

CAREGIVERS

Taking care of someone with cancer can be challenging. Family members, partners, neighbors, and close friends who take on a caregiving role feel cancer's deep emotional impact. You may feel a roller coaster of emotions—from joy to sadness or from closeness to loneliness. These emotions may even occur all in one day.

This resource uses information shared by caregivers through **Cancer Support Community's Cancer Experience Registry**. It will talk about navigating some of the challenges of caregiving. It will also talk about ways to reduce stress and the emotional toll of cancer, as well as ways to get support to address your own needs.

Who Are Caregivers?

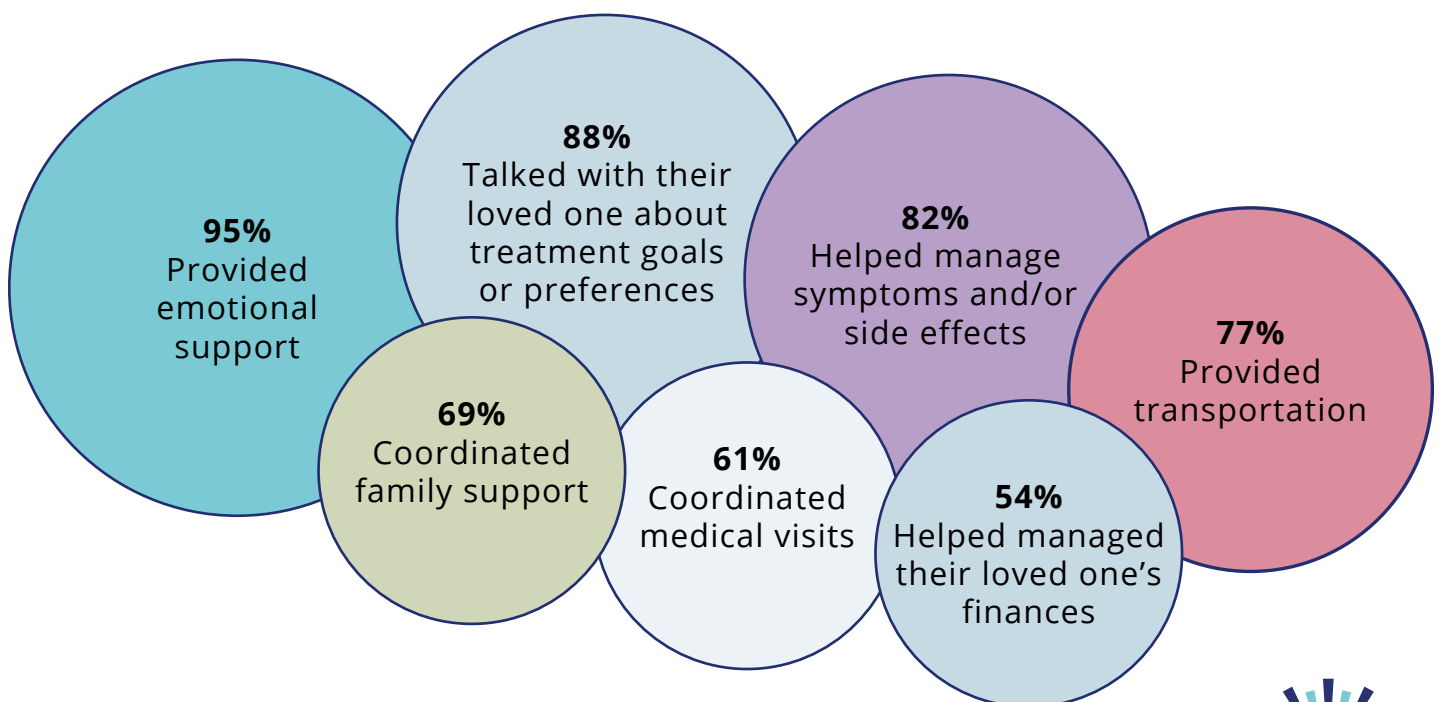
In the United States, nearly 53 million adults identify as a caregiver. That is more than 1 in 5 people.

