# ASCO<sup>®</sup> answers Caregiving

Trusted Information About Caring For Someone With Cancer from the American Society of Clinical Oncology



**Doctor-Approved Patient Information** 



#### **ABOUT ASCO**

Founded in 1964, the American Society of Clinical Oncology (ASCO) is the world's leading professional organization representing physicians who care for people with cancer. With more than 35,000 members, ASCO is committed to improving cancer care through scientific meetings, educational programs, and peer-reviewed journals. ASCO is supported by its affiliate organization, the Conquer Cancer Foundation, which funds ground-breaking research and programs that make a tangible difference in the lives of people with cancer.

# ASCO<sup>®</sup> Cancer.Net

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#### **ABOUT CANCER.NET**

The best cancer care starts with the best cancer information. Well-informed patients are their own best advocates and invaluable partners for physicians. Cancer.Net (www.cancer.net) brings the expertise and resources of the American Society of Clinical Oncology (ASCO), the voice of the world's cancer physicians, to people living with cancer and to those who care for and about them. All the information and content on Cancer.Net was developed and approved by the cancer doctors who are members of ASCO, making Cancer.Net an up-to-date and trusted resource for cancer information on the Internet. Cancer.Net is supported by the Conquer Cancer Foundation, which provides funding for breakthrough cancer research, professional education, and patient and family support.

ASCO patient education programs are supported by:



# Caregiving

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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 changes completely. For some friends and family members, this means taking on more tasks and responsibilities to help their loved one. We use the terms caregiver or carer to refer to friends and relatives who assume this important supportive role.

Caregivers are part of an important team of family, friends, volunteers, and health care professionals who support a person with cancer. There is no "right" way to be a caregiver. Each situation is different. As the disease and treatment changes, so does the caregiver's role.

Many caregivers say they were thrust into a caregiving role without much warning or preparation. 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 you can complete to 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 and satisfying 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.

# **The Health Care Team**

Primary Care Doctor:	Pharmacist:
Contact Information:	
	Contact Information:
Madiaal On apla sist:	
Medical Oncologist:	
Contact Information:	
Radiation Oncologist:	
Contact Information:	
	OTHER IMPORTANT CONTACTS, INCLUDING OTHER
	OR COMMUNITY SERVICES:
Surgical Oncologist:	
Contact Information:	
	Contact Information:
Oncology Nurse:	
Contact Information:	
	Contact Information:
Oncology Social Worker:	
Contact Information:	
	Contact Information:
Palliative Care Specialist:	
Contact Information:	

# **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 or arranging for help. No single description applies to all people with cancer and their families.

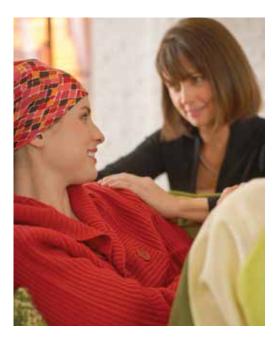
### **TIPS FOR CAREGIVING**

- 1. Remember caregiving is a team effort.
- Be proactive, organized, and plan as much as possible.
- Be a problem solver identify problems, find out what is needed, and follow through.
- 4. Recognize your personal strengths and weaknesses.
- 5. Set boundaries and ask for help.
- 6. Promote open and honest communication.
- 7. Talk about your concerns.
- 8. Seek out information and guidance.

# **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 or email. He or she may arrange for people 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 up-to-date. He or she might arrange for friends who live nearby to drive his or her parent to appointments.



# **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. Some of the responsibilities caregivers may take on include:

### DAILY TASKS:

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

### **PRACTICAL SUPPORT:**

- Coordinating medical appointments
- Driving to appointments
- 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**

Some caregivers may try to help too much. Talk with your friend or family member about the type of support he or she needs most. If your loved one is still able and wants to continue doing specific tasks, encourage him or her 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 his or her sense of independence will make him or her feel better about asking for and needing assistance.

