
2. www.cancer.org/treatment/caregivers/what-a-caregiver-does.html
3. www.cancer.org/treatment/treatments-and-side-effects/physical-side-

- [effects/emotional-mood-changes/depression.html](#)
4. <http://csn.cancer.org/>
 5. www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-diagnosis.html
 6. www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-treatment.html
 7. www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/health-insurance-laws/family-and-medical-leave-act.html
 8. www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/types-of-health-insurance-plans.html
 9. www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/health-insurance-laws/what-is-cobra.html
 10. www.healthcare.gov/

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