

Caregiving for
Your Loved One
With Cancer

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Caregiving for Your Loved One With Cancer

The CancerCare Connect Booklet Series offers up-to-date, easy-to-read information on the latest treatments, managing side effects and coping with cancer.

To order free copies of this booklet, please use the online order form on our website, www.cancercares.org.

Founded in 1944, CancerCare® is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

CancerCare relies on the generosity of supporters to provide our services completely free of charge to anyone facing a cancer diagnosis. If you have found this resource helpful and wish to donate, please do so online at www.cancercares.org/donate. You may also mail a check, payable to CancerCare, to CancerCare, Attn: Donations, 275 Seventh Avenue, New York, NY 10001.

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Caregiving can be a full-time job, but help is available for this very important role.

If you are helping to care for a loved one with cancer, you are a “caregiver.” You may see what you’re doing as something natural: taking care of someone you love. Still, for many people, caregiving isn’t easy. But there are many things you can do to make it less difficult.

This e-booklet is designed to help you, the caregiver. It is filled with tips from the professional oncology social workers at CancerCare, a national nonprofit organization that has helped people with cancer and their caregivers for more than 70 years. Our social workers help people cope with the emotional and practical challenges of cancer.

Read this e-booklet straight through, or refer to different sections as you need them. Some sections may not apply to your situation. Use this e-booklet in whatever way works best for you. Be sure to talk with your loved one often about what he or she feels would be most helpful.

The Role of the Caregiver

Caregivers provide important emotional, practical and physical care for a person with cancer. Often, caregivers are family members or friends. They may live nearby or far away from the person they care for.

There are many different ways to be a caregiver. Caregiving can mean helping your loved one with daily activities, such as getting to the doctor or preparing meals. It can also mean helping the person cope with feelings that come up during this time.

The kind of support that a caregiver provides will be different for each person. In general, caregiving tasks fall into three categories: medical, emotional and practical.

Helping to Manage Your Loved One’s Treatment

Sometimes, a person diagnosed with cancer feels overwhelmed and may need someone to help him or her sort through treatment options. Or, he or she may want someone there to help listen to the doctor’s instructions. A person receiving treatment might need a caregiver’s help in managing side effects or taking medication.



Here are some ways to help manage your loved one's treatment:

Gather information. Learn about your loved one's diagnosis and possible treatment options. One good place to start is by asking the doctor or nurse what resources he or she recommends. There are also many reliable websites and cancer organizations that can provide accurate, up-to-date medical information. Please see page 22 of the e-booklet for a list of reliable websites.

Go to medical appointments together. Before a visit with the doctor, write down any questions the two of you would like to ask. Bring a notebook or portable voice recorder, so you can keep track of the doctor's answers and refer to them later. If you need to speak with the health care team without your loved one present, find out about the rules of the Health Insurance Portability and Accountability Act (HIPAA). This law gives patients greater access to their own medical records and more control over how their health information is used. Your loved one will need to give written permission, by signing a consent form, before doctors can share information with you about his or her medical treatment.

Learn how to help with physical care. Depending on how they are feeling, people coping with cancer and treatment may need help with a wide range of activities they would normally do themselves, such as bathing or dressing. Ask your loved one to let you know how he or she wants you to help with these tasks.

Ask about special instructions. Check with the doctor or nurse to find out if there are any specific instructions you should be aware of. For example, are there any tips for managing a particular side effect, or does a special diet need to be followed during treatment? Keep the doctor's phone number in a place that is easy to find in case you have questions.

Questions to Ask the Doctor

Here are some questions you or your loved one might want to ask the doctor:

- What are the goals of treatment?
- How long will treatment last?
- Do you have any written information about this treatment?
- What are the side effects of this treatment?
- Are there any ways to help manage side effects?
- How do we know if a side effect is severe enough to call you?
- Are there any other treatment options?
- Are there any clinical trials we should be aware of?
- What is the best way to let you know when we have questions about treatment?

Learn about organizations that help with medical care.

If you need help managing some of your loved one's medical needs, ask your doctor or hospital social worker about local home health agencies. These agencies may send nurses to the home to give medications, monitor vital signs or change bandages, for instance. Home health agencies can also send care providers who attend to other personal needs such as bathing, dressing, cooking or cleaning.

Providing Emotional Support

Going through cancer is often described as an emotional roller coaster, with many ups and downs. As a caregiver, you may see your loved one experience a wide range of emotions. While this can be difficult for both of you, your willingness to listen and offer support will make a difference.

