

ASCO[®]answers

Caring for a Loved One With Cancer



**Trusted Information About Caregiving From the
American Society of Clinical Oncology**

Cancer.Net[®]

ASCO | KNOWLEDGE CONQUERS CANCER

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Founded in 1964, the American Society of Clinical Oncology, Inc. (ASCO®) is committed to the principle that knowledge conquers cancer. Together with the Association for Clinical Oncology, ASCO® represents nearly 45,000 oncology professionals who care for people living with cancer. Through research, education, and promotion of the highest-quality and equitable patient care, ASCO works to conquer cancer and create a world where cancer is prevented or cured, and every survivor is healthy.

ASCO furthers its mission through Cancer.Net and Conquer Cancer, the ASCO Foundation.

Cancer.Net (www.cancer.net), brings the expertise and resources of ASCO to people living with cancer and those who care for and about them. All the information and content on Cancer.Net is developed and approved by members of ASCO, making Cancer.Net an up-to-date and trusted resource for cancer information.

Conquer Cancer, the ASCO Foundation (www.conquer.org), funds research for every cancer, every patient, everywhere. As ASCO's foundation, Conquer Cancer supports groundbreaking research and education so both doctors and patients have the resources they need.

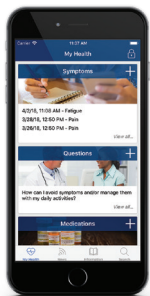
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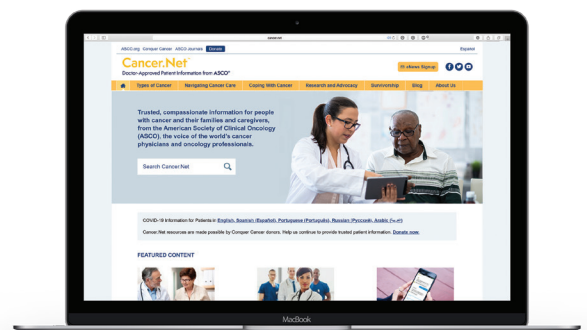
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ASCO ANSWERS is a collection of oncologist-approved patient education materials developed by ASCO for people with cancer and their caregivers.

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Introduction

When someone you care about is diagnosed with cancer, life can change quickly and in many ways. For some family members and friends, this means taking on more tasks and responsibilities to help their loved one. We use the terms “caregiver” or “care partner” to refer to relatives and friends who take on this important supportive role.

Caregivers are an important part of the team of people who support and care for a person with cancer. This network can include family, friends, volunteers, and health care professionals. There is no single “right” way to be a caregiver. Each situation is different. And, as the disease and treatment changes, so does the caregiver’s role.



Many people do not have much warning or preparation before they become a caregiver to a loved one with cancer. This *ASCO Answers* guide is designed to help caregivers learn more about their role and provide support. Throughout this booklet, you will find practical tips for supporting someone with cancer, as well as advice for communicating with your family and the health care team. There are also workbook pages at the end of this guide to help you keep track of important information, like appointments, medication schedules, and household chores.

Caring for a person with cancer can be physically and emotionally demanding. At the same time, it can also be a meaningful, comforting, and fulfilling experience. By being organized and taking care of yourself, you can make sure you are able to fill this role for as long as you are needed.

Caregiving Basics

Caregivers provide important physical, practical, and emotional support to a person with cancer. For some, this may mean providing 24-hour care. For others, it may mean researching medical information, arranging for help, or running specific errands. No single description applies to all situations with people with cancer and their families.

Types of caregivers

There are a number of different caregiving roles that a spouse, family member, friend, or neighbor may fill, including:

Live-in caregiver. One person takes the lead as the primary caregiver. This usually is a spouse or partner, but it may be a nearby friend or neighbor. According to the Family Caregiver Alliance, most caregivers live within 20 minutes of the person they care for.

Shared responsibility caregivers. Some caregivers divide responsibilities within a group of friends and family. Each member of this caregiving team has different skills, and these strengths are combined to provide effective care.

Long-distance caregiver. Sometimes, a family member or friend who does not live near the person with cancer becomes the primary caregiver. A long-distance caregiver often coordinates tasks and services by phone, text, or email. This person may arrange for others who live nearby to help the person with cancer on a day-to-day basis. For example, a grown son or daughter who lives 3,000 miles away may help by taking care of insurance, bookkeeping, or setting up a family website to exchange information and keep everyone updated. They might arrange for friends who live nearby to drive their parent to and from their medical appointments or grocery shopping.

TIPS FOR CAREGIVING

1. Remember that caregiving is a team effort involving a group of people.
2. Be proactive, organized, and plan as much as possible.
3. Be a problem solver—identify problems, find out what is needed, and follow through.
4. Recognize your personal strengths and weaknesses.
5. Ask for help when you need it.
6. Communicate openly and honestly.
7. Talk about your concerns.
8. Seek out information and guidance.
9. Remember to take care of yourself.
10. Realize that you aren't expected to do it all yourself.

Caregiving tasks

Caregivers have a range of responsibilities that they may perform on a daily or as-needed basis. These tasks may change throughout the person's illness and recovery. Some of the responsibilities caregivers may take on include:

Daily tasks:

- ▶ Assisting with toileting, bathing, and dressing
- ▶ Giving medications
- ▶ Assisting with meals, grocery shopping, and other errands
- ▶ Helping manage symptoms and side effects
- ▶ Doing household chores
- ▶ Childcare and/or pet care

Practical support:

- ▶ Coordinating medical appointments
- ▶ Driving to and from appointments
- ▶ Talking with the health care team
- ▶ Advocating for the person with cancer
- ▶ Handling insurance and billing issues
- ▶ Filling prescriptions

Emotional support:

- ▶ Listening
- ▶ Providing company and encouragement
- ▶ Keeping friends and family members informed



Determining caregiving needs

A good first step is to talk with the person with cancer about the type of support they need most. If your loved one is still able and wants to continue doing specific tasks, encourage them to do so. This could mean cooking meals, taking the dog for a walk, or paying bills. Helping the person you are caring for keep a sense of independence will make them feel better about asking for and needing assistance. Some caregivers try to help too much or do everything for the person at first. Being flexible and quickly sizing up what's needed in different situations will be very helpful to both of you.

Being able to make choices also helps people with cancer feel more in control of their situation. You may find it helpful to talk with the person's cancer care team about what

caregiving may be needed at different points in the treatment plan. However, be sure to include the person with cancer in discussions and decisions, at the doctor's office and at home. This could be as simple as deciding what to eat for breakfast or which outfit to wear to an appointment. Or, it could be as complex as where to live or whether to join a clinical trial. It is very important for the person with cancer to feel like an active member of their own care team.

