

## Support for Caregivers of Cancer Patients

There are different types of caregivers for people with cancer. Some are family members, while others are friends. People of different races and cultures give care to others in their own way. Every situation is different and there isn't one way that works best.

Caregiving may be

- helping with day-to-day activities such as doctor visits or preparing food
- giving medicines or helping with physical therapy or other clinical tasks
- helping with tasks of daily living such as using the bathroom or bathing
- coordinating care and services from a distance by phone or email
- giving emotional and spiritual support



Credit: iStock

## Coping with Being a Cancer Caregiver

Giving care and support during this time can be a challenge. Many caregivers put their own needs and feelings aside to focus on the person with cancer. This can be hard to maintain for a long time, and it's not good for your health. The stress can have both physical and psychological effects. If you don't take care of yourself, you won't be able to take care of others. It's important for everyone that you give care to *you*.

For more information, see the NCI booklet *When Someone You Love Is Being Treated for Cancer*.

## Changing Roles

Whether you're younger or older, you may find yourself in a new role as a caregiver. You may have been an active part of someone's life before, but perhaps now that they're a cancer

patient, the way you support them is different. It may be in a way in which you haven't had much experience, or in a way that feels more intense than before.

Even though caregiving may feel new to you now, many caregivers say that they learn more as they go through their loved one's cancer experience. Common situations that they describe are below.

- Their loved one only feels comfortable with a spouse or partner taking care of them.
- Caregivers with children struggle to take care of a parent too.
- Parents may have a hard time accepting help from their adult children.
- Caregivers find it hard to balance taking care of a loved one with job responsibilities.
- Adult children with cancer may not want to rely on their parents for care.
- Caregivers may have health problems themselves, making it physically and emotionally hard to take care of someone else.

Whatever your roles are now, it's very common to feel confused and stressed at this time. If you can, try to share your feelings with others or join a support group. Or you may choose to seek help from a counselor.

**“Mom was always the rock in the family. Now it's almost as though we're the parents and she's the child. It's hard because we have our own children to take care of and jobs to go to.”**

**—Brian**

## **Ask for Help**

Many caregivers say that, looking back, they took too much on themselves. Or they wish they had asked for help from friends or family sooner. Take an honest look at what you can and can't do. What things do you need or want to do yourself? What tasks can you turn over or share with people? Be willing to let go of things that others can help you do. Some examples may be:

- helping with chores, such as cooking, cleaning, shopping, or yard work
- taking care of the kids or picking them up from school or activities
- driving your loved one to appointments or picking up medicines
- being the contact person to keep others updated

Accepting help from others isn't always easy. But remember that getting help for yourself can also help your loved one—you may stay healthier, your loved one may feel less guilty about all the things that you're doing, some of your helpers may offer useful skills and have extra time to give you. Websites such as SignUpGenius or Lotsa Helping Hands can help you organize requests and tasks.

## **Be Prepared for Some People Not to Help**

When someone has a serious illness such as cancer, friends and family often reach out to help. And sometimes people you *don't* know very well also want to give you a hand. But it's important to realize that there are others who may not be able to help you. You might wonder why someone wouldn't offer to help you or your family when you're dealing with so much. Some common reasons are:

- some people may be coping with their own problems
- some may not have the time
- they are afraid of cancer or may have already had a bad experience with cancer. They don't want to get involved and feel pain all over again
- some people believe it's best to keep a distance when people are struggling
- sometimes people don't realize how hard things really are for you. Or they don't understand that you need help unless you ask them for it directly
- some people feel awkward because they don't know how to show they care

If someone isn't giving you the help you need, you may want to talk to them and explain your needs. Or you can just let it go. But if the relationship is important, you may want to tell the person how you feel. This can help prevent resentment or stress from building up. These feelings could hurt your relationship in the long run.

## **Taking Care of Yourself**

All family caregivers need support. But you may feel that your needs aren't important right now since you're not the cancer patient. Or that there's no time left for yourself. You may be so used to taking care of someone else that it's hard for you to change focus. But caring for your own needs, hopes, and desires can give you the strength you need to carry on. (See the Caregiver's Bill of Rights in the booklet *When Someone You Love Is Being Treated for Cancer: Support for Caregivers*.)

### **Ways to take care of yourself**

Taking the time to recharge your mind, body, and spirit can help you be a better caregiver. You may want to think about the tips below.