You may also hear the term “care partner” used instead of caregiver. In this resource, the term caregiver will be used. This term describes anyone who provides or arranges help for a person with an illness or health concern. This type of help can be physical, emotional, spiritual, financial, or logistical support. A cancer caregiver is anyone who provides support and informal care to someone diagnosed with cancer. In this resource, the term “loved one” is used to describe the person diagnosed with cancer. This could be someone who you have any type of relationship with and assist with their care needs.

There are different types of caregivers. Some caregivers may be immediate family members or partners. Some may be related to the person diagnosed with cancer in other ways. Some caregivers may even be unrelated but still closely connected to the person. This can include neighbors, colleagues, and close friends. Every situation is different. Caregivers come in different forms and provide care in a variety of ways.

Different Ways to Provide Care

Everyone’s cancer experience is unique. The decisions and support needed for one person may differ from someone else. This makes the role of a caregiver unique as well. Some caregivers may find that they often help with daily activities, like bathing or assisting with medicines. Others may help more with researching information and resources. In the Cancer Experience Registry (CER), caregivers discussed several ways that they provided support:



The caregiving experience may be ongoing for a long period of time, whether you are local or long-distance. There may be times when your loved one's care needs are intense or periods when their care needs are minimal. There are many things you can do to help a person with cancer, no matter the distance.

When you offer to help from a distance, be specific about what you can do. You may ask if you can order and have dinner delivered on a certain day of the week. Or you may help research support resources in the community. Be sure to suggest things you know you can follow through with. Before jumping in, it may help to ask questions and listen to those who are local. You are not intruding by asking how to best support everyone. Let them help you understand the situation and determine what you can do. They may want you to call in or video chat during appointments to talk with the health care team. Even letting your loved one 'vent' their frustrations may be most helpful at the time.

Some other ways to provide support from a distance, include:

- Researching treatment information and care options
- Organizing and keeping track of appointments or important documents
- Arranging transportation and other services
- Communicating updates to family and/or friends
- Providing emotional support



Cancer Experience Registry Caregiver

CSC's Cancer Experience Registry (CER) is an online research study. The CER aims to understand the emotional, physical, social, and financial impact of cancer.

It is an opportunity for any adult impacted by cancer to share their experience. The annual CER Report describes general findings from the survey. This includes any unmet needs among patients, survivors, and caregivers. CSC uses these findings to identify and address gaps in cancer care. This helps us to better influence outcomes such as survival, quality of life, and health care cost. By gathering important insights from those affected by cancer, we can create better outcomes for patients and caregivers today, and for future generations.



To learn more or sign up for the CER, visit
www.CancerSupportCommunity.org/Registry

You can also scan the QR code to learn more.

Caregiving From a Distance

Even if you do not live with the person you care for, you may still find yourself in the caregiver role. Local caregivers live close to the person they care for but may not live in the same home. The term "long-distance caregiver" describes anyone who provides some form of support to a person with a health concern, even though they live further away from the person needing care.

As a long-distance caregiver you may be the person responsible for your loved one's care. In this case you would be considered a primary caregiver. If you are not the primary person responsible for your loved one's care, then you would be considered a secondary caregiver. Whether you are a long-distance or local caregiver, serving in the primary or secondary role, you may find that you will need to share tasks with others. You may share these duties with other siblings, a parent, friends, or outside hired support.

Navigating Challenges

Each person manages the challenges of cancer differently. Still, cancer can lead almost everyone to experience higher levels of stress. Navigating a cancer diagnosis may impact family roles and relationships. It may also bring unexpected financial and career challenges. As a caregiver, it is important to understand how to best handle these challenges when they arise.