Use the **Identifying the Help Needed** worksheet at the end of this guide to help determine their caregiving needs.



To learn more about being a caregiver, visit www.cancer.net/caregiving.

COMMUNICATING THE PATIENT'S STORY TO OTHERS

Family and friends often rely on the primary caregiver for news and updates about how the person with cancer is doing. But, it can feel overwhelming keeping many individuals updated one-by-one about the status of the person you're caring for while also handling caregiving duties and managing your own life. To help, many caregivers use online tools to provide updates while avoiding the need to repeat the same information to different people. These tools allow caregivers to update everyone at once and it keeps your updates in one place, where others can check in on their own schedules. Many also allow visitors to offer their support and well wishes, which may be appreciated by you and the person you're caring for.

Some ways to share updates include:

- ▶ Create a free website to share updates online, such as CaringBridge, Lotsa Helping Hands, or MyLifeLine (see page 32).
- ▶ Send messages using an email or text list.
- ▶ Record a message on your phone's voicemail or answering machine when you have updates. Then, people can call and listen to the latest update.
- ▶ Start an invitation-only (or "closed") group on a social media platform.

Remember to think about the privacy of the person you're caring for before you decide to share medical updates. Emails may be forwarded or read by others when left open. It is easy to access many websites or to simply call a phone number. Because the information you're making available to lots of people is sensitive and personal, it is important to have a discussion with the person you're caring for about your plans before starting a website, social media group, email newsletter, or phone recording.

Caregiving at Home

People with cancer now spend much less time in the hospital than they did in the past. For instance, many people receive treatment at an outpatient treatment center or take cancer medications at home. This means that family members and friends play a large role in the day-to-day care of a person with cancer. Family caregivers are doing things that, until recently, were done by trained health care professionals. This may include bandaging and wound care, help with catheters, giving medications, watching for symptoms and side effects and reporting them to the health care team, and other tasks.

This section describes a few of the responsibilities you may need to take on. However, it is not a complete list. If you have any questions or concerns, talk with a member of the health care team. You are all working together to provide the best possible care for your loved one.

Family members and friends play a large role in the day-to-day care of a person with cancer.

Going to appointments

Throughout treatment, someone with cancer may need to go to the hospital or clinic several times during the week. Unfortunately, cancer treatment may have very unpleasant and distressing side effects. Treatments like chemotherapy can cause weakness, pain, fatigue, nausea, hair loss, and difficulty concentrating. Treatment may also affect a person's ability to be self-sufficient and independent. Because of this, caregivers may need to provide transportation to and from the hospital, clinic, or doctor's office, in addition to providing support during appointments and treatment sessions.

A little planning can help make these appointments much easier. Here are a few things to know before leaving the house:

- ▶ Where is the office located? What is the building address? Which floor is the office on? What is the room or suite number?
- ▶ Where should you park? Will you have to pay for parking?
- ▶ Which entrance to the building should you use?
- ▶ How far will you need to walk?
- ▶ Will a wheelchair or assistance at the door be needed?
- ▶ How long will this visit likely last?

If you are unable to take your loved one to an appointment, there are other transportation options to consider:

- ▶ Other family, friends, or neighbors
- ▶ Members of religious or community organizations the person with cancer belongs to
- ▶ Volunteer driver programs through a church or hospital
- ▶ Hospital vans
- ▶ Other caregiving families that might help carpool
- ▶ Private door-to-door transportation services, such as ride-sharing apps
- ▶ Paratransit, which is public transportation for older adults and people with a disability

If possible, schedule transportation assistance at least one week in advance. Then, confirm the date and time the day before the appointment. Talk with an oncology social worker or patient navigator if you need help arranging transportation to and from appointments.

The **Appointment Information Sheet** at the end of this guide can be helpful for recording details before and after each visit.

Talking with the doctor

Some people with cancer like to have their caregiver's support when they talk with the doctor. This could mean:

Making a list of questions before an appointment. Sit down with the person with cancer at home and think about the most important issues or concerns you'd like to discuss with the doctor. And, keep a notepad handy to jot down questions as you think of them. These questions should reflect the doubts, concerns, and issues of all family members. Before each appointment, rank the questions in order of importance. At the beginning of the appointment, make sure to tell the doctor that you would like to have time to ask 2 or 3 questions.

MAKING A TRAVEL BAG

Having a travel bag packed and ready to go before each appointment can be helpful. That way, no matter who is taking the person with cancer to an appointment, they will have everything that's needed. Keep the bag in the same location, and let each driver know where it is located.

Items to include in a travel bag:

- Office address and directions
- Medication list (see page 38)
- Insurance cards
- Identification
- Small amount of money
- House key
- Cellphone
- Emergency contact information
- A healthy snack
- A bottle of water
- Wipes, tissues, or paper towels
- Sweater, sweatshirt, wrap, or blanket
- Book, magazine, tablet, or something else to provide entertainment
- Notebook and pen or another way to record information

Providing new details. Information about symptoms and side effects or other things you've noticed can help the doctor make more informed decisions about your loved one's care.

Keeping track of information. You can help listen to and remember the information given by the health care team at appointments. You may want to take notes or record important conversations. Or, ask for a printed summary of the visit or available test results before leaving the doctor's office.

It is normal to want to protect friends and family members by limiting which information from appointments you share with others. This may not be helpful and may actually cause more hurt and anxiety. It is better to be open and share the worry than to worry alone. However, always make sure you have permission from the person with cancer before sharing any personal medical information with others.

Managing symptoms and side effects

Cancer and cancer treatment often cause symptoms and side effects. Often people with cancer hesitate to talk about these issues, but it is important to talk openly and honestly about what is happening during treatment. Preventing and controlling side effects is a major focus of the health care team, but they can't help if they don't know something is wrong.

As a caregiver, one of the most important things you can do during treatment is to talk honestly and regularly with the person with cancer and the health care team about symptoms and side effects. This will help the team provide relief while still providing effective cancer care. Remember that the health care team will work to make each day the best day possible for your loved one.

Tracking details of side effects at home will provide helpful information to the health care team, such as when a side effect occurred and how severe it was. You can use the **Tracking Symptoms** chart at the end of this guide to help keep track of and discuss symptoms and side effects. You may want to send this information to a member of the health care team through email or text. This can speed up communication and help avoid unnecessary worry or trips to the emergency room.

TRACKING SYMPTOMS WITH A MOBILE APP

You can also easily keep track of symptoms using the free Cancer.Net Mobile app. It is available for both Android and iOS (iPhone, iPad).