## **Make time for yourself**

- **Find time to relax.** Take at least 15-30 minutes each day to do something for yourself. For example, try to make time for a nap, exercise, yard work, a hobby, watching tv or a movie, or whatever you find relaxing. Do gentle exercises, such as stretching or yoga. Or, take deep breaths or just sit still for a minute. See Learning to Relax.
- **Don't neglect your personal life.** It's okay to cut back on personal activities, but don't cut them out entirely. For example, look for easy ways to connect with friends.
- **Keep up your routine.** If you can, try to keep doing some of your regular activities. If you don't, studies show that it can increase the stress you feel. You may have to do things at a different time of day or for less time than you normally would, but try to still do them.
- **Ask for help.** Find larger chunks of time that you can take for yourself by asking for help. Think about things others can do or arrange for you, such as appointments or errands.

## **Understand your feelings**

Giving yourself an outlet for your own thoughts and feelings is important. Think about what would help lift your spirits. Would talking with others help ease your load? Or would you rather have quiet time by yourself? Maybe you need both, depending on what's going on in your life. It's helpful for you and others to know what you need.

You may also be able to find some comfort by reading the Emotions and Cancer section of our website. See if any of them relate to you and what you can do for support.

## **Join a support group**

Support groups can meet in person, by phone, or online. They may help you gain new insights into what is happening, get ideas about how to cope, and help you know that you're not alone. In a support group, people may talk about their feelings, trade advice, and try to help others who are dealing with the same kinds of issues. Some people like to go and just listen. And others prefer not to join support groups at all. Some people aren't comfortable with this kind of sharing.

If you can't find a group in your area, try a support group online. Some caregivers say websites with support groups have helped them a lot.

## **Learn more about cancer**

Sometimes understanding your loved one's medical situation can make you feel more confident and in control. For example, you may want to know more about his or her type and stage of cancer. It may help you to know what to expect during treatment, such as the tests and procedures that will be done, as well as the side effects that will result.

### **Talk to others about what you're going through**

Studies show that talking with other people about what you're dealing with is very important to most caregivers. It's especially helpful when you feel overwhelmed or want to say things that you can't say to your loved one with cancer. Talk to someone you can really open up to about your feelings or fears. You're allowed to feel angry, frustrated, or overwhelmed.

You may want to talk with someone outside your inner circle. Some caregivers find it helpful to talk to a counselor, such as a social worker, psychologist, or leader in their faith or spiritual community. These types of experts may be able to help you talk about things that you don't feel you can talk about with friends or family. They can also help you find ways to express your feelings and learn ways to cope that you hadn't thought of before.

### **Share time with your loved one with cancer**

Cancer may bring you and your loved one closer together than ever before. Often people become closer as they face challenges together. If you can, take time to share special moments with one another. Try to gain strength from all you're going through together, and what you have dealt with so far. This may help you move toward the future with a positive outlook and feelings of hope.

### **Write in a Journal**

Research shows that writing or journaling can help relieve negative thoughts and feelings. And it may actually help improve your own health. You might write about your most stressful experiences. Or you may want to express your deepest thoughts and feelings. You can also write about things that make you feel good, such as a pretty day or a kind coworker or friend.

### **Look for the positive**

It can be hard finding positive moments when you're busy caregiving. It also can be hard to adjust to your role as a caregiver. Caregivers say that looking for the good things in life and feeling gratitude help them feel better. And know that it's okay to laugh, even when your loved one is in treatment. In fact, it's healthy. Laughter releases tension and makes you feel better. Keeping your sense of humor in trying times is a good coping skill.

### **Look for ways to feel thankful**

You may feel thankful that you can be there for your loved one. You may be glad for a chance to do something positive and give to another person in a way you never knew you could. Some caregivers feel that they've been given the chance to build or strengthen a relationship. This doesn't mean that caregiving is easy, stress-free, or without frustrations. But finding meaning in caregiving can make it easier to manage.

## Caring for Your Body

You may find yourself so busy and concerned about your loved one that you don't pay attention to your own physical health. But it's very important that you take care of your health, too. Doing so will give you strength to help others. It's important to:

- **stay up-to-date with your medical needs**

Keep up with your own checkups, screenings, and other appointments.

- **watch for signs of depression or anxiety**

Stress can cause many different feelings or body changes. But if the changes last for more than two weeks, talk to your doctor. Some caregivers realize they have become depressed and need help.