In the CER, caregivers spoke about areas where they wanted more help during their loved one's cancer experience. Over 70 percent of caregivers in the survey wanted help with providing emotional support. Over 60 percent wanted help managing negative feelings like guilt, anger, and stress. During this experience, it is important to recognize the stressors of cancer. Recognize when these stressors are impacting your life — or the life of others you care about. Reach out to people with experience and who understand what you're going through. Talk with a support group, a counselor, or other experts. These conversations will show you that you are not alone. You may also have a chance to get advice on how to handle your situation.

It is important to identify what can be done to regain balance. Try not to be too self-critical. Do not expect that you will do everything perfectly or get things right on the first try. Continue to seek help from other people or supportive services when you need it.

Consider looking into “respite care” options in your local community as well. Respite care is organized short-term care that primary caregivers can arrange. This form of support can be a great source of relief. It allows caregivers to take a short break from their day-to-day duties. Respite care can occur in the home, a healthcare facility, or at an adult day center. Local community groups may also provide these services. Some insurance plans, as well as Medicare and Medicaid, may help cover costs related to respite care. Be sure to talk with your loved one's health care team or a social worker to learn more.

Caregiving can feel overwhelming. With reliable information, practical guidance, and support, you can feel more control over your situation.

MYLIFELINE®

Cancer Support Community's private support community website that connects cancer patients and caregivers with friends and family, and others like them, through discussion forums and private sites with an interactive blog and calendar to manage practical support and events. To learn more, visit www.MyLifeLine.org.

Remembering Your Needs

Sometimes caregivers may find that they put their own needs aside as they care for someone else. This may happen without you even realizing it. As you try to support the person you care for, be sure to also think about how to best support your own needs.

Some days it may feel like it is selfish to take time and care for yourself. That is not the case! Remember: It is essential to take care of yourself. You and your loved one may have a long, sometimes bumpy, road ahead. By taking care of your own needs, you can better support them through this experience.

Coping with Stress & Mental Health Concerns

The stress that comes with navigating the cancer experience can lead to a variety of emotions. At times, you may feel like you have too many responsibilities between caregiving and your everyday life. You are not alone in feeling the emotional effects of this role. It is natural to feel frustrated and tired at times.

Experiencing a cancer diagnosis can impact a person's mental health. It can even worsen any already existing mental health concerns. This is true whether you are the person diagnosed with cancer or a caregiver. Mental health refers to your overall emotional, psychological, and social well-being. In the CER, 67 percent of caregivers said their emotional/mental health became much or somewhat worse after taking on the caregiving role. Over 60 percent of caregivers wanted more help with taking care of their own mental health needs.

Remember that your mental health is as important as your physical health. As a caregiver, be sure to make time to reflect on how you are feeling and coping as things change. Everyone manages stress, worry, and other emotions differently. Think about how you cope when things become challenging or stressful. Then consider ways you may want to improve or develop more healthy coping skills.



Some ways to cope and maintain your mental health as a caregiver, may include:

- 1 Identifying your support network**—keep in mind friends and loved ones you can reach out to and talk with
- 2 Asking the cancer care team if there are resources** or support groups available for caregivers
- 3 Connecting with a therapist, social worker, psychologist, and/or community or religious leader** to talk with about your experiences
- 4 Connecting with a local CSC or Gilda’s Club location**
- 5 Connecting with other caregivers to exchange ideas** and coping strategies on CSC’s Caregiver Support discussion forum through [MyLifeLine.org](https://www.mylifeline.org).

Emotions like sadness or anxiety may last for a long time and begin to impact daily life. You may also experience other challenging and unexpected emotions, like anger, resentment, or guilt. While these feelings are common, it is important to seek support from a mental health specialist or social worker. It is important to recognize feelings of depression or anxiety. Ignoring these feelings may lead to isolation and other issues. After a while, these feelings can make it more difficult to support the person you care about. Seeking support from an expert early on can give you the tools to problem-solve, prevent symptoms from worsening, and get to a better place.

To learn more about Coping with Mental Health Concerns, visit www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns.