Visit www.cancer.net/app to learn more.

When to call the doctor

Some side effects require immediate medical attention. Caregivers should always ask how to reach a member of the health care team at any time. This includes a phone number to call after hours, on weekends, and during holidays. In an emergency, you may need to call 911 or the emergency services number in your area.

But when should you call the doctor? This is an important question to ask a member of the health care team. The doctor, nurse, or another health care provider can tell you the possible side effects that may occur and explain when you should call for help.



If you do need to call the doctor, it is important to tell them exactly what is happening. Be specific.

- ▶ What symptom(s) or side effect(s) is your loved one experiencing?
- ▶ How often?
- ▶ How long has it been going on?
- ▶ Does anything make it better or worse?
- ▶ How severe is it on a scale of 0–10 (where 0 = no symptom and 10 = worst imaginable)?
- ▶ Is it getting in the way of daily activities?
- ▶ What should you do?

Number to call after hours or on weekends:



For more information about managing specific side effects, visit www.cancer.net/sideeffects.

■ Giving medications

Your loved one may have to take many different medications at home. These include medicines to treat the cancer as well as medicines to help relieve symptoms or side effects of treatment. To make sure the person with cancer gets the most benefit, it is important that they take each medication exactly as instructed.

Following these instructions can be hard. For instance, some medications may need to be taken with food, while others are best on an empty stomach. Some medications may have to be given in the morning, some at bedtime, some as needed, and some multiple times a day. Some medications may be taken by mouth; others are injected. There can be topical creams, transdermal patches, and more. Certain foods or supplements may need to be avoided due to possible drug interactions, which is an unwanted effect. Ask the nurse or pharmacist if you have any questions about medications. This section provides some tools and strategies to help you manage this caregiving task at home.



■ Keeping track of medications

It is very important to figure out the best way to keep track of all prescribed medications and when they should be taken. Some caregivers make a list, chart, or spreadsheet. Then they post it on the refrigerator or bulletin board so it is easy to find and reference regularly. This is also helpful when someone else comes to help. Bring this list to each doctor's appointment. That way you will be able to update it if a new prescription is added, a current medication is stopped, or a dose changes.

You can use the **Making a Medication List** worksheet at the end of this guide to help keep track of the medications the person with cancer will be taking. You can also use the Cancer.Net Mobile app (www.cancer.net/app) to record medications and to keep track of when it is given.

Talk with the health care team about medications on a regular basis. For example, if your loved one loses weight, they may not need to take blood pressure medications any more. Or, if they are no longer experiencing a side effect, there may not be a need to continue with specific medications. Stopping medications when they're no longer needed can lower costs and reduce the chance of drug interactions and side effects. And it's one less medication to keep up with.

Remembering medications

There are a number of ways to help your loved one remember to take their medications as directed. For example, you can create a calendar or checklist together. Or you may want to suggest setting an alarm or daily phone reminder at the times when they need to take specific medications.

Some people with cancer find it helpful to organize (or have someone else organize) their medications on a weekly basis. For medications that are taken by mouth, you can buy a pill organizer with different slots for morning, noon, evening, and bedtime. This can save time and make it easier to keep track of whether medications have been taken.

However, always keep the original medication container for reference. And be sure to store medications as directed. For example, some cancer medications need to be refrigerated, while others need to be kept out of the light.



Safe storage of pain medications

Pain is a common side effect of cancer and cancer treatment. As a result, managing and treating pain is an important part of a person's overall cancer treatment plan. If the pain is an ongoing problem or doesn't get better, consider asking to talk with a palliative care doctor for help. If the person with cancer is experiencing moderate or severe pain, the doctor may prescribe opioids, also known as narcotics.

Opioids are effective at relieving cancer pain. However, they are dangerous if they are accidentally swallowed by a family member or pet. In addition, people who abuse drugs may seek them out. Therefore, it is important to take steps to safely and securely store opioid pain medication. These include:

- ▶ Always store pain medication in a bottle that has a child-resistant lid.
- ▶ Keep all opioids in one location where a pet, child, teenager, or stranger would not easily find them. Do not store pain medication in many different places around the house or leave it sitting out.
- ▶ Talk with the doctor about whether you should keep pain medication in a secure lockbox that only you and the person with cancer have access to.
- ▶ Make sure used fentanyl skin patches are kept away from others. After a patch is used up, fold it in half so the sticky parts seal themselves and then safely dispose of it.
- ▶ Only share details about prescription(s) with others who need to know.

Handling insurance and bills

A cancer diagnosis can be expensive. In addition to treatment costs, many people find they have extra, unplanned expenses related to their care, such as transportation costs, lost wages, childcare, and drug co-pays. Even with health insurance, these costs can add up and become a source of stress and anxiety for people with cancer and their families.

It is important to talk with the person with cancer about their financial situation. Caring for someone with cancer can be financially challenging, both for the patient and the caregiver. Discuss who will perform which medical services, the patient's insurance coverage for those services, and how specific things like co-pays for medications or therapy will be paid. Knowing this information can help guide future health care choices.

Tracking costs

The financial side of cancer care comes with a lot of paperwork. Your loved one may ask you to help keep track of it all. They may also need help figuring out what's covered by insurance and what the deductibles and co-pays are. It is a good plan to set up a system for tracking costs and regularly update the information to keep it current. The following suggestions may help as you start to track medical costs and set up your own organizational system.

Keep important paperwork on file. It's a good idea to keep medical bills, Explanation of Benefits reports from the insurance company, pharmacy receipts, and other receipts for health care expenses all in one place. File new information as soon as possible so it doesn't get misplaced.



Get permission to talk with the insurance company.

The person with cancer may ask you to talk with their insurance company if there are problems. But first, they may need to give permission for the insurance company to talk with you about their coverage.

Ask for an insurance case manager. Many insurance companies will assign a person to help manage insurance concerns for a person with a serious illness. This way, you can talk with the same person each time you need to call. This person can help you learn what is covered by insurance, how to handle insurance issues, and help you find home care.

Take good notes. Keep a written record of all conversations you have with any insurance company representatives, including the date, name of the person you spoke with, and what was said. Put the newest records at the front of your file so you have a clear and current list of these discussions.

Keep track of all unreimbursed medical expenses. This information may include the dates of each service, the amount paid, and the name of the provider. A person with cancer may be able to claim these expenses for tax purposes. A tax professional can provide advice on current rules and eligible expenses.

Ask for help. Local agencies may be able to help you and your loved one manage financial issues related to cancer treatment. Ask your health care team about local resources.