- **take your medicine as prescribed**

Ask your doctor to give you a large prescription to save trips to the pharmacy. Find out if your grocery store or pharmacy delivers.

- **try to eat healthy meals**

Eating well will help you keep up your strength. If your loved one is in the hospital or has long doctor's appointments, bring easy-to-prepare food from home. For example, sandwiches, salads, or packaged foods and canned meats fit easily into a lunch container.

- **get enough rest**

Listening to soft music or doing breathing exercises may help you fall asleep. Short naps can energize you if you aren't getting enough sleep. Be sure to talk with your doctor if lack of sleep becomes an ongoing problem.

- **exercise**

Walking, swimming, running, or bike riding are only a few ways to get your body moving. Any kind of exercise (including working in the garden, cleaning, mowing, or going up stairs) can help you keep your body healthy. Finding at least 15-30 minutes a day to exercise may make you feel better and help manage your stress.

**“When I get home from class, my mom and I take turns running while one of us stays with my dad. My run is my time for me, and the only way I can keep it together.”**

**—Gail**

New stresses and daily demands often add to any health problems caregivers already have. And if you're sick or have an injury that requires you to be careful, it's even more important that you take care of yourself. Here are some changes caregivers often have:

- fatigue (feeling tired)
- weaker immune system (poor ability to fight off illness)
- sleep problems
- slower healing of wounds
- higher blood pressure
- changes in appetite or weight
- headaches
- anxiety, depression, or other mood changes

## **Long-Distance Caregiving**

It can be very hard to be away from a loved one who has cancer. You may feel like you're a step behind in knowing what is happening with their care. Yet even if you live far away, it's possible for you to give support and be a problem-solver and care coordinator.

Caregivers who live more than an hour away from their loved ones most often rely on the telephone or email as their communication link. But either of these methods can be rather limiting when trying to assess someone's needs. Aside from true medical emergencies, long-distance caregivers often need to judge whether situations can be dealt with over the phone or require an in-person visit.

### **Stay in touch with others who are near your loved one**

Develop a relationship with one or two key members of the health care team, such as a nurse, social worker or patient educator. It may help you feel more at ease to have direct contact with someone involved in the medical care of your loved one. You and other family members could arrange conference calls or online meetings with them and other members of the team for updates. Other tips include:

- create a list of people who live near your loved one whom you could call day or night in a crisis or just to check in
- share a list of home, work, and cell phone numbers, and email addresses with the health care team. You should also give this to others who are local in case of an emergency
- look into volunteer visitors, adult day care centers, or meal delivery services in the area

- make a list of websites in your loved one's area to give you quick access to resources
- ask if the hospital keeps visitor information packets or lists that list area agencies and contacts

## **Important things to know or do as a long-distance caregiver**

The National Institute on Aging suggests these tips below:

- Try to learn as much as you can about your loved one's illness.
- Make sure at least one family member has written permission to receive medical and financial information about your loved one.
- If you can, gather and organize important paperwork for your loved one such as healthcare, medical care, advance directives, and any financial and legal issues that need to be in order.
- Put all vital information in one place such as a notebook or shared, secure online document. This may include medical care, financial records, or anything else you think is important for other family members or caregivers to have.

## **Other ways to stay connected to your loved one from a distance**

- Ask a local family member or friend to update you daily by email or text. Or, consider creating a website to share news about your loved one's condition and needs. There are a number of sites available. Examples are Caring Bridge and Lotsa Helping Hands.
- Sign up for online ways to connect with people. Programs using video and instant messaging to communicate are very common. For example, Zoom and FaceTime are ways people connect from a distance.
- Airlines or bus lines may have special deals for patients or family members. The hospital social worker may also know of other resources, such as private pilots, advocacy organizations, or companies that help people with cancer and their families with transportation.
- If you're traveling to see your loved one, time your flights or drives so that you have time to rest when you return. Many long-distance caregivers say that they don't allow themselves enough time to rest after their visits.
- Review your long-distance and cell phone plans. See if you can make any changes that would reduce your bills.
- For more tips, see the National Institute on Aging's Long-Distance Caregiving page.

## **Related Resources**



Caring for the Caregiver

When Someone You Love Has Advanced Cancer: Support for Caregivers

Informal Caregivers in Cancer (PDQ®)–Patient Version

Facing Forward: When Someone You Love Has Completed Cancer Treatment

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