

Caregiving for
Your Loved One
With Cancer

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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 case management, 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 master's-prepared oncology social workers.

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This booklet provides information, guidance and resources for people helping to care for a loved one with cancer.

Use this booklet in whatever way works best for you—read it straight through or refer to specific sections as you need them. Be sure to share the information you find most helpful with your loved one.

The Role of the Caregiver

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

Please remember that if you are a caregiver, you do not have to be alone as you provide support to your loved one with cancer. People in your personal network (family, friends, partners/spouses, neighbors) may be eager to help, especially if you are specific in your needs and requests. As a caregiver, be sure to take some time to think about the people in your life and how they are best suited to help you, and match your request to their strengths. For example, you might ask a friend or family member who loves to shop to pick up a few things at the store; ask a friend who's a good listener to come over for a chat with you and your loved one; ask a family member or friend who has extra time to spend a few hours with your loved one so you can run errands or take a break.

There are also professional resources available to you, including the oncology social workers at CancerCare, who are specially trained to help people and their caregivers cope with the emotional and practical challenges of cancer. Additional resources are listed at the end of this booklet.

Guidance for Caregivers

The kind of support that a caregiver provides will be different for each person. In general, caregiving support falls into one of three areas: informational, practical and emotional. This booklet provides examples of how caregivers can help in each of these areas.

Informational Support

A person diagnosed with cancer can feel overwhelmed and may need informational support (whether written, visual, audio or verbal) directly related to their diagnosis and treatment. Here are specific types of support caregivers can provide:

Learn about your loved one's diagnosis and possible treatment options. Ask for information from your loved one's health care team and ask what additional resources they recommend.

Understand the potential side effects of the chosen treatment approach. Your loved one's health care team can provide information on potential side effects, based on the specific drug or drugs used in treatment. It may be helpful to ask the health care team about common concerns, challenges, symptoms and side effects to expect as well as circumstances that need immediate attention.

Help your loved one communicate with health care professionals.

As you help your loved one manage their cancer, it's important to remember that you are both consumers of health care. In addition to educating yourself about the diagnosis and treatment options, get to know the members of their health care team, including doctors, nurse practitioners, physician assistants, nurses, dietitians, psychologists, occupational therapists, physical therapists, chaplains, social workers and patient navigators. Here are a few things you, as a caregiver, can do to ensure that communication with the extended health care team is as effective as it can be:

- **Help create a health care journal.** Having a health care journal or notebook (either on paper or in a digital format) will allow your loved one to keep all of their health information in one place. It should include the names and contact information (and photos if possible) of the members of their health care team and details of their treatment plan. The journal can also be used as a diary to capture their experiences while undergoing treatment and your experiences as a caregiver.
- **Help prepare a list of questions for their next appointment.** This list should include your questions and concerns as well as those of your loved one. Because the doctor may have limited time, create the list in order of importance. If the doctor has limited time, consider which questions may be best addressed by other members of the health care team.
- **If you can, accompany your loved one to medical appointments or be present during telehealth sessions.** Even if they have a journal and a prepared list of questions or concerns, it's always helpful for them to have support at appointments. You may think of additional questions to ask, or remember details about their symptoms, treatment, or overall quality of life that they may have forgotten. If you can't be there in person for whatever reason, see if you can arrange to provide support via the phone or your mobile device.

- **Write down the doctor's answers.** Taking notes will help you and your loved one remember the doctor's responses, advice and instructions. If you have a mobile device, ask if you can use it to take notes or record the discussion, which will help you review the information later.



Practical Support

There are many ways that caregivers can help with practical matters (the activities of daily living), including:

Personal care. Depending on how they are feeling, people going through cancer treatment may need help with a number of activities they would normally handle themselves, such as bathing, eating, toileting, or dressing. Ask your loved one to let you know if they want help with these activities. Some people may want help, but would prefer that it is provided by a paid helper, rather than a spouse, adult child, significant other or friend. If that's the case with your loved one, ask a member of their health care team for recommendations on local home health and community agencies that can provide these services.