For more information about managing the cost of cancer care, visit www.cancer.net/managingcostofcare.

Caregiving at a Medical Facility

Seeing someone you care for in the hospital, rehabilitation center, assisted living facility, or other medical facility can bring many emotions. In addition to compassion and concern, you may experience stress, anxiety, or guilt. This mixture of conflicting emotions is common and completely normal. By being prepared and organized, you will be able to better manage this difficult situation and make sure your loved one receives the best possible care during their stay at a medical facility.

Working with the health care team

As a caregiver, you are an important part of the health care team. When the person you care for is in the hospital or other medical center, one of your main roles is to be their advocate. This means asking questions and helping make decisions about their care. Research shows that patients and caregivers who are more involved with their care tend to have better results.

Patients and caregivers who are more involved with their care tend to have better results.

Find out who is part of the health care team. Cancer care usually involves several health care professionals, and it is important to know who is taking care of your loved one. It may take some time and effort to feel like you have a handle on who is in charge. Ask everybody who walks into the room to provide a card or write their name on the whiteboard and have them explain their role.

Reach out to the nurses. Get to know the nurses who are caring for your loved one, and let them know you will be the point of contact. Make sure your contact information is listed clearly in the medical record and in the room of the person with cancer. Nurses are excellent sources of information and support who can answer many of your questions. They can also help you understand medical procedures and hospital processes.

Keep a running list of questions. Find out when the doctor plans to visit so you can be there and ask questions. It also helps to write down or record the answers. Many hospital rooms have whiteboards that you and the medical staff can use to write questions or communicate other information. If you don't understand what the doctor is saying, ask them to explain more. It's okay to speak up.



Meet with a hospital social worker or case manager. A social worker or case manager can help with insurance issues, finding financial support, arranging transportation, and coordinating care between several doctors. They can also provide emotional support and information about local caregiving resources. At the end of a hospital stay, they often help with planning issues, such as follow-up care.

■ Making medical decisions

People with cancer often ask family members for their opinions before making treatment decisions. Sometimes, family members may disagree with each other and with the person with cancer about the best choice. This can create conflict at a time when you need each other's support the most.

If a loved one asks you to help choose a treatment, keep in mind these questions:

- ▶ Do they understand the risks of treatment and the potential outcomes of their choices?
- ▶ Have they openly stated their wishes? Are other caregivers respecting these wishes?
- ▶ Is this treatment consistent with their beliefs and values?

Always consider the patient's viewpoint first. They have the right to be heard and the right to change their mind. Your loved one also has the right to state their wishes in advance and have them respected when the time comes.

Remember, your loved one has asked for your help because they respect your opinion. However, they may make a choice that is different from what you might choose for

yourself. It is important, even when conflict occurs, to keep talking with each other and support their decisions.

As the treatment plan begins, consider having open conversations with them, either one-on-one or with important family members. Discuss what each person would want at the end of life. Remember, this conversation starts at home. Be open to the fact that everyone can change their mind, but having this discussion early may be helpful for avoiding conflict in the future.

Some of the hardest decisions are those made in the final weeks or months of life. During this time, it may be difficult but it is important to talk openly about your loved one's treatment priorities. It may be helpful to ask the oncologist for a prognosis. If a specific prognosis cannot be given, consider asking if the doctor would be surprised if the end of life occurred in the next six months. Your loved one may want to live as long as possible, regardless of how hard treatment is. Or they may wish to maintain a specific quality of life, even if that means stopping treatment. These topics can be hard for you, the person with cancer, and your family to talk about. If so, ask a doctor, nurse, clergy member, social worker, palliative care specialist, or counselor to lead the discussion.

■ Being a health care proxy

There may come a time when the person you are caring for is unable to make medical decisions on their own. Examples include falling into a coma or having a heart attack or stroke. If this happens, a health care proxy or medical power-of-attorney gives a trusted family member or friend the power to talk with the doctors and participate in making medical decisions, either temporarily or permanently.

If you have been made a health care proxy, knowing the types of treatments the person with cancer does and does not want will reassure you that you are making the best choices. Sometimes the person you are caring for may have put these wishes in writing using forms called advance directives. Advance directives are legally binding instructions that define someone's preferences for life-sustaining medical care. Advance directives include documents such as a living will or Physician Orders for Life-Sustaining Treatment (POLST) form. These forms have different names in different states, and forms can be different depending on where you live. Be sure to check with the health care team to decide which forms to use.

As a caregiver, following an advance directive is one of the most important things you can do. Even if you don't agree with all of their decisions, people with cancer need to know you will respect their wishes.

WHAT MAKES A HEALTH CARE PROXY EFFECTIVE?

The American Bar Association recommends that the person serving as health care proxy should have all of the following traits:

- ▶ Is older than 18 and meets any other legal criteria in the patient's state for acting as a health care proxy
- ▶ Is someone the patient trusts with their life
- ▶ Is willing to speak on the patient's behalf and separate their own personal feelings from the patient's wishes
- ▶ Lives close by or could travel to be at the patient's side if needed
- ▶ Knows the patient well and understands what that person feels is important or values
- ▶ Will talk about sensitive issues now and will listen to the patient's wishes
- ▶ Is available to fulfill this role for the foreseeable future
- ▶ Is able to handle any conflict of opinion that may develop between family members, friends, and medical personnel
- ▶ Will advocate strongly for the patient in the face of any obstacle



To learn more about advance directives, visit www.cancer.net/advancedirectives.

Caregiving from a Distance

If you live more than an hour away from the person you are caring for, you are said to be “caring from a distance.” Being a long-distance caregiver can be challenging, both emotionally and practically, but it is not impossible. There are still a number of ways you can help and stay informed.

Tasks and responsibilities

A long-distance caregiver often does many of the same tasks as a caregiver who lives nearby. However, the way you go about fulfilling these roles may be different.

Be a part of the health care team. Because you will not be able to go to every appointment or treatment session, make a point to introduce yourself to the health care team when you are in town. Give them your phone number(s) and other contact information in case they need to reach you. You may need to sign a release or have your loved one’s permission to discuss their medical condition and treatments.

Get organized. Collect and sort medical, financial, and legal information. Make sure the correct legal documents, such as advance directives, are completed and on file wherever cancer care is given.



Recruit and organize local volunteers. Family, neighbors, friends, and members of religious, civic, and social organizations who live nearby may want to help with caregiving tasks. There are resources online where you can list specific tasks a person with cancer needs help with. Through these sites, family and friends can volunteer and coordinate tasks. This is also an easy way to update a large group of people about your loved one's status. The **Caregiving Support and Resources** section in this guide has information about some options to help you. You can use the **Caregiving Action Plan** worksheet at the end of this guide to help you coordinate tasks and keep track of which roles people are filling.