Coping with a “New Normal”

Life may look very different after a cancer diagnosis. When a person you care about is diagnosed with cancer, you may need to develop a “new normal.” This means putting the reality of cancer care and follow up into your future plans and goals. You may have to adjust your goals to fit the present situation. As things change, your new normal may also change.

Remember to pace yourself. Be sure to carve out time to manage your own needs and responsibilities. Here are some things to keep in mind as you navigate this experience:

Keep up with your own health needs. Be sure to care for your own health and well-being. Setting time to care for yourself will greatly benefit your loved one as well. Make note of any changes in your physical or mental health. Let your doctor and health care team know when these changes occur.

It is also important that you keep up with regular checkups and other appointments for specific concerns. Do your best to eat regularly and get enough sleep. Try to stay physically active as well, even if that means taking a 15-minute walk. Limit any use of substances, like smoking, alcohol, and drugs. Try not to judge yourself harshly. You are doing the best you can with the resources you have. And that is enough!

Find balance and focus on one goal at a time. It can be overwhelming to think about adding more tasks to your already full plate. Taking time for yourself and setting priorities will help you regain some control. It will also give you more time and energy to be the caregiver you would like to be. Make a list of tasks. Decide what is important, what can be let go, and what needs to be adjusted. You may have to say no to some tasks or ask for help from others.

If you have fallen behind in any area, remember that you don’t have to change your routine all at once. Instead, pick one task at a time that you would like to focus on. Then set a specific and reasonable goal. For example, if reading helps you de-stress and you want to be more consistent, a specific goal could be to “read for 15 minutes a day.” Then schedule that reading time into your planner or calendar, just as you would any other important appointment. You may need to be flexible and adjust this time as needed. Still, having the goal planned is a great first step.

Accept your limitations and ask for help when needed. As a caregiver, you have so much to manage. There is only one of you. And you cannot do everything by yourself. Accepting limitations does not mean you are letting other people down. It is okay to have others help where they can. Try hiring someone or asking for help from friends, family, or a local organization. Make a list of things you feel okay with letting go of. This can be letting others help with chores, errands, or home care assistance. Setting up a network of resources can give you support while letting you focus on what is most important. You and your loved one will benefit in many ways from having your family and friends help where needed.

Stay connected to others. It is important to share your feelings with people you are comfortable with, you trust, and who are important to you. Talking with a counselor or therapist can help you cope with distress, anxiety, and depression. Joining a support group with others going through similar experiences can be a big relief.

Being a caregiver is an important role that you may be performing now or will perform in the future. It is rewarding, yet the responsibilities can often be stressful and take up a great deal of your time. It is important to enjoy the parts of life that are not connected to your role as a caregiver. Doing the things that bring you joy outside of this role can also be a great way to reduce stress. Making your needs a priority and taking care of yourself will help in the long run as you go through this experience.

CANCER SUPPORT HELPLINE®

If you need help finding resources or want help getting information about cancer, call CSC's toll-free Cancer Support Helpline® at **888-793-9355**. It is staffed by community navigators and resource specialists who can assist you Monday - Thursday 11:00 a.m. - 8:00 p.m. ET and Friday 11:00 a.m. - 6:00 p.m. ET.

Resources

Cancer Support Community • 888-793-9355
www.CancerSupportCommunity.org/Caregivers

Caregiver Action Network • 855-227-3640
www.CaregiverAction.org

National Alliance for Caregiving • 202-918-1013
www.Caregiving.org

Family Caregiver Alliance • 800-445-8106
www.Caregiver.org

National Cancer Institute • 800-422-6237
www.Cancer.gov

American Cancer Society • 800-227-2345
www.Cancer.org

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 190 locations, CSC and Gilda's Club network partners provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.



MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/Become-Advocate.

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This booklet is available to download and print yourself at www.CancerSupportCommunity.org/Caregivers.

For print copies of this publication or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.





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Frankly Speaking About Cancer: Caregivers Program Partners



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