Listen to your loved one. It is important to listen without judging or “cheerleading.” We are often tempted to say “you will be fine” when we hear scary or sad thoughts. But simply listening to those feelings can be one of the most important contributions you make.

Do what works. Think about how you’ve helped each other feel better during a difficult time in the past. Was a fun outing a helpful distraction? Or do the two of you prefer quiet times and conversation? Do whatever works for you both, and don’t be afraid to try something new or make modifications to plans that you enjoyed before.

Support your loved one’s treatment decisions. While you may be in a position to share decision making, ultimately it is the other person’s body and spirit that bear the impact of the cancer. Get information about support groups. Joining a support group gives your loved one a chance to talk with others coping with cancer or caregiving and learn what they do to manage difficult emotions. Sometimes, support groups are led by social workers or counselors. Ask a hospital social worker for a referral, or contact CancerCare. We offer face-to-face, telephone, and online support groups for people with cancer and caregivers.

Coping With Difficult Feelings

People with cancer often feel emotions such as:

- **Sadness.** Sadness can come and go during treatment. For some people, it can be more constant or last longer.
- **Anger.** For example, people can be angry about the way treatment and side effects make them feel, or about the changes their diagnosis has made in their lives.
- **Worry.** Cancer can be one of the most stressful events a person experiences. Common worries include fear of treatment not working, of cancer returning or spreading, and of possibly losing control over one’s life and future. Other worries that existed before the cancer diagnosis, such as work or financial concerns, can add to the stress.

If it’s needed, continue your support when your loved one’s treatment is over. This can be an emotional time for many people. Despite being relieved that the cancer is in remission (stopped growing or disappeared), you and your loved one may feel scared that it will return. The end of treatment also means fewer meetings with the health care team, on which you and your loved one may have relied for support. You may also have questions about how treatment ending impacts your role as a caregiver, so getting support during this transition can be helpful.

Recommend speaking with an oncology social worker or counselor. If you think your loved one may need additional support coping with his or her emotions during this time, suggest speaking with a professional who can help, such as an oncology social worker.

Helping Your Loved One with Practical Matters

In addition to helping with medical and emotional concerns, caregivers often help by taking on many practical tasks. Some day-to-day activities caregivers can do include running errands, pitching in with household chores, preparing meals and helping with child care.

Because cancer can also place a tremendous strain on a family's finances, caregivers are often left with the task of managing financial matters, too.

Here are some tips for finding financial help for costs related to cancer:

Review your loved one's insurance policies to understand what's covered. Your insurance company can assign a case manager who can explain what services and treatments the plan does and doesn't cover and answer any questions. Case managers work for insurance or other types of agencies. They help clients gain access to resources and services. He or she can also help explain any out-of-network benefits the policy may offer, such as medical services from doctors not on your insurance plan.

Understand what your loved one is entitled to. Some types of aid for people with cancer are required by law. These programs are called entitlements—government programs that give financial and other aid to people in certain groups such as those with cancer. A hospital or community social worker can direct you to the governmental agencies that oversee these programs.

Ask for help. If you need help with hospital bills, speak to a financial counselor in the hospital's business office. He or she can help work out a monthly payment plan. If your loved one expects to run out of money, or has already, talk to his or her creditors. Many landlords, utilities and mortgage companies are willing to work out a payment plan before a crisis develops. Reaching out for help early on is most helpful.

Apply for financial help. For many people, expensive cancer medicines pose a financial challenge. Fortunately, there are many programs to help qualified individuals get medications for free or at a low cost. For more information, contact the Partnership for Prescription Assistance (www.pparx.org), listed among the resources. CancerCare also provides financial help. We provide limited grants for cancer-related costs such as transportation and child care. We also provide referrals to other organizations that can provide assistance. Call us at 800-813-HOPE (4673) to learn more.



Keeping Track of Important Papers

Many people find it helpful to keep all records or paperwork in one place. This will make things easier if you have questions or are trying to plan ahead.

Important documents include:

- Copies of medical records
- Prescription information
- Health insurance records
- Disability insurance
- Long-term care insurance
- Pensions
- Social Security records
- Veterans benefits
- Bank statements
- Wills
- Health care proxy
- Power of attorney protected

Taking Care of Yourself

Taking care of a loved one can be a positive experience. For example, some people say that caregiving strengthened their relationship. But it can also be very stressful. Many caregivers say it often feels like a full-time job. Caregiving can be even more challenging if you have many other responsibilities, like working, raising children, or caring for your own health.