Explore professional services. Contact the health care team, social worker, or state or local health department for referrals for reliable home care services. Home care services can range from providing basic medical care to assisting with household tasks, meals, and personal care. There is a list of organizations and resources you may find useful on page 32. Talk with the insurance company about which home care services are covered as part of their policy. Ask friends and family who have been in this situation before if they can recommend a home health aide or home care nurse.

Put an emergency plan in place. Make sure your loved one's phone has important numbers on speed dial, including 911; yourself; other family, friends, and support people; health care providers; and neighbors.

Prepare for unplanned travel. Be prepared to travel if the person with cancer needs your help. Try setting aside vacation or sick days from work and study the travel options that will work for you on short notice. Enlist a friend or neighbor to pick up mail, water plants, or care for your home in case you need to leave suddenly. You can also arrange for someone to help care for your own family while you are away. Research places that may be able to provide pet care on short notice, if needed.

Find emotional support. Many long-distance caregivers feel guilty about living far away from the person with cancer. Or they may feel overwhelmed by the challenges of coordinating care from afar. Seek out support for yourself from family, friends, or a counselor to help deal with stress and emotional struggles. Many hospitals and advocacy groups host support groups for caregivers. Twitter chats or Facebook groups are also good ways to connect with others who are in a similar situation.

Making the most of visits

When visiting the person with cancer, plan ahead and use the time wisely. The following suggestions can help you make the most of a visit.

Meet with a member of the medical team. Set up an appointment with the health care team to discuss any medical issues and the general care plan. Before the trip, prepare a list of questions for the health care team. It is important to include the person with cancer and the primary local caregiver in these discussions, if possible.

Meet with your loved one's support network. Arrange to meet with friends, neighbors, and members of community organizations who are helping provide care. Ask if they have any concerns or suggestions for ways to improve care. Try to keep an open mind about what they say or suggest. Also, ask that they contact you right away if they notice any problems.

Schedule a break for local caregivers.

If possible, plan to take over some of the local caregivers' tasks. This provides local caregivers with a break. It also gives you the chance to reassess the caregiving needs and resources first hand. Observe their condition and the condition of the surroundings. Is there food in the refrigerator? Is the house clean? Is the person bathed and groomed? Spend time talking with your loved one about the care they are receiving. Ask if there is anything you can do from afar once you leave and return home.



Take time to reconnect. Schedule quality time with the person you are caring for. Think about activities you enjoy doing together that will take both of your minds off cancer. This could be as simple as watching a favorite movie, going outside, or sharing a meal together.



To learn more about talking with someone with cancer, visit www.cancer.net/talkingaboutcancer.

Taking Care of Yourself

One of the most important—but often neglected—tasks for caregivers is caring for themselves. Many caregivers believe their time and energy is better spent helping their loved one and their personal needs aren't important right now. However, a caregiver's physical, emotional, and mental health is vital to the well-being of the person with cancer. To be a good caregiver, you need to take care of yourself.

To continue to be a good caregiver, you need to take care of your physical, emotional, and mental health.

Coping with stress

Caregiving is a stressful experience. At times, you may feel like everything is on your shoulders or that no matter what you do, it's not enough. This may lead to:

- ▶ Feeling exhausted all of the time
- ▶ Getting sick more often than usual
- ▶ Not sleeping enough
- ▶ Feeling impatient, irritated, or forgetful
- ▶ Not enjoying things you used to like
- ▶ Withdrawing from people

Recognizing signs of overload is important to do. There are many things you can do to make the situation better. The **My Stress Management Plan** worksheet at the end of this guide can help you identify sources of stress and find ways to manage it.

Set boundaries. Setting limits helps you and the person you care for. This may mean asking for help from others so you can take a break. This is called respite care. It is also important to say “no” when someone asks you to do something you don't want to do or don't have the energy for.

Ask for help. Make a list of people who the person with cancer trusts and can help with specific caregiving tasks. Family, friends, members of religious groups, and people in community groups are often willing to assist. Many people want to help but aren't sure you want or need it. You can also hire professional caregivers or people to help with chores, errands, or childcare, if finances allow, to free up some of your time.

Find support. Feeling angry, guilty, alone, afraid, and/or sad is common for caregivers. Talking with other people who are caring for a family member or friend with cancer can help you cope. Ask an oncology social worker to connect you with local resources, such as support groups. Or, use the list of resources on page 32 to find a national or online group.

Make time for yourself and other relationships. Doing something you enjoy gives you a much-needed break. Spend time with other people who are important to you, even if in shorter periods than usual. Maintaining supportive relationships is important for your continued health and well-being.



Keep yourself healthy. Taking care of your body is important to make sure you are able to provide the best possible care. This means making time to exercise, eat healthy foods, and stay hydrated.

Get enough sleep. Caregivers often have trouble sleeping. You may be getting up during the night to help your loved one. You may be staying up late to get things done. Or, your thoughts and emotions may keep you awake. Feeling rested will help you stay at your best, so try to go to bed and get up at the same time every day. Also, ask friends and family to avoid calling when you're usually asleep unless it is an emergency.

Be mindful of alcohol and other substances. Some caregivers turn to alcohol and other substances to help deal with the stress, anxiety, fatigue, sleep problems, and fear they are experiencing. The line between use and abuse is not always clear. In general, limit the number of alcoholic beverages you drink to one drink a day for women and two drinks a day for men. Remember, one drink is 12 ounces (oz) of beer, 5 oz of wine, or 1.5 oz of 80-proof distilled spirits (liquor).