Being able to make choices also helps people with cancer feel more in control of their situation. Continue to include your loved one in discussions and decisions. 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 the care team. Being flexible and assessing the situation is essential.

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

# Identifying the amount of help needed

Use this worksheet to identify the areas where your loved one could use assistance. Because caregiving needs will likely change throughout the person's illness, 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			
Child care and/or pet care			

Other support my loved one has asked for: \_\_\_\_\_

# **Caregiving at Home**

People with cancer now spend much less time in the hospital than they did in the past. 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 injections, dispensing medications, and a number of other tasks.

This section describes a few of the non-medical responsibilities you may need to take on. However, it is not a comprehensive 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.



# Going to appointments

Throughout treatment, someone with cancer may need to go to the hospital or clinic a number of 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 interfere with 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 company during appointments and treatment sessions.

A little bit of planning can help make getting to 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 your loved one need a wheelchair or assistance at the door?
- How long will this visit likely last?

Family members and friends play a large role in the day-to-day care of a person with cancer. 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 your loved one belongs to
- Volunteer driver programs through churches or hospitals
- Hospital vans
- Other caregiving families that might help carpool
- Private door-through-door transportation services
- Paratransit, which is public transportation for the elderly and disabled

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

### TALKING WITH THE DOCTOR

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



Making a list of questions before an appointment. Sit down with your loved one and think about the most important issues or concerns you'd like to discuss. These questions should reflect the

doubts, concerns, and issues of all family members. Then 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.

**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 your loved one receives.

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 before leaving the doctor's office.

It is normal for people to want to protect friends and family members by buffering information they receive at their appointments. This may not be helpful and may actually cause more hurt and anxiety. It is better to be open and share the worry than worry alone. However, always make sure you have your loved one's permission before sharing any personal medical information with others.

### 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 your loved one to an appointment, he or she will have everything that's needed all in one place. 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 12)
- □ Insurance cards
- □ Identification
- □ Small amount of money
- □ House key
- □ Cellphone
- □ Emergency contact information
- $\Box$  A healthy snack
- □ A bottle of water
- $\Box$  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

# **Appointment information sheet**

Use this page to keep track of important information related to your loved one's medical appointments. You may want to print additional copies and organize them in a three-ring binder or file folder.

APPOINTMENT DATE AND TIME:	
With (provider):	
Where:	Reason for appointment:
Phone number:	Covered by insurance?
Health changes, symptoms, or side effects 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:	Support services recommended?  Yes  No Name and contact information:
Other tests scheduled?	

# Managing symptoms and side effects

Cancer and cancer treatment often cause a variety of symptoms and side effects. Often people with cancer hesitate to talk about these issues because they are afraid it will affect their treatment and overall survival. Remember, cancer care is a team effort, so it is important to talk openly and honestly about what is happening during treatment. Preventing and controlling side effects is a major focus of your loved one's health care team, but they can't help if they don't know something is wrong.

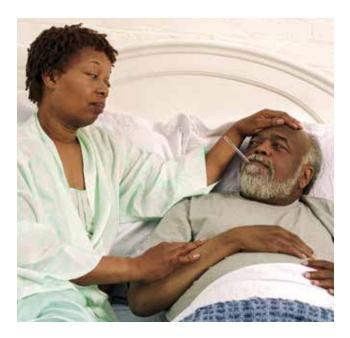
As a caregiver, one of the most important things you can do during treatment is to talk honestly with the health care team about symptoms and side effects. This will help the team make treatment as tolerable as possible while still providing effective cancer care.

You can use the chart on the next page to help keep track of and discuss symptoms and side effects. You may want to choose one person who is technologically savvy to send this information to a member of the health care team through email or text on a daily or weekly basis. This can speed up communication and help you avoid unnecessary worry or trips to the emergency room.

You can also easily keep track of your loved one's symptoms using the free Cancer.Net app. It is available for both Android and iOS (iPhone, iPad). Visit www.cancer.net/app for more information.