Health care. As a caregiver, you may be involved in some health care tasks that are more typically handled by a nurse, such as administering medication, monitoring symptoms and changing bandages. If you need help with these health care needs, ask the doctor, nurse or hospital social worker about local home health agencies that can send in-home nurses to provide these (and other) services.

Organizing medications. Keeping track of prescription and over-the-counter medications can be a challenge under any circumstances. An inexpensive pill organizer (available at most drugstores) allows for the sorting of medications by day of week and time of day. There are also free medication reminder

Household tasks and errands. If you are a caregiver to a spouse or significant other, you may already be handling a large share of household tasks and errands. This would be a good time to take short-term responsibility for additional chores, if possible.



Emotional Support

It's hard to watch someone you care about go through the difficult emotions that may arise with a cancer diagnosis, which can range from denial to sadness to anger. There are things you, as a caregiver, can do to help both of you cope:

Listen to your loved one. It's important to listen without judging, dismissing or "cheerleading." Simply listening to and validating what your loved one is expressing can be one of the most important contributions you make.

Support your loved one's treatment decisions. While you may be in a position to share decision making, ultimately it is your loved one who bears the impact of their cancer and its treatment.

Get information about support groups. Joining a support group gives your loved one a chance to talk with others coping with cancer and learn what they do to manage difficult emotions. Ask a hospital social worker for a referral, or contact CancerCare. CancerCare offers free face-to-face, telephone and online support groups for people affected by cancer. There are also support groups specifically for caregivers that may be available.

Continue your support when your loved one's treatment is over. The end of treatment means fewer meetings with the health care team, whose support you have likely relied on. You may also have questions about how to transition away from being a caregiver, so getting support during this transition can be helpful.



Remember to Take Care of Yourself

Taking care of a loved one can be a positive experience, but it can also feel like a full-time job and be very stressful. Many caregivers tend to put their own needs and feelings aside; however, it's important for you to take good care of yourself. Here are some tips to help you do so:

Ask for help. Consider using My Cancer Circle™ (mycancercircle.net) to organize help from friends and family. My Cancer Circle is a free, private, and customizable online tool that enables people facing cancer to organize and coordinate a circle of family members and friends to provide practical and emotional support. This tool provides caregivers of people facing cancer a simple, effective answer to a question they are constantly asked, "What can we do to help?" In addition to family, friends and neighbors, look for professional or volunteer resources in your community. volunteer resources in your community.

Stay active. Experts recommend at least 150 minutes (2.5 hours) of moderate-intensity aerobic activity per week, preferably spread throughout the week. Aerobic activity includes the use of cardio machines, walking, running, hiking, swimming and dancing. If there are hobbies that you enjoyed prior to becoming a caregiver, it may be important for your overall wellbeing and quality of life to continue to spend some time on those hobbies when possible.

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 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 for an extended period of time.

Get enough sleep. Caregiving can be emotionally and physically draining, and you should try to get enough sleep. The Centers for Disease Control and Prevention (CDC) recommends at least seven hours per night for adults. Also, take naps during the day if you need them.

Keep up with your own checkups, screenings and medications.

Your health is very valuable. Stay on top of your own medical appointments, and have a system for remembering to take any medicines you need to stay healthy.

Get 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. Here are some tips to help you cope:

- **Take a break.** Take some time for yourself regularly. Even if it's just for a few minutes, doing something you like can help you recharge.
- **Open up to friends and family.** Ask friends or family members if they would be willing to be "on call" in times of stress. You can also plan a regular "check-in" time. And be sure to make time for socializing with friends or family, preferably outside of your home.
- **Talk to a professional about your feelings and concerns.** Many caregivers feel overwhelmed and alone. Speaking with a counselor or oncology social worker may help you cope. CancerCare's oncology social workers are just a phone call away.
- **Join a support group for caregivers.** 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 a similar situation.

The Importance of Clinical Trials

Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.