Sometimes, caregivers tend to put their own needs and feelings aside. It is important, though, for you to take good care of yourself. This will make the experience less stressful for you.



Some Emotions the Caregiver May Feel

When caring for a loved one with cancer, caregivers may experience:

- **Guilt.** Sometimes caregivers feel guilty that they are healthy. Others may feel badly about enjoying things in life that their loved one cannot. It is also common for caregivers to feel that they are not doing enough to help.
- **Anger.** Caregivers may feel angry with the cancer itself, or with themselves, their loved one, family members, doctors, or others. Pinpointing the source of the anger can help you better manage the feeling.
- **Sadness.** It's natural to feel sad when someone you love is ill. You might also miss the life the two of you had before cancer.
- **Worry.** At times, you may feel tense, nervous, or scared, or have difficulty relaxing. This is normal. Examples of things caregivers often worry about include their loved one's health, paying the bills, and how other family members are coping.
- **Discouragement.** Being a caregiver can sometimes feel like a long, bumpy road. It's easy to get discouraged from time to time. This is especially true if your loved one's condition worsens.
- **Feeling overwhelmed.** It is common to feel overwhelmed as a caregiver. Providing practical and emotional support to someone with cancer can feel like a full-time job.

Staying Healthy

Caregivers spend a lot of time looking after the health of their loved ones. This often means that the caregiver spends less time focusing on his or her own needs, such as eating well and exercising. Yet taking care of your own physical health is an important part of caregiving.

Here are some tips for caring for your health:

Stay active. Experts recommend exercising for at least 30 minutes each day. Activities can include walking quickly, jogging, or riding a bike. Keep in mind that you don't have to set aside a lot of time to exercise—you can work it into your day. For example, take the stairs instead of the elevator, or park your car farther away than you normally do.

Pay attention to what you're eating. Keeping a balanced diet is an important part of taking care of yourself. Include fruits and vegetables in your meals. Nuts, yogurt, and peanut butter sandwiches are easy snacks with lots of protein that will keep your energy level up. Pack snacks if you know you will be with your loved one at the doctor's office or the hospital all day.

Get enough sleep. Caregiving can be emotionally and physically draining. You may find yourself more tired than usual. Try to get enough sleep, and take naps when you need them.

Rest regularly. As a caregiver, you may find that it is hard to relax, even if you have time for it. Deep breathing, meditating, or gentle stretching exercises can help reduce stress.

Long-Distance Caregiving

For some people, caregiving can come in untraditional ways. Many people living with cancer have caregivers who live far away. We refer to those individuals as “long-distance caregivers.” This is a term and an experience that can be unfamiliar and confusing. If you are fulfilling this role, you can be a meaningful part of your loved one’s cancer experience whether you live locally or are caring from a long distance.

Supporting Your Loved One

Caregivers who are not local to their loved one can provide significant emotional support, a listening ear, and offer a sense of camaraderie and social support for their loved ones by phone, text, e-mail and via Skype—technology is certainly an advantage and can help you to feel connected and “in the loop.”

Staying in touch and being emotionally available to talk about difficult subjects often helps the person with cancer to feel supported, and can help the long-distance caregiver feel like they are contributing and being helpful. This layer of emotional support is often as helpful as providing physical care, so it is important to keep this in mind.

Keep up with your own checkups, screenings, and medications. Your health is very valuable. Stay on top of your doctor appointments, and have a system for remembering to take any medicines you need to stay healthy.

Getting Emotional Support

Caregiving is hard work that can affect your emotional well-being. Taking care of yourself includes coping with many of your own feelings that come up as you care for your loved one. Many people feel more emotional than usual when they are coping with a loved one’s cancer. This is normal.

You cannot make difficult feelings go away, but there are things you can do to feel better.



Here are some tips for coping with the emotional impact of your loved one's cancer:

Take a break. If possible, take some time out for yourself regularly. Even if it's just for a few minutes, doing something you enjoy can help you recharge. For example, listening to relaxing music or going for a walk might help you clear your head.

Be aware of your limits. Remember that there are only so many hours in a day. Feel free to say "no" when people ask you to take on tasks you don't have the time or energy to complete.

Keep a journal. Writing sometimes helps people organize their thoughts and come up with practical solutions. Writing about your thoughts, feelings, and memories can also strengthen your spirit.