### WHEN TO CALL THE DOCTOR

Some side effects require immediate attention. One of the most important things for caregivers to know is 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 the circumstances of when you should call for help.

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

- What symptoms or side effects is your loved one experiencing?
- How often?
- How long have they been going on?
- Does anything make them better or worse?
- How severe are they on a scale of 0–10 (where 0 = no symptom and 10 = worst imaginable)?
- Are they 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**.

# **Tracking symptoms**

Check the box next to any symptom that your loved one experiences. Next to each checked symptom, write a number from 1 to 3 indicating how severe it was. 1 = mild; 2 = moderate; and 3 = 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 Location: Description:							
Sleep problems							
Weight loss							

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

# **Giving medications**

During cancer treatment your loved one may have a number of different medications to take at home. To make sure your loved one gets the most benefit, it is important that he or she takes each medication exactly as instructed.

Following these instructions can be hard. Some medications need to be taken with food, some without. Some medications 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 are topical creams, transdermal patches, and other important details. Ask the nurse or pharmacist if you have any questions about medications.

### **KEEPING TRACK OF MEDICATIONS**

It is important to figure out the best way to keep track of all of the medications your loved one has been prescribed 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 when someone else

# **Medication list**

Use this page to help keep track of all the medications your loved one is taking. Be sure to list prescriptions, as well as over-thecounter medicines, vitamins, and other supplements. If you prefer to track these electronically, use the Cancer.Net app to take notes and pictures of the medications.

Prescriptions are filled at: \_\_\_\_\_

Phone number: \_\_\_\_\_

Name of medication (both brand name and generic)	Dose	What it looks like	Prescribing doctor	When to take	Other directions

Problems or questions to ask about medications:

comes to help. It is also helpful to 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.

As your loved one's health changes, talk with the health care team about his or her medications. For example, if your loved one loses weight he or she may not need to take blood pressure medications any more. Or, if he or she is 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 TO TAKE MEDICATIONS**

There are a number of ways to help your loved one remember to take his or her 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 he or she needs 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 treatment plan. If your loved one 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 your loved one have access to.
- Make sure used fentanyl skin patches are kept away from others. After using a patch, fold it in half so the sticky parts seal themselves and then safely dispose of it.
- Only share details about your loved one's 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, child care, and drug copays. 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 your loved one about his or her financial situation. Caring for someone with cancer can be financially challenging, both for the patient and the caregiver. Discuss who will perform medical services and how specific things like 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. He or she may also need help figuring out what's covered by insurance and what the deductibles and co-pays are. The easiest way to handle this is to set up a system for tracking costs. 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 all 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.

Your loved one may ask you to talk with the insurance company if there are reimbursement problems. To be able to do this, your loved one may need to give permission for the insurance company to talk with you about problems and disputes.

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 for your loved one.

**Take good notes.** Keep a written record of all conversations you have with an insurance company representative, 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. Your loved one 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.

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

# **Caregiving at the Hospital**

Seeing someone you care for in the hospital can be overwhelming. In addition to compassion and concern, you may experience stress, anxiety, and guilt. This mixture of conflicting emotions is common and completely normal. By being prepared and organized, you will be able to handle this difficult situation and make sure your loved one receives the best possible care.

# 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, one of your main roles is to be his or her advocate. This means helping make decisions about your loved one's care. Research shows that 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.** 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. Also have them explain and define their role in your loved one's care.

**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 your loved one's room. 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 patients so you can ask questions. It also helps to write down or record the answers. Many hospital rooms have whiteboards 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 him or her to explain more. It's okay to speak up.

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

#### 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 on 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 their loved ones 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:

• Does my loved one understand the risks of treatment and the potential outcomes of his or her choices?

- Has my loved one openly stated his or her wishes? Are other caregivers respecting these wishes?
- Is this treatment consistent with my loved one's beliefs and values?

Always consider the patient's viewpoint first. Your loved one has the right to be heard and the right to change his or her mind. Your loved one also has the right to state his or her wishes and have them respected.