Here are a few things, as a caregiver to a person with cancer, that you should know:

- A member of their medical team can provide guidance as to whether a clinical trial is right for their specific circumstances. Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before your loved one participates in a clinical trial, they will be fully informed as to the risks and benefits of the trial, including any possible side effects.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- Participation in a clinical trial is voluntary. Your loved one can stop taking part in a clinical trial at any time for any reason.

General Side Effects

Some side effects can occur across treatment approaches. This section, for you to share with your loved one, provides tips and guidance on how to manage these side effects should they occur. It's important that side effects are reported right away so that your loved one's health care team can help manage them.

Not all people being treated for cancer experience all of these side effects and people may experience treatment-specific side effects not listed here.

Managing Digestive Tract Symptoms

Nausea and vomiting

- Avoid food with strong odors, as well as overly sweet, greasy, fried or highly seasoned food.
- Eat meals that are chilled, which often makes food more easily tolerated.
- Nibble on dry crackers or toast. These bland foods are easy on the stomach.
- Having something in your stomach when you take medication may help ease nausea.



Constipation

- As hydration is important to avoid constipation, make sure to drink plenty of fluids. Also, limit your intake of caffeine and alcoholic beverages, as they can cause dehydration.
- Include foods high in fiber in your daily diet, such as fruit (especially pears and prunes), vegetables and cereals. If your health care team approves, you may want to add synthetic fiber to your diet, such as Metamucil, Citrucel or FiberCon.
- Be as physically active as you can, after checking with your health care team on the level of physical activity that is right for you.
- If your doctor has prescribed a “bowel regimen,” make sure to follow it exactly.

Diarrhea

- Drink plenty of water. Ask your doctor about using drinks such as Gatorade which provide electrolytes. Electrolytes are body salts that must stay in balance for cells to work properly.
- Over-the-counter medicines such as loperamide (Imodium A-D and others) and prescription drugs are available for diarrhea but should be used only if necessary. If the diarrhea is bad enough that you need medicine, discuss it with your doctor or nurse.
- Choose fiber-dense foods such as whole grains, fruits and vegetables, all of which help form stools.
- Avoid food high in refined sugar and those sweetened with sugar alcohols such as sorbitol and mannitol.

Managing Loss of Appetite

- Eating small meals throughout the day is an easy way to take in more protein and calories, which will help maintain your weight. Try to include protein in every meal.
- To keep from feeling full early, avoid liquids with meals or take only small sips (unless you need liquids to help swallow). Drink most of your liquids between meals.
- Keep high-calorie, high-protein snacks on hand such as hard-boiled eggs, peanut butter, cheese, ice cream, granola bars, liquid nutritional supplements, puddings, nuts, canned tuna or trail mix.
- If you are struggling to maintain your appetite, talk to your health care team about whether appetite-building medication could be right for you.



Managing Fatigue

Fatigue (extreme tiredness not helped by sleep) is one of the most common side effects of many cancer treatments. Here are a few tips that may help reduce fatigue:

- Take several short naps or breaks during the day.
- Take short walks or do some light exercise, if possible.
- Try easier or shorter versions of the activities you enjoy.
- Ask your family or friends to help you with tasks you find difficult or tiring.
- Save your energy for things you find most important.

There are also prescription medications that may help. Your health care team can provide guidance on whether medication is the right approach for your individual circumstances.

Fatigue can be a symptom of other illnesses, such as anemia, diabetes, thyroid problems, heart disease, rheumatoid arthritis or depression. Be sure to ask your doctor if they think any of these conditions may be contributing to your fatigue.

It can also be beneficial to speak with an oncology social worker or oncology nurse to help manage your fatigue. These professionals can work with you to manage any emotional or practical concerns that may be causing symptoms and help you find ways to cope.

Managing Flu-Like Symptoms

The fever and aches that may occur with treatment can be managed with a combination of rest and medication. Acetaminophen (such as Tylenol) is often a doctor's first choice to treat these symptoms. Nonsteroidal anti-inflammatory drugs (NSAIDs) can also help, but should be taken only if recommended by your doctor, as they can cause other side effects. NSAIDs include aspirin, ibuprofen (Motrin and others) and naproxen (Naprelan, Midol, Aleve and others).