Other tips that can help. Also consider the following ideas:

- ▶ Making a list of priorities for each day that sets out realistic goals
- ▶ Listening to soothing or uplifting music
- ▶ Practicing relaxation techniques, such as meditation or yoga
- ▶ Going outside regularly for fresh air and sunlight
- ▶ Keeping a journal to write down your personal thoughts and experiences

Balancing work and caregiving

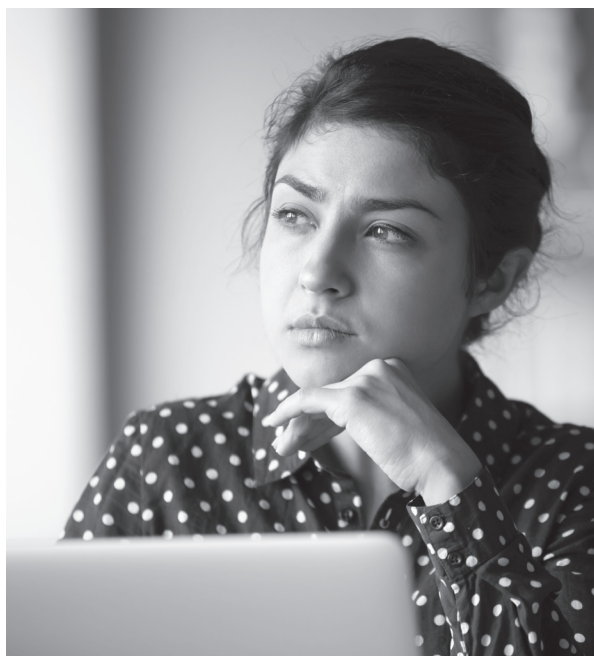
Caregiving can be a full-time need, especially during diagnosis and treatment and near the end of life. However, many caregivers also have jobs. This can cause work-related issues like missed days, decreased productivity, and potential job discrimination.

For people with certain types of jobs, such as hourly workers, temporary employees, and the self-employed, it can be very difficult to balance work and caregiving. For people with salaried positions in larger companies, there are certain legal protections and benefits to help you take time off for caregiving and still keep your job.

Family and Medical Leave Act

The Family and Medical Leave Act (FMLA) is a federal law that guarantees up to 12 weeks of time off per year to take care of a seriously ill family member. While taking leave, an employee's job and their employer-sponsored health insurance are protected.

Although the FMLA helps caregivers balance job responsibilities and time spent caregiving, people are only able to take time off if they are caring for a spouse, parent, or child. The law doesn't include caregivers of parents-in-law, grandparents, siblings, aunts, or uncles. It also only applies to larger companies, and not every employee qualifies for it.



Some states have a state law that is similar to the FMLA. A few states allow a greater range of people who can be cared for and some cover smaller employers.

Other options for taking time off

If you don't qualify for FMLA benefits, your employer may still be able to help. Explain your situation to your supervisor or human resources (HR) department. Ask if you can adjust your schedule to allow you to do caregiving tasks, like go to appointments or treatment sessions, without taking leave from your job. Some employers are flexible in these situations.

Some companies may allow you to use paid leave time if you are caring for a spouse or close relative. You may be able to work half-days or split shifts, or take one day a week off for appointments. You'll need to plan ahead and be ready to clearly communicate and regularly balance what you can keep doing and how much extra time off you'll need.

Financial help

If you are taking time off work, you will probably need to find a way to replace your lost wages. Disability insurance is often an option for people with cancer but not for caregivers. However, as of 2019, California, New Jersey, New York, and Rhode Island offer state-paid leave programs for some caregivers. Connecticut, the District of Columbia, Maine, Massachusetts, Oregon, and Washington also have similar programs that are in the process of being put into effect.

In addition, some state-run Medicaid programs cover some in-home assistance for people with cancer. These programs help the person with daily tasks of living, such as getting dressed and cooking. Many states have specific Medicaid programs that pay an individual's family member to provide this in-home assistance. You can find out whether your state has a program by contacting your local Medicaid office, social services, or health department. These used to be called Cash and Counseling programs.

Resolving family conflicts

Caring for a person with cancer often brings families together, with members supporting one another. However, the pressures of cancer and caregiving may also reignite old family conflicts or create new ones. These conflicts can make it difficult for family members to work together.

Families that express their feelings in healthy ways and work together can resolve caregiving conflicts more easily. Families in which members solve problems alone and tend to disagree might have more difficulty coping. It is important for families to recognize and discuss how they react to stressful situations.



Although resolving family conflicts can be challenging and uncomfortable, it is important to address issues quickly. This allows the family to focus their time and energy on providing the best possible care to the person with cancer. Each family member should consider whether it is more important to be right or to provide support.

The following suggestions can help families work together to become a supportive network for the patient and each other.

- ▶ Expect and accept differences of opinion and coping styles.
- ▶ Involve the person with cancer, if possible. They should always be a central part of all care-related discussions and actions.
- ▶ Don't be afraid to ask for help with caregiving responsibilities, and learn how to graciously accept help that is offered.
- ▶ Appreciate family members who are trying to help, even if the help is not exactly what you need.
- ▶ Recognize that some family members will not change or put aside their feelings or behaviors, even during this difficult time.
- ▶ Be realistic in dividing caregiving tasks. Allow family members to help in the ways they are able. Divide tasks according to each person's abilities, lifestyle, and schedule.
- ▶ Caregiving tasks can vary, even day to day. Encourage family members to remain flexible and pitch in when others need extra help.
- ▶ Get outside help from friends, the local community, and volunteer organizations.
- ▶ Be an example to others in the family by taking care of yourself physically and emotionally.
- ▶ Use online tools to schedule tasks and communicate information. That way, everyone can easily get the latest information, no matter where they are.
- ▶ Keep in mind that you are all working towards the same goal—helping the person with cancer—and that there are different ways to achieve this goal.
- ▶ With your loved one's permission, share their end-of-life wishes and decisions with other family members, acknowledging that this is a personal, individual decision and not everyone might agree with it.

It may be helpful to hold regularly scheduled family meetings. This is a time to encourage everyone to discuss issues and concerns. Those who cannot attend in person may want to join by phone or video conferencing. During these meetings, everyone should respectfully listen to others and express their opinions when necessary.

Managing family life

Your everyday life and family responsibilities don't go away when you are caring for someone with cancer. The kids will still need to be picked up from practice, the grandkids will still want to come over for dinner, and your spouse will still want to talk about a bad day at work. Maintaining your usual schedule and relationships can be both comforting and difficult during this time.

Communicating with your partner or spouse

If you are feeling more stress than usual in your relationship, you are not alone. Having to make so many decisions and being pulled in so many directions can be hard. Some of the most common things couples feel stressed about when one becomes a caregiver are:

- ▶ How to support each other
- ▶ Changing roles and routines
- ▶ Less time together
- ▶ Financial issues
- ▶ Managing daily life, such as work, chores, and childcare

Every couple handles stress in a different way. Try to be open and honest with your spouse or partner about the way you are feeling. You may also want to:

- ▶ Share how you both are coping
- ▶ Look at things that are causing you both stress
- ▶ Discuss ways you can support each other
- ▶ Talk about choices and changes you can make
- ▶ Make time to focus on things besides cancer
- ▶ Talk about your hopes and plans for the future
- ▶ Talk with a counselor or find a support group

Facing these issues together can sometimes make your relationship stronger. But staying close through this stressful time requires open communication, patience, and understanding.