Remember, your loved one has asked for your help because he or she respects your opinion. However, he or she 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 your loved one's decisions.

Some of the hardest decisions are those made in the final weeks or months of life. During this time, it is helpful to talk openly about your loved one's treatment priorities. He or she may want to live as long as possible, regardless of



how hard treatment is. Or he or she may wish to maintain a specific quality of life, even if that means stopping treatment. These topics can be hard for your family to talk about. If so, you can ask a doctor, nurse, clergy member, social worker, 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 for him- or herself. Examples include if he or she falls into a coma or has a heart attack or stroke. If this happens, a health care proxy or

medical power-of-attorney gives a friend or family member the power to talk with the doctors and participate in making medical decisions, either temporarily or permanently.

If your loved one has made you his or her health care proxy, knowing the types of treatments your loved one does and doesn't want will reassure you that are you 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 outline a person'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.

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.

### CHARACTERISTICS OF A HEALTH CARE PROXY

According to the American Bar Association, a health care proxy should have all of the following characteristics:

- Is over 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 his or her life
- Is willing to speak on the patient's behalf and separate his/her personal feelings from the patient's
- Lives close by or could travel to be at the patient's side if needed
- Knows the patient well and understands what is important to him or her
- 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/advancedcancer.

# **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 difficult, both emotionally and practically, but it is not an impossible task. 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 his or her 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 anywhere your loved one receives care.



**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 on the Internet 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.

**Explore professional services.** Contact your loved one's 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 31. Talk with your loved one's insurance company about which home care services are covered as part of his or her policy.

**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; healthcare providers; and neighbors.

**Prepare for unplanned travel.** Be prepared to travel if your loved one needs your help. Try setting aside vacation or sick days from work and research travel options. 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.

**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 host support groups for caregivers. Tweet 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 your loved one, 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 your loved one's health care team to discuss any medical issues and the care plan. Before the trip, prepare a list of questions for the health care team. It is important to include your loved one 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 some relief. It also gives you the chance to reassess the caregiving needs and resources first hand. Observe your loved one's 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 he or she is receiving.

**Take time to reconnect.** Schedule quality time with your loved one. Think about activities you enjoy doing together that will take both of your minds off cancer.

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

# **Organizing local volunteers**

Use this chart to help keep track of family, neighbors, friends, and members of religious, civic, and social organizations who would like to help with daily or weekly caregiving tasks.

	Name and Contact Information			
Tasks				
Housekeeping				
Personal care and hygiene				
Laundry				
Shopping				
Managing medications				
Driving to appointments				
Cooking meals				
Child care and/or pet care				
Companionship				

# **Taking Care of Yourself**

One of the most important—but often neglected—tasks for caregivers is caring for themselves. Many caregivers say 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.

Research has shown that the emotional health of caregivers may affect the people they care for. According to the results of one clinical study, people with cancer are more likely to develop depression if their husbands, wives, or partners experience symptoms of depression.

# **Coping with stress**

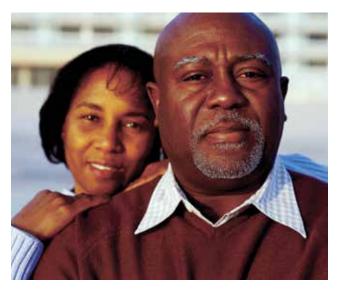
Caregiving is an understandably stressful experience. At times you may feel like everything is on your shoulders or that no matter what you do, it's not enough. This may lead to:

- 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
- Withdrawing from people

Recognizing these signs of overload is important because there are a number of things you can do to make the situation better.

**Set boundaries.** Setting limits helps you and the person you care for. This may mean asking for help so you can take a break. 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 whom your loved one trusts and can help with specific caregiving tasks. Family, friends, members of religious groups, and



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



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 child care 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 31 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. 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 for your loved one. This means making time to exercise, eating healthy foods, and staying 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. It's important to remember that one drink is 12 ounces (oz) of beer, 5 oz of wine, or 1.5 oz of 80-proof distilled spirits (liquor).