CancerCare's Free Support Services and Programs

Being a caregiver to a person living with cancer can be very difficult, and adjusting to the necessary changes in your life can be challenging.

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and offer information on support groups and other resources.

To learn more about how CancerCare can help, call us at 800-813-HOPE (4673) or visit www.cancercares.org.



Frequently Asked Questions

Q: My husband was just diagnosed with cancer. What questions should he and I ask the oncologist about the recommended treatment approach?

A: Here are some questions you should ask; others will likely arise in the course of your discussion.

- What are the goals of treatment?
- How long will treatment last?
- Do you have any written information about this treatment?
- What medical procedures and expenses does my insurance plan cover?
- 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?
- How frequent are medical appointments? What can we expect during the appointments?

Q: My sister has cancer. I want to help with caregiving, but I live far away. What can I do?

A: Even from a distance, you can provide ongoing emotional support to your sister and to her primary caregiver. It is sometimes easier for people to talk about difficult topics over the phone than in person, so be willing to have in-depth and serious conversations. You can also help coordinate medical appointments (and send reminders to your sister and her caregiver about those appointments), attend telehealth appointments, provide verbal updates to other family members and share information on how your sister is feeling (if she agrees) in an on-line journal such as CaringBridge. If you think it would be helpful, you can also send periodic “care packages” containing things your sister would enjoy.

Q: I am wondering if my wife might be eligible for a Medicare or Medicaid. Can you tell me about those programs?

A. Here is a description of these two government programs.

Medicare

Medicare is a federal health insurance program for individuals 65 or over. It may also be available to individuals who have been deemed “disabled” by the Social Security Administration for two years. There are four components to Medicare. It’s important to know what coverage is provided in each component to receive the best care.

Part A covers certain inpatient hospitalization, hospice care and limited home care services. When an individual becomes eligible for Medicare, Part A is typically available with no monthly cost. If you have paid Medicare taxes while working, Part A doesn’t require any premium.

Part B covers outpatient services like doctor's visits and preventive services. Part B includes a deductible that may change year to year.

Part C (also known as Medicare Advantage) offers private health plans and can be useful for those looking for all-in-one medical and drug coverage. However, some Medicare Advantage HMOs restrict which doctors and hospitals you can use. These plans must offer at least the same benefits as other parts of Medicare that are available but have different rules, costs and coverage restrictions.

Part D (also known as Medicare Prescription Drug Plan) covers outpatient prescription drugs.

Even with Medicare A and B there are still "gaps" in coverage. Most people with health insurance through Medicare choose to purchase a Medicare Supplement plan, available from many insurance companies or through an insurance broker.

For more information, visit [medicare.gov](https://www.medicare.gov).

Medicaid

Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. Medicaid is administered by states in accordance with federal requirements. The program is funded jointly by states and the federal government.

For more information, visit [medicaid.gov](https://www.medicicaid.gov).

Additionally, Social Security Disability Insurance or Supplemental Security Income may be able to help with the cost of health insurance. For eligibility requirements, call 800-772-1213 or visit www.socialsecurity.gov/disability/.

Resources

CancerCare®

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

American Cancer Society

800-227-2345
www.cancer.org

Cancer.Net

Patient information from
the American Society of
Clinical Oncology
888-651-3038
www.cancer.net

CAREGIVER RESOURCES

Family Caregiver Alliance

888-445-8106
www.caregiver.org

My Cancer Circle

www.mycancercircle.net

Well Spouse Association

800-838-0879
www.wellspouse.org

Cancer Support Community

888-793-9355
www.cancersupportcommunity.org

National Cancer Institute

800-422-6237
www.cancer.gov

Medicine Assistance Tool

888-477-2669
www.medicineassistancetool.org

GOVERNMENT WEBSITES

For information about Medicare:

www.medicare.gov

For information about Medicaid:

www.medicaid.gov

CLINICAL TRIALS WEBSITES

EmergingMed

www.emergingmed.com

National Cancer Institute

www.cancer.gov

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