Open up to friends and family. Ask friends or family members if they would be willing to be "on call" in times of stress. Or plan a regular "check-in" time when you can get together or call each other.

Consider developing your spiritual side. For some people, this means participating in religious activities. Others find spirituality in art or nature. No matter what your beliefs are, developing your spiritual side could provide comfort during this time.

Talk to a professional about your feelings and worries. Many caregivers feel overwhelmed and alone. You may need more than friends or family members to talk to. Speaking with a counselor or oncology social worker may help you cope with some of your feelings and worries. CancerCare's oncology social workers are just a phone call away.

Could It Be Depression?

It is normal to feel sad or angry when a loved one has cancer. However, talk to your doctor if you have any of these feelings or symptoms for more than two weeks:

- Feeling particularly overwhelmed or helpless
- Prolonged periods of crying
- Inability to enjoy things
- Difficulty concentrating
- Trouble sleeping or sleeping too much
- Upset stomach
- Weight loss or weight gain
- Thoughts of hurting yourself

These may be signs of depression, and help is available. Talk with your doctor to find the best treatment for you.

Join a support group for caregivers. Talking with other caregivers can also help you feel less alone. CancerCare offers free face-to-face, telephone, and online support groups for caregivers. These groups provide a safe haven where you can share your concerns and learn from others who are going through similar situations.

Go easy on yourself. Sometimes, you may feel you could have done something differently. Try not to be too hard on yourself. Focus on all the positive things you are doing for your loved one.

Getting Help With Caregiving Responsibilities

As a caregiver, it is important to know and accept your own limits. Having a support system is part of taking care of your loved one and yourself. Decide which tasks you will do on your own, and which you will need help with.

Here are some things you can do that will help you in your role as a caregiver:

Check with family and friends. Are there any family members, friends, members of your faith community, co-workers, neighbors, or others you can ask for assistance? Often people want to help. You just need to ask. Be specific about the kind of help you need, and keep records of who is handling what task. Certain websites including www.mycancercircle.com and lotsahelpinghands.com, can make it easier by providing calendars and other helpful tools for coordinating care.

Learn about respite care programs. Respite care gives family and friends a break from caregiving. While you run errands or take some personal time, respite caregivers spend time with your loved one temporarily. They may help with feeding, bathing, or daily routines. Ask for a referral from a health care professional, friend, or local service agency.

Know your rights. If you work for a company with 50 or more employees and have worked there for at least one year, you are probably allowed unpaid leave under the Family and Medical Leave Act (FMLA) to provide care for your loved one. Many smaller companies allow their employees to use sick days and vacations for caregiving purposes. Ask your human resources department for help and to find out whether this law applies to your company.

Contact CancerCare. Our professional oncology social workers understand the unique challenges that caregivers face. We can work with you one-on-one to develop strategies for coping with whatever emotional or practical challenges you may experience. Contact us at 800-813-HOPE (4673) or visit our website, www.cancercare.org.



Resources

CAREGIVING

CancerCare

www.cancercare.org
800-813-HOPE (4673)

Family Caregiver Alliance

www.caregiver.org
800-445-8106

My Cancer Circle

www.mycancercircle.lotsahelpinghands.com

National Family Caregivers Association

www.thefamilycaregiver.org
800-896-3650

Well Spouse Association

www.wellspouse.org
800-838-0879

RELIABLE MEDICAL INFORMATION

American Cancer Society

www.cancer.org
800-227-2345

Cancer.Net

Cancer.net

National Cancer Institute

800-422-6237

National Comprehensive Cancer Network

www.nccn.org
215-690-0300

Resources Continued

COUNSELING AND SUPPORT GROUPS

CancerCare

www.cancercare.org
800-813-HOPE (4673)

Cancer Support Community

www.cancersupportcommunity.org
888-793-9355

FINANCIAL HELP

CancerCare

www.cancercare.org
800-813-HOPE (4673)

Partnership for Prescription Assistance

www.pparx.org
888-477-2669

Patient Advocate Foundation

www.patientadvocate.org
800-532-5274

Social Security Administration

www.ssa.gov
800-772-1213

END-OF-LIFE CARE

Hospice Foundation of America

www.hospicefoundation.org
800-854-3402

National Hospice and Palliative Care Organization

www.nhpco.org
800-658-8898



Resources Continued

HOME CARE RESOURCES

National Association for Home Care & Hospice

www.nahc.org

202-547-7424

U.S. Administration on Aging

www.eldercare.gov

800-677-1116

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