Also consider:

- Making a list of priorities for each day that sets out realistic goals
- Talking with a friend, clergy member, or counselor about your experiences and feelings
- Spending time with supportive friends, even if you have to scale back these activities while you juggle other responsibilities
- Listening to soothing or uplifting music
- Practicing relaxation techniques, such as meditation or yoga

# **Balancing work and caregiving**



Caregiving can be a fulltime job, especially during diagnosis and treatment and near the end of life. However, many caregivers are also employed. This can

cause work-related issues like missing days, decreased productivity, and potential job discrimination.

For people with certain types of jobs, such as temps, freelancers, consultants, entrepreneurs, and hourly workers, 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 have an expanded definition of whom you can care 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 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,



California, New Jersey, and Rhode Island offer state-paid leave programs for caregivers.

In addition, some state-run Medicaid programs cover inhome assistance for people with cancer. These programs help the person with daily tasks of living, such as getting dressed and cooking. About 15 states have Cash and Counseling 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.

# **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 provide high-quality 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.

- Expect and accept differences of opinion and coping styles.
- Involve the person with cancer, if possible. He or she 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 it.
- Appreciate family members who are trying to help, even if the help is not exactly what you need.
- Be realistic in dividing up 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 will vary day to day and week to week. 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.

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



# **Managing family life**

Your everyday life and 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. Maintaining your usual schedule and relationships can be difficult during this time and add additional stress.

### 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 child care

Every couple handles stress in a different way. Your age and the amount of time you've been in the relationship will affect how you cope with the experience of caregiving and illness. 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 can be extremely difficult. To reduce burnout from this balancing act, it is important to simplify your routine, stay organized, and ask for help. You will also feel better if you are able to create a safe, secure 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.





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.
- Make emergency back-up plans for child care, 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, child care, and after school activities.

Despite the challenges, parenting and being a caregiver helps model for your children how family members care for each other.

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

# 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...

How am I dealing with all of this?

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

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

# **Exploring Other Caregiving Options**

Caring for someone with cancer is often an enormous responsibility. 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 high-quality care. And, you will be able to focus on the things that you do best to provide support.



# **Professional home care services**

One option to consider is a professional home care service. These organizations send medical or non-medical 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.

- Registered oncology nurses can provide wound care, give chemotherapy, help with nutrition concerns, and manage pain.
- Home health care aides can handle less complex medical issues, such as checking a patient's temperature and blood pressure.
- Physical therapists treat conditions or injuries that affect a person's ability to move.
- Occupational therapists teach people ways to do daily tasks that are more difficult after an illness or injury.
- Hospice care providers offer physical, emotional, social, and spiritual support for people living with advanced cancer and their families.

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



Home care is most often provided by non-medical 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 receive training to provide more complex services along with a nurse. These services may include wound or ostomy care. An ostomy is a surgically created opening for getting rid of body waste.

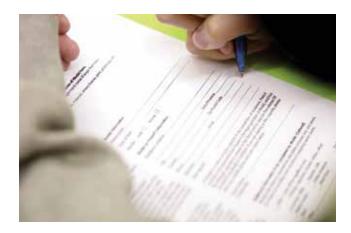
**Personal attendant.** A personal attendant provides personal care services and performs light household tasks, such as cooking, laundry, and basic cleaning.

**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 his or her 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 your loved one's health care team to find out what type of home care services he or she needs. An oncology nurse or social worker will be able to provide home care options 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?



- Which insurance plans do you accept?
- What is the billing process?
- How do you oversee the quality of care a person receives?
- Who is the contact for 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.** You or your loved one will need to pay for services not covered by an insurance plan. Long-term care provided by an aide, attendant, or companion often requires out-of-pocket payment. 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 31.