Parenting while caregiving

Juggling your responsibilities as a parent and a caregiver may be an ongoing balancing act. To reduce burnout, it is important to simplify your routine, stay organized, and ask for help. You will also feel better if you create a safe and trusted environment for your children while you care for someone with cancer.



Here are a few tips:

- ▶ Give your children age-appropriate explanations about what you are doing and why you are doing it. Reassure them that nothing they did caused the cancer. Ask if they have heard anything about cancer that they don't understand and encourage them to ask questions.
- ▶ Explain that it is normal for people with a family member who has cancer to be worried and sad sometimes. Encourage them to express their feelings in ways they find helpful. This may be by talking with someone, writing a story, drawing a picture, or playing with toys.
- ▶ Maintain a regular schedule and routine as often as possible. Most children find comfort in structure.
- ▶ Plan ahead for any emergencies, including backup plans for childcare, and tell your children about these plans in advance. For example, say, "Aunt Susan will stay with you at our house if I need to take care of Grandma." Or, "Mrs. Jones will pick you up from school when I take Uncle Joe to the doctor."
- ▶ Tell your children's daycare or school and their friends' parents about your family member's illness, providing updates when necessary. Consider sending a text or email so that adults who interact with your children will have consistent, accurate information.
- ▶ Enlist the help of neighborhood or school-based parent groups. These groups can help with carpooling, childcare, and afterschool activities.

Despite the challenges, it may help to remember that parenting and being a caregiver helps show your children how family members love and care for each other.



For more information about taking care of yourself, visit www.cancer.net/caringforcaregiver.

Exploring Other Caregiving Options

Caring for someone with cancer often takes a lot of time and causes many changes in people's everyday lives. Many caregivers and families realize they can't do it all on their own. If you feel like you have too much to cope with, consider exploring other caregiving options.

Asking for help is a sign of strength, not weakness. By seeking assistance, you can help both the person you are caring for and yourself. The person you care for will continue to receive good care. And you will be able to focus on the things that you do best to provide support.

Asking for help is a sign of strength, not weakness.

Professional home care services

One option to consider is a professional home care service. These organizations send medical or nonmedical professionals to help provide high-quality care and/or help manage other caregiving tasks.

Health care professionals typically help with medical responsibilities that families are not able to perform or are uncomfortable doing.

Medical professionals who may provide home care include:

Registered oncology nurse. An oncology nurse can provide wound care, give chemotherapy, help with nutrition concerns, and manage pain.

Physical therapist. A physical therapist can treat conditions or injuries that affect a person's ability to move.

Occupational therapist. An occupational therapist teaches people ways to do daily tasks that are more difficult after an illness or injury, so they can live more independently.

Hospice care provider. A hospice care provider offers physical, emotional, social, and spiritual support for people living with advanced cancer and their families.

Home care is most often provided by nonmedical professionals, such as:

Home health aide/home care aide. A home health aide helps with daily tasks, such as bathing, dressing, using the toilet, cooking, cleaning, and running errands. Some home health aides are specially trained to provide more complex services. These services may include wound or ostomy care. An ostomy is a surgically created opening for getting rid of body waste.

Personal attendant. A personal attendant provides personal care services and performs light household tasks, such as cooking, laundry, and basic cleaning.

Companion. A companion offers comfort and companionship to people who cannot leave the home or stay at home alone. Some companions perform limited household tasks, such as preparing lunch. A companion may stay with the person to give family caregivers a break. Companions are often volunteers, but some receive payment from the person with cancer or their family.

Home care personnel can be hired through home care agencies, homemaker and home care aide agencies, home care registries, or independent providers. Talk with the health care team to find out what type of home care services are needed. An oncology social worker or nurse will be able to provide information on local home care resources and tell you where to find these services.

Choosing a home care service

It is important to feel comfortable with the person you are bringing into your home. Consider asking potential providers the following questions:

- ▶ How long have you been in business?
- ▶ Are you accredited by a recognized agency?
- ▶ Do you specialize in a specific aspect of home care (such as nutrition)?
- ▶ Do you have references?
- ▶ Do you have experience with people with cancer?
- ▶ How do you handle emergencies?
- ▶ Do you provide a written treatment plan that states the specific tasks that you will perform? Do you notify the family if the plan changes?
- ▶ Are you comfortable giving medications?
- ▶ Will you be able to help with preparing food and meals?
- ▶ Which insurance plans do you accept?
- ▶ What is the billing process?
- ▶ How do you oversee the quality of care a person receives?
- ▶ Who do I contact with questions or complaints?



Paying for home care services

Medicare and Medicaid. These government-run insurance programs usually cover part-time home care provided by skilled medical professionals, such as nurses, doctors, or therapists. A doctor must approve and review the services, and these services must be provided by a Medicare-certified home care agency. The Veterans Administration also pays for some home care services for qualified veterans.

Private insurance companies and health maintenance organizations (HMOs). Insurance companies often cover some short-term home care services, but coverage varies from plan to plan. Many will pay for skilled medical care but not for personal care, such as aide or attendant care. Check with the insurance company before beginning home care services. Some companies may require you to use specific home care agencies or personnel. Private long-term care insurance may also pay for longer-term home care services.

Self-pay. Someone will need to pay for services not covered by an insurance plan. Long-term care provided by an aide, attendant, or companion often needs to be paid for out of pocket. In some instances, you may be responsible for taxes. Talk with your accountant or tax preparer about the tax laws in your area.

Community organizations and state and local governments. These organizations may have programs that help pay for home care services. A list of organizations can be found on page 32.

Community resources

Many communities have a wide range of resources available to support people with cancer and their caregivers. These include:

Case management. Some organizations have trained case managers who help coordinate home care, transportation, and meals. Some case management services may be free for certain people.

Legal aid. Local legal organizations may be able to help with legal documents, such as advance directives and wills.

Financial assistance and counseling. Local agencies may be able to help you and the person with cancer manage financial issues related to cancer treatment.

Food delivery. Some for-profit and nonprofit organizations deliver healthy meals directly to a person's home.

OTHER COMMUNITY RESOURCES



For more information about support services and links to national organizations, visit www.cancer.net/support.

Caregiving Support and Resources

You can find additional information and tips about caregiving and links to caregiver support and resource organizations on ASCO's patient education website at www.cancer.net/caregiving.

The following national organizations also provide resources about caring for someone with cancer, supportive care, end-of-life care, and other topics addressed in this booklet. Because programs and services continually change, visit www.cancer.net/support to find the most current information.

4th Angel Mentoring Program

www.4thangel.org
866-520-3197

Family Caregiver Alliance

www.caregiver.org
800-445-8106

American Cancer Society

www.cancer.org
800-227-2345

Friend for Life Cancer Support Network

www.friend4life.org
866-374-3634

CancerCare

www.cancercare.org
800-813-4673

Imerman Angels

www.imermanangels.org
866-463-7626

Cancer Hope Network

www.cancerhopenetwork.org
877-467-3638

Inspire

www.inspire.com
800-945-0381

Cancer Support Community

www.cancersupportcommunity.org
888-793-9355

Lotsa Helping Hands

www.lotsahelpinghands.com

Caregiver Action Network

www.caregiveraction.org
855-227-3640

MyLifeLine.org

888-793-9355

CaringBridge

www.caringbridge.org
651-789-2300

National Alliance for Caregiving

www.caregiving.org
202-918-1013

National Association for Home Care & Hospice

www.nahc.org
202-547-7424

National Association of Area Agencies on Aging

www.n4a.org
202-872-0888

National Cancer Institute

www.cancer.gov
800-422-6237

National Resource Center for Participant-Directed Services

www.caregiver.org/national-resource-center-participant-directed-services
800-445-8106

Rosalynn Carter Institute for Caregiving

www.rosalynncarter.org
229-928-1234

The United Way

www.unitedway.org
703-836-7112

Well Spouse Association

www.wellspouse.org
732-577-8899

OTHER RESOURCES

The Health Care Team

Primary Care Doctor: _____
 Contact Information: _____

Medical Oncologist: _____
 Contact Information: _____

Radiation Oncologist: _____
 Contact Information: _____

Surgical Oncologist: _____
 Contact Information: _____

Oncology Nurse: _____
 Contact Information: _____

Oncology Social Worker: _____
 Contact Information: _____

Palliative and Supportive Care Specialist:

Contact Information: _____

Pharmacist/Pharmacy: _____

Contact Information: _____

Home Health Care Provider: _____

Contact Information: _____

**Other important contacts, including
 other health care providers,
 neighbors or friends, or community
 services:**

Name: _____

Contact Information: _____

Name: _____

Contact Information: _____

Name: _____

Contact Information: _____

Name: _____

Contact Information: _____

Identifying the Help Needed

Use this worksheet to identify the areas where the person with cancer may need help. Because caregiving needs will likely change over time, you may want to make copies of this page and review this information often.

Activity	Able to do alone	Needs some help	Needs a lot of help
Bathing			
Dressing			
Grooming			
Using the bathroom			
Getting out of bed			
Taking medications			
Shopping for food and other items			
Doing housework			
Doing laundry			
Cooking meals			
Driving to and from appointments			
Doing yardwork			
Paying bills			
Childcare and/or pet care			

Other support that has been asked for:

Appointment Information Sheet

Use this page to keep track of important information related to their medical appointments. You may want to make additional copies and organize them in a three-ring binder or file folder.

Appointment date and time: _____

Provider's name: _____

Patient portal website: _____

Where: _____ Phone number: _____

Reason for appointment: _____ Covered by insurance? Yes No

_____ Co-pay: \$ _____

Health changes, symptoms, or side effects to discuss: _____

Emotional and social needs or issues to discuss: _____

Questions to ask the doctor: _____

I remember the doctor saying: _____

I need more information about: _____

Procedures or tests performed during the appointment? Yes No

Results: _____

Other tests scheduled? Yes No

Date, time and location of these tests:

Support services recommended?

Yes No

Name and contact information:

Next appointment: _____

Tracking Symptoms

Check the box next to any symptom that the person with cancer experiences. Next to each checked symptom, write a number from 1 to 10, indicating how severe it was. 1 = mild; 5 = moderate; and 10 = severe. You may want to make copies of this page to use throughout this person's care.

Week of: _____

Treatment(s) received: _____

Symptom	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Appetite loss							
Difficulty concentrating							
Fatigue							
Fever							
Nausea and vomiting							
Pain <i>Location:</i> <i>Description:</i>							
Sleep problems							
Headache							
Loss of balance							

Questions or concerns to talk about with the health care team:

My Stress Management Plan

Use this page to figure out the best ways for you to manage caregiving stress.

I know I am feeling stressed because...

This stress is being caused by...

My ideas on how to deal with this stress are...

What I need from my family right now is...

What I need from my friends right now is...

Caregiving Action Plan

What type of support can be helpful for you and the patient? Use a chart like this to divide tasks among family, friends, professionals, and others.

Activity	Family/ friends	Community resources	Professional resources
Helping with meals and grocery shopping			
Doing household chores			
Childcare			
Pet care			
Driving to and from appointments			
Filling and picking up prescriptions			
Keeping family and friends informed			
Helping manage symptoms and side effects			
Coordinating medical appointments			
Giving medications			
Handling insurance and billing issues			

Do You Need Support?

You might find it helpful to talk with a doctor or a counselor if you check any of these boxes:

- I feel exhausted all of the time.
- I eat too little or too much.
- I get sick more often than usual.
- I am not able to sleep well.
- I feel impatient, irritated, or forgetful.
- I have trouble focusing or making decisions.
- I don't enjoy things I used to enjoy.
- I am withdrawing from people.
- I cry a lot.
- I have headaches and/or unexplained pains.
- I am drinking more alcohol than usual.
- I can't find any time for myself.

Looking for More Patient Information Resources?

Visit www.cancer.net/ascoanswers to see all of the available titles in the *ASCO Answers* series.

ASCO Answers Guides are comprehensive booklets, covering survivorship and caregiving. Worksheets and checklists are included.

ASCO Answers Fact Sheets are brief introductions to different cancer types and topics in diagnosis, treatment, and side effects. More than 50 fact sheets are available, including select titles in Spanish.

Patients and Caregivers: For more educational materials, visit www.cancer.net/ascoanswers to find and download all of our available materials.

Oncology Professionals: For free promotional materials for your practice, email contactus@cancer.net.



AMERICAN SOCIETY OF CLINICAL ONCOLOGY
KNOWLEDGE CONQUERS CANCER

AMERICAN SOCIETY OF CLINICAL ONCOLOGY

2318 Mill Road, Suite 800

Alexandria, VA 22314

Phone: 571-483-1300

Fax: 571-366-9530

www.asco.org | www.cancer.net

For more information about ASCO's patient information resources,
call toll-free 888-651-3038 or e-mail contactus@cancer.net.

WE WANT TO HEAR FROM YOU

If you found this material helpful or if you have comments or suggestions
about how it could be better, please let us know at contactus@cancer.net.