### **Community resources**

Many communities have a wide range of resources available to support caregivers. These include:

**Case management.** Some organizations have trained case managers that 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 action plan

Start by making a list of all of your caregiving tasks. Then, use this chart to decide how to divide the tasks between friends, family, professionals, and other volunteers. You can get referrals to agencies and community resources from your loved one's doctor, oncology social worker, or nurse. You can also learn more from members of local or online support groups or state and county health agencies.

Task	Family/Friends	Professional Resources	Community Resources

# **Caregiving Support and Resources**

You can find additional information about caregiving and links to caregiver support and resource organizations on Cancer.Net. The following national organizations also provide resources about caring for someone with cancer, 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

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

CancerCare www.cancercare.org 800-813-4673

Cancer Support Community www.cancersupportcommunity.org 888-793-9355

Cancer Hope Network cancerhopenetwork.org 800-552-4366

Caregiver Action Network caregiveraction.org 202-454-3970

Caregivinghelp.org 773-381-6008 Family Caregiver Alliance caregiver.org 800-445-8106

Friend for Life Cancer Support Network www.friend4life.org 866-374-3634

Friends' Health Connection www.48friend.org 800-483-7436

Imerman Angels imermanangels.org 877-274-5529

Inspire www.inspire.com 800-945-0381

Lotsa Helping Hands lotsahelpinghands.com

MyLifeLine.org 720-883-8715 National Alliance for Caregiving www.caregiving.org 301-718-8444

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 Family Caregivers Association www.thefamilycaregiver.org 800-896-3650 National Resource Center for Participant-Directed Services cashandcounseling.org 617-552-6582

Peer Support Network www.peersupportnetwork.org 561-702-0727

Rosalynn Carter Institute for Caregiving www.rci.gsw.edu 229-928-1234

The United Way www.unitedway.org 703-836-7112

Well Spouse Association www.wellspouse.org 800-838-0879

### **OTHER RESOURCES:**


# **Looking for Other Patient Information Resources?**

Cancer.Net offers a variety of guides, booklets, and fact sheets to help patients learn more about their disease and treatment.

### **ASCO ANSWERS GUIDES**

ASCO Answers Guides feature comprehensive information about the diagnosis, treatment, side effects, and psychosocial effects of a specific cancer type, as well as practical information for patients and families. Topics include:

- Breast Cancer
- Colorectal Cancer
- Non-Small Cell Lung Cancer
- Small Cell Lung Cancer
- Prostate Cancer
- Survivorship
- Caregiving

### **ASCO ANSWERS FACT SHEETS**

ASCO Answers Fact Sheets provide a one-page (front and back) introduction to a specific type of cancer or cancerrelated topic. Each includes an overview, illustration, terms to know, and questions to ask the health care team. Cancer.Net has more than 65 fact sheets available (including some in Spanish), covering different cancer types, diagnosis and treatment, and side effects. Some available titles are:

- Kidney Cancer
- Acute Lymphocytic Leukemia
- Appetite Loss
- Understanding Chemotherapy

### ASCO ANSWERS BOOKLETS

ASCO Answers Booklets provide in-depth, practical guidance on specific topics in cancer care. Learn about:

- Advanced Cancer Care Planning
- Managing Cancer-Related Pain
- Managing the Cost of Cancer Care
- Managing Your Weight After a Cancer Diagnosis
- Palliative Care
- Stopping Tobacco Use After a Cancer Diagnosis

For Patients and Caregivers: If you are interested in additional educational materials, visit www.cancer.net/ ascoanswers to find all of our available materials in electronic format.

**For Oncology Professionals:** Bulk quantities are available for purchase. Bundled versions are also available for purchase. Bundles include guides for oncology professionals and patient guides. Available bundles cover survivorship, weight management, and tobacco cessation. Visit www.cancer.net/estore or call 1-888-273-3508 to place your order. To request free promotional materials for your practice, please send an email to contactus@cancer.net.



#### WE WANT TO HEAR FROM YOU

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

### 